

# Global Health Action

Supplement 1, 2013



BUILDING NEW KNOWLEDGE

Guest Editors: Laetitia Rispel and Sharon Fonn



Umeå Centre for  
Global Health Research

## Global Health Action

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Public health challenges in a global context are to be found in the widening gap between the winners and losers of globalisation. To meet these challenges it is crucial not only to act constructively on what is already known and evaluate the results, but also to establish what we have yet to learn and still need to implement. The Journal therefore specifically welcomes papers that report on results and evidence derived from practical implementations of current knowledge, but also papers suggesting strategies for practical implementations where none already exist. Thus the aim of *Global Health Action* is to contribute to fuelling a more concrete, hands-on approach to global health challenges. The journal particularly invites articles from low- and mid-income countries, while also welcoming South-South and South-North collaborations. All papers are expected to address a global agenda and include a strong implementation or policy component.

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Peter Byass

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Email: [peter.byass@epiph.umu.se](mailto:peter.byass@epiph.umu.se)

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# Building new knowledge: Celebrating the Wits School of Public Health (WSPH)

Notwithstanding worldwide aggregate improvements in the health of individuals and communities, (1, 2) overall progress has been marred by a multiplicity of factors. These include: the changing burden and complexity of disease profiles; the social, political, economic and environmental drivers of ill-health, unacceptable health inequalities between and within countries, and inadequate or poorly performing health systems (1, 3). Common shortcomings of contemporary health systems include fragmented, inappropriate, misdirected or poor quality care which mitigate against a comprehensive and balanced response to population health needs (1). All these challenges are more acute in sub-Saharan Africa, which faces additional problems of financial and human resource constraints and low investment in health research (3, 4).

In South Africa, health status indicators are poor relative to the country's economic development and health care expenditure (5). This is exacerbated by the sub-optimal performance of the health system, particularly at the district level (6–9). Significant efforts are required to overcome the HIV and TB epidemics, address persistent health inequalities, improve the quality of health care provision, and improve health outcomes (6). Schools of Public Health in Africa have a critical role to play in responding to these many systemic issues that confound improvements in population health. While solutions are complex, key priorities for action include: revitalising *primary health care* (PHC); addressing the *crisis in human resources for health*; conducting *relevant research* to respond to the advanced health and social transitions underway in the country, increase our understanding of barriers to improved population health, and to the performance of the health system; and *policy advocacy and engagement* that promotes effective stewardship and leadership of the health system (10–16).

In this supplement of *Global Health Action* we present a contribution of the School of Public Health at the University of the Witwatersrand (Wits) in Johannesburg to these critical issues. The mission of the Wits School of Public Health (WSPH) is to respond to the public health challenges facing South and sub-Saharan Africa, through research, the production of skilled, critical and adaptable graduates, and contributing to international scholarship and capacity building. The supplement brings together two commentaries and 23 scholarly articles that share

historical developments at the WSPH, present methodological innovations in public health and explore themes that have captured global attention in recent years: improving the health of communities and of workers; understanding population health risk factors; human resources for health; and optimising health system performance.

## Approach and methods

In January 2012, the WSPH obtained funding from a strategic University fund for the supplement. The overall goal of the supplement was to bring together a series of papers exploring trends, developments and new directions for scientific enquiry regarding public health in South Africa and in the region, while speaking to an international public health audience. Another important goal was to address a critical human resource challenge in the region, that of nurturing and developing the next generation of African scholars.

In March 2012, we invited all staff (including honorary staff), post-graduate students, alumni and WSPH collaborators to submit abstracts that correspond to the diverse and multi-disciplinary areas of endeavour of the School. An intensive review process provided inputs and support on how to develop these abstracts further. Thereafter full papers were elicited and authors were invited to a writing workshop. In preparation for the workshop, pairs of authors were asked to peer review each other's papers. Simultaneously, senior academics provided external expert review. This provided the opportunity for junior academics to compare their reviews with that of senior academics. The two-day writing retreat, where mentors were available to work with authors, provided guidance for junior authors and a supportive environment and time away for all authors to focus on their writing. A further process of paper revision and refinement followed, prior to the authors submitting their papers to *Global Health Action*.

For each paper, we selected national and international peer reviewers to ensure that local content would be accurate and that papers would be sound, relevant, and interesting to an international audience as well. An extensive peer review process was followed, including re-assessment by the same reviewers in some instances. The papers were accepted for publication and went to production only after peer-reviewers recommended

acceptance. The result is this supplement in which we are *building new knowledge* and which includes a number of first time, first-author publications from African academics and post graduate students.

### Themes and focus

The two commentaries by our predecessors John Gear (17) and William Pick (18), trace the historical developments of public health at Wits University. Both authors highlight: the importance of an enduring set of values of human rights, equity and social justice; the need to respond to the broader political and social context in the development of public health; the unique focus on population health rather than individual health; the multi-disciplinary nature of the discipline; and the methodological, educational and health service innovations that characterised the first two decades of community (or public) health at the University. As is still the case today, the WSPH prides itself on the diversity of its research and teaching endeavours, its involvement and influence on many aspects of public health ranging from shaping national and international health policy, through health service delivery to the development of human resources for health.

Many issue highlighted in these historical overviews are common strands running through the subsequent papers: the centrality of the measurement sciences to the discipline of public health; improving the health of communities and of workers; understanding population health risk factors; concerns with policy design and implementation; challenges related to human resources for health; and optimising health system performance.

### Measurement sciences and health determinants

Measurement sciences are fundamental to public health. The WSPH both has strong research and training capacity in this area. In the first paper in this theme, Chirwa et al. (19) investigate the degree to which misclassification in infectious disease modelling can affect research findings and describe how household composition dynamics are important in infectious diseases that have long incubation periods. In light of limited information on long-term fertility transitions of refugee populations, Williams et al. (20) use demographic methods to examine the changes in the fertility of former Mozambican self-settled refugees over a period of 17 years and compare their overall fertility patterns with those of an established community in rural South Africa. The authors found that refugees 'take on' the fertility patterns of the host communities, but point out that further declines in fertility will only occur by addressing endemic poverty in the area and increasing education and job opportunities for women.

Both Sartorius (21) and Musenge et al. (22) explore spatial analysis as a method for understanding determinants of mortality at household, village and district level

in relation to all cause and HIV/TB mortality respectively. Both papers draw out the policy relevance of this approach and identify social determinants of health as important in predicting mortality. Community characteristics and in particular socio-economic status and childhood mortality in Tanzania are explored by Nattey et al. (23). The authors explore the usefulness of a mortality concentration index and comparing mortality outcomes by wealth quintiles. They demonstrate the association between under-five mortality on the one hand and household socio-economic inequalities and maternal education on the other hand. Ramsoomar et al. (24) examine the prevalence of lifetime alcohol use during adolescence in an urban township of Johannesburg and its association with child and maternal socio-demographic factors. The findings suggest that gender, maternal education, and socio-economic status are predictors of alcohol use during adolescence.

### Training for transformation

Two articles in this supplement address training. Christofides et al. (25) describe a new Master of Public Health (MPH) programme at the WSPH that focuses on communication for social change. The MPH programme acknowledges the need to train graduates in an evidence-based approach to develop and evaluate interventions to improve population health through policy changes, the environment in which healthy choices are made and individual behaviours. The authors argue for investments in institution building for African programmes in Africa for Africans. The article by Khan et al. (26) reviews the response of medical schools in one South African province to the need to transform the race and gender make up of students and graduates. They note the progress in redressing historical disparities and inequities in terms of race and gender, but point out that further efforts are needed to ensure that student intakes and graduations are in line with the South African population profile.

### Occupational health

Mining has a long history in South Africa and the WSPH has a strong focus on occupational health. Neat compartmentalisation into categories however does not describe reality. The article by Ndlovu et al. (27) illustrates that commercial exploitation of mineral resources has health consequences for the surrounding communities. However, these communities are further disadvantaged by insufficient compensation and measures that address the source of the problem. Nelson (28) explores the exposure to silica in various forms of mining in South Africa and its health consequences. The author confirms the hazards of silica exposure and the inadequate responses from the employers, the possible risk of exposure to asbestos in both platinum and diamond miners, exacerbated by the

inadequacy of exposure information. Banyini et al., (29) explore why miners who could benefit from post mortem autopsy and related compensation under-utilize this potential benefit, using in-depth qualitative methods. The authors identify a range of socio-cultural barriers to obtain consent for an autopsy, but note that multi-faceted awareness and knowledge-building interventions are possible and should be implemented with healthy mine-workers.

### *Optimal performance of the health system*

In light of the international discourse on universal health care coverage, Govender et al. (30) assess the South African government employee health insurance scheme and describe the factors associated with low uptake of the scheme. The authors note that the barriers to enrolment include insufficient information, unaffordability of payments and perceived administrative complexity. While the conditions around the existing scheme are not directly comparable with plans in South Africa to set up a national health insurance (NHI) system, the article illustrates the paradox of low-uptake of health insurance among population groups with the greatest potential health need, thus informing planning around the proposed NHI.

Rural populations are often confronted with poor access to services and du Toit et al. (31) explore the degree to which there is consensus about measures needed to improve rural health service provision. Although not unique to rural areas, their findings identify human resources for health as an important constraint. Blaauw et al., (32) describe health worker job satisfaction in a multi-country study. Of interest in this study, and as yet insufficiently explained, is the finding that notwithstanding better working conditions in South Africa compared to Tanzania and Malawi, South African health care providers are the least satisfied in their jobs. Ditlopo et al. (33) explore a financial incentive that was introduced to improve nurses' salaries in the South African public health sector. They illustrate the unintended negative consequences that can occur when policy development is not well aligned with the health sector's capacity to implement such policies. The article by Doherty et al. (34) describes the careful planning and consultation with multiple stakeholders around the introduction of a new cadre of health care provider, the clinical associate, in South Africa to avoid conflict among different cadres. The clinical associates are meant to improve capacity and care at district hospital level. The article concludes that while initially successful the way forward for this category of health worker is not assured.

Another challenge facing the South African health sector is how systems can be strengthened in the face of vertical programme implementation. Kawonga et al. (35) explore, through the lens of health information systems,

how staff tasked with overall district health system responsibilities interact with those responsible for HIV services. The authors conclude that reporting systems of vertical services may undermine the overall goal of health systems strengthening.

Providing ongoing care for chronic conditions is becoming increasingly important for South Africa, and indeed for other low and middle-income countries, particularly those in sub-Saharan Africa. Sengayi et al. (36) explore predictors of loss to follow up in children on HIV treatment and found a curious relationship between loss to follow-up and being cared for by their mothers. They raise the question of differential access to treatment between children and their mothers. Chronic care is also an important service for the ageing population in South Africa. Gómez-Olivé et al.'s (37) survey of people over 50 years of age living in rural areas suggest high levels of chronic health conditions associated with higher levels of health care use. The authors caution that current health services in South Africa are inadequately prepared for the management of chronic conditions.

Research by Kimani-Murage (38) in the same rural area looked at possible predictors of chronic ill-health outcomes associated with metabolic syndrome by investigating the nutritional status of children. A combination of early stunting and adolescent obesity found in this area may predict an important chronic disease epidemic in the future. Bertram et al. (39) also predict an increase in the burden of chronic ill-health by using existing data to estimate the Years Lost due to Disability associated with diabetes. Providing health care services for patients with chronic health problems is a challenge and Ndou et al. (40) assess the role of community health workers in providing this care. They conclude, not surprisingly, that as for any intervention with community health workers, training, supervision, and operational support are required. Nxumalo et al. (41) explore various models of community health worker programmes, and find that coherent and stable communities, compared with communities of great heterogeneity and characterized by high levels of migration, are easier to work in. The authors note that support for community health workers is important.

### **Conclusion**

South Africa, as is the case in other African countries, faces formidable public health challenges, some of which have been explored in this supplement. At the same time, the supplement illustrates the importance of building a vibrant African academy, able to lead high quality, multidisciplinary research that generates new knowledge, is policy-relevant and that makes a positive impact on public and population health. The articles are authored by individuals from different disciplinary backgrounds and with a range of theoretical approaches, ranging from

the social to the bio-medical sciences, competent in qualitative and/or quantitative research methods.

As is the case with our parent university, the WSPH is cognisant of the rapid and ongoing changes in the global, regional and national context and the need to respond to the profound public health challenges of the twenty-first century. Hence, the WSPH combines skills and approaches that respond to the advanced health and social transitions underway, emphasising the need to understand health policy and health systems and the need for advanced skills to develop, test, cost and evaluate interventions for broader population health improvements in South Africa and in the whole of Africa. We take pride in our contribution to the expansion of public health knowledge since democracy in South Africa, and in the growth and development of Public Health at Wits.

The supplement also underscores the need for greater investment in African Schools of Public health. First, through their training programmes, these Schools play a critical role in addressing critical human resource needs in the region and in building the next generation of practitioners and public health leaders. Second, investment will enable these Schools to enhance their capacity to lead globally-competitive research. Such research will ensure the production of new knowledge and guidance on how best to: address many of the causes of premature mortality or morbidity among Africans; implement proven interventions to prevent premature morbidity and mortality; and design and implement the reforms necessary for a well-functioning health system. Further research is also needed to determine why leadership and management action to implement known and effective public health interventions is found wanting at almost all levels of the health system.

In conclusion, the supplement highlights the need for strong government stewardship and leadership, in promoting the health of people, through action on the social determinants of health and action to improve the performance of the health system. A critical imperative is to use our collective knowledge to improve population health of those most in need, through collaboration and effective partnerships, regionally, nationally and internationally, across various sectors and across various stakeholders.

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*Laetitia C. Rispel*  
Current head of the Wits  
School of Public Health

*Sharon Fonn*  
Past head of the Wits  
School of Public Health, 2003–2011  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
South Africa

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## Public health in South Africa 1975–89: reflections on a momentous past

John Gear\*

Inaugural chair of the Department of Community Health, University of the Witwatersrand

It is an honour for me to reflect on a momentous period in the evolution of South Africa's Public Health. In 1979, Wits University appointed its first full-time Chair of Community Health to a post, which had been approved four years earlier. The delay in filling the post was a product of bureaucratic challenge and uncertainty around the job description of the incumbent. The bureaucratic challenge centred on the post being a tri-partite appointment, with the successful candidate answerable to the National Department of Health, the Provincial Department of Hospital Services, and the University of the Witwatersrand. A further complication was that most public health activities took place under the auspices of the Johannesburg Municipality which was not a part of the tri-partite arrangement but which had a strong presence on the selection committee.

There was much confusion back then as to what constituted community health, or public health, as it had been previously named and is now renamed. The short-listed candidates for the chair were a paediatrician with strong primary health care (PHC) credentials and a physician with a background in health service management and epidemiology. The physician was a hot-blooded 30-something year-old revolutionary recently returned from Oxford University and the powerful influence of Sir Richard Doll, a committed socialist with alleged links to communism! It is unclear why a conservative selection committee gambled on the latter. What follows are some reflections of that now retired revolutionary.

### Context

At the time of my appointment, the political environment was hostile in the aftermath of Steve Biko's death in custody and the 1976 student revolution in Soweto. This resulted in the withdrawal of doctors from many Soweto clinics and the wonderful response of concerned medical practitioners who devoted hours of teaching to the upgrading of clinic-based nurses to function as primary care clinicians in a 'doctorless' environment. Nurses

'specialised' in either adult or paediatric primary care. However, infrastructure deficiencies and the illogical separation of preventive and curative health care delivery by municipal and provincial authorities challenged both effectiveness and efficiency.

The 1978 Declaration of Alma Ata on PHC set a new gold standard for health care delivery and called for a major shift in health resource allocation, PHC facilities to be the centre piece and the first point of contact between health consumer and health care provider, and the relocation of decision making from a top-down to a bottom-up approach. The PHC approach also called for community participation and inter-sectoral collaboration. This was foreign to and strongly resisted by South Africa's policy-makers.

The Wits medical students were highly politicised, and their leadership was an extraordinary cohort of young people seeking to correct the injustices perpetrated by the apartheid state. They had their own publication *Critical Health* which highlighted health care injustices, and they offered first aid classes to young Sowetans seeking to play their role in the growing revolution. They were supported by a growing number of influential and outraged staff members at the University.

This was the cauldron in which Community Health at Wits was forged. In the decade that followed, the department grew in stature, credibility, and influence despite having few permanent posts, limited resources, having to face setbacks and harassment, and parent institutions whose responses varied from lukewarm tacit support to overt hostility.

### 1980–89

This decade was characterised by carving a niche for academic community health in the hostile corridors of a Medical School steeped in the Oslerian clinical tradition of bedside teaching. There were many who were sympathetic to the need for academic community health but who failed to grasp that its focus was on *population health*

and not individual health. The research tools of community health were biostatistics and epidemiology, descriptive and analytical studies culminating in the definitive evidence derived from the double-blind prospective trial with an adequate sample size. These tools were largely foreign to clinicians still wedded to case studies, to clinical intuition and conventional wisdom often derived from bombastic teachers with a compelling stage personality. It is gratifying to see that most clinicians are now fully committed to the hard science of evidence-based medicine as espoused by Cochrane and perfected by a new generation of clinical scientists.

By 1989, the Department of Community Health was the leading publisher, per staff capita, of articles in refereed journals in the Medical School. Wits Community Health provided leadership for a special edition of the *South African Medical Journal* on the Expanded Programme of Immunisation in South Africa – the majority of papers coming from our own staff and students.<sup>1</sup> The success of this decade rested solely on the passion and quite extraordinary talent and dedication of young students and staff, many in untenured contract posts, supported by loyal administrative personnel for whom no request was unreasonable. Each individual rose to the multiple challenges of academic credibility, research relevance, the inequality of apartheid health care, bringing services to the underserved and unserved sectors of society, health service and health system deficiencies and curriculum reform.

The products of the responses to these challenges included the creation of the Health *Services* (later *Systems*) Development Unit (HSDU), the Centre for Health Policy (CHP), the Wits Rural Facility (WRF), the clinical rural blocks, the Senaoane Health Project in Soweto, the Diploma in Health Service Management to complement the existing Diploma in Public Health, the first comprehensive community health textbook directed at the needs of a developing country, and the establishment of a doctoral student base. Doctoral topics included effectiveness and efficiency of PHC delivery, occupational health hazards notably silicosis and asbestosis, impact of tuberculosis, chronic disability among rural adults, and adult education in the training of PHC nurses. The department prided itself on this wide range of interest and involvement and the consequent growing influence it was to exert on many aspects of health care delivery ranging from policy, through delivery to development to appropriately trained personnel. Another key element of the successes of the 1980s related to the collegiate collaboration amongst like-minded groups at Wits Medical School. We convened ourselves into a *School of Public Health* (Community Health, National Centre for Occupational Health, Family Medicine, Community

Dentistry, HSDU, and the CHP incorporating the Women's Health Project). Two departments, Paediatrics and Nursing Education, were supportive but faculty resisted according formal recognition for reasons that never became clear. It was our view that this was to prevent the establishment of a power base calling for curriculum reform, more physical space, and a presence on key faculty structures.

Lack of recognition did not stop us, and we moved from a few offices in the old Colin Gordon Building in Esselen Street, Hillbrow, to the 4th floor at the Parktown Medical School and finally on to the 10th floor where we gradually acquired more and more space. Staff served on the Faculty Executive, the Undergraduate Committee, and the Curriculum Committee. We played seminal roles in the convening of new committees including the Ethics Committee and the Rural Block Committee. Time (3 weeks) for rural block release teaching in the final year of medical studies was negotiated, a visiting support programme of clinical consultants to rural hospitals (Elim, Letaba, and Tintswalo) was arranged, and a permanent presence for Community Health in a rural setting was initiated with the establishment of the HSDU. HSDU evolved into the Health *Systems* Development Unit and spawned the CHP and the WRF, all within this inaugural decade.

Postgraduate training for specialists in community health was a major initiative to expand on the part-time offerings of the diplomas in tropical medicine, public health, and occupational health. To guarantee adequate exposure to the key sub-disciplines meant that service and teaching outlets had to be arranged with relevant stakeholders. These were the National, Provincial, Municipal and Homeland Health Authorities for service exposure, Medical Research Council's Division of Biostatistics and Epidemiology, National Centre for Occupational Health, and Community Health's own academic initiatives for research exposure and other institutions and Faculties for theoretical content, including the South African Institute of Medical Research (SAIMR), the Graduate School of Business and the University Departments of Sociology and Social Anthropology.

The various health service providers ostensibly sponsored registrar posts. Each provider was reluctant to release their appointee for rotation through our various learning experiences, arguing that at all times their employee was accountable to them. This was despite the Academic Head of Community Health enjoying a tri-partite status with *locus standi* in the national and provincial departments and the university. Flexibility to allow rotation was achieved by a generous gesture from the Gazankulu Homeland Health Department agreeing to create two posts for the HSDU, thereby releasing two HSDU posts for the other rotations. The final rotation consisted of 10 appointees rotating between five service

<sup>1</sup>See *South African Medical Journal*; Volume 72; Sept 1987.

sites. Our final challenge was to persuade the usually conservative and traditional South African Medical and Dental Council to recognise a rotation through institutions and experiences previously outside their ambit. Our motivation succeeded and we started what was undeniably the most comprehensive, and what we believed was the most relevant, programme for specialist training in public health in South Africa.

Little of this success would have been possible without generous financial support notably from the Anglo-American Chairman's Fund Educational Trust over many years, Dutch and Swedish Funders, the European Economic Community and American Philanthropic Foundations. Their belief in what we were doing was inspirational and added a further critical dimension to the material support that they gave so generously.

### Postscript

In 2012, as I look back on those early days, I feel that somewhere something went dramatically and almost fatally awry. Was it complacency when the new democratic government was sworn in? Was it sabotage by the old order? Was it the inexperience and lack of skills of the new order? Was it a combination? What was the impact of corruption and misguided expenditure? Had we been naive in advocating universally accessible health care for all South Africans? Had the foundations that were laid been faulty or were they sabotaged? The waters were further muddied by the devastation of the HIV & AIDS pandemic and government denial and failure to endorse primary clinical care nurses as the central pillar of effective health care delivery.

Somehow we got caught up in ideological debates about the need for doctor-centric health care and medical

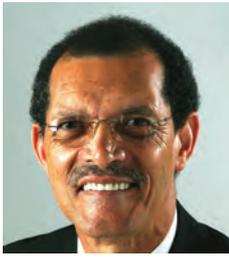
assistants as an alternative. What we had was viable but needed rolling-out. Instead, we had indecision, an action vacuum and a rapid decline in the quality of health care. A burgeoning private health care sector was a distraction. Furthermore, the fear and reluctance of a too-loyal loyal rank and file to engage with and, if necessary, criticise the health leadership, led to wastage and indeed unnecessary deaths. We are all culpable - citizens and health care professionals alike.

This pessimism is offset by the huge body of public health knowledge that has been painstakingly accumulated during the last 15 years, the growth in Public Health at Wits, lessons from the Agincourt Demographic Project and CHP's research over two decades, the great advances in postgraduate offerings, the expansion of interest in rural health care and engagement with local and international policy makers, and most recently, the construction of a building to house the now formally endorsed School of Public Health. The current leadership is up to the task. Mortality statistics are recovering. Changes in the Health Ministry bode well. It is now time for Wits to stand tall in providing ideas, data and evidence that will guide policy formulation, develop human resources, and offer inspiration and critique whether sought or not. The precedent was set in the 1980s; the next decade calls for renewed and redoubled effort.

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#### \*John Gear

Department of Community Health  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
PO Box 124, Still Bay 6674  
South Africa  
Email: [jjgear@easycoms.co.za](mailto:jjgear@easycoms.co.za)



## Reflections on Public Health in South Africa, 1993–2002

William Pick\*

Head of Department of Community Health (1993–2001) and Inaugural Head of the Wits School of Public Health (2001–2002)

**N**ews of the completion of the new Wits School of Public Health (WSPH) building reminded me of the dream that so many of us had when the School was founded just over a decade ago. At the time I wrote: ‘The year 2001 will be remembered as the year in which the Wits School of Public Health was established. This event marks a defining moment in the development of Public Health at Wits. The establishment of the school has over a short period of a few months brought a new dimension to the way in which we function. No longer can Public Health be regarded as the Cinderella of health sciences at Wits ... the School has demonstrated its academic worthiness.’ The new building serves to reinforce this notion. The establishment of the School did not happen without opposition from within the Faculty of Health Sciences and the university. Similarly, finding a building suitable for the rapidly expanding School of Public Health did not happen without a struggle. Initial efforts led to the university architects drawing up plans for a multi-story School of Public Health building near the entrance of the Medical School. However, the university did not see its way clear to supporting such an undertaking and the plans were shelved. Efforts to acquire premises on Oxford Road, which members of staff inspected and liked, were similarly not supported by the university. It is for this reason, amongst others, that it is such a tremendous privilege to see the new building finally a reality – indeed a dream come true.

### Public Health: 1993–2002

Public Health at Wits, as elsewhere, was not the stuff that medical faculties were made of in the 1990s. Two factors influenced the trajectory of the academic discipline of Public Health significantly. The first was the dramatic political change in South Africa which led to the establishment of a new democratic order with human rights, including the right to health and health care, enshrined in the country’s constitution. The School played a significant role in shaping national health policy

in South Africa. In 1994, two of the nine ministerial committees were chaired by staff in the School, and many other staff members served on a range of committees and advisory bodies that ultimately influenced government thinking and health policies in the democratic era. The second major event was the HIV and AIDS disaster, which had a devastating effect on mortality and morbidity in South Africa and brought enormous challenges to its health system. These external factors had an impact on the development of Public Health in significant ways. The new government had a large constituency to whose needs it had to respond to. As a result, it looked to Public Health to address the dire health problems faced by a large majority of South Africans, while the HIV epidemic exposed the worst failings of the South African Public Health system.

Notwithstanding these imperatives, material support for academic Public Health was not forthcoming. It took a lot of nagging and some strong words to eventually gain seven additional academic posts from the Gauteng Health Department in 2002, bearing in mind that the WSPH only had about nine provincial Health Department funded posts at the time, some of which were ‘frozen’ during the implementation of financial austerity measures as part of the government’s Growth Equity and Redistribution (GEAR) policy in the late 1990s.

The emergence of Public Health at Wits also benefited from the readmission of South Africa to the world community, leading to exposure to many academics prominent in international Public Health. The school benefited from a regular stream of international visitors from other parts of Africa, Latin America, Asia, the United States of America and the United Kingdom. In South Africa, the 1990s saw several initiatives to start regional schools of Public Health. Wits University was part of the five-university initiative, called the Transvaal School of Public Health (later named the Thusano School of Public Health or TSPH), which aimed to strengthen the discipline of Public Health in the northern regions of South Africa. All in the Faculty did not

support the TSPH as some felt that trans-university courses and programmes would compromise Wits' academic standards. These barriers had to be overcome and eventually an agreement at the level of the university Vice-Chancellors formalised the TSPH.

Following the World Development Report 1993, which argued the economic case for investing in health, there was a growing realisation that the global burden of diseases like malaria, HIV & AIDS and tuberculosis had a negative impact on the world economy. As a result, the world's rich nations established the Global Fund that supported the response to these three killer diseases. This gave added impetus to a worldwide resurgence of Public Health and provided much needed resources for Public Health research in South Africa.

In keeping with its commitment to strengthen South Africa's Public Health capacity, the WSPH initiated a Master of Public Health (MPH) programme and an MSc in Epidemiology in addition to the existing diploma courses, despite the enormous strain put on the limited teaching resources. This resulted in student numbers growing exponentially.

Meanwhile, the rural health initiatives started by John Gear, flourished. The Wits Rural Facility underwent a new incarnation; the Health Services (later Systems) Development Unit thrived, and spawned the Agincourt Project, which has since become one of the leading demographic and health surveillance sites in the world. Agincourt, in turn, gave birth to the Rural AIDS and Development Action Research programme (RADAR).

The Centre for Health Policy (CHP) excelled in the new post-apartheid environment and provided policy support for many government initiatives. It grew in size and the Women's Health Project, which it housed,

became a leader in the struggle for gender equality in health care. This went on to have an enormous influence in shaping South Africa's new abortion legislation.

Urban Health was not to be left out as the School, as part of the WHO Collaborating Centre for Urban Health, continued to work in inner city areas such as Hillbrow and the Alexandra Township to the north of Johannesburg city centre. The emergence of Urban Health as a major field of endeavour internationally, led to the publication of the Urban Health Bulletin, the Healthy Cities movement and an increasing international collaboration of the School with partners in Europe, Africa, Latin America and South East Asia.

The novel addition of the Division of Oral Public Health enriched the academic endeavour of the WSPH, bringing much needed attention to the field of health promotion.

As I reflect on the Wits School in the 1990s, I am struck by the confluence of events, internationally and nationally, which provided a window of opportunity for Public Health to play a significant role in the improvement of the human condition. I have no doubt that the new School of Public Health building will stand as a beacon of hope for the improvement of population health, especially for the marginalised, dispossessed, oppressed and disempowered, in South Africa and beyond.

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**\*William Pick**

School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
A106 Dolphin Beach  
1 Marine Drive  
Table View 7441  
South Africa

# Estimating the extent of household contact misclassification with index cases of disease in longitudinal studies using a stochastic simulation model

Tobias Chirwa<sup>1\*</sup>, Sian Floyd<sup>2</sup> and Paul Fine<sup>2</sup>

<sup>1</sup>Division of Epidemiology and Biostatistics, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, UK

**Background:** Household contact with an index case of an infectious disease is a known risk factor for infection transmission. However, such contact may be underestimated due to the dynamic nature of households, particularly in longitudinal studies. Such studies generally begin with contact defined at a single point in time ('snap-shot'), leading to contact misclassification for some individuals who actually experienced contact before and after the snapshot.

**Objective:** To quantify contact misclassification with index cases of disease in households.

**Methods:** Historical data of 112,026 individuals from 17,889 households from an epidemiological study on leprosy in northern Malawi were used. Individuals were interviewed in the early 1980s and followed up over 5 years. It was possible to trace whether individuals died, changed household within the area, or moved out of the area between the two surveys.

Using a 10% sample of households as the starting population and parameters for demographic and household changes over 5 years, the extent of contact misclassification was estimated through a simulation model of household dynamics, which traced contact with index cases in households over time. The model thereafter compared initial contact status and 'true' contact status generated from simulations.

**Results:** The starting population had 11,401 individuals, 52% female, and 224 (2%) leprosy index cases. Eleven percent of the households had at least one index case resident and 10% (1,177) of non-case individuals were initial contacts. Sensitivity of initial contact status ranged from 0.52 to 0.74 and varied by age and sex. Sensitivity was low in those aged 20–29 and under 5 years but high in 5- to 14-year-olds. By gender, there were no differences among those aged under 5; females had lower sensitivity among those aged under 20 and higher for those above 30, respectively. Sensitivity was also low in simulations of long incubation periods.

**Conclusion:** This work demonstrates the implications of changes in households on household contact-associated disease spread, particularly for long durations of follow-up and infections with long incubation periods where earlier unobserved contact is critical.

Keywords: *household; contact; simulation; misclassification; demography; sensitivity; longitudinal studies*

Appendices available online under Reading Tools.

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One way to determine risk of disease in populations or communities is through contact tracing to see whether someone who has had contact with index cases develops the disease. Such contact is often recorded at school, household or familial level – standardised settings which control for the environment or human behavioural factors.

Over decades, households and closed communities have proved to be useful (1–4) for generating knowledge of the communicability of various infections. In these instances, exposure and susceptibility are derived by observing spread within households, where close contact and mixing are easily identified (2, 5–8). If an infected person is present in a household, household members may be at an elevated risk of infection because closeness of contact is likely to be related to dose intensity or degree of infectivity (1, 2), which, in turn, is related to the infection transmission and occurrence of disease.

There have been several studies of infection transmission in households, mainly acute communicable diseases such as measles, influenza, and diphtheria (1–6, 9–13), where index cases of infection are easily identified and incubation periods are short. In contrast, for chronic infections (14–16), it is much harder to derive infection transmission knowledge because of the long and variable incubation period of the disease (17, 18) and the dynamic contact networks over time (6, 7, 19). Although many studies on actual transmission have been carried out and are well documented, very few (5, 6, 19) have looked at the number of the susceptible population that have been missed due to the assumption that the contact's details have remained static (19–22).

Although there are practical challenges, studies have been conducted which have attempted to trace contacts over time. For example, studies of newly diagnosed tuberculosis cases emphasise examining all close contacts at the time of diagnosis (14, 23–25) and retrospective investigation to trace their contact histories (26, 27). However, contact histories of diagnosed cases prior to the time of diagnosis are subject to considerable error, especially so for those who lived in different households compared to the one in which they lived when recorded at the time of diagnosis (2, 15, 24, 26, 27). Furthermore, casual and transient contact with infectious cases in these households, over time, may go unnoticed but could play a significant role in transmission of infection. Models developed on the risk of contact are simplistic and make assumptions that are not informed by direct data sources (6, 7, 19). Therefore, there is considerable scope for misclassification. This necessitates investigations through simulations of household dynamics to provide an understanding of the magnitude of the problem of contact misclassification through dynamic contact networks.

While some studies have acknowledged problems of misclassification and the use of simplistic random mixing

assumptions (6, 28), very few have investigated these issues further except through validation studies conducted outside the study populations (6, 21, 23, 24, 29). This study aimed to quantify misclassification of contacts with an index case of disease in households.

## Methods

### *Study design and population*

This study utilised data from a large epidemiological study of leprosy in Karonga District, Northern Malawi. Details of the methodology, including data management and procedures to ensure good quality data, are explained elsewhere (30, 31). Briefly, the data were collected through two linked population surveys. The first survey (LEP-1) was carried out from early 1979 to 1984 and the second survey (LEP-2) from 1986 to 1989. Individuals were assessed for disease in LEP-2. Individuals were uniquely identified and linked to households in which they resided during LEP-1 and LEP-2. An effort was made in LEP-2 to trace all individuals identified in LEP-1. It was therefore possible to collect socio-demographic data and trace whether individuals died, changed household within the area or moved out of the area between the two surveys.

A household was defined as a group of people living together and acknowledging one person as the head. Information collected on uniquely identified households included geographical location, head of household and household assets. Index cases were defined as individuals diagnosed as having leprosy prior to or at their first examination in the LEP-1 survey. Incident cases were those cases diagnosed only *after* the first examination. Observed contacts were individuals who resided in a household with an index case of leprosy whereas non-contacts were individuals who were assumed to never have had any household contact with an index case of disease.

### *Sensitivity of initial contact status*

Before describing the stochastic micro-simulation model, we first define sensitivity of initial contact status. The simulation model of household changes traced contact histories of individuals over time. The contact status generated through simulations was considered as the 'true' underlying state of household contact status of an individual by the end of follow-up. This study compared initial (observed) contact status at baseline and 'true' underlying contact status from simulations and computed *sensitivity* of initial contact status, defined as the proportion of true contacts that were correctly observed as contacts at the start of follow-up.

Due to the long and variable incubation period of diseases such as leprosy and tuberculosis, some incident cases that arise during the follow-up period may be attributable to earlier household contact before the

period of study rather than that recognised at baseline or during follow-up. Thus, sensitivity was calculated using two approaches to take into account, separately, household contacts before and during the study.

'Forward' sensitivity is appropriate for situations in which the incubation period of disease is relatively short and most contacts leading to disease occur during the study period. 'Forward' sensitivity of contact status was thus defined as the proportion of individuals in contact with at least one (index) case at any time during follow-up that were correctly observed as contacts at baseline.

'Backward' sensitivity relates to the measure of relevant contact, which occurred in the past, before baseline assessment. 'Backward' sensitivity of contact status was defined as the proportion of individuals who were in contact with at least one (index) case prior to the onset of follow up that were correctly recognised as contacts at the start of follow-up.

### Micro-simulation model for household dynamics

A stochastic micro-simulation model of household dynamics, which affect household contact status over a period of time, was developed using extrinsic processes, mainly demographic events (32), model dynamic contact networks, as outlined by Bansal et al. (19). The key demographic events modelled at individual level were: birth, death, marriage, migration into and out of the district, respectively, and individual household change within the district. These events were chosen because they are critical to changes in a population structure and that directly affect household composition, with implications for household contact with index cases of disease.

An initial sample of individuals and their attributes (32) was obtained from the actual LEP population defined by age, sex, and household. Initially, non-case individuals who were resident in households with an index case of disease were considered as contacts whereas those who were resident in non-case households were considered as non-contacts. The demographic events were simulated on an individual and annual basis. Histories of

household contact with index cases were tracked through the simulation model and values of sensitivity of initial contact status were calculated based on these histories. The annual probabilities of an individual experiencing change of household and each of the demographic events were derived from either the LEP or census data (Table 1) (33).

Figure 1 presents an overview of the micro-simulation model. Only key procedures for household contact are presented below, with further details of the specific procedures presented in Appendix A.

### Change of household

The simulation modelled annual movements of individuals within the study area by checking whether their current household was different compared to the one they resided in the preceding year. If the two households were different, then the model recorded a change in household.

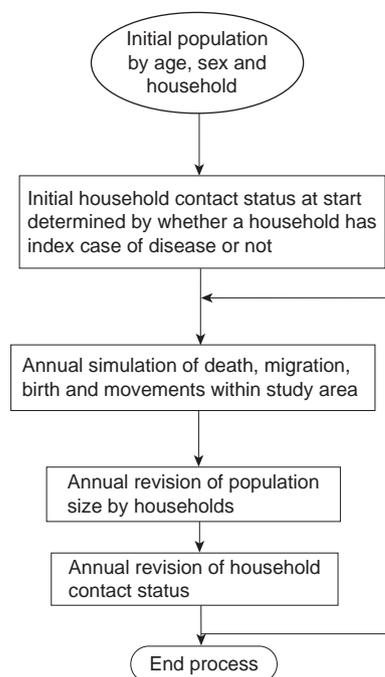
At the start of the simulation, the 'true' contact status of an individual was set to either 'Yes' if they were already in household contact with an index case at the start of the simulation or 'No' if they had no such household contact. The 'true' contact status was successively updated on an annual basis during the simulation period. In addition, the initial duration of contact with an index case was set to either 0 if one was not in household contact with a case or one for those already in contact with an index case at the start of the simulation.

If an individual who had been in contact with a case before moved into a case household, the duration of contact was incremented by one. If the individual had not been in contact with a case before only their 'true' contact status is changed to 'Yes'. For all changes in household that were executed by the simulations, the new and previous sizes of households were increased and decreased by 1, respectively.

Furthermore, if an index case of disease moved into a household, the 'true' contact status of individuals in that household who were not in contact with a case before was changed and duration of contact was increased by 1. However, if individuals in the new household were

**Table 1.** Annual probabilities of demographic events occurring by age and sex, Karonga District, northern Malawi 1979–89

Event	Sex	Age group (in years)								
		0	1–4	5–9	10–14	15–19	20–24	25–29	30–44	45+
Death	Male	0.1523	0.0392	0.0077	0.0047	0.0033	0.0038	0.0069	0.0063	0.0254
	Female	0.1259	0.0297	0.0071	0.0045	0.0024	0.0062	0.0051	0.0074	0.0226
Change of household	Male	0.0500	0.0500	0.0439	0.0476	0.0836	0.1274	0.0799	0.0321	0.0168
	Female	0.0528	0.0528	0.0558	0.1125	0.1801	0.1079	0.0658	0.0428	0.0347
Out-migration	Male	0.0229	0.0229	0.0204	0.0247	0.0402	0.0535	0.0403	0.0283	0.0075
	Female	0.0252	0.0252	0.0276	0.0321	0.0387	0.0459	0.0228	0.0173	0.0049



**Fig. 1.** Overview of the stochastic micro-simulation model for household dynamics.

already contacts, only the duration of contact was increased.

#### Demographic events

The positions of individuals in a household were categorised as ‘head’, ‘member’, and ‘other’ (visitor, employed worker, renter, or their relatives). A ‘member’ could be a spouse, child, or a relative to the spouse of head or head himself. Allocation of positions to household occupants was carried out to maintain culturally recognised household structures after simulating demographic and other key events, but did not have any implications for determining contact status.

If any individual other than a head of household died, out-migrated or changed household, the individual’s record was marked for removal from their current household. If the individual were in a single-person household, that household was dissolved.

A head of household is a key individual and any demographic event associated with a head has implications for household dissolution and further contact with index cases of disease. If a head of household died, out-migrated, or changed household within the district, the oldest ‘member’ of that household aged more than 18 years was assigned as the new head. However, if the oldest ‘member’ was below 18, that household was dissolved and its occupants were randomly allocated to other existing households using the neighbourhood preference approach explained in this article. Such allocation of

positions and to households was justified from the LEP data (33).

#### Household allocation procedure

Allocation of households to individuals marked as having either changed households, in-migrated or whose households had been dissolved was carried out on an annual basis. Individuals who changed households were either randomly allocated (with probability 0.05) to newly formed households or to existing households.

The allocation of individuals to existing households was influenced by ‘proximity’ of households. It was assumed (and this was the case in LEP data) that the closer the household serial numbers, the smaller the physical distance between the households and the more likely a movement was to occur between them.

Generation of the destination existing (new) household serial number for individuals who moved was a function of the previous household, based on a standard normal random value and pre-determined constant standard deviation. Explicitly,  $H_n = H_0 \pm Z^* \sigma$ , where  $H_n$  and  $H_0$  are new and previous household serial numbers;  $Z$  and  $\sigma$  are the standard normal random value and standard deviation, respectively. The choice of standard deviation was such that a large proportion of individuals were allocated to nearby households although some still moved considerable distances.

#### Generation of incident cases

It was inevitable that some initial index cases would be lost to migration and death during the simulation period. Thus, to avoid depletion of ‘index cases’ over time, incident cases were generated based on age and sex incidence rates obtained from previous studies in the same population. The incident cases generated in simulations of long incubation periods were assumed to become infectious at onset of disease and to remain infectious for 3 years.

#### Simulation runs

In general, 50 simulations of up to a 5-year period each were run and each simulation run produced ‘forward’ and ‘backward’ sensitivity of contact status values by age and sex. For ‘backward’ sensitivity, the length of observation time prior to the start of study, required to identify the relevant ‘window of opportunity of contact’ was carefully defined since not *all* earlier contact may be relevant for disease that may be observed in the study period.

This was achieved by running a series of simulations of 10-year periods and investigating how varying the length of observation time prior to the start of study affected household contact status misclassification. Fifty simulations of 10-year periods each were run with incubation periods of 5, 7 and 9 years separately.

For example, to calculate sensitivity based on an  $n$ -year incubation period and for a 10-year simulation period, we were interested in contacts arising between  $b-n$  and  $e-n$ , where  $b$  and  $e$  are beginning and end of the cohort study period, respectively.

The mean sensitivity of contact status was the average over all the simulation runs. The 95% confidence intervals of sensitivity of contact status are calculated assuming normality with standard deviation calculated from the generated sensitivity values. The crude 95% confidence intervals (34) were given by obtaining the 2.5th and 97.5th percentiles of values of sensitivity of initial contact status. Values of the sensitivity have been estimated for different age and sex categories and long incubation period circumstances. The simulations were run using SAS/IML (Macros).

### Stability of the model

Stability of the model was investigated by comparing structure of the population and household size distribution before and after simulations. The household size, age, and sex distributions were approximately similar (data not shown) reflecting how well the simulation captures the original structure. The minor differences were considered acceptable for the purpose of tracking contact status.

## Results

This section presents results from the simulation model. It includes both forward and backward sensitivity of contact status based on annual household changes and also based on the duration of follow-up. Results from demographic and household dynamics analysis based on these LEP data have been published elsewhere (33, 35).

### Sensitivity of contact status

#### Forward sensitivity based on lower and upper mean rate of household change

Being the most important input parameter for determining misclassification, simulations of 5-year periods each were run separately using the 95% lower and upper confidence limits of the annual rate of change of household (Table 2) to assess the extent of variation in sensitivity. The sensitivity values obtained from these simulations were compared to those obtained using the 'mean' annual rate of household change. Only small differences in the 'forward' sensitivity of contact status were observed regardless of whether one used the 95% confidence limits or mean. Thus, it was deemed adequate to only investigate sensitivity values based on the mean annual rate of changing household.

**Table 2.** Annual probabilities of change of household (95% confidence intervals), return moves and in-migration by age and sex, Karonga District, Northern Malawi, 1979–89

95% confidence interval for annual probabilities of change of household by age and sex, Karonga District, northern Malawi 1979–89										
Sex										
Male	Lower limit	0.0477	0.0477	0.0417	0.0450	0.0796	0.1208	0.0742	0.0284	0.0127
	Upper limit	0.0523	0.0523	0.0460	0.0502	0.0878	0.1342	0.0853	0.0357	0.0212
Female	Lower limit	0.0504	0.0504	0.0533	0.1081	0.1739	0.1020	0.0621	0.0403	0.0297
	Upper limit	0.0552	0.0552	0.0584	0.1170	0.1866	0.1140	0.0694	0.0478	0.0442
Conditional probabilities of individuals making return (as opposed to forward) moves to households by age and sex, Karonga District, northern Malawi 1979–89										
Male		0.52	0.52	0.52	0.58	0.24	0.33	0.20	0.44	0.75
Female		0.41	0.41	0.41	0.27	0.18	0.14	0.38	0.21	0.36
Annual in-migration rates (per person) in Karonga District, Malawi 1986–89										
Male		0.0120	0.0120	0.0192	0.0188	0.0241	0.0315	0.0349	0.0202	0.0068
Female		0.0115	0.0115	0.0185	0.0246	0.0349	0.0417	0.0436	0.0184	0.0083

### Forward sensitivity of contact status

Table 3 presents estimates of the ‘forward’ sensitivity of contact status by age (defined at LEP-1) and sex, with duration of follow-up varying from 1 to 5 years.

As expected, the sensitivity declined with duration of follow-up. Sensitivity values for a 1-year period of follow-up were over 85% whereas those for a 5-year period ranged between 50 and 75%.

The age and sex distribution of sensitivity values for the 5-year duration of follow-up were the same under 50 and 100 simulation runs of the model. The sensitivity values showed no apparent sex differences for children aged less than 5. The distribution of the forward sensitivity peaked at 73 and 68% in boys and girls aged 5–9 years, respectively. The values were lower among females than males in age groups 5–19 and were lowest in the 25–29 age groups in both males and females (56 and 52%, respectively). Household contact misclassification decreased with age for individuals over 30, with greater misclassification for males than females.

### Crude 95% confidence intervals for ‘forward’ sensitivity

The sources of uncertainty in sensitivity of contact status may be due not only to variation in change of household but also to stochastic variability in the simulations. The latter reflects our uncertainty about the relation between the contact status and demographic events of interests. In that regard, the crude 95% confidence limits of sensitivity of contact status from the simulation model capture this stochastic variability.

From Figs. 2a and 2b, we noted that the crude 95% confidence intervals for the sensitivity of contact status were much wider than those obtained using a relative precision of 20% (chosen arbitrarily) of the mean annual household change. The width was more pro-

nounced for those aged less than 1 year and those aged 25–29 years.

The crude 95% confidence intervals gave the bounds within which the true value of age/sex specific sensitivity of initial contact status was expected to lie without varying the input parameters of the model. However, even after varying the estimates of change of household by up to 20%, we still got values of sensitivity of initial contact status that lay within the crude 95% confidence intervals across all age groups.

### Backward sensitivity of initial contact status

Some incident cases that arise during a follow-up period of study may partly be attributable to contact which occurred prior to the period of study. Table 4 shows the expected trend of decline in sensitivity of initial contact status with increasing incubation period.

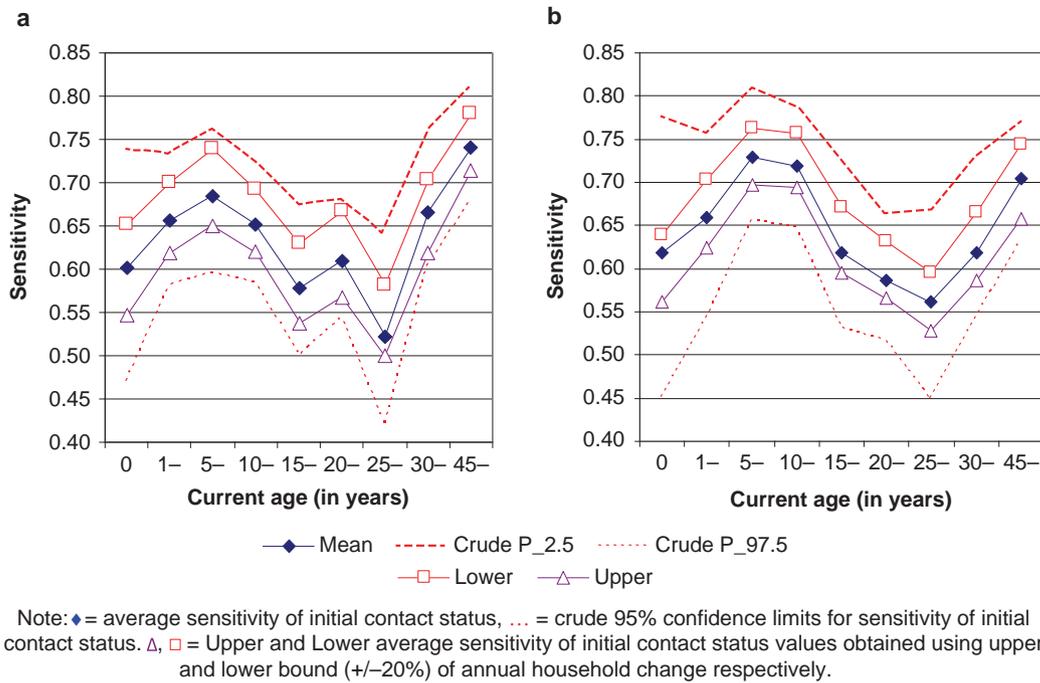
## Discussion

This paper has demonstrated some of the complicated household dynamic issues, which affect efforts to study contact-associated spread of infectious diseases. As shown by Pickles (2–4) at community level, real-time contact tracing, even in acute infections, has challenges of identifying source cases of infection, their contacts as well as secondary cases. This problem is greater in chronic infections with long incubation periods. Whereas in acute infections, it is safe to assume static contact networks, this assumption fails in chronic infections where contact networks are dynamic. Thus, without good quality data, estimation of infection transmission through household contacts is a challenge.

Furthermore, various mathematical or statistical models have been developed to investigate infection transmission through contact networks (5, 19, 21–23, 29, 36). Most of these have assumed static contact leading to the

**Table 3.** Forward sensitivity of initial contact status by age and sex from 50 simulation runs with different duration of follow-up based on contact with all index cases

Age group (in years)	Duration of follow-up (in years)									
	1		2		3		4		5	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
0	0.89	0.87	0.79	0.80	0.71	0.71	0.66	0.65	0.62	0.60
1–4	0.93	0.91	0.86	0.83	0.78	0.78	0.70	0.70	0.66	0.66
5–9	0.92	0.92	0.84	0.82	0.81	0.78	0.77	0.72	0.73	0.68
10–14	0.90	0.89	0.85	0.81	0.79	0.73	0.74	0.69	0.72	0.65
15–19	0.87	0.87	0.80	0.78	0.72	0.72	0.64	0.64	0.62	0.58
20–24	0.87	0.83	0.77	0.75	0.69	0.69	0.66	0.66	0.59	0.61
25–29	0.86	0.89	0.77	0.79	0.69	0.67	0.60	0.54	0.56	0.52
30–44	0.87	0.90	0.76	0.81	0.69	0.76	0.64	0.71	0.62	0.67
45+	0.90	0.92	0.85	0.87	0.79	0.82	0.74	0.77	0.70	0.74



*Fig. 2.* (a) Crude confidence intervals of initial contact status versus ‘true’ contact status (sensitivity) for females by age. (b) Crude confidence intervals of initial contact status versus ‘true’ contact status (sensitivity) for males, by age.

potential under-estimation of household contact associated risks. This paper is one such attempt to use dynamic household contact networks and to provide relevant background for future improvements where more reliable data are available. We were able to estimate movements of index cases and their contacts and contact status misclassification.

Despite the significance of the results for public health, the study was not without limitations. The major assumption made was that rates of deaths, migration, and movement between households are constant and random during the period of the simulation. However, in most societies, household change by a parent may imply particular changes for their children but such data were not available.

We also assumed that disease status in index cases is not misclassified, that distance between households does not affect infection and that the incubation period is fixed. It is known that incubation period, for example, of tuberculosis (37, 38), may depend on age at exposure and dose of the infectious agent. Because little is known on the distribution of the incubation period of leprosy, we assumed different fixed incubation periods.

Finally, this study only looked at tracing contact within households to investigate the traceable extent of misclassification. Household is one of the many contact points and contact outside the household such as at work, school, travel, and community gatherings were not considered in our simulations.

Not even a detailed stochastic simulation model such as this can capture all of the household changes. A model is by definition a simplification of reality and should not be over-interpreted. The complexity of the model can vary depending on time and the research question. In this paper, the objective was to enhance the understanding of the principles of household dynamics and how they affect household contact.

The propensity of an individual to change household has important implications for contact status misclassification. A low sensitivity of initial contact status measure is a reflection of a high rate of household change. This study has shown that the distribution of sensitivity values with age is inversely related to the rate of household change, which is low in children but high in young adults. The observed earlier lower sensitivity among young adult females compared to males is related to earlier household change for females largely due to early onset of marriage. There were no apparent sex differences in sensitivity values for children aged less than 5 years, as their movements are largely dependent on their parents or guardians.

The longer the duration of follow-up, the greater the misclassification of contact status due to increased household dynamics. The ‘forward’ and ‘backward’ perspectives in this paper describe an important distinction of contacts arising during the follow-up period and unobserved earlier relevant contact before the start of study. We observed that, in general, values for ‘backward’ sensitivity

**Table 4.** Values of backward sensitivity of contact status (standard deviation) for contacts of all index cases from simulations with long incubation period after 50 simulation runs of a 10-year period with fixed 5 years of follow-up

Age group (in years)	Length of incubation period (in years)					
	5		7		9	
	Male	Female	Male	Female	Male	Female
0–9	0.60 (0.0308)	0.60 (0.0295)	0.52 (0.0374)	0.52 (0.0310)	0.48 (0.0318)	0.48 (0.0308)
10–14	0.62 (0.0358)	0.59 (0.0394)	0.54 (0.0413)	0.50 (0.0438)	0.51 (0.0478)	0.45 (0.0386)
15–19	0.61 (0.0291)	0.57 (0.0405)	0.53 (0.0401)	0.46 (0.0391)	0.47 (0.0405)	0.43 (0.0456)
20–24	0.60 (0.0367)	0.60 (0.0482)	0.50 (0.0505)	0.50 (0.0424)	0.43 (0.0421)	0.46 (0.0586)
25–29	0.57 (0.0468)	0.67 (0.0373)	0.47 (0.0471)	0.57 (0.0434)	0.40 (0.0565)	0.54 (0.0475)
30–44	0.64 (0.0427)	0.78 (0.0390)	0.56 (0.0426)	0.71 (0.0484)	0.51 (0.0529)	0.70 (0.0448)
45+	0.68 (0.0320)	0.67 (0.0327)	0.60 (0.0449)	0.61 (0.0350)	0.56 (0.0402)	0.57 (0.0410)

are lower than ‘forward’ sensitivity of initial contact status. Further, the longer the incubation period, not only are differences more pronounced but also the lower the ‘backward’ sensitivity. This shows that the likelihood for an actual earlier contact to go unrecognised can be great leading to high contact status misclassification. It is therefore important to appreciate that, when dealing with household contact-associated spread of diseases, such as leprosy and tuberculosis, much of the new disease observed during follow-up may well be attributable to unobserved earlier household contact.

The effect of household change may be reduced by conducting studies on infection transmission within households for shorter periods of follow-up and for only those areas where the household change rates are low, thus ensuring minimum contact status misclassification. However, where such conditions are not possible, estimations of misclassification values from this study are useful in obtaining reliable estimates of risk of disease associated with household contact in the same or similar population settings.

This study has shown the extent of household contact misclassification in a rural African setting in northern Malawi. The demographic trends and issues that drive mobility in various African countries are similar (39–45) and the findings are generally applicable regionally. However, availability of good quality data to derive parameters for modelling to generate reliable estimates of risk of disease is a challenge. Currently, there is an increase in longitudinal studies, especially demographic surveillance sites (19, 46–48), where such data is increasingly available for use in more appropriate dynamic contact networks modelling.

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**\*Tobias Chirwa**

Division of Epidemiology and Biostatistics  
 School of Public Health  
 Faculty of Health Sciences  
 University of the Witwatersrand, Johannesburg  
 7 York Road, Parktown 2193  
 South Africa  
 Email: tobias.chirwa@wits.ac.za

# Convergence in fertility of South Africans and Mozambicans<sup>†</sup> in rural South Africa, 1993–2009

Jill Williams<sup>1,2\*</sup>, Latifat Ibisomi<sup>2,3</sup>, Benn Sartorius<sup>4</sup>, Kathleen Kahn<sup>2,5,6</sup>, Mark Collinson<sup>2,5,6</sup>, Stephen Tollman<sup>2,5,6</sup> and Michel Garenne<sup>2,7,8</sup>

<sup>1</sup>Institute of Behavioral Science, Population Program, University of Colorado Boulder, Boulder, CO, USA; <sup>2</sup>MRC/Wits Rural Public Health and Health Transitions Research Unit, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Demography and Population Studies Programme, School of Social Sciences, Faculty of Humanities, University of the Witwatersrand, Johannesburg, South Africa; <sup>4</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg; <sup>5</sup>Centre for Global Health Research, Umeå University, Umeå, Sweden; <sup>6</sup>INDEPTH Network, Accra, Ghana; <sup>7</sup>Epidémiologie des Maladies Emergentes, Institut Pasteur, Paris, France; <sup>8</sup>Institut de Recherche pour le Développement (IRD), Unite Mixte Internationale (UMI) Résiliences, Paris, France

**Background:** Although there are significant numbers of people displaced by war in Africa, very little is known about long-term changes in the fertility of refugees. Refugees of the Mozambican civil war (1977–1992) settled in many neighbouring countries, including South Africa. A large number of Mozambican refugees settled within the Agincourt sub-district, underpinned by a Health and Socio-demographic Surveillance Site (AHDSS), established in 1992, and have remained there. The AHDSS data provide a unique opportunity to study changes in fertility over time and the role that the fertility of self-settled refugee populations plays in the overall fertility level of the host community, a highly relevant factor in many areas of sub-Saharan Africa.

**Objectives:** To examine the change in fertility of former Mozambican self-settled refugees over a period of 16 years and to compare the overall fertility and fertility patterns of Mozambicans to host South Africans.

**Methods:** Prospective data from the AHDSS on births from 1993 to 2009 were used to compare fertility trends and patterns and to examine socio-economic factors that may be associated with fertility change.

**Results:** There has been a sharp decline in fertility in the Mozambican population and convergence in fertility patterns of Mozambican and local South African women. The convergence of fertility patterns coincides with a convergence in other socio-economic factors.

**Conclusion:** The fertility of Mozambicans has decreased significantly and Mozambicans are adopting the childbearing patterns of South African women. The decline in Mozambican fertility has occurred alongside socio-economic gains. There remains, however, high unemployment and endemic poverty in the area and fertility is not likely to decrease further without increased delivery of family planning to adolescents and increased education and job opportunities for women.

**Keywords:** *fertility decline; education; adolescent fertility; birth intervals; labour force participation; contraception; socio-economic development; refugees; adaptation; Agincourt health and socio-demographic surveillance site*

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Africa is home to about a fifth of the world's refugees, most of whom have been victims of forced migration (1). However, little is known

about the long-term impact of refugee status on fertility rates. Most studies of migration and fertility in Africa have focussed on examining the impact of rural to urban

<sup>†</sup>There are family and kinship ties between present-day South Africans and Mozambicans that extend back for generations. Many thousands of Mozambicans entered South Africa as refugees during and after the civil war during the 1970s and into the 1980s. Most who settled in the vicinity of Agincourt sub-district chose to remain and this was facilitated by common kinship and family ties. Today, a high proportion of these former Mozambican refugees are eligible for and have accessed South African ID documents and enjoy all the rights of South African citizenship. Their children, born in South Africa, are regarded as fully South African.

migration on fertility or, less common, the impact of circular migration on fertility in rural populations (2–4).

War and resettlement can place both upward and downward pressure on fertility in the short term. Upward pressure may come from the desire to replace those lost in war, while downward pressure on fertility may come from the disruption of life and relationships caused by war (5). Studies of these effects over the short term find that many factors – including social characteristics of people prior to war – determine fertility levels in the short- and medium-term after war (5, 6). Biological factors such as subfecundity caused by malnutrition can also play a role in suppressing refugee fertility in the short term. Studies on forced migration and resettlement suggest that fertility of refugees in the long run is influenced by the same social and demographic factors that impact on fertility for everyone, such as education, age, socio-economic status, and urban or rural residence (5).

However, most studies on refugee fertility are conducted in refugee camps and the situation may differ for refugees not living in camps. Populations that settle in host countries without residing in camps are likely to be different from those in refugee camps since they are not served directly by aid programs. Many studies of the fertility of self-settled refugees exist in developed countries with vital registration systems. However, studies of self-settled refugee populations in Africa where vital registration systems are lacking are rare. Prospective data from the Agincourt sub-district in Mpumalanga Province in rural northeast South Africa provide an opportunity to examine the change in fertility of self-settled Mozambican refugees over a period of 16 years (1993–2009) and to examine their impact on overall fertility levels in the area. Earlier research using data from the Agincourt health and socio-demographic surveillance site (AHDSS) found that Mozambican refugees in Agincourt contributed to a noticeable increase in the average number of children borne (total fertility rate – TFR) by women in the 1980s measured retrospectively through birth histories (7). Subsequently, the TFR for all of Agincourt has dropped from 3.7 in 1993 to a low of 2.3 in 2002 and has hovered around 2.5 since then. This fertility decline is similar to that across rural South Africa during the same period (6, 7).

Fertility decline in South Africa generally is attributed in part to the widespread use of modern contraceptives. A national family planning programme was started in 1974 in large part due to an ideological response by the *apartheid* regime to the spectre of rapid population growth among the African population. The programme provided free modern contraceptives in public health clinics, including oral and injectable contraceptives (6, 7). The 1998 Demographic and Health Survey found that 51.2% of sexually active African women in rural areas

used some form of modern contraception (8). In 2003 this number increased to 61% (9).

Despite the observed decrease in fertility in the AHDSS since the early 1990s, little is known about the fertility of Mozambican women over time in Agincourt – if, when, and how fast their fertility decreased since the early 1990s. In this study, we examine changes in fertility levels and patterns over time through a comparative analysis between the two main population groups in Agincourt – South Africans and Mozambicans. We examine (1) TFRs, (2) age specific fertility rates (ASFR), (3) timing of first and second births, and (4) trends in selected socio-economic characteristics likely to influence changes in fertility of Mozambican women in Agincourt.

## Methods

We use prospective longitudinal data on births in the AHDSS in Agincourt to examine the fertility of Mozambican women and compare it to that of African South Africans in the same area. The AHDSS covers much of what is now the Agincourt sub-district but was previously part of an *apartheid* Bantustan (or ‘homeland’), Gazankulu, where African South Africans were resettled as part of the *apartheid* regime’s strategy of ‘separate development’ (10). Most of the people, both South Africans and Mozambicans, in this area belong to the Shangaan speaking.

Agincourt itself is only about 40 km west of the southern Mozambique border. About a third of the population living in the area covered by the AHDSS are Mozambican, most having entered the country as refugees in the early to mid-1980s during the Mozambican civil war between 1977 and 1992 (11). Despite voluntary repatriation programmes in 1994, a large proportion of refugees elected to stay in the area. Therefore, the AHDSS arguably contains the largest population of self-settled refugees under health and demographic surveillance in the world (12).

Our analysis is based on 21 villages covered by the AHDSS from 1993–2009 and uses data from women aged 15–49 who gave birth in Agincourt.<sup>1</sup> Information on births, including limited information on the use of contraception prior to a birth, is collected in regular census rounds conducted since the baseline in 1992. Additional data on individuals and households are collected through special modules in the annual census update. The education of individuals is updated regularly and our analysis

<sup>1</sup>The proportion of Mozambican women in the population remained about one-third throughout the study period. Since 1994 some Mozambicans have migrated voluntarily into the area and are included in the analysis with Mozambican refugees. However the percentage of in-migrants was minimal for the majority of the study period. Until 2007 less than 4% of the Mozambican population in the AHDSS were in-migrants. By 2009, 17.6% of the Mozambican population in the AHDSS were in-migrants.

uses the highest level of education recorded for women. Women’s employment status was captured in 2000, 2004, and 2008. Household asset status has been measured every second year since 2001 and is used to create measures of household wealth.<sup>2</sup>

The standard method for estimating the age pattern of fertility (technically referred to as ASFR) and the level of fertility measured by the TFR are used to examine fertility trends. The latter is defined as the average number of children that a woman would have by the end of her reproductive life if the current age pattern of fertility were to remain unchanged. Descriptive statistics are used to describe changes in the age pattern of fertility over time. A discrete time event framework is used to evaluate women’s progression from a first to a second birth within five years and smoothed survival curves are presented. Other socio-economic trends are examined by estimating levels of employment, household wealth, and formal education.

## Results

### Total fertility rates

Figure 1 is based on prospective data beginning in 1993 which shows fertility declining significantly in both population groups in the early 1990s. Figure 1 also shows that Mozambican refugees had higher fertility rates than South Africans until late 2000s, 20–29 years after their initial influx.

Fertility levels were quite different in the two populations during the 1990s, with Mozambican women maintaining higher fertility than South Africans. Thereafter, the two populations increasingly exhibit similar fertility levels, converging from 2000 when the confidence intervals around the fertility estimates for the two groups started overlapping. Figure 1 also suggests a stall in the fertility decline of both populations since 2002. This corroborates research suggesting that fertility decline may have stalled in South Africa (6, 15).

### Patterns of childbearing

The convergence of total fertility of the two population groups is driven primarily by the decline in fertility among Mozambican women to the levels of South African women. This suggests that Mozambican women were adopting fertility behaviours similar to those of the host population. To test this hypothesis we compared age-specific fertility rates and the timing

<sup>2</sup>Every second year starting in 2001, an asset survey has been conducted in all households of the Agincourt surveillance site. A set of these household assets can be used to develop a wealth (SEP) index for each household (13). The sum of these assets was used to create an absolute asset count for each household. This score was then used to define three socio-economic strata based on tercile cut-offs and categorised: more poor, poor, less poor (14).

of first and second births between the two populations at the beginning and end of the observation period.

### Age-specific fertility rates

Figure 2 compares the age-specific fertility rates of Mozambican and South African women in 1993 and 2009. Panel A of Fig. 2 demonstrates a strikingly different age pattern of childbearing in 1993 between the two groups of women: Mozambicans have slightly lower adolescent fertility rates (aged 15–19) but higher fertility rates in all other age groups, with a significant peak at ages 25–29. In contrast, South Africans have fairly constant fertility rates across women aged 15–34 until they begin to fall and continue a downward trend at older ages.

However, by 2009, Panel B of Fig. 2 shows that the age-specific fertility patterns for Mozambican and South African women were quite similar, with very little difference at all ages. The gap between the age-specific fertility rates of the two groups found in 1993 disappears due to significantly lower fertility rates for Mozambican women at ages 20–49. Fig. 2 also shows that fertility decline in the Mozambican population has come most notably from declines in fertility across ages 20–34.

### Timing of first births

The age-specific fertility rates suggest similarly high levels of adolescent fertility for Mozambican and South African women. Further analysis of the age distribution of first births for Mozambican women (Table 1) shows increases in the proportion of first births to adolescents over time. This suggests that Mozambicans are following a pattern found in the area by previous research (16) of consistently high adolescent fertility despite a decline in overall fertility.

Table 1 also shows that more recently in the period 2003–2005, Mozambican women have a statistically

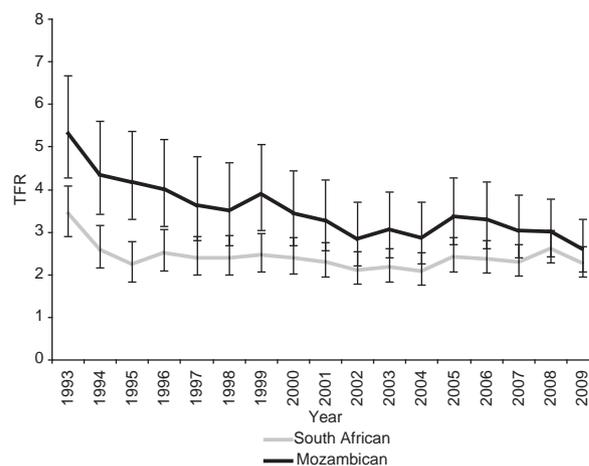


Fig. 1. Total fertility rates (TFR) of South Africans and Mozambicans in Agincourt 1993–2009 with a 95% confidence interval.

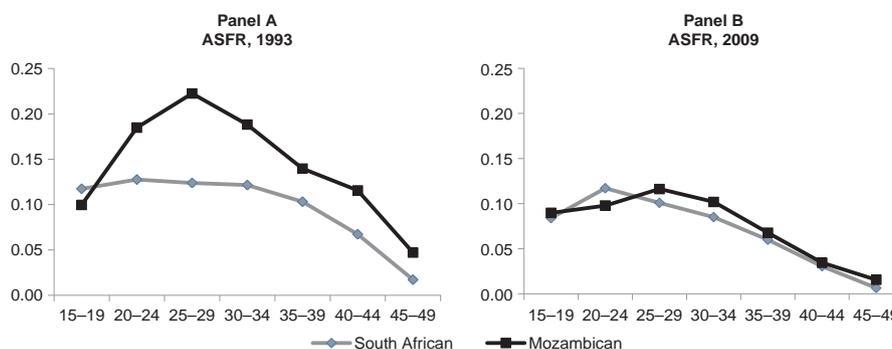


Fig. 2. Age specific fertility rates (ASFR) of the two population groups in the AHDSS, 1993 and 2009.

significant higher percentage of first births occurring to adolescents (59.3%) than South African women (52.6%). For that same period, the average age at first birth for Mozambican women is below 20 (19.7) and above 20 (20.36) for South African women. While adolescent fertility appears to be decreasing for South African women, it appears to be increasing for Mozambican women.

Further analysis also suggests lower contraceptive use by Mozambican women prior to their first birth. At the time of their first birth, Mozambican women consistently reported lower contraceptive use prior to conceiving than South African women. Five per cent of Mozambican women compared to 9.5% of South African women with first births from 1995 to 1999 reported using contraception at some time before their first birth. These figures were 23% and 28%, respectively, for first births occurring from 2003 to 2005. High adolescent fertility has been a source of concern in South Africa and so it is important to recognise the lower use of contraception before a first birth as well as the increase in the percentage of first births to adolescents for Mozambican women (16).

#### Timing of second births

Previous research on the fertility of host South Africans has shown that fertility decline for African South

Africans has been driven by significant widening of birth intervals explained primarily by increases in the use of modern contraception (17). Wide birth intervals may also be a result of adolescent non-marital fertility followed by late marriage and low marital fertility (16). Contraceptive use in Agincourt has been shown through qualitative research to be used primarily after the first birth to delay subsequent births (16, 18, 19). In the early 1990s, a majority of South African women in Agincourt delayed second births for more than five years, while a majority of Mozambican women did not. Panel A of Fig. 3 shows that only 40% of South African women that had first births between 1993 and 1995 had a second birth within five years as compared to more than 70% of Mozambican women. Over time, however, the pattern of second births among Mozambican women has become similar to that of South African women. Panel B of Fig. 3, shows that for women experiencing a first birth between 2003–2005 the percentage of Mozambican and South African women progressing to a second birth within five years was similar, relatively low, and not statistically significant (43% and 38% respectively).

The changes in age-specific fertility rates, timing of first births and extended first birth intervals indicate that Mozambican women are achieving lower fertility

Table 1. Age at first birth by nationality and period (%)

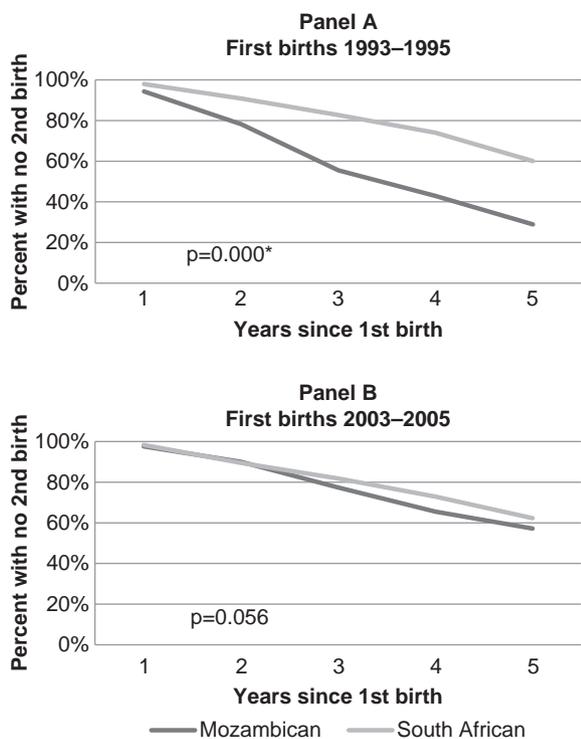
	1993–1995		2003–2005	
	Mozambican	South African	Mozambican	South African
Age at first birth				
15–19	56.37	60.53	59.27	52.57**
20–24	29.78	29.51	28.38	32.75 <sup>+</sup>
25–29	9.74	7.29 <sup>+</sup>	10.04	10.12
30–40	4.12	2.67	2.32	4.56*
N	534	1,125	518	1,383

Significance test for difference between Mozambican and South African.

<sup>+</sup> Significant at 0.1 level.

\*Significant at 0.05 level.

\*\*Significant at 0.01 level.



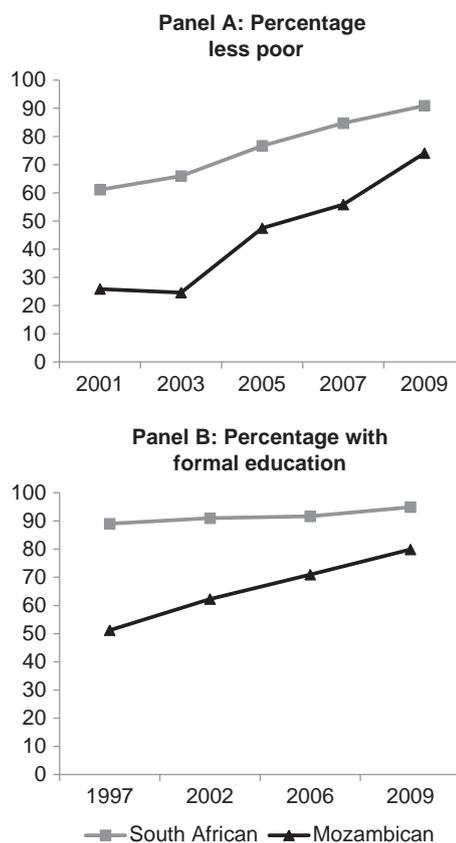
**Fig. 3.** Smoothed discrete survival function curves showing the percentage of women with no second births up to 5 years after a first birth in two time periods 1993–1995 and 2003–2005 by nationality. \*The curves are statistically significant at the  $p < 0.001$  level according to a log-rank test for equality of survivor functions.

by adopting patterns of childbearing typical for South African women in Agincourt.

**Trends of selected socio-economic characteristics**

To further explore the fertility decline and the convergence of fertility in the two populations, we examine select socio-economic factors that may be ‘underlying’ drivers of the decline in the TFR among the Mozambicans. Increases in education, labour force participation and income have been found to reduce fertility (20–22). Historically, Mozambicans have been socially and economically disadvantaged in the Agincourt sub-district. However, over time their socio-economic status has improved and policy changes in 2004 enabled Mozambicans (as permanent residents) to access South African state resources such as child grants and old-age pensions (23). Panel A of Fig. 4 shows the percentage of women of childbearing age whose households fall into the category ‘less poor’, or the top socio-economic strata of the wealth index. This demonstrates the economic gains of Mozambicans and their convergence with South Africans over time.

Panel B of Fig. 4 shows a rapid increase in the percentage of Mozambican women with some formal education and a slight increase for South African women.



**Fig. 4.** Household wealth status 2001–2009 and education 1997–2009 of South African and Mozambican women of age 15–49 in the AHDSS.

Increased access to formal education likely contributed to the decrease in fertility for Mozambican women.

An analysis of the labour force participation of women of reproductive ages shows that formal employment increased slightly during the past decade for South Africans (from about 28% in 2000 to 30% in 2008) but decreased for Mozambicans (from about 27% to 23% over the same period). The very high unemployment of both groups suggests limited formal economic opportunities for women, which might have contributed to the recently observed stall in fertility decline.

Education and wealth indicators suggest that over the period of study Mozambican women’s status improved and converged with that of South African women. However, these gains are relatively modest and Mozambican women remain disadvantaged, particularly in relation to formal employment, within the relatively poor population of the rural setting.

**Discussion and conclusion**

Approximately 20 years after the civil war in Mozambique, demographic characteristics of self-settled refugees of Mozambican origin in Agincourt are converging with those of their South African hosts. While the TFR

in Mozambique itself has remained near 5 (24), the Mozambican TFR in Agincourt was 2.6 in 2009, its lowest level to date. Both population groups now show similar fertility patterns, with a high proportion of first births in the 15–19 age range and delayed childbearing thereafter.

The findings of this study suggest adaptation of the Mozambican refugees in the AHDSS to the fertility patterns of their host community. Adaptation theory states that exposure to cultural norms and local costs of childbearing will lead migrants to change their fertility behaviour to converge with that of natives in the destination (25). This appears to be the case, particularly through 2005 when the majority of the population of Mozambican women in Agincourt were former refugees. The fertility of more recent Mozambican migrants might additionally be suppressed due to the disruption caused by migration.

The adaptation of Mozambican refugees to the lower fertility regime in South Africa has important implications for many areas of sub-Saharan Africa hosting refugee populations. The adaptation of Mozambicans in South Africa is likely facilitated by a shared language and culture. Self-settled refugees are also probably more likely to be exposed to and adjust to the local norms of childbearing compared to refugees living in camps.

Access to contraception through the South African health system is a key component of the decrease in fertility of Mozambicans. Another important component is the improvement in socio-economic status partly attributable to access to education and host government social grants. Reducing the economic disadvantage of refugees and integrating refugees into local programmes and services encourages adaptation and can compensate for other factors that may otherwise increase the fertility of refugees such as poverty, lack of education, and lack of reproductive health services. Integration encourages adaptation and will likely benefit host communities by lowering the fertility of refugees.

Overall fertility decline in Agincourt over the past few decades has been driven primarily by the decline in fertility of Mozambican women. South African women's total fertility declined primarily in the early 1990s and has been wavering around 2.5 since 1995. Fertility decline has also been minimal for Mozambican women since 2002. With fertility decline stalling in both groups it remains to be seen if fertility will go below replacement level (2.5 in South Africa) as predicted by earlier research (26). Further research is needed to determine the impact of factors such as infant mortality, changing marriage patterns, migration, and HIV on fertility in Agincourt and throughout South Africa.

Findings presented here suggest a few areas of future intervention that would be helpful in settings such as Agincourt. The pattern of childbearing in Agincourt

shows that delaying first births could reduce overall fertility rates. Others have argued that family planning programmes in South Africa need to be reoriented to address the contraceptive needs of adolescents before first births (18). Since contraception and family planning advice are provided largely by nurses working from primary health care facilities, strengthening the adolescent-friendly and responsiveness of clinic-based services is important. Programmes in Agincourt should pay special attention to Mozambican adolescents, whose reported contraceptive use is lower than that of South Africans. Increasing contraceptive use before age 20 will lower adolescent fertility and overall fertility rates. Furthermore, if programmes can successfully increase condom use, they may have the added benefit of reducing HIV transmission.

In other settings, increasing access to family planning and reproductive health programmes for all women has been shown to improve women's economic and health outcomes and to enhance economic growth (27). However, the lingering effects of apartheid policies of differential development are evident in the low education and very high unemployment of women in Agincourt. Programmes that improve education and create job opportunities for all women, particularly Mozambican women, are needed to complement improvements in family planning and reproductive services in order to overcome endemic poverty in the area. Efforts to improve reproductive health services and improve the socio-economic status of women are likely to be synergistic, with each encouraging lower fertility and economic growth.

The primary limitations of our study are data driven. We do not have information on important variables such as prospective data on marriage, fertility desires, or detailed information on contraceptive use, to run models examining the proximate determinants of fertility.

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**\*Jill Williams**  
 Institute of Behavioral Science  
 University of Colorado Boulder  
 Boulder, CO 80309, USA  
 Tel: 303-492-5253  
 Email: Jill.Williams@Colorado.edu



# Modelling determinants, impact, and space–time risk of age-specific mortality in rural South Africa: integrating methods to enhance policy relevance

Benn Sartorius\*

School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** There is a lack of reliable data in developing countries to inform policy and optimise resource allocation. Health and socio-demographic surveillance sites (HDSS) have the potential to address this gap. Mortality levels and trends have previously been documented in rural South Africa. However, complex space–time clustering of mortality, determinants, and their impact has not been fully examined.

**Objectives:** To integrate advanced methods enhance the understanding of the dynamics of mortality in space–time, to identify mortality risk factors and population attributable impact, to relate disparities in risk factor distributions to spatial mortality risk, and thus, to improve policy planning and resource allocation.

**Methods:** Agincourt HDSS supplied data for the period 1992–2008. Advanced spatial techniques were used to identify significant age-specific mortality ‘hotspots’ in space–time. Multivariable Bayesian models were used to assess the effects of the most significant covariates on mortality. Disparities in risk factor profiles in identified hotspots were assessed.

**Results:** Increasing HIV-related mortality and a subsequent decrease possibly attributable to antiretroviral therapy introduction are evident in this rural population. Distinct space–time clustering and variation (even in a small geographic area) of mortality were observed. Several known and novel risk factors were identified, and population impact was quantified. Significant differences in the risk factor profiles of the identified ‘hotspots’ included ethnicity; maternal, partner, and household deaths; household head demographics; migrancy; education; and poverty.

**Conclusions:** A complex interaction of highly attributable multilevel factors continues to demonstrate differential space–time influences on mortality risk (especially for HIV). High-risk households and villages displayed differential risk factor profiles. This integrated approach could prove valuable to decision makers. Tailored interventions for specific child and adult high-risk mortality areas are needed, such as preventing vertical transmission, ensuring maternal survival, and improving water and sanitation infrastructure. This framework can be applied in other settings within the region.

**Keywords:** mortality; space–time risk; determinants; population attributable fractions; demographic surveillance system; rural; South Africa

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Increased HIV infection and the re-emergence of tuberculosis (TB), especially in sub-Saharan Africa, has been accompanied by a resurgence of drug-resistant strains of malaria and TB closely associated

with HIV/AIDS (1, 2). This has had a substantial impact on mortality in the region.

Reliable mortality data are a prerequisite for planning health interventions, yet such data are often not available

or reliable in developing countries, including those in sub-Saharan Africa (3). In many instances, health and socio-demographic surveillance systems (HDSS), though not representative at the national level, are often the only means to assess and more clearly understand population levels, trends, and determinants on a prospective basis (4, 5).

Recent advances in data availability and analytic methods have created new opportunities to improve the analysis and modelling of diseases on a local, national, or regional basis (6, 7). Spatial analysis and, for example, Bayesian geostatistical modelling are powerful and statistically robust tools for identifying high-mortality areas in a heterogeneous and imperfectly known environment and associated determinants (6, 8). An increasing body of literature on spatial analysis of health outcomes in developing countries has been motivated by the availability of geo-referenced data and by the recent advances in methods and software that can implement such complex models (7, 9). The identification of geographical clusters of high-risk mortality is an important policy issue that has received limited attention, especially the ability to identify individuals, households, and villages at elevated risk. This study contributes to other literature that investigates mortality and its risk factors that are important from a public health perspective (10). The study also provides guidance regarding the distribution of health services and other spatially-targeted interventions for disease control, mortality reduction, and resource allocation in rural South Africa and has application to broader sub-Saharan Africa.

Addressing health inequities in populations is a major challenge (11), and research that documents and quantifies inequities is needed to inform policies to close health gaps in the developing world. Evidence on reducing inequities within countries is growing. Successful approaches include those that improve geographic access to health interventions in poor communities, subsidize health care and health inputs for the poor, and empower poorer communities (12).

This study aims to describe and develop a framework that captures the space–time dynamics and determinants of age-specific mortality in rural South Africa.

## Methods

### Study area and population

The Agincourt HDSS is located in a sub-district in north-east South Africa (Fig. 1). There was a baseline census in 1992 that collected data on all individuals and households in the population (13). This has been followed by annual updates of births, deaths, and in- and out-migrations. It is a poor rural sub-district that includes former Mozambican refugees, temporary migrant workers, and a more stable permanent population (13). The site at present

covers an area of about 400 km<sup>2</sup> and contains 25 villages, 13,500 households, and 84,000 individuals. There is a full geographic information system (GIS), containing locations of all households within the site, which is updated annually. A household is defined as a group of people who reside and eat together, plus the linked temporary migrants who would eat with them on return. Verbal autopsies (VAs), a method of determining individuals' causes of death in populations without a complete vital registration system, were introduced in 1993. A full VA is conducted on every death recorded during the annual census update and is administered to the closest caregiver of the deceased by a trained fieldworker (14). Three medical practitioners assess VAs to determine likely cause of death. Causes of death (main, immediate, and/or contributing) are coded to be consistent with the International Classification of Diseases (ICD-10). The main cause of death was used in these analyses.

The study population comprised infants (<1 year), children (1–4 years), young adults (15–49 years), and older adults (50–64 years) in the original 21 villages for the period 1992–2008. Children aged 5–14 were not included in the more detailed analyses given their very low mortality rate (<1 death per 1,000 person years) and corresponding absolute number of deaths. Data from four new villages added to the site since 2007 were also not included in the analysis as they contributed minimal data to the study period.

### Outcome and explanatory variables

The dichotomous age-specific mortality outcomes were defined as follows:

- Infant – mortality within the first 365.25 days of life
- Children – mortality between 1 and 4 years of age
- Young to middle-age adults – mortality between 15 and 49 years of age
- Older adults – mortality between 50 and 64 years of age

Person time was defined as time (in years) contributed by an individual during the study period until right censoring (0) or death (1). The time to right censoring was set to either the date of permanent out-migration during the study period or as 31 December 2008 if the individual was present and alive. Demographics (gender, nationality), time period, season, maternal factors (former refugee status, age at pregnancy, death of mother during their offspring's infancy or childhood, education) and fertility factors (parity, birth intervals, sibling death), household factors (size mortality experience, household head demographics, socio-economic status based on household assets, food security), health seeking (distance to nearest health facility, antenatal clinic attendance), migration patterns, and household elevation (climatic proxy) were

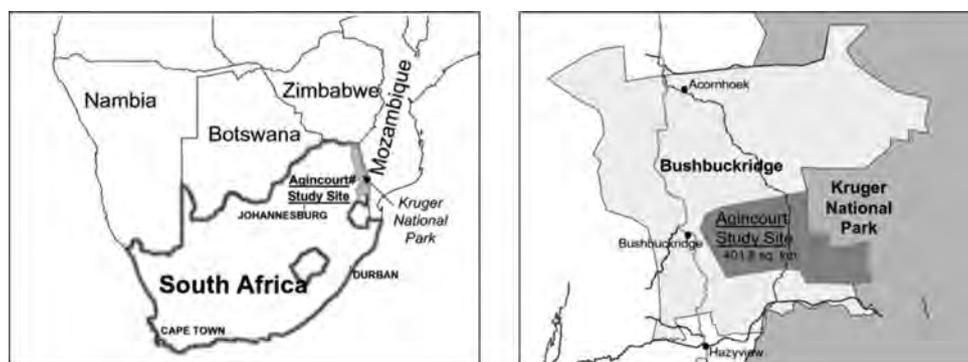


Fig. 1. Maps showing the location of the Agincourt HDSS (41).

included as explanatory variables. Household socio-economic status (SES) was based on living conditions, assets and services including building materials of main dwelling, water and energy supply, ownership of modern appliances and livestock, and means of transport. These assets were used to construct an SES index using a multivariate statistical technique for categorical data, namely multiple correspondence analysis (MCA) (15).

#### Risk factor analysis

A preliminary bivariate risk factor analysis was conducted to assess the relationship between mortality and each covariate. Covariates significant at the 10% level were then incorporated into the multivariable model. Given the inherent spatial and temporal correlation of longitudinal HDSS data, problems arise when using standard statistical methods as they assume independence of outcome measures (e.g. mortality). Objects in close proximity are often more alike, and common exposures (measured or unmeasured) may influence adult mortality similarly in households of the same geographical area, introducing spatial correlation in mortality outcomes. Including the spatial effect of proximity is important for an efficient estimation of parameters and prediction (16). Ignoring this correlation introduces bias in the risk factor analysis as the standard error of the covariates is underestimated, thereby overestimating the significance of the risk factors. Geostatistical models relax the assumption of independence and assume that spatial correlation is a function of distance between locations. They are highly parameterised models, and their full estimation has only become possible in the last decade by formulating them within a Bayesian framework (17) and estimating the parameters via Markov chain Monte Carlo (MCMC) simulation. With the development of MCMC methods and software such as WinBUGS (18), Bayesian approaches are being applied to the analysis of many social and health problems in addition to disease mapping and modelling or kriging (19). Thus, Bayesian geostatistical multivariable models are needed to analyse longitudinal data in order to address these problems.

Different analytical dataset structures were used for the various age groups. This dictated the corresponding modelling approach to examine the multivariable association between the significant covariates and age-specific mortality. For infants, a negative binomial model (selected due to over dispersion) was used with an offset of time in days contributed in the first year given their higher risk earlier on. For children (1–4 years), a monthly discrete time logistic or event history approach was used to track any changes of selected covariates in the given intervals. A monthly time interval was used as it was a better approximation of the risk than using a yearly interval. For the adult models, a continuous time to event or survival approach (Weibull parametric model) was adopted that split episodes of time for any relevant changes in selected covariates, for example, change of location or household. For a detailed comparison of the strengths and weaknesses of each analytical approach, please see Appendix 1. Details of the infant and child statistical models and selected results have been published previously (20, 21). However, the infant results in this paper include important additional variables (mother death due to HIV or non-HIV, breastfeeding) not used previously. A spatial random effect at the village level was included to take account of spatial correlation and was modelled using a multivariate Gaussian distribution with a covariance matrix expressed as a parametric function of the distance between pairs of village centroid points (17). Furthermore, an unstructured household-level random effect was included to take into account repeated household observations where time episodes were split to incorporate any time varying issues such as change of household physical location. MCMC simulation (22) was employed to estimate the model parameters. Detailed formulation of the models as well as the WinBUGS codes to implement each can be found in Appendices 2 and 3, respectively.

#### Model assessment

Model comparison in STATA was based on the Akaike information criterion (AIC). The deviance information

criterion (DIC) was used to assess the various Bayesian multivariable models (23). Both the AIC/DIC are a measure of the relative goodness of fit of a statistical model. Generally, the smaller the AIC/DIC, the better the model fit.

### *Spatial analysis*

The Kulldorff spatial scan statistic (24) was used to identify significant spatial clustering of mortality. Simulation-based Bayesian Poisson kriging (25) was also used to produce smoothed maps of all-cause mortality risk within the whole HDSS area. All-cause and cause-specific baseline models used included a constant and spatial random effect only. All identifying features (such as village centroids, boundaries) have been removed from the maps to ensure confidentiality and avoid stigmatisation of potentially high-risk villages. The HIV and tuberculosis mortality risk map is also not shown for the abovementioned reason. Model spatial estimates were exponentiated to give relative risk (RR). Risk maps were developed using a heat scale of the location specific RR prediction. Darker areas reflect increasingly higher RR, while increasingly lighter areas indicate lowering RR. A simple map showing potentially high-risk areas as a function of straight-line distance to nearest health facility was constructed using a circular buffer zone around health facilities based on significant cut-off found in the risk factor analysis.

### *Software*

Data were extracted from the Agincourt database using Microsoft SQL Server. The analysis was carried out in STATA version 10.0 SE (26) and WinBUGS (18). Risk maps were constructed in MapInfo Professional version 9.5.

## **Results**

### *Demographic and mortality profile*

The demographic and mortality profile of the study samples are provided in Table 1. Overall 9,035 deaths occurred during 1992–2008, based on 1,110,166 person-year time contributed, at an overall crude mortality rate of 8.1 per 1,000 person-years. The highest mortality rates occurred among infants followed by the older adult (50–64 years) age group (29 and 19 per 1,000 person-years, respectively). The mortality rate among children and younger adults (15–49 years) was similar at 5.7 and 6.9 per 1,000 person-years, respectively. Among infants 216 deaths occurred during the perinatal<sup>1</sup> period and 251 in the neonatal<sup>2</sup> period, that is, the majority occurred in the perinatal or early neonatal phase. The overall perinatal

and neonatal mortality rates were 7.6 and 8.8 per 1,000 person-years, respectively. The lowest mortality rates were observed in the 5–14 year age group. Among adults (15–64 years), mortality rates showed a steady increase by 5-year grouping with a non-linear excess in the 30–34 and 35–39 age groups due to HIV/AIDS.

### *Leading causes of death by age group, 1992–2008*

The leading cause-of-death in all age groups (Table 2) was HIV/TB. Among children, the second most prominent cause-of-death was diarrhoea or malnutrition. Among younger adults (15–49 years), external causes of death, namely assault and transport accidents, featured as the second and third top causes-of-death, with life-style-related diseases following. In the older adult age group (50–64 years) following HIV/TB, chronic non-communicable diseases featured prominently.

### *Temporal trends in age-specific mortality*

A significant increase in all age group mortality rates was observed over the study period (Fig. 2), especially due to the impact of the HIV epidemic from the late 1990s to mid-2000s. All-cause mortality began to plateau around 2004 following rollout of the antiretroviral therapy (ART) programme in 2003 and reduction of HIV-related mortality. The temporal trend terms included in each multivariable model confirmed the significant increase in mortality across all age-groups over the study period both linearly and by period (Table 3).

### *Major risk factors for age-specific mortality*

Infants: maternal death in the infant's first year (especially due to HIV/TB), higher number of cumulative household deaths, no breastfeeding, and previous birth interval less than 1 year emerged as highly significant risk factors for all-cause infant mortality (Table 3). Mother being a migrant remained significantly protective. Male gender, increasing parity, and death of previous child were no longer significant risk factors following multivariable adjustment. No significant association was observed between infant mortality and household SES, increasing distance to nearest health facility and climate (using elevation as a proxy which corresponds to the rainfall gradient in the sub-district).

Children: maternal death between the child's first and fifth birthdays, particularly due to HIV/TB, was the most prominent risk factor from the multivariable analysis (Table 3), followed by father death due HIV/TB, four or more children aged less than 5 years living within the household, Mozambican origin of the mother, and winter season. Increasing age of the child remained highly protective. No significant association was observed between mortality risk and increased distance to nearest health facility. In contrast to infants, however, a significant and increasing trend of protective association

<sup>1</sup>Perinatal period: last period of gestation up to first 7 days of life.

<sup>2</sup>Neonatal period: within the first 28 days of life.

**Table 1.** Demographic profile of study sample by age group, 1992–2008

Characteristic	Infants ( <1 years)	Children (1–4 years)	Children (5–14 years)	Adults (15–49 years)	Adults (50–64 years)	Overall <sup>b</sup>
Denominator (person-years)	28,470	116,729	311,387	549,030	70,864	1,110,166
Female (%)	16,030 (50.4)	20,838 (50.3)	34,770 (50.8)	99,994 (56.6)	4,062 (59.5)	576,680 (51.9)
South African (%)	20,382 (64.1)	25,848 (62.3)	43,870 (65.2)	66,926 (66.9)	4,292 (62.9)	117,448 (64.1)
Deaths (% of overall deaths)	826 (9.1)	669 (7.4)	289 (3.2)	3,798 (42.0)	1,337 (14.8)	9,035 (100)
Mean age at death (standard deviation)	126.2 days (112.7)	2.1 years (0.9)	10.0 years (2.9)	34.6 years (8.5)	57.3 years (4.5)	41.8 years (26.8)
Median age at death (interquartile range)	99 days (16–217)	1.9 years (1.4–2.6)	10.0 years (7.5–12.5)	34.8 years (28.4–41.5)	57.0 years (53.5–61.4)	40.7 years (24.2–63.8)
Mortality rate <sup>a</sup>	29.0	5.7	0.9	6.9	18.9	8.1

<sup>a</sup>Per 1,000 person-years.

<sup>b</sup>Includes 5–14 and 65+ age groups.

was observed with increasing household SES based on the bivariate analysis.

**Adults:** The most prominent risks for 15–49 year mortality following multivariable adjustment were male gender, being a migrant, increasing number of other household deaths, household head death, and distance to nearest health facility (>6 km) (Table 3). Increasing wealth of household, household head being male, and older than 40 years were significant and prominent protective factors. Villages with a mortality proportion of HIV/TB above the median value remained at a significantly higher risk. Mozambican ethnicity and education were no longer significant after multivariable adjustment.

The most prominent risks for 50–64 year mortality following multivariable adjustment were male gender, being a migrant, and death of household head (Table 3). Households headed by older males again reduced older adult mortality risk. Mozambicans appeared to have

significantly lower risk in this age group when compared to South Africans. In contrast to the findings for younger adults, following multivariable adjustment in the 50–64 year model, distance to nearest health facility (>6 km) and household SES were no longer significant risk factors.

Based on the risk prediction for straight-line distance to health facility, we can see that two villages in particular, one in the upper and the other in the lower south-east region, appear to have a higher mortality risk as a function of increased distance to the nearest local clinic in the Agincourt sub-district (Fig. 3). We also observe that there are other villages that appear to be far from the nearest health facility.

### *Spatial distribution of age-specific mortality*

Spatial risk estimates based on a Bayesian kriging model suggest a higher risk of infant mortality on the eastern border of the site while child mortality was concentrated

**Table 2.** Top five causes-of-death by age group, 1992–2008

Rank	Infants ( <1)	No. (percent)	Children (1–4)	No. (percent)	Adults (15–49)	No. (percent)	Adults (50–64)	No. (percent)
1	HIV/TB	132 (16.6)	HIV/TB	192 (29.5)	HIV/TB	1,545 (43)	HIV/TB	317 (24.7)
2	Diarrhoea or malnutrition	104 (13.1)	Diarrhoea or malnutrition	164 (25.2)	Assault	164 (4.6)	Vascular	159 (12.4)
3	ARI or pneumonia	103 (13)	External	39 (6)	Transport accident	134 (3.7)	Neoplasms	88 (6.9)
4	Perinatal condition <sup>a</sup>	93 (11.7)	ARI or pneumonia	27 (4.2)	Vascular	109 (3)	Digestive	54 (4.2)
5	Congenital	25 (3.1)	Congenital	13 (2)	Neoplasms	106 (2.9)	Suicide	35 (2.7)

<sup>a</sup>Based on ICD-10 main cause-of-death only, that is, P00–P96 (not inclusive of date of birth and date of death timing).

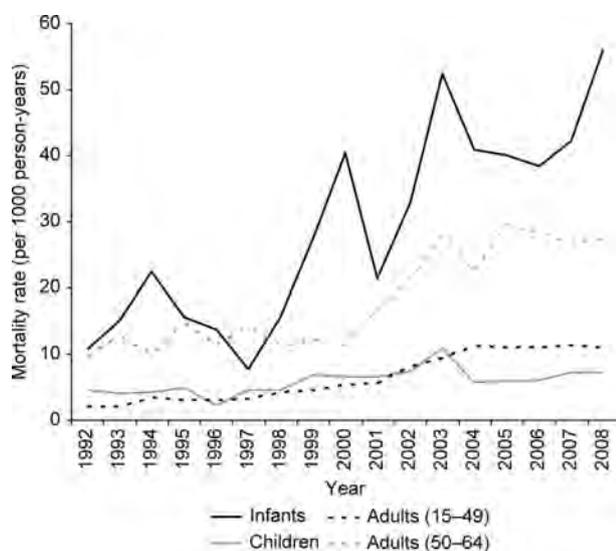


Fig. 2. Age-specific mortality rates by year, 1992–2008.

in two distinct foci: upper central and south-east corner of the sub-district. Five distinct foci of higher mortality in the 15–49 year age-group were observed using Bayesian kriging (Fig. 4). Three are in the central to upper central region of the site and two in the south east. These correlate to areas with higher risk of infectious disease mortality in this age group, largely HIV/TB. A very similar pattern was seen in the 50–64 year age-group when compared to 15–49 years though with one minor difference in that one village in the south-east was no longer at higher risk and one additional village in the upper central region emerged as high risk. Similarly, this distribution is largely driven by HIV/TB mortality. Higher non-communicable disease mortality risk was observed in one particular village in the upper central region of the site.

#### Potential proximate reasons for the observed high-risk clusters

The high age-specific mortality clusters (Kulldorff spatial cluster scan statistic  $p < 0.05$ ), when compared to the lower mortality clusters, had significantly ( $p < 0.05$ ):

- more deaths due to HIV/TB and diarrhoea or malnutrition
- lower duration of breastfeeding
- higher number of deaths of previous children
- higher number of mothers dying of HIV/TB
- lower mean maternal education years
- higher number of cumulative household deaths
- younger household heads
- higher incidence of household heads dying
- more Mozambican household heads
- lower SES

- higher temporary migration rates
- lower proportion of individuals with secondary or higher level education.

#### Discussion

This study has demonstrated the usefulness of advanced epidemiological modelling in assessing risk factors and producing smooth maps of mortality risk in a population.

Earlier work in South Africa and Agincourt has shown the profound impact of HIV/TB on mortality across most age groups (27–29), with higher than normal mortality rates evident. The results show that infectious diseases (particularly HIV/TB) were the most prominent cause-of-death over the study period and have largely contributed to the observed mortality trends. The levelling out of mortality round 2005 is possibly linked to the ART rollout, which began in South Africa round 2004. Current studies in this area are assessing the impact of ART rollout on mortality, as well as specific villages or areas where equity of access may be an issue. Mortality from non-communicable disease has also increased significantly in adults 30 years and older in the rural Agincourt sub-district (29) and has implications with regard to the epidemiological transition.

Results suggest that strong and significant space–time mortality disparities exist, even within a small geographic area. This distribution is being driven by a complex web of multilevel interacting factors that have likely increased communicable disease mortality (HIV) and non-communicable disease mortality (in the older age-group) in specific risk areas. According to the spatial analyses, the south-east and upper central regions of the site were consistently identified as high-risk areas for most age groups, thus indicating a definite non-random element to the mortality distribution in this rural sub-district. A strong geographical pattern of higher infectious disease mortality risk (particularly HIV/TB and diarrhoea/malnutrition) and former Mozambican settlements lying to the east of the site was also generally observed. Mozambican settlements in the south-east have generally been shown to have poorer access to water, sanitation, and waste disposal; in addition, they had fewer schools and poor quality of housing and were particularly isolated from public transport (30, 31).

Key individual and household level determinants have been confirmed and certain novel determinants have emerged. The results confirmed the importance of infant and child mortality risk factors such as maternal age, birth spacing, season, village and ethnic group (32, 33). Lack of breastfeeding in infancy and maternal death during infancy or childhood (1–4) were major risk factors as were a higher number of cumulative household deaths. Other reports indicate that infants who survive the death of the mother have a 10% chance or less of living past the

**Table 3.** All-cause multivariable risk factor analyses for age-specific mortality using Bayesian modelling

Factors	Infants (<1)	Children (1–4) <sup>a</sup>	Young adults (15–49)	Older adults (50–64)
	IRR (95% BCI) <sup>b</sup>	OR (95% BCI) <sup>b</sup>	HR (95% BCI) <sup>b</sup>	HR (95% BCI) <sup>c</sup>
<b>Temporal</b>				
Year (continuous)	1.25 (1.07, 1.58) <sup>c</sup>	1.05 (1.04, 1.07) <sup>f</sup>	–	–
By period				
1992–1997	–	–	1	1
1998–2003	–	–	2.61 (2.42, 2.83) <sup>c</sup>	2.59 (2.16, 3.08) <sup>c</sup>
2004–2008	–	–	2.90 (2.52, 3.32) <sup>c</sup>	4.07 (2.85, 5.60) <sup>c</sup>
<b>Proximate individual- and household-level determinants</b>				
Increasing age in years	n/a	0.51 (0.46, 0.56) <sup>b</sup>	1.06 (1.06, 1.07) <sup>c</sup>	1.04 (1.02, 1.06) <sup>c</sup>
Winter season	n/a	1.33 (1.12, 1.57) <sup>b</sup>	–	–
Male gender	1.10 (0.83, 1.41) <sup>c</sup>	e	1.47 (1.38, 1.56) <sup>c</sup>	3.03 (2.64, 3.48) <sup>c</sup>
Mozambican (maternal for infants and children)	e	1.12 (0.90, 1.38) <sup>b</sup>	0.94 (0.87, 1.02) <sup>c</sup>	0.59 (0.50, 0.70) <sup>c</sup>
Maternal death (in first year for infants or 1–4 for children)				
Not due to HIV/TB	6.01 (3.18, 11.37) <sup>c</sup>	5.45 (2.99, 8.75) <sup>b</sup>	n/a	n/a
Due to HIV/TB	30.78 (12.13, 78.11) <sup>c</sup>	15.11 (8.39, 24.54) <sup>b</sup>	n/a	n/a
Migrant: ≥6 months outside site per year (maternal status for infants and children)	0.71 (0.48, 1.02) <sup>c</sup>	e	1.17 (1.09, 1.25) <sup>c</sup>	1.23 (1.04, 1.44) <sup>c</sup>
Paternal death (prior birth to within first year for infants or 1–4 for children)				
Not due to HIV/TB	e, f	1.51 (0.75, 2.54) <sup>b,f</sup>	n/a	n/a
Due to HIV/TB	e, f	2.19 (0.95, 4.06) <sup>b,f</sup>	n/a	n/a
Tertiary education (maternal for infants and children)	d	d	–	–
Secondary or higher for adult models	n/a	n/a	0.98 (0.91, 1.05) <sup>c</sup>	0.56 (0.40, 0.77) <sup>c</sup>
Cumulative other household deaths	7.24 (5.70, 9.28) <sup>c</sup>	g	–	–
Number of other household deaths				
None	g	g	1	e
1–4	g	g	1.17 (1.09, 1.25) <sup>c</sup>	e
5+	g	g	1.81 (1.39, 2.30) <sup>c</sup>	e
Household head:				
Male	e	0.78 (0.60, 1.02) <sup>b</sup>	0.53 (0.50, 0.57) <sup>c</sup>	0.40 (0.35, 0.45) <sup>c</sup>
Death	e, f	d	4.52 (4.16, 4.91) <sup>c</sup>	6.74 (5.70, 7.92) <sup>c</sup>
≥40 years of age	1.44 (1.08, 1.90) <sup>c</sup>	e	0.62 (0.58, 0.66) <sup>c</sup>	0.15 (0.13, 0.17) <sup>c</sup>
Mozambican	e	1.71 (1.40, 2.09) <sup>b</sup>	e	e
<b>Infant and child specific factors</b>				
Parity	e	e	n/a	n/a
Death of previous sibling	1.56 (0.75, 2.90) <sup>b</sup>	1.63 (1.08, 2.45) <sup>b</sup>	n/a	n/a
Never breastfed	203.7 (113.9, 342.4) <sup>c,e</sup>	e	n/a	n/a
Increasing birth weight	d	d	n/a	n/a
Other child born less than one year prior	8.07 (1.33, 28.02) <sup>c</sup>	g	n/a	n/a

Table 3 (Continued)

Factors	Infants (<1)	Children (1–4) <sup>a</sup>	Young adults (15–49)	Older adults (50–64)
	IRR (95% BCI) <sup>b</sup>	OR (95% BCI) <sup>b</sup>	HR (95% BCI) <sup>b</sup>	HR (95% BCI) <sup>c</sup>
Four or more children in the household	g	1.44 (1.13, 1.80) <sup>b</sup>	n/a	n/a
Socio-economic determinants				
Household SES (MCA) quintile for infant and child models; tertile for adult models				
Most poor	e	g	1	1
Poor	e	g	0.76 (0.69, 0.84) <sup>c</sup>	0.78 (0.58, 1.05) <sup>c</sup>
Least poor	e	g	0.65 (0.58, 0.71) <sup>c</sup>	0.78 (0.58, 1.03) <sup>c</sup>
Unknown	e	g	1.48 (1.26, 1.71) <sup>c</sup>	1.01 (0.75, 1.35) <sup>c</sup>
Village level determinants				
Proportion of village deaths due HIV/TB ( $\geq 17\%$ ) <sup>h</sup> (proxy for high prevalence)	–	–	1.92 (1.40, 2.69) <sup>c</sup>	e
Average migrant months per year per village individual	–	–	0.95 (0.87, 1.07) <sup>c</sup>	e
Environmental or geographic factors				
Distance to nearest health facility (>6 km)	e	e	5.34 (3.11, 9.98) <sup>c</sup>	1.20 (0.17, 8.63) <sup>c,e</sup>
Climatic proxy (elevation in metres)	e	e	0.998 (0.997, 0.998) <sup>f</sup>	0.998 (0.997, 0.999) <sup>f</sup>
Additional model parameters				
Individual unstructured variation ( $\sigma_u^2$ )	–	0.04 (0.01, 0.11)	0.11 (0.08, 0.14)	0.16 (0.10, 0.27)
Spatially structured variation ( $\sigma_\varphi^2$ )	0.08 (0.03, 0.23)	0.23 (0.10, 0.48)	2.21 (1.09, 4.11)	0.25 (0.11, 0.56)
Autoregressive structured temporal variation ( $\sigma_\tau^2$ )	0.60 (0.27, 1.57)	0.29 (0.12, 0.68)	–	–
Dispersion parameter (r) for negative binomial model	0.03 (0.025, 0.035)	–	–	–
Shape parameter (Weibull)	–	–	1.93 (1.86, 1.99)	1.92 (1.83, 2.01)
Deviance Information Criterion (DIC)	8,103	8,612	49,576	10,193

<sup>a</sup>Results for child model published previously in (45).

<sup>b</sup>Measure of association based on analytical data structure and model type for given age-group; incidence rate ratio (IRR), odds ratio (OR); hazard ratio (HR); BCI stands for Bayesian credibility interval (similar in interpretation to a conventional 95% confidence interval).

<sup>c</sup>Significant in bivariate analysis, estimate following multivariable adjustment.

<sup>d</sup>Significant (at 10% level) in bivariate analysis but substantial missing data so not included in final multivariable model.

<sup>e</sup>Not significant at 10% level in bivariate analysis.

<sup>f</sup>Small numbers (hence wide BCI's).

<sup>g</sup>Significant at bivariate level but not run in Bayesian multivariable framework due to co-linearity with another predictor.

<sup>h</sup>Median split.

age of 1 year (34). A complex interaction of higher HIV prevalence, large distance from nearest health facility, low SES, low education, high household mortality burden, and high migrancy rates (increased risk behaviour) appear to be driving communicable disease mortality, particularly HIV. Low SES and few employment oppor-

tunities locally have led to adults migrating externally for work. Migration patterns have been shown to influence HIV risk (35, 36), and temporary or labour migrants are more vulnerable to HIV than more settled populations. This has been shown in other African and southern African countries (37). One village in the upper central



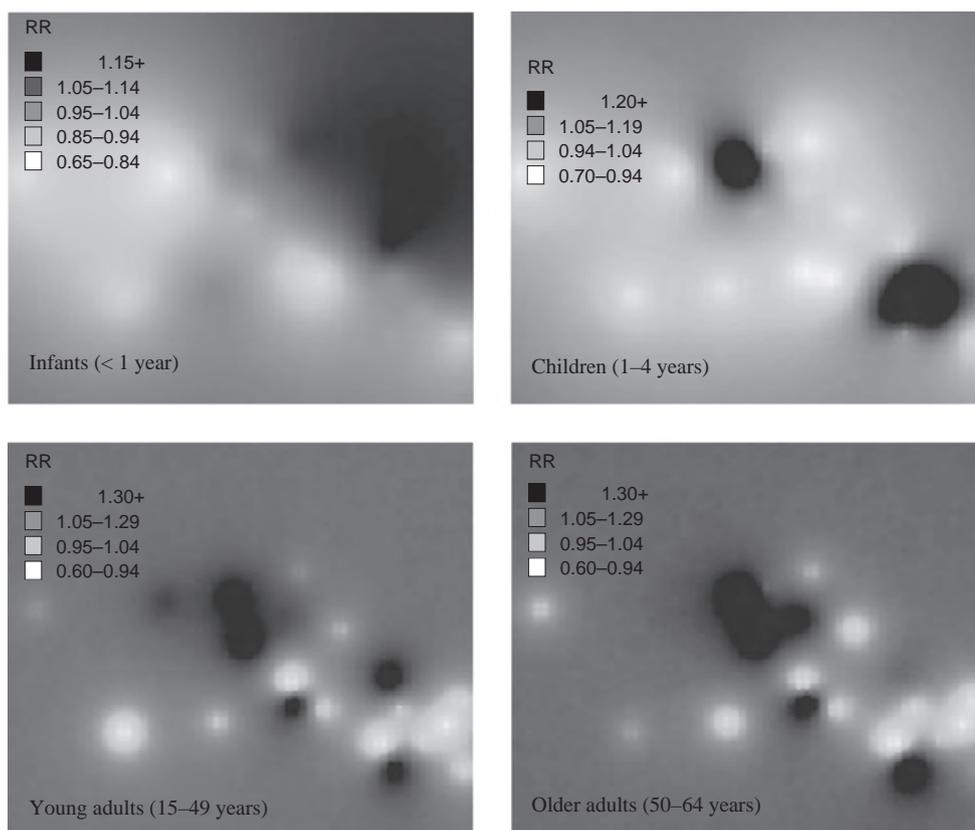
*Fig. 3.* Geographic risk of adult mortality adjusting for distance to nearest health facility at prediction point using a univariate Bayesian spatial kriging model that includes distance to health facility as the risk factor (white and black scale represents lowest and highest risk, respectively).

region appears to be at consistently higher risk across all age groups and has a significantly younger and highly mobile population, potentially engaging in higher risk behaviour with more time spent away as described by

Collinson (31). Health education messages are also needed that focus on high-risk sexual behaviour that increases risk for HIV infection, and its consequences. Death of household members also appeared to be a significant risk in all age-groups. Previous research indicates that HIV has arguably had the greatest impact at the household level in terms of dissolution and reduced economic status (38).

There are several studies relating geographical access to use of health facilities. As one would expect, members of communities that are more distant use the facilities less than those that live nearer, but this does not necessarily translate into increased mortality risk (39). In this study, we did not observe significant excess risk associated with increased distance to nearest health facility among infants and children, and this has been demonstrated previously in this setting (20, 21). Conversely, larger distance from the nearest health facility had a significantly higher risk associated with adult (15–49 years) mortality. This has been shown in a previous study on adult mortality in China (40).

A limitation of the study is the potential to miss infant deaths, particularly neonatal deaths, which would underestimate the overall infant mortality burden. However, infant death ascertainment has improved in the study site, especially towards the end of the study period (41).



*Fig. 4.* Maps of all-cause mortality risk by age group within the Agincourt sub-district based on baseline Poisson model without covariates.

Determination of cause-of-death through VA is more problematic for diseases that have less specific symptoms such as HIV/AIDS (42). Thus it is likely that the HIV burden may have been underestimated. However, previous validation studies of the VA in Agincourt HDSS have shown that it performs well in this high HIV prevalence setting (43). Levels of stigma associated with HIV are high in South Africa particularly prior to the introduction of HAART and may have also contributed to this underestimation.

## Conclusion

This work has contributed through the testing, refinement, and application of various advanced spatial-temporal analyses and statistical modelling of risk factors to large longitudinal cohorts such as an HDSS. The novel application of methodologies in public health contributes to our understanding of factors related to mortality and how to quantify them accurately for correlated geostatistical and longitudinal data. This study also contributes to the development of public health interventions by targeting clusters of adverse health outcomes that appear to aggregate geographically and in time as well as the tracking and targeting of other emerging (or re-emerging) communicable diseases that are compromising achievements made in developing countries (44). In particular, space-time modelling and mapping can be an effective tool in public health by showing and monitoring diffusion patterns of communicable diseases and in searching for infectious agents. The identification of disparities in the distribution of mortality and related risk factors in space and time, can guide effective policy interventions and programmes. The methods developed, assessed, and used in this thesis contribute to our understanding of risk factor modelling of large correlated longitudinal data.

This study should be regarded as a first step in prioritising specific areas for follow-up public health efforts and evaluating their impact in this rural setting. Targeting prevention of HIV/TB and antiretroviral roll-out in significant child and adult mortality clusters and ensuring maternal survival appear key to improving infant and child mortality rates. Further spatial assessment of antiretroviral therapy (ART) rollout that started in this area in 2007 as well as identifying any villages or areas not accessing ART equitably is also critical. The provision of adequate water and sanitation is needed in the mortality clusters particularly in the south-east where diarrhoeal mortality appears high.

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**\*Benn Sartorius**

School of Public Health  
 Faculty of Health Sciences  
 University of the Witwatersrand, Johannesburg  
 7 York Road, Parktown 2193  
 Johannesburg, South Africa  
 Tel: +27 (11) 717 26 27  
 Fax: +27 (11) 717 20 84  
 Email: benn.sartorius@wits.ac.za

# The contribution of spatial analysis to understanding HIV/TB mortality in children: a structural equation modelling approach

Eustasius Musenge<sup>1,2\*</sup>, Penelope Vounatsou<sup>3</sup>,  
Mark Collinson<sup>1,4,5</sup>, Stephen Tollman<sup>1,4,5</sup> and  
Kathleen Kahn<sup>1,4,5</sup>

<sup>1</sup>MRC/Wits Rural Public Health & Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Division of Epidemiology and Biostatistics, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Swiss Tropical and Public Health Institute, University of Basel, Basel, Switzerland; <sup>4</sup>Centre for Global Health Research, Umeå University, Umeå, Sweden; <sup>5</sup>INDEPTH Network, Accra, Ghana

**Background:** South Africa accounts for more than a sixth of the global population of people infected with HIV and TB, ranking her highest in HIV/TB co-infection worldwide. Remote areas often bear the greatest burden of morbidity and mortality, yet there are spatial differences within rural settings.

**Objectives:** The primary aim was to investigate HIV/TB mortality determinants and their spatial distribution in the rural Agincourt sub-district for children aged 1–5 years in 2004. Our secondary aim was to model how the associated factors were interrelated as either underlying or proximate factors of child mortality using pathway analysis based on a Mosley-Chen conceptual framework.

**Methods:** We conducted a secondary data analysis based on cross-sectional data collected in 2004 from the Agincourt sub-district in rural northeast South Africa. Child HIV/TB death was the outcome measure derived from physician assessed verbal autopsy. Modelling used multiple logit regression models with and without spatial household random effects. Structural equation models were used in modelling the complex relationships between multiple exposures and the outcome (child HIV/TB mortality) as relayed on a conceptual framework.

**Results:** Fifty-four of 6,692 children aged 1–5 years died of HIV/TB, from a total of 5,084 households. Maternal death had the greatest effect on child HIV/TB mortality (adjusted odds ratio = 4.00; 95% confidence interval = 1.01–15.80). A protective effect was found in households with better socio-economic status and when the child was older. Spatial models disclosed that the areas which experienced the greatest child HIV/TB mortality were those without any health facility.

**Conclusion:** Low socio-economic status and maternal deaths impacted indirectly and directly on child mortality, respectively. These factors are major concerns locally and should be used in formulating interventions to reduce child mortality. Spatial prediction maps can guide policy makers to target interventions where they are most needed.

Keywords: *HIV/TB; child mortality; conceptual framework; spatial analysis; pathway analysis; South Africa*

Appendices available online under Reading Tools.

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**T**uberculosis (TB) and the HIV epidemic are among the top public health priorities especially in sub-Saharan Africa. The sub-Saharan African region, which constitutes 10% of the world's population, is

home to more than 67% (22.9 million) of people living with HIV (1). TB, which is preventable and curable, was responsible for 25% of HIV-related deaths in 2009 and infected 33% of those living with HIV.

As a result, the World Health Organization (WHO) aims to reduce TB-related deaths by 1 million by 2015 (2). South Africa's population is about 7% [50.6 million (3)] of the sub-Saharan African population, yet accounts for 24.6% (5.63 million of the 22.9 million) of people living with HIV and an estimated 67% of these have TB. South Africa ranks as the country with the highest co-infection rates (1).

Children are affected in two ways: a very high proportion of child deaths (60% in the year 2000) are attributed to the HIV epidemic (4), and approximately 1.9 million children have been orphaned by the HIV epidemic in South Africa (1). The nation at the onset of the 21st century had an estimated 70,000 children [about 25% rate of mother-to-child-transmissions (MTCT)] newly infected, whereas 10 years later only 10,000 [3.5% rate of MTCT (5)], which is indicative of an improved and more effective mother-to-child prevention programme (6). In public health, determining patterns of disease occurrence provides the first steps toward increased understanding of determinants and potentially greater control of the disease (7). Understanding the associated factors of child HIV/TB mortality and how these are geographically distributed is key for effective interventions.

Several determinants of child mortality have been reported over the past three decades. In the 1980s, researchers explored medical, socio-economic, and demographic causes of child mortality (8). In the 1990s, fertility behaviour, nutritional status, breastfeeding and infant feeding, the use of health services by mothers and children, ecological variables, and socio-economic status were studied (9). In the 21st century, the focus has been on HIV exposure, poor maternal health, inadequate infant care, increased exposure to infections, deaths of parents or caregivers, immune system abnormalities, poor nutrition, reduced breastfeeding and antiretroviral treatment exposure (10). These determinants are interrelated and can be combined into a conceptual framework. This combined with spatial aspects forms social ecological models, which are a component of the fast developing systems science that examines multiple effects and inter-relatedness of social elements in an environment (11). Analysis of such frameworks can now be handled with the aid of structural equation models also known as pathway analysis.

The motivation for spatial analysis in epidemiological modelling is based on the notion that people living in a household and those in close proximity share similar exposures, which impact on the observed outcomes. In HIV/TB epidemiological research, the focus has largely been on drug development, societal integration, personal nutrition, physical health, and care giving (8–10, 12). Country-wide or region-specific pooled results are often reported, disregarding geographical confounding that commonly exists. Little has been done to interlink

factors associated with child HIV/TB mortality or model their impact on areas of residence (households) (13). The few studies implementing spatial analysis have looked across different infectious diseases (14–16), used different study designs (cross-sectional and longitudinal) (17, 18), and considered varying levels of analysis (village, household, and individual) (16, 18, 19). As this is an emerging field, few studies have focused on HIV/TB cause-specific mortality assessing geographical differentials in South Africa over time (19).

The primary aim of this paper was to investigate the cause-specific (HIV/TB) mortality determinants and their spatial (geographical) distribution in the Agincourt sub-district of rural northeast South Africa for children aged 1–5 years in 2004. Our secondary aim was to model how the associated factors were interrelated as either direct (underlying) or indirect (proximal) factors of child HIV/TB mortality using pathway analysis based on the Mosley-Chen conceptual framework that incorporates social, biological, and ecological determinants of child mortality (8).

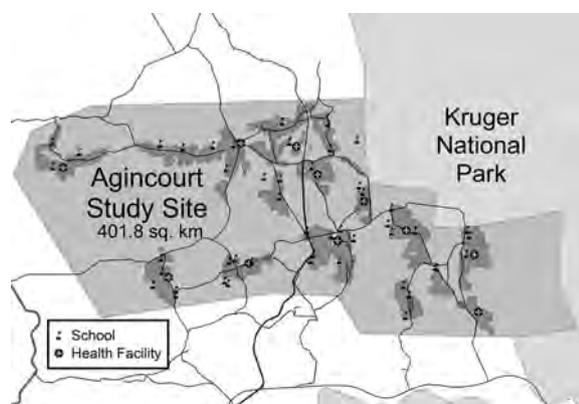
## Methods

### *Agincourt sub-district data and study design*

The Agincourt health and socio-demographic surveillance system was established in 1992 in a remote rural sub-district in the Bushbuckridge Municipality of Mpumalanga Province, northeast South Africa near the Mozambique border (20). There are annual census updates that collect socio-demographic information including in-migration and out-migration, mortality, fertility, health, and behavioural data (20).

In this study, we extracted data for 2004 describing a cross-sectional study of households in the study site. In that year, the Agincourt health and socio-demographic surveillance system covered a sub-district population of over 70,000 persons living in approximately 12,000 households scattered throughout 21 neighbouring villages. There were several health facilities in the area as shown in Fig. 1.

Cause of death data were obtained through verbal autopsies conducted on every recorded death during the year (21). Trained lay field workers conducted interviews within 1–11 months after a death, with the closest caregiver of the deceased in his/her mother tongue. Two medical practitioners independently determined cause of death; a third diagnosis was sought to resolve discrepancies. Their consensus cause of death was classified according to the WHO International Classification of Diseases 10 (ICD10) (22). The reported signs and symptoms ascertained HIV/TB mortality in children, and in some instances this was substantiated by the mother's cause of death (22). Over 90% of the health and socio-demographic surveillance system (HDSS)



**Fig. 1.** Agincourt sub-district in 2004 showing villages (grey shading) schools (flags), and health facilities (circled grey crosses).

households were geo-coded, thus enabling spatial analyses at household level.

### **Dependent and independent variables**

The study sample included all children aged between 1 and less than 5 years who were registered in the Agincourt HDSS between January and December 2004. The independent variables used were child's gender, nationality and age; mother's age, parity and death; gender of household head, cumulative deaths in household, number of household dwellers, minimum distance to health facility, and household socio-economic status. The latitude and longitude of each household were used to construct the variables for the spatial correlation (random effects), based on the straight line (Euclidean) distances between all pairs of households. The dependent variable was death due to HIV and TB determined by the ICD10 codes A16–A19<sup>1</sup> for TB and B20–B24<sup>2</sup> for HIV. The verbal autopsy cannot reliably distinguish HIV and TB due to low sensitivity and specificity; thus, these were combined in our analysis (23).

### **Conceptual framework: determinants of child mortality**

As a way of interrelating child mortality determinants, we formulated a hybrid conceptual framework for child mortality determinants and disease ecology as proposed by Mosley-Chen and Meade (8, 24). This approach integrates ecological, social, and biological variables in

<sup>1</sup>A16 = Respiratory tuberculosis; not confirmed bacteriologically or histologically; A17 = Tuberculosis of nervous system; A18 = Tuberculosis of other organs; A19 = Miliary tuberculosis.

<sup>2</sup>B20 = Human immunodeficiency virus (HIV) disease resulting in infectious and parasitic diseases; B21 = Human immunodeficiency virus (HIV) disease resulting in malignant neoplasms; B22 = Human immunodeficiency virus (HIV) disease resulting in other specified diseases; B23 = Human immunodeficiency virus (HIV) disease resulting in other conditions; B24 = Unspecified human immunodeficiency virus (HIV) disease.

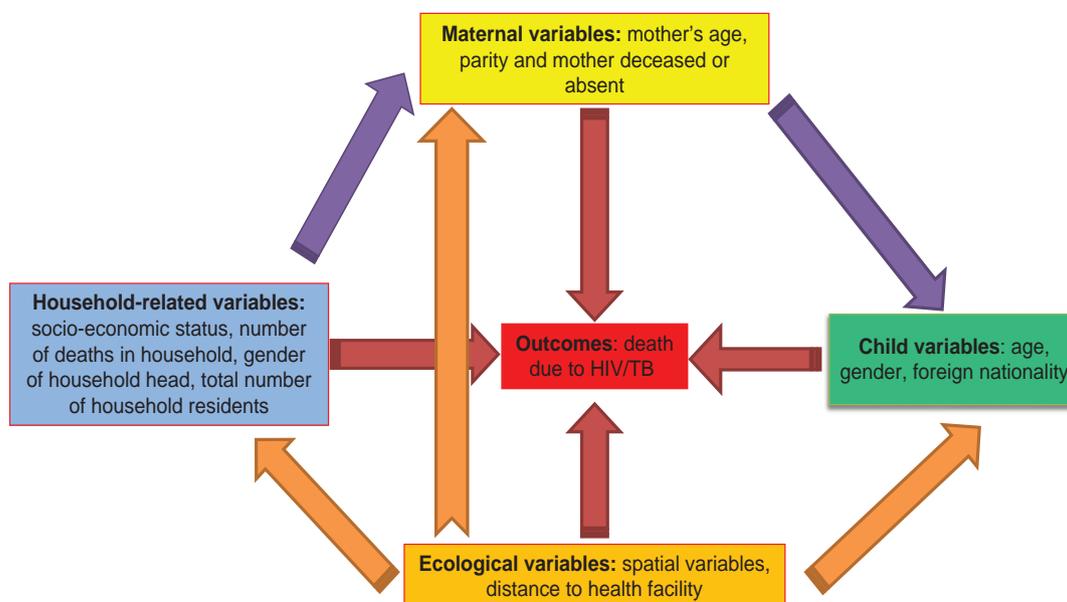
the analysis, with the idea that these determinants operate through a common set of either 'proximate' (intermediate or indirect) or 'underlying' (direct) variables that impact on HIV/TB child mortality (8, 25–27). Variables are either endogenous (outcome variables) or exogenous (explanatory) or both, and these are modelled using structural equation models. Details of the structural equation model are given in Appendix 1.

We used the observed variables: child specific, mother specific, household related; and unobserved (latent) variables: socio-economic quintiles and spatial (ecological) variables. We tested the pathways shown in Fig. 2, to measure the direct and indirect determinants of child mortality for the Agincourt sub-district in 2004. Two approaches that complemented each other were used in our modelling. Firstly, we modelled the HIV/TB mortality determinants for children aged 1–5 years in 2004 and adjusted for their spatial random effects. In relation to our Fig. 2, we estimated the direct effects pathways (red arrows) from all categories of the explanatory (exogenous) variables controlling for confounders amongst them and their spatial or geographical effects (orange arrows). Results for these are presented in Table 1 and Fig. 3. Lastly, using the significant variables as outcomes (endogenous), we determined the indirect effects (proximal denoted by purple arrows) within and between categories to establish those factors impacting on child HIV/TB mortality.

### **Statistical methodology**

We modelled the child HIV/TB mortality data to find associated factors and determine geographic disparities. Statistical techniques take into account spatial correlations by introducing spatially structured random effects into the model. These are usually based on independent observations. However, with multilevel correlated structures commonly used, maximum likelihood estimation (MLE) methods often underestimate the standard error; thus, the statistical significance is overestimated (28). Analysis was carried out using a geospatial logit regression model, which catered for individual- and household-level random effects (29). Inference was done using classical MLE and Bayesian inference techniques to fit the non-spatial and spatial models, respectively. Bayesian estimation of the many parameters was done using Markov Chain Monte Carlo (MCMC) simulations with the aid of Metropolis Hastings (MH) steps (29). Geospatial prediction maps showing the geographical coordinates, adjusting for child HIV/TB mortality determinants, were used in the analysis.

Data extraction was carried out using Structured Query Language (SQL), data management was done in STATA 10.0 (30), and structural equation modelling was performed in STATA 12.1 (Stata Corporation, College Station, Texas, USA). The Bayesian models were fit using



**Fig. 2.** Conceptual framework for modelling childhood HIV/TB-related mortality [adapted from Meade (24)]. The red arrows reflect a direct effect on mortality and the purple (explanatory variables) and orange (spatial random effects) arrows depict an indirect effect.

software available in the public domain: BayesX version 2.1 for the spatial modelling and R-cran version 2.12.2 for geospatial mapping using the analysis and mapping packages, mapproj, maps, spBayes, and Multilevel B-spline Approximation (MBA) (31, 32).

### Ethical clearance and informed consent

While this study used secondary data, the original study on which it was based was careful to consider ethical issues. Verbal informed consent was obtained when the Agincourt health and socio-demographic update rounds were conducted and also when verbal autopsy data were collected from a close relative of the deceased. To avoid emotionally stressing the interviewee, a culturally accepted period of 1 month was observed before the interview was conducted. Risks of stigmatisation were minimised through special training of fieldworkers on the importance of confidentiality. This work was granted ethical clearance by the University of the Witwatersrand's Committee for Research on Human Subjects (No. 960720 and M081145).

### Results

Of the 6,692 children between 1 and less than 5 years, with a mean age of 2.8 years, 54 HIV/TB-related deaths were recorded in the HDSS in 2004. There were 5,084 fully geo-coded households that recorded children either living or dead. Just over half the children were female (51%), and more than a third (36%) were born to former Mozambican refugees. The mean age of mothers was 29 years, and the mean distance to the nearest health facility was 2.33 km. Table 1 shows the results for the descriptive,

univariate, and multivariable logit regression analyses. Maternal death had the greatest effect on child HIV/TB mortality [logit = 1.386 (0.707)], equivalent to an adjusted odds ratio (AOR) of 4.00 [95% Bayesian credible interval (BCI) = 1.01–15.80] controlling for spatial correlation and keeping all other variables constant.

Multivariable analysis showed three further significant predictors of child mortality in 2004, which were child, maternal, and household specific. Adjusting for spatial correlation and keeping all other variables constant, there were several significant determinants of child HIV/TB mortality. Child-specific differentials showed that boys were almost twice as likely to die compared to girls [logit = 0.641 (0.291); AOR = 1.89; 95% BCI = 1.07–3.36]. As the children got older, there was a protective effect against death; for every year the child aged, the likelihood of death decreased by about 50% [logit = -0.630 (0.137); AOR = 0.53; 95% BCI 0.40–0.70]. Male-headed households had a 60% lower risk of child HIV/TB mortality compared to female-headed households [logit = -0.895 (0.30); AOR = 0.41; 95% BCI 0.23–0.74].

Spatial disparities can be viewed on maps, which can show unexpected relationships that may have been overlooked in standard regression analysis. We obtained household-specific posterior odds ratios, which were adjusted for child-, maternal-, and household-related variables in the multivariable models. One main hotspot emerged with high mortality in the north, and there were two southerly areas with low mortality. The odds ratio posterior map in Fig. 3 shows the hotspot area between longitude 20° and 25° and latitude -2,750° and -2,745°. This area is characterised by the following: higher rate

Table 1. Child HIV/TB mortality: descriptive statistics and results of two multiple logit regression analyses, Agincourt sub-district 2004

Variable	Summary number (%)	Univariate logit coefficient (standard error)	Non-spatial multiple logit coefficient (standard error)	Spatial Multiple logit coefficient (standard error)
Age of child in years <sup>1</sup>	2.77 ± 1.20	-0.617 (0.131)**	-0.601 (0.146)**	-0.630 (0.137)**
Gender				
Female	3,379 (50.52)	0	0	0
Male	3,310 (49.48)	0.556 (0.283)*	0.698 (0.303)*	0.641 (0.291)*
Child's parents former refugee				
Yes	2,388 (35.71)	0		
No	4,299 (64.29)	-0.137 (0.280)		
Mother's age in years <sup>1</sup>	28.70 ± 7.59	-0.003 (0.018)		
Cumulative household deaths <sup>2</sup>	0.68 ± 0.96 (0-6)	0.684 (0.086)**		
Mother deceased by 2004				
No	6,634 (99.13)	0	0	0
Yes	58 (0.87)	1.508 (0.732)*	1.504 (0.867)*	1.386 (0.707)*
Minimum distance to health facility <sup>1</sup>	2.33 ± 1.61	0.078 (0.083)		
Household size <sup>1</sup>	4.88 ± 2.92	-0.011 (0.048)		
Gender of household-head				
Female	2,434 (36.37)	0	0	0
Male	4,258 (63.63)	-0.865 (0.418)**	-0.880 (0.302)**	-0.895 (0.30)**
Parity <sup>2</sup>	2.12 ± 1.43 (1-10)	0.085 (0.090)		
Socio-economic status quintiles				
Most poor	1,823 (27.24)	0		
Very Poor	1,073 (16.03)	-0.112 (0.393)		
Moderately poor	1,120 (16.74)	-0.516 (0.444)		
Poor	1,316 (19.67)	-0.425 (0.406)		
Least poor	1,360 (20.32)	-0.458 (0.406)		
Non-spatial variance			0.10; 95% BCI (0.001; 0.68)	0.04; 95% BCI (0.001-0.40)
Spatial variance estimate				0.04; 95% CI (0.001-0.28)
Deviance information criteria			457.26 ± 15.56	555.87 ± 11.65

\* $p < 0.05$ ; \*\* $p < 0.01$ .<sup>1</sup>mean ± standard deviation, <sup>2</sup>mean ± standard deviation (range). 95% BCI = 95% Bayesian credible interval.

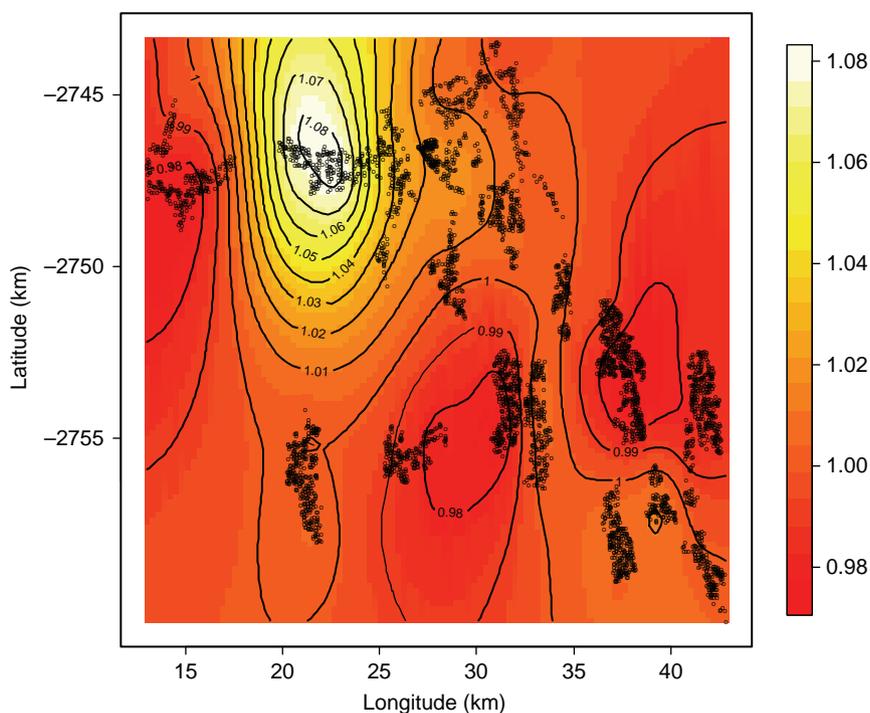


Fig. 3. Child HIV/TB mortality: posterior adjusted odds ratio map, Agincourt sub-district, 2004.

of maternal deaths, more male child mortality, lack of a health facility, and being furthest from any health facility as shown in Fig. 1.

The results from the conceptual framework analysis of child HIV/TB mortality are shown in Fig. 4 and Table 2. All of the connected arrows show pathways that were statistically significant whether directly or indirectly. Being male (logit =  $5.2 \times 10^{-3}$ ) and older child age (logit =  $-4.6 \times 10^{-3}$ ) both impacted directly on HIV/TB mortality controlling for potential confounders related to the maternal and households variables. Upon treating male household headship as an exogenous variable, this directly impacted negatively on child HIV/TB deaths (logit =  $-7.6 \times 10^{-3}$ ), adjusting for household variables. Moreover, when male headship was an endogenous variable, the following household variables indirectly impacted mortality: better socio-economic status and larger household size had a protective effect (logit =  $7.7 \times 10^{-3}$ ) and increase in household deaths resulted in greater child HIV/TB mortality (logit =  $-8.3 \times 10^{-2}$ ).

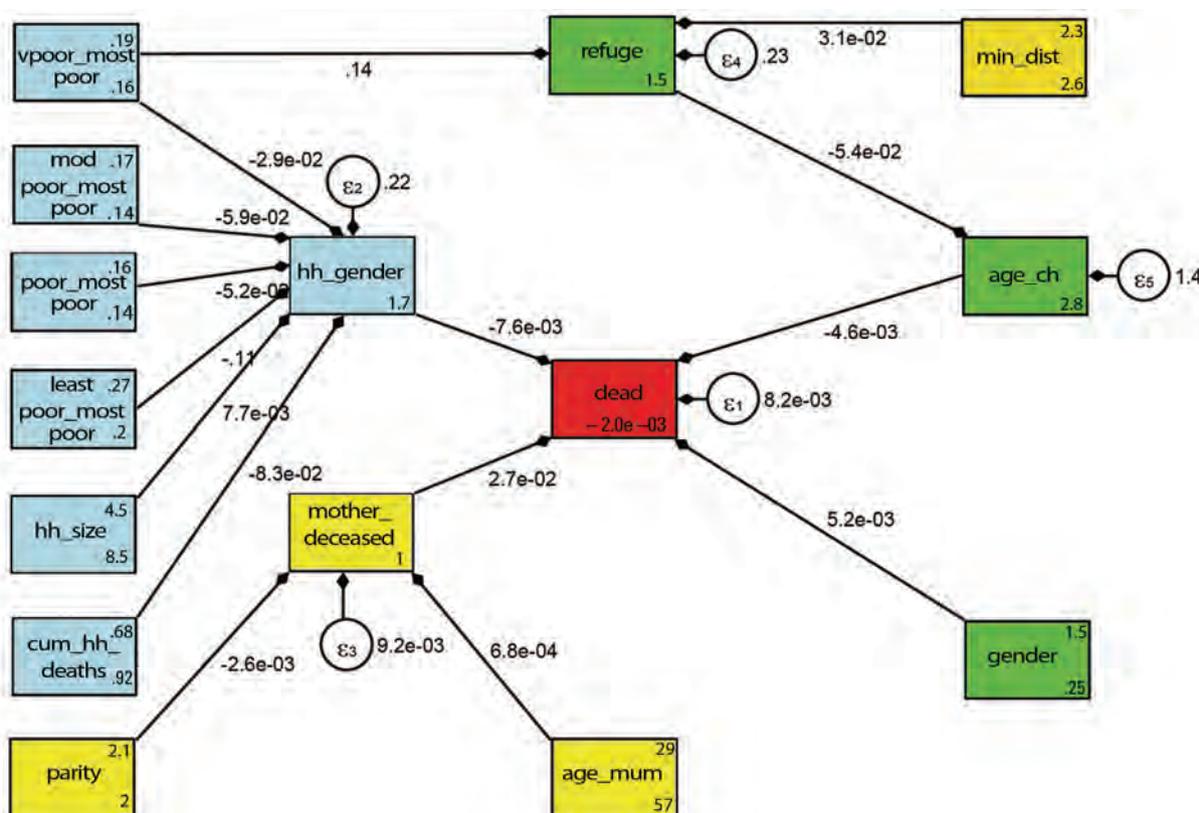
Table 2 details the direct pathways for child HIV/TB deaths (arrows directly linked to the red square) and the indirect pathways showing all possible routes for child HIV/TB deaths as shown in Fig. 4. In our analysis, poverty indirectly impacted on HIV/TB child mortality as conferred by two pathways: first, male headship of households (protective), and second, refugee status (a risk) controlling for child's age (as shown on Table 2 foot note). The greatest direct impact on child HIV/TB

mortality was maternal death (logit =  $2.7 \times 10^{-2}$ ), adjusting for the indirect effects of parity (logit =  $-2.6 \times 10^{-3}$ ) and mother's age (logit =  $6.8 \times 10^{-4}$ ).

## Discussion

In this study, we showed that HIV/TB child mortality is influenced by a combination of child, maternal, household, and spatial determinants. Over the years 2002–2005, HIV/TB alone accounted for 34% of all-cause mortality among children living in the area (23). While being male was a risk factor for HIV/TB mortality as children got older, irrespective of sex they were less likely to die. A major finding in our study was that maternal death had the greatest direct impact on HIV/TB child deaths. A comparable study in the same area, adjusting for spatial random effects at village level, showed that infants whose mothers had died were at greater risk of death during the first 12 months of life (16).

The main source of TB transmission among children are adults, as shown by a study on a high-risk spatial cluster in South Africa with an incidence three times higher than the WHO levels (17). The most likely cause of HIV infection was mother-to-child transmission. Prevention of mother-to-child transmission (PMTCT), using a single-dose of nevirapine (sdNVP) administered to the child and mother, was found to reduce child mortality by about 9% in South Africa (33). Between 2004 and 2012 the guidelines for PMTCT and ART eligibility have changed. There is also a seven-fold lower (from 25 to



**Fig. 4.** Conceptual framework pathways results for Agincourt sub-district child mortality determinants in 2004. Key for variable names: very poor versus most poor (**vpoor\_mostpoor**), moderately poor versus most poor (**modpoor\_mostpoor**), least poor versus most poor (**leastpoor\_mostpoor**), poor versus most poor (**poor\_mostpoor**), age of child in years (**age\_ch**), household size (**hh\_size**), cumulative household deaths (**cum\_hh\_deaths**), gender of household head (**hh\_gender**), mother age in years (**age\_mum**), mother deceased by 2004 (**mother\_deceased**), child born to former refugee parents (**refuge**), gender (**gender**), minimum distance to health facility (**min\_dist**) parity (**parity**), child deceased in 2004 (**dead**). Other: the arrows pointing from the exogenous (explanatory) to endogenous (dependent) variables and the error terms ( $\epsilon$ ) placed on all five endogenous variables.

3.5%) rate of infection from mother to child over the period 2000–2010 (5). Kimani-Murage et al. (2009) found that knowledge of child HIV status influenced the manner of care-giving as well as acceptance and up-take of community-wide interventions (31). The mother's survival significantly increases the likelihood of the child's survival, a finding that strengthens the current policy focus on maternal health. In South Africa, a comprehensive three stage process has been set up to improve maternal, foetal, infant, and ultimately child survival through antenatal care, labour and delivery, and postnatal care (34). Reduction of TB morbidity and mortality is the focus of the WHO 2015 goal of zero new TB infections and zero TB-related deaths (2). The positive impact of the PMTCT programme and ART access has also been demonstrated in another rural South Africa site (35).

In Agincourt, female-headed households had a higher child mortality compared to those headed by males. Studies in Tanzania, Zambia, and Limpopo province

South Africa showed similar results (36–38). The pathway analysis (Fig. 4) demonstrates that male-headship does not independently lead to lower mortality but is a proxy for better socio-economic status of households. Main breadwinners are usually male with females having fewer opportunities in the labour market and consequently earning less. The absence from the household of a male due to death or permanent out-migration tended to impact negatively on household socio-economic status, leading to 90% greater child mortality odds (39). In other African countries, similar patterns were observed as men temporarily migrate within a country or to neighbouring countries due to either pull or push factors (40–42). HIV/TB deaths have lowered the life expectancy of working men from the area who often “return home to die” from their jobs (21). A recent qualitative study found that a father's unemployment, inability to work, and reluctance to provide support were common factors in HIV-infected households (31). From our pathway analysis (Table 2 and Fig. 4), we observed an indirect impact on child HIV/TB

**Table 2.** Direct, indirect and total effects of child HIV/TB mortality in 2004, Agincourt sub-district

	Direct effects on the deceased child as shown in Fig. 2 conceptual framework					Indirect effects on child HIV/TB death	Total effects on child HIV/TB death
	Gender of household-head	Child a former refugee	Child deceased	Mother deceased by 2004	Age of child in years		
Very poor vs most poor	-0.029 (0.019)	0.140 (0.015)***				$2.6 \times 10^{-4}$ ( $1.6 \times 10^{-4}$ ) <sup>ns!</sup>	$2.6 \times 10^{-4}$ ( $1.6 \times 10^{-4}$ ) <sup>ns</sup>
Moderately poor vs most poor	-0.059 (0.020)***					$4.5 \times 10^{-4}$ ( $2.1 \times 10^{-4}$ )**	$4.5 \times 10^{-4}$ ( $2.1 \times 10^{-4}$ )**
Poor vs most poor	-0.052 (0.020)***					$4.0 \times 10^{-4}$ ( $2.0 \times 10^{-4}$ )**	$4.0 \times 10^{-4}$ ( $2.0 \times 10^{-4}$ )**
Least poor vs most poor	-0.111 (0.018)***					$8.4 \times 10^{-4}$ ( $3.0 \times 10^{-4}$ )***	$8.4 \times 10^{-4}$ ( $3.0 \times 10^{-4}$ )***
Household size vs most poor	0.008 (0.002)***					$-5.9 \times 10^{-5}$ ( $2.5 \times 10^{-5}$ )**	$-5.9 \times 10^{-5}$ ( $2.5 \times 10^{-5}$ )**
Cumulative household deaths	-0.083 (0.006)***					$6.4 \times 10^{-4}$ ( $2.1 \times 10^{-4}$ )***	$6.4 \times 10^{-4}$ ( $2.1 \times 10^{-4}$ )***
Minimum distance to health facility		0.031 (0.004)***				$7.72 \times 10^{-6}$ ( $4.88 \times 10^{-6}$ ) <sup>ns</sup>	$7.72 \times 10^{-6}$ ( $4.88 \times 10^{-6}$ ) <sup>ns</sup>
Male household-head			-0.0076 (0.002)***				-0.0076 (0.002)***
Mother deceased by 2004			0.027 (0.012)*				0.027 (0.012)**
Age of child in years			-0.0046 (0.001)***				-0.0046 (0.001)***
Gender			0.0052 (0.0023)**				0.0052 (0.0023)**
Mother's age (years)				0.001 (0.000)***		$1.9 \times 10^{-5}$ ( $9.99 \times 10^{-6}$ )*	$1.9 \times 10^{-5}$ ( $9.99 \times 10^{-6}$ )*
Parity				-0.003 (0.001)**		$-7.0 \times 10^{-5}$ ( $4.0 \times 10^{-5}$ ) <sup>ns</sup>	$-7.0 \times 10^{-5}$ ( $4.0 \times 10^{-5}$ ) <sup>ns</sup>
Parents former refugee					-0.054 (0.032)*	$-2.5 \times 10^{-4}$ ( $1.5 \times 10^{-4}$ )*	$-2.5 \times 10^{-4}$ ( $1.5 \times 10^{-4}$ )*
Intercept	1.719 (0.017)***	1.537 (0.011)***	-0.002 (0.014)	0.995 (0.005)***	2.814 (0.054)***		

\* $p < 0.10$ ; \*\* $p < 0.05$ ; \*\*\* $p < 0.01$ ; ns: not significant; !: indirect effects computed as the product along the related pathways, i.e  $-0.029 \times -0.0076 + 0.14 \times -0.054 \times -0.0046 = 2.55 \times 10^{-4} \approx 2.6 \times 10^{-4}$ .

mortality: as the number of household deaths increased, the risk of child deaths was higher. This suggests that households with a greater burden of mortality are more vulnerable socio-economically through loss of breadwinners and high health care and funeral costs. This compromises a family's ability to feed and care for all children, including those who are HIV positive. We also observed that former Mozambicans are at greater risk of child HIV/TB deaths, indicating the need for health care interventions that target these marginalised and vulnerable households.

### Strengths and limitations of the study

The strengths and limitations of this paper are discussed in four categories: classification of exposures and outcomes; local or global relevance of results; confounding and effect modification; and analysis deviance.

A major strength in our observed variables is that the data are consistently updated, corrected, and checked for inconsistencies. Nevertheless, there are potentially two variable-related biases, namely selection and recall bias. Selection bias may occur if permanent out-migrants differ from residents or temporary migrants, which results in incomparable groups. Recall bias on the outcome variable mortality is unlikely as death is a major household event. However, it may affect the quality of the verbal autopsy interview, conducted at least 1 month but up to 11 months after death, and hence the ability of medical experts to assign a likely cause of death.

Our study focused on one sub-district only, but demonstrated geographical differentials in child HIV/TB mortality. There was one main hotspot with highest mortality and a visible downward trend in mortality moving southwards. These patterns are comparable to those found in other studies carried out in the area (16, 19). While many rural areas are not geo-coded to enable direct comparison of trends and patterns, our findings reflect similar patterns in other rural settlements at least in northeast South Africa.

To deal with confounding variables, we used multiple regression and added the spatial random effects in our modelling and also performed pathway analysis. Mediation was tested for in the pathway analysis as we determined factors directly and indirectly related to mortality and malnutrition. However, we were unable to model time varying covariates as this was a cross-sectional study design.

The robustness of our analysis procedures was demonstrated in that after catering for the spatial household random effects, we obtained narrower confidence bands compared to the non-spatial analogue. Therefore, catering for the spatial random effects further improves the model and parameter estimation compared to classical statistical models. Bayesian and pathway analysis combined were able to handle the complex structure of

hierarchical data from the Agincourt health and socio-demographic surveillance system. Other advantages of Bayesian modelling include the ability to adjust for spatial confounding, and the ability to handle many parameters and inclusion of prior-known information on the distribution of data.

### Conclusion

The growing field of spatio-temporal epidemiology brings in person, place, and time aspects in the risk factor analysis. Spatial Bayesian models provide better-fitting models compared to non-spatial models. This procedure also enables the drawing of risk maps, which can be used by policy makers to target and develop community-based interventions.

Going forward, further studies investigating trends over time using spatio-temporal Bayesian analysis will strengthen the evidence on associated factors and trends found in this study and demonstrate the value of this analytic approach. Studies comparing deaths due to other causes with those for HIV/TB in children would add policy value. Similarly, adopting a secondary analysis of a cohort study design would have enabled temporality to be investigated in greater detail and survival analysis to be undertaken. Moreover, a combination of qualitative and quantitative analysis methods is needed to understand the proximal and distal factors that influence child HIV/TB mortality. Findings that can be used for national policy would require sentinel sites located strategically across the country.

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The authors declare that they have no competing interests.

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**\*Eustasius Musenge**

Division of Epidemiology and Biostatistics  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand  
7 York Road, Parktown  
Johannesburg 2193  
South Africa  
Tel: +27 11 717 2610  
Email: Eustasius.Musenge@wits.ac.za

# Relationship between household socio-economic status and under-five mortality in Rufiji DSS, Tanzania

Cornelius Nattey<sup>1,2,3</sup>, Honorati Masanja<sup>2,3</sup> and Kerstin Klipstein-Grobusch<sup>3,4\*</sup>

<sup>1</sup>National Institute for Occupational Health, Johannesburg, South Africa; <sup>2</sup>Ifakara Health Institute, Ifakara, Tanzania; <sup>3</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>4</sup>Julius Global Health, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, The Netherlands

**Background:** Disparities in health outcomes between the poor and the better off are increasingly attracting attention from researchers and policy makers. However, policies aimed at reducing inequity need to be based on evidence of their nature, magnitude, and determinants.

**Objectives:** The study aims to investigate the relationship between household socio-economic status (SES) and under-five mortality, and to measure health inequality by comparing poorest/least poor quintile mortality rate ratio and the use of a mortality concentration index. It also aims to describe the risk factors associated with under-five mortality at Rufiji Demographic Surveillance Site (RDSS), Tanzania.

**Methods:** This analytical cross sectional study included 11,189 children under-five residing in 7,298 households in RDSS in 2005. Principal component analysis was used to construct household SES. Kaplan–Meier survival incidence estimates were used for mortality rates. Health inequality was measured by calculating and comparing mortality rates between the poorest and least poor wealth quintile. We also computed a mortality concentration index. Risk factors of child mortality were assessed using Poisson regression taking into account potential confounders.

**Results:** Under-five mortality was 26.9 per 1,000 person-years [95% confidence interval (CI) (23.7–30.4)]. The poorest were 2.4 times more likely to die compared to the least poor. Our mortality concentration index [−0.16; 95% CI (−0.24, −0.08)] indicated considerable health inequality. Least poor households had a 52% reduced mortality risk [incidence rate ratio (IRR) = 0.48; 95% CI 0.30–0.80]. Furthermore, children with mothers who had attained secondary education had a 70% reduced risk of dying compared to mothers with no education [IRR = 0.30; 95% CI (0.22–0.88)].

**Conclusion:** Household socio-economic inequality and maternal education were associated with under-five mortality in the RDSS. Targeted interventions to address these factors may contribute towards accelerating the reduction of child mortality in rural Tanzania.

Keywords: *inequality; socio-economic status; principal component analysis; mortality concentration index*

Appendices available online under Reading Tools.

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Sub-Saharan African countries are confronted with a myriad of problems in their effort towards development. Prominent among them are diseases, poverty, and armed conflict. Diseases like malaria, diarrhoea, and the ongoing HIV epidemic are the major causes of under-five morbidity and mortality. Child mortality is a good indicator of child health and survival (1).

Globally, significant progress has been made in reducing mortality rates among children. Between 1990 and 2010, the under-five mortality rate declined by 35% – from an estimated 88 deaths per 1,000 live births to 57 (2). The global rate of decline has also accelerated in recent years – from 2.1% per annum during 1990–2010 to 2.6% during 2005–10 (2). The annual rate of decline in Africa – where almost half of all child deaths occur –

increased from 1.8% during 1990–2010 to 2.8% during 2005–10. Despite this improvement, most countries in the region are unlikely to achieve the fourth Millennium Development Goal target of a two-thirds reduction in 1990 mortality levels by the year 2015 (2).

Bilateral donors such as the United Kingdom's Department for International Development have put improvement of the health of poor people as their top priority in the health sector (3), as has the World Health Organization (4) and the World Bank (5), which recognises low socio-economic status (SES) and avoidable child mortality as not simple inequalities, but inequities that are unjust and unfair.

Poor children are more exposed to risks of disease through inadequate water and sanitation, indoor air pollution, crowding, poor housing conditions, and high exposure to disease vectors (6). They are also more likely to have lower resistance to infectious diseases because they are undernourished (an underlying cause of about 50% of deaths in children younger than age 5) (7); to have diets deficient in one or more essential micronutrients (e.g. vitamin A, iron); to have a low birth weight as a result of poor maternal nutrition, infections during pregnancy, and short birth intervals; and to have recurrent disease episodes (6). The deprivation of poverty goes beyond low income. Low income is associated with lower levels of education, and lower education is associated with disease exposure. For example, in a poor household, knowledge can make the difference between taking advantage of piped water to wash hands and not doing so (8). Knowledge plays a role in, for example, securing a nutritious diet and making appropriate use of health care services (9). Poverty thus increases exposure and reduces resistance to disease, a synergy that contributes to the wide inequities in child survival.

A recent review suggests a linear relationship between maternal education and childhood mortality and the absence of a threshold effect: even a few years of maternal education make a difference (10). In the same review, poverty was suggested as the underlying factor in many cases of child death.

Although there have been improvements in the health status of Tanzanians, infant and child mortality is still high in rural Tanzania. In a poor rural area of Tanzania, the poorest children were 27% less likely to seek care from an appropriate provider than better off but still poor, and children from the poorest families were not as likely as their better-off peers to have received antimalarials for fever or antibiotics for pneumonia (11). The Tanzania second National Strategy for Growth and Reduction of Poverty 2010 (NSGRP-II) (12) document has a development vision to reduce under-five mortality from 154 in 2002 to 79 per 1,000 live births by 2010. Subsequently, in the most recent Tanzania Demographic and Health

Survey Report (TDHS) (13), under-five mortality was reported to be 88 per 1,000 births, denoting a considerably decrease of under-five mortality in the period 2002–10. Still, the 2010 TDHS report showed marked differentials between wealth quintiles and child mortality, with under-five mortality declining gradually with increasing wealth in rural Tanzania.

Rufiji in the Pwani region is a relatively poor subsistence rural area in Tanzania. The Rufiji district is one of the six districts of the Pwani region, Tanzania. It has a population size of about 226,000 of which 87,000 (about 38% of the district) are under periodic surveillance (14). The Rufiji Demographic Surveillance Site (RDSS) commenced field operations in November 1998. The DSS approach involves periodic monitoring of households and members within households in cycles or intervals, known in the RDSS as 'rounds' every four months, that is, three times a year each. The RDSS collects information on demographic, socio-economic, and environmental characteristics of a population of about 87,000 people in 31 villages along the coastal area of Tanzania, south of Dar es Salaam in the Rufiji River basin. A team of trained fieldworkers went from household to household to collect this information in Swahili after obtaining informed consent from each household head. At first glance, the population of RDSS appears to be uniformly poor. However, within this community there are poverty gradients; hence, the focus in this current analysis is to investigate whether, among poor rural Tanzanian populations, wealth index as a proxy for SES and health inequality assessed by concentration index and poorest/least poor quintile mortality rate ratio is related to under-five mortality.

Although previous studies (15, 16) have suggested an association between SES and child mortality at RDSS, information on mortality differentials linked to health inequality could provide further evidence for targeted intervention towards reduction of under-five mortality.

## Methods

### *Design and study setting*

Based on the data from repeated four-monthly cross-sectional surveys, an analytical cross-sectional study was carried out including all households residing within the RDSS in 2005. Data were extracted from the RDSS database including information on all individuals, household head, household assets, and deaths that occurred in 2005.

The study sample comprised 11,189 children younger than age five on 31 December 2005 in 7,298 households in the RDSS for whom information on household SES characteristics were available. There were 289 under-five

deaths in 2005; for the current analysis, information on 251 deaths was available.

### Assessment of SES

Socio-economic status was measured using an asset index, based on ownership of assets, water and sanitation facilities, power source, and housing quality as recommended by Filmer and Pritchett (1998) (17). Assets (Appendix A) were combined into a wealth index using weights derived through principal component analysis (PCA). The PCA involves breaking down assets (e.g. radio, bicycle) or household service access (e.g. water, electricity) into categorical or interval variables. The variables are then processed in order to obtain weights and principal components. Based on this index, SES of households was divided into quintiles (i.e. poorest, very poor, poor, less poor, and least poor) representing proxies for SES.

### Assessment of health inequality

Health inequality in under-five mortality was measured using the concentration index proposed by Wagstaff et al. (18). It is computed from the mortality concentration curve, which plots the cumulative proportions of children ranked by the household's SES against the cumulative proportions of under-five mortality. It estimates the extent of socio-economic inequality in mortality. The concentration index is similar to the relative index of inequality frequently used by epidemiologists (19). It takes values between  $-1$  and  $1$ . A value of  $0$  indicates equity in the health variable. A negative value indicates excess concentration of health among the poor, and a positive value indicates that the poor are less healthy than would be expected had the distribution been equitable. Then, we used the poorest/least poor quintiles mortality rate ratio (PPR) to compare rates prevailing in the poorest quintiles with those in the least poor quintiles. This approach ignores the information contained in the middle three quintiles.

### Other variables

Further explanatory variables included in the analysis were maternal education, maternal age, maternal occupation, maternal marital status, and sex of child. Information on birth weight and distance to facility and nutritional status, known risk factors of under-five mortality, were not collected at the RDSS and hence were not available for analysis, presenting a limitation of this study.

### Mortality rate

The under-five mortality rate was measured by dividing the total number of deaths in a wealth quintile by the calculated person-years observed (PYO) for all children younger than age 5 in that particular quintile for the year

2005. It was expressed per 1,000 PYO. Infant mortality rates were calculated the same way by wealth quintile.

### Statistical analysis

The PYO from 1 January 2005 to 31 December 2005 were computed for all children younger than age 5 residing in the RDSS during this time period. Mortality rates were estimated for infants ( $<1$  year) and children younger than age 5 by Kaplan–Meier (K–M) survival estimates of incidence (mortality) rates and were expressed per 1,000 PYO. Trend tests (Chi-squared) were used to determine the significance of any mortality gradient across wealth quintiles. Concentration index and PPR were estimated as measures of health inequality.

Univariate and multivariate Poisson regression analysis were used to determine the association between SES, maternal characteristics, and mortality in children younger than age 5 and infants. Potential confounders such as mothers' education, age, and occupation were controlled for in the multivariate model. This was based on their significance in the univariate analysis. Corresponding *P* values were calculated to test for statistical significance at the 5% level. We used STATA 10.0 by StatCorp for our statistical analysis.

Ethical approval was obtained from the University of the Witwatersrand's Committee for Research on Human Subjects and the Ifakara Health Research and Development Centre Institutional Review Board.

### Results

Socio-demographic characteristics of children, mothers of children, and household heads are presented in Table 1. In 2005, data were available for 11,189 children younger than age five living in 7,298 households contributing 9,342 person-years. There was a similar proportion of boys (49.9%) and girls (50.1%) during the period under study. Approximately one out of three households was headed by a female. Slightly less than half (46.7%) of the heads of household had primary education compared to a third (33.6%) without any education. The ages of mothers ranged from 14 to 47, with a mean age of 26.6 years (SD 7.8). The majority of mothers were 21–29 years old ( $n=4,454$ ; 39.8%). A total of 5,695 (51%) had attained primary education, whilst 4,777 (43%) had no school education.

The relationship between SES and overall under-five mortality is summarised in Table 2. Mortality rates were shown to be highest in the poorest quintile [40.7 per 1,000 PYO; 95% confidence interval (CI) (32.6–50.9)] and lowest in the least poor quintile [17.1 per 1,000 PYO; 95% CI (12.1–24.2)]. In general, mortality rates decreased as wealth index quintile increased. Children in the poorest quintile were 140% more likely to die before reaching their fifth birthday than those in the least poor households. There was a statistically significant inverse

**Table 1.** Socio-demographic characteristics of 11,189 children younger than age 5 at Rufiji Demographic Surveillance Site, 2005

Variable	Frequency	Percentage
<b>Sex of child</b>		
Male	5,604	50.1
Female	5,585	49.9
<b>Age of child (years)</b>		
<1	2,427	21.7
1–2	2,155	19.3
2–3	2,260	20.2
3–4	2,184	19.5
4–5	2,163	19.3
<b>Under-five SES</b>		
Poorest	2,251	20.1
Poorer	2,246	20.1
Poor	2,218	19.8
Less poor	2,239	20.0
Least poor	2,235	20.0
<b>Household head sex</b>		
Male	7,750	69.3
Female	3,439	30.7
<b>Household head education</b>		
No education	3,726	33.6
Primary education	5,221	46.7
Secondary education	470	4.2
Non-formal education	537	4.8
Others	1,199	10.7
<b>Household head marital status</b>		
Not married	972	8.7
Married	7,837	63.1
Widow/divorced/separated	1,142	10.1
Other	1,238	11.1
<b>Household head occupation</b>		
Not employed	151	1.4
Farming/animal husbandry	7,096	63.3
Casual worker	2,563	22.9
Student	28	0.3
Others	1,351	12.1
<b>Maternal age (years)</b>		
Under 20	2,791	24.9
21–29	4,454	39.8
30+	3,648	32.6
Missing	296	2.7
<b>Maternal education</b>		
No education	4,777	42.7
Primary education	5,695	50.9
Secondary education	376	3.4
Non-formal education	43	0.4
Missing	298	2.6
<b>Maternal marital status</b>		
Not married	1,905	17.0
Married	7,180	69.8

**Table 1 (Continued)**

Variable	Frequency	Percentage
Widow/divorced/separated	1,089	9.7
Other	89	0.8
Missing	296	2.7
<b>Maternal occupation</b>		
Not employed	763	6.8
Farming/animal husbandry	8,457	75.6
Casual worker	1,710	15.3
Student	87	0.8
Others	172	1.5

trend ( $P < 0.001$ ). The mortality concentration index of  $-0.16$  [95% CI ( $-0.24, -0.08$ )] showed a pro-poor concentration of under-five mortality.

Table 3 shows results from the relationship between SES and mortality from Poisson regression for children younger than age 5 with relative risks described as incident rate ratio. In univariate Poisson regression, children in the least poor households were shown to have a 58% significantly reduced risk of dying as compared to the poorest households [crude incidence rate ratio (IRR) = 0.42;  $P < 0.001$ ; 95% CI (0.27–0.62)]. Subsequent adjustment for maternal education, maternal age, and maternal occupation only marginally attenuated the observed association between SES and under-five mortality [adjusted IRR = 0.48;  $P = 0.002$ ; 95% CI (0.30–0.80)]. Chi-squared test for trend across wealth index quintiles was significant for children younger than age 5 ( $P < 0.001$ ). Children younger than age 5 whose mothers had attained secondary education had a 70% reduced mortality risk [adjusted IRR = 0.30;  $P = 0.006$ ; 95% CI (0.22–0.88)] and those whose mothers had attained primary education had a 24% reduced mortality risk [adjusted IRR = 0.76;  $P = 0.008$ ; 95% CI (0.62–0.90)] compared to those whose mothers had not attained any formal education after adjusting for SES, maternal age, and maternal occupation.

Subsequent analysis of infant mortality rates across the different wealth quintiles showed similar results to under-five mortality in Table 4, with infant mortality rate to be highest in the poorest quintile at 158.5 per 1,000 PYO [95% CI (114.9–218.8)] and lowest in the least poor quintile at 106.3 per 1,000 PYO [95% CI (69.3–163.1)]. Children in the poorest households were about 50% more likely to die during infancy than those in the least poor as reflected in the poorest to least poor ratio of 1.5. A mortality concentration index of  $-0.07$  [95% CI ( $-0.13, -0.0003$ )] for infants is an indication of excess mortality in poorest infants household, confirming the difference in infant mortality rates amongst the poorest and the least poor.

**Table 2.** Under-five (<5 years) mortality rates by wealth quintile at Rufiji Demographic Surveillance Site, 2005 with inequality measures

Quintile	N	Under-five person years observed (PYOs)	Deaths (<5 years)	Under-five mortality rate/1,000 PYOs (95% CI)
1st (poorest)	2,251	1,891.6	77	40.7 (32.6–50.9)
2nd (poorer)	2,246	1,878.1	53	28.2 (21.6–36.9)
3rd (poor)	2,218	1,846.7	48	25.9 (19.6–34.5)
4th (less poor)	2,239	1,857.4	41	22.1 (16.3–30.0)
5th (least poor)	2,235	1,867.7	32	17.1 (12.1–24.2)
Total	11,189	9,341.6	251	26.9 (23.7–30.4)
		Chi-square trend		$P < 0.001$
		Poorest–least poor ratio		2.4
		Concentration index		–0.16 (–0.24, –0.08)

## Discussion

The current study investigated the relationship between household SES, health equity, and under-five mortality in

a rural area in Tanzania. Presence of significant socio-economic inequality in under-five mortality at RDSS was observed, adding to the body of evidence regarding the

**Table 3.** Univariate and multivariate analysis of risk factors for under-five (<5 years) mortality at Rufiji Demographic Surveillance Site, 2005

Variable	(Unadjusted) IRR	95% CI	P	(Adjusted) IRR*	95% CI	P
<b>Wealth index</b>						
Poorest (reference)	1			1		
Poorer	0.69	0.48–0.98	0.04	0.82	0.55–1.30	0.37
Poor	0.63	0.45–0.92	0.02	0.66	0.43–1.03	0.68
Less poor	0.54	0.37–0.79	0.00	0.61	0.33–0.39	0.03
Least poor	0.42	0.27–0.63	0.00	0.48	0.30–0.80	0.00
<b>Sex of child</b>						
Male (reference)	1					
Female	0.81	0.63–1.03	0.08			
<b>Maternal education</b>						
No education (reference)	1			1		
Primary	0.70	0.52–0.95	0.02	0.76	0.62–0.90	0.01
Secondary	0.23	0.06–0.93	0.03	0.30	0.22–0.88	0.01
<b>Mothers age (years)</b>						
Under 20 (reference)	1			1		
21–29	0.86	0.63–1.19	0.37	0.84	0.58–1.23	0.39
30+	1.03	0.75–1.42	0.86	0.94	0.64–1.40	0.80
<b>Marital status</b>						
Married (reference)	1					
Not married	1.38	0.97–1.98	0.07			
Divorced/separated	1.80	0.82–2.06	0.08			
Other	1.86	0.51–5.35	0.39			
<b>Maternal occupation</b>						
Not employed (reference)	1			1		
Farming	0.58	0.34–0.98	0.04	0.56	0.30–1.04	0.07
Casual worker	0.53	0.28–0.98	0.04	0.62	0.32–1.20	0.16
Student	1.23	0.36–4.25	0.74	1.31	0.36–4.80	0.68
Other	0.96	0.35–2.65	0.94	0.83	0.29–2.30	0.73

IRR = incidence rate ratio.

\*Adjusted for maternal education, maternal age and occupation.

**Table 4.** Infant (0–1 year) mortality rate by wealth quintile at Rufiji Demographic Surveillance Site, 2005 with inequality measures

Quintile	N	Infants person years observed (PYOs)	Deaths (0–1 year)	Infant mortality rate/1,000 PYOs (95% CI)
1st (poorest)	495	233.4	37	158.5 (114.9–218.8)
2nd (poorer)	521	234.4	26	110.9 (75.5–162.9)
3rd (poor)	491	221.4	27	122.0 (83.6–177.8)
4th (less poor)	469	207.1	24	115.9 (77.7–172.9)
5th (least poor)	451	197.5	21	106.3 (69.3–163.1)
Total	2,427	1,093.8	135	123.4 (104.3–146.1)
		Chi-square trend		<i>P</i> = 0.1
		Poorest–least poor ratio		1.5
		Concentration index		–0.07 (–0.13, –0.0003)

important role of SES in under-five mortality. Measures employed were PCA to derive a wealth index as a proxy for SES, and the use of the PPR and the mortality concentration index to reflect health inequality. PCA has previously been shown to provide a reliable index reflecting combined information on household assets (20). Internal consistency of the constructed wealth index was assessed by examining its distribution against the wealth quintiles of the household variables that had been used for its creation. Patterns on how the asset and household variables change with the quintiles were as expected indicating sensitivity of the PCA approach to differences in SES. The gradients are sufficient to predict health outcomes such as under-five mortality even in a source population that appears to be broadly homogeneous with regard to poverty. The derived PPR value of 1.5 for children younger than age 5, contrasting children in the first (least poorest) to the fifth (poorest) wealth quintile, and a mortality concentration index of –0.16 in the least poor households indicate disproportionate concentration of under-five mortality among the poor and hence health inequity in the current study.

The method employed in the current study to compute mortality rates used person-years as a reference and differs from the method used in DHS reports in Tanzania using live births as the reference category. Subsequently, we report mortality rates for infants and children younger than age 5 that differ from previous DHS reports from Tanzania. The Pwani region, where the RDSS is located, is characterised by a high malaria prevalence [21% in children younger than age 5 as reported in the 2007–08 Tanzania HIV and Malaria Indicator Survey (21)] and a HIV prevalence of 7.3% in adults and 0.9% in children younger than 15 years of age (22). High malaria incidence and the ongoing HIV epidemic in combination with low access to high-quality maternal health care may have contributed to the high infant mortality discussed in this study.

### *Factors associated with under-five mortality*

In previous research, it has been suggested that children born to poor mothers in rural areas face great challenges of survival (23). They are often born at home, without any contact with the health system. An analysis of 50 developing countries found that children born to mothers in the poorest fifth of a population were almost 30% more likely to die as compared to those in the richest fifth (24). Children born to mothers in rural areas in Burkina Faso were more likely to die compared to those in the urban areas (25). Disparities within some countries are especially dramatic. For example, in India, children born to the poorest mothers died at a rate that is 56% higher than babies born to the richest mothers, and in Bolivia, the newborn mortality rate was 70% higher among the poor (24).

Previous studies conducted in South Africa (26–28), Kenya (29), and Nigeria (30) observed higher SES to protect against child mortality and are thus very consistent with the findings of the current study, providing further evidence that wealth inequality is an important risk factor of child mortality. Appropriately identifying disparities in health outcomes is essential, as it informs policy makers about groups that are in greater need of assistance. Even though the population we studied could have been easily identified as homogeneously poor, we have shown that it is not. This has important implications for policies aimed at improving child health outcomes amongst the poor as even in this context trade-offs between universal coverage and targeting health interventions may have to be considered.

Children of mothers with primary (and secondary) education have a significant decreased mortality risk compared to those of mothers with no education. Likewise, mothers who missed out on schooling are more likely to be poor, to get pregnant younger, and more often, to have more children, to be less knowledgeable about family planning and HIV prevention and to be unprepared to look after the health and wellbeing of their babies (31).

Mothers with less education are furthermore less likely to receive skilled medical care during pregnancy and child-birth. In Egypt, for example, only 33% of women with no education receive any prenatal care, and only 17% receive regular prenatal care, while 75% of women with secondary or higher education receive prenatal care and 60% receive regular care (32). Educated women are more likely to be mothers who are healthy, well nourished, economically empowered and resourceful when it comes to caring for themselves and their babies. Women being educated may in fact be a product of a broader social transformation and not just a predictor of child well-being independent of SES. There is the need to further explore the social determinants of women's education and child health.

The potential limitation of this analysis is that it does not adjust for the weight of the child at birth due to RDSS having no data on birth weight. In previous research (32), it has been suggested that children with low birth weight are at increased risk of dying. At the same time, low birth weight has been shown to be associated with low SES. Likewise, family size and distance to health facility were observed to be related to both SES and under-five mortality; however, unfortunately these data were not also available for this analysis (11).

## Conclusion

Household socio-economic inequality and maternal education were observed to be strongly associated with under-five mortality in rural Tanzania. Our study adds to the understanding of the drivers of under-five mortality in rural settings, suggesting that targeted interventions to address these factors would likely contribute towards a reduction of child mortality in rural Tanzania.

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**\*Kerstin Klipstein-Grobusch**

Division of Epidemiology and Biostatistics  
School of Public Health, Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road  
Parktown, 2193  
South Africa  
Tel: +27 11 717-2543  
Fax: +27 11 717 2084  
Email: Kerstin.Klipstein-Grobusch@wits.ac.za

# Alcohol use in early and late adolescence among the Birth to Twenty cohort in Soweto, South Africa

Leane Ramsoomar<sup>1\*</sup>, Neo K. Morojele<sup>1,2</sup> and Shane A. Norris<sup>3</sup>

<sup>1</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Alcohol and Drug Abuse Research Unit, Medical Research Council (MRC), Cape Town, South Africa; <sup>3</sup>Developmental Pathways for Health Research Unit, School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** Alcohol is a risk factor for the leading causes of mortality and morbidity among young people globally. Youth drinking, initiated in early adolescence and continued into early adulthood, is influenced by maternal socio-demographic factors and maternal education. Limited prospective data exists in South Africa on the prevalence of alcohol use during adolescence and adolescent and maternal socio-demographic correlates.

**Objective:** To examine the prevalence of lifetime alcohol use during early (13 years) and late (18 years) adolescence in Soweto, South Africa, and its association with child and maternal socio-demographic factors.

**Methods:** Data on alcohol use in early adolescence (age 13 years) and late adolescence (age 18 years) were collected using self-completed pen and paper and self-completed computer-based questionnaires, respectively. Univariate analyses were conducted on child (gender and number of school years repeated by grade 7), maternal socio-demographic correlates (education, marital status, and age), and household socioeconomic status (SES). Bivariate logistic regression analyses examined associations between alcohol use and all child and maternal socio-demographic factors. Multivariate logistic regression analyses were conducted on all the variables found to be significantly ( $p < 0.10$ ) associated with alcohol use to examine the predictive value on alcohol use at early and late adolescence.

**Results:** Lifetime alcohol use increased from 22% at early adolescence to 66% at late adolescence. In multivariate analyses, gender, maternal education, and SES predicted lifetime alcohol use at early adolescence, while gender, maternal education, marital status, and SES were predictive of the same at late adolescence.

**Conclusion:** This study aids researchers and practitioners to identify maternal and child socio-demographic risk profiles for alcohol use to inform policies and programmes.

Keywords: *adolescent alcohol use; alcohol prevalence; maternal correlates; socio-economic status*

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Alcohol is a risk factor for leading causes of mortality and morbidity among young people. Globally, the harmful use of alcohol accounts for 2.5 million deaths (4% of total), and 69.4 million (4.5% of total) disability-adjusted life years (DALYs) (1, 2). In the 15–29 age group, 9% of total deaths are alcohol-related annually.

Safe levels of consumption have not been established for adolescent populations. This is unsurprising, given that adolescents are physiologically and psychologically

more vulnerable to the effects of alcohol. Physiologically, their smaller body sizes result in a lower threshold for the effects of alcohol. Behaviourally, the disinhibitory effect of alcohol makes adolescents vulnerable to a range of risk behaviours including sexual risk, interpersonal violence, traffic-related accidents, unintentional injuries, and death (3, 4). Given that safe levels of alcohol use have not been established in adolescent populations, any use of alcohol, particularly in early adolescence, may be a predictor of later alcohol problems (5). Evidence from the

South African National Youth Risk Behaviour Surveys conducted in 2002 and 2008 indicate that 49.1% of learners had drunk at least one or more drinks of alcohol in their lifetime (6). In 2008, this increased slightly to 49.6% (7). Of note is that in both surveys, 12% of learners reported having their first drink before 13 years of age (6, 7). This is of particular concern given that early initiation of alcohol is associated with substance abuse problems later in life (5).

Further to early initiation of alcohol use, the same surveys indicate that harmful/hazardous alcohol use (defined as  $\geq 5$  standard alcoholic drinks per day for males and  $\geq 3$  drinks per day for females) is also a significant problem for South African youth (6, 7). Nationally, males report more binge drinking than females overall (4, 6, 7). However, binge drinking among females has increased significantly (4, 6, 7). This early initiation of alcohol use, coupled with the harmful/hazardous use of alcohol found among South African youth, has serious consequences for public health. Hence, identifying correlates of alcohol use particularly during early adolescence is vital for prevention and intervention programmes.

Internationally there is increased focus on adolescent alcohol use for several reasons. First, adolescence constitutes a tenuous period when young people face several developmental and social challenges which place them at risk, for example, physical violence, traffic accidents, unintentional injuries, and death (4, 8). Second, alcohol use has been associated with other health risk behaviours such as smoking, other drug use, and sexual risk behaviours (9–11). Third, alcohol use initiated during adolescence can extend into later life and result in substance use disorders (5, 6).

Previous studies have shown that factors including the individual, family, and SES influence adolescent behaviour (12, 13). Specifically, the role of the mother has been examined in relation to several adolescent behaviours, including sexual risk, drug use, psychopathology, and alcohol use (12, 14, 15).

In South Africa, where adolescent drinking and early initiation of alcohol use is showing an increasing trend (4), limited research exists on adolescent and maternal socio-demographic variables as correlates for alcohol use. Of the limited studies conducted, researchers argue that it may be more pragmatic to target adolescent personal attributes, and peer and parental level factors than the social environment for prevention planning (11). On the contrary, social factors, such as living in communities with limited alcohol policing, easy access to alcohol, and low religiosity (16, 17), have also been cited as targets for prevention planning.

Flisher et al. (17) examined substance use among high school students in Cape Town, South Africa, and found lower rates of substance use, including alcohol use,

among *black*<sup>1</sup> females. They advocate for the importance of recognising demographic factors, such as race and gender as correlates of alcohol use in tailoring alcohol prevention programmes.

Global evidence indicates that males outnumber females with regard to frequency of alcohol use, binge drinking, and alcohol use disorders (2). This is consistent with evidence from the South African studies (5–7).

Regarding the role of SES on adolescent alcohol use, a review of 28 studies internationally found no clear pattern of associations between SES and alcohol consumption in adolescence. Five found positive associations, that is, high SES was related to high alcohol use; five reported negative associations, that is, low SES was related to higher alcohol use. Sixteen studies found no association between SES and alcohol use (18). While much evidence has indicated that adolescents with low SES have a higher inclination for alcohol use (19), other research indicates that adolescents from higher SES categories may also be at risk for substance use (including alcohol use) disorders (20). However, other literature shows differences by developmental stage in the association between SES and substance use. Specifically, adolescents with low SES were more likely than adolescents with higher SES to engage in substance use, while for adults the opposite was true (21).

Previous research has found that parental marital status is a key influencing factor in adolescent alcohol use, that is, adolescents who come from families where parents were separated or had divorced had a higher inclination for alcohol use (22). Similarly, evidence regarding the influence of maternal educational status has consistently revealed that mothers with higher educational levels are less likely to have adolescent children who use alcohol (16, 23).

All these studies provide a window into the role of socio-demographic factors in adolescent alcohol use, but they also have important limitations. Many are school-based studies that do not include youths outside of the school system who may face compounding risk factors for substance use. Flisher and Chalton (24) found that in-school youths were less likely to use substances and engage in sexual risk behaviours (the latter being girls only) than adolescents who dropped out of school. Moreover, in the South African context, many studies on adolescents capture alcohol use at only one point in time and, to the knowledge of the authors, none have

<sup>1</sup>The terms 'white, black, Indian/Asian, and coloured' originate from the *apartheid* era. They refer to demographic markers and do not signify inherent characteristics. Their continued use in South Africa is retained to track transformation and to identify vulnerable sections of the population to be targeted for prevention and intervention programmes.

examined the role of maternal socio-demographic factors in association with alcohol use.

The present study seeks to address some of these limitations by examining alcohol use in a community sample, comprising both in-school and out-of-school adolescents and the association of maternal correlates and alcohol use at two key developmental stages (early and late adolescence). Examining alcohol use at two time points enables one to demonstrate the enduring effect of maternal and child socio-demographic correlates on alcohol use behaviour. Knowledge of demographic correlates assists researchers and practitioners in identifying sub-groups of adolescents with specific maternal (e.g. low education, being a single mother) and child (e.g. gender, repetition of school grades) socio-demographic risk profiles.

## Hypotheses

This study tested three hypotheses:

1. Lower maternal education is associated with having children with a higher inclination for alcohol use during adolescence.
2. Lower SES is associated with having children with a higher inclination for alcohol use during adolescence.
3. Children of women who are not married (single not living together) at birth have a higher inclination for alcohol use during adolescence than children whose mothers are married at birth.

## Methods

### Study population

The study sample comprised of singleton children and their mothers from a birth cohort study, the Birth to Twenty (Bt20) study. This birth cohort study follows 3,273 children and their families in Soweto, Greater Johannesburg, in the Gauteng Province of South Africa. The study enrolled mothers who were 6 months pregnant with their children at the study inception. As the children were born 7 weeks after Nelson Mandela's release from prison in February 1990, they became colloquially known as 'Mandela's children' (25). The township of Soweto is the most populous black urban residential area in the country, with approximately 1 million people. Having originated in 1903, Soweto was the site of the 1976 uprising when school children protested against the *apartheid*<sup>2</sup> system in South Africa. The Bt20 study aims to track child and adolescent health and development

from birth to early adulthood, along several domains – physical, social, and psychological. The retention rate of the overall cohort is 70%, with the highest attrition rate occurring during the infant years, due to permanent out-migration of mothers to rural areas following the delivery of their babies (25). Black children comprised the major race group in the study sample (78.5%), followed by coloured (11.7%), white (6.7%), and Indian (3.5%) children. The mean age of the biological mothers of the index children was 25.9 years old, and the ages ranged from 13 to 48 years old. Ethical clearance for the study was obtained under the Bt20 study from the University of the Witwatersrand Committee for Research on Human Subjects, protocol no. M080320.

### Alcohol use and socio-demographic assessment

Table 1 presents operational definitions of the variables measured in this study.

Demographic information on the mothers and children were collected at/or within the 3 years following the birth of the child. At early adolescence (Wave 1 of the present study) risk-behaviour (such as tobacco and lifetime alcohol use) data were collected using a self-administered paper-based questionnaire. At late adolescence (Wave 2 of the present study), other risk behaviours such as tobacco, sexual activity, and detailed alcohol use (frequency and patterns of drinking, alcohol use disorders, and peer/best friend drinking) data were collected using a self-complete computer-based questionnaire. The interviewer-administered questionnaires included a wide range of indicators inclusive of socio-demographic factors, community norms, household and family circumstances, education, parent-child and peer relationships, and parental monitoring (25).

### Statistical analysis

The analytical study sample consists of two waves of cross-sectional data from the birth cohort study, which mark two developmental periods and are contextualised within this study as early adolescence (13 years) and late adolescence (18 years). Data collected from all participants on alcohol use at the early and late adolescence time points were analysed using the *Statistical Package for the Social Sciences 20* (IBM SPSS Statistics; version 20; New York, USA). Univariate frequency analyses were conducted on the demographic variables including child gender, the number of schooling years repeated by grade 7, household SES, and mother's years of education, age, and marital status at or within the 3 years following the birth of the child. Household SES was calculated based on an asset index derived from a listing of household assets (home type, home ownership, electricity in home, television, car, fridge, washing machine, phone). The use of an asset indicator as a proxy measurement for SES

<sup>2</sup>The *apartheid* era was characterised by a separatist regime, during which the government of the day legitimised the differentiation of people based on race difference, whites, Indians, coloured (mixed ancestry), and blacks (of African descent).

**Table 1.** Operational definitions of variables used at Wave 1 (year 13) and Wave 2 (year 18) of the analytical sample

Variable name	Variable source	Variable operationalisation	Variable coding
Child gender	Baseline Bt20 Demographic Questionnaire	Gender of child	Male =0 Female =1
School years repeated by grade 7	Wave 1 and 2 (year 13 and 18) Adolescent Questionnaire	Total number of 'repeat' school years up to grade 7	No school years repeated =0 1 school year repeated =1 2 school years repeated =2
Lifetime alcohol use	Wave 1 and 2 (year 13 and 18) Adolescent Questionnaire	Ever drunk alcohol in lifetime	No =0 Yes =1
Household SES	Baseline Bt20 Demographic Questionnaire	Asset index based on a list of eight assets in the baseline household. Scores for all variables were added to obtain a value from 0 to 7, and then recoded into five SES categories	Lowest =0 (0, 1, 2 assets) Low =1 (3 assets) Medium=2 (4 assets) Higher =3 (5 assets) Highest =4 (6, 7, 8 assets)
Maternal age	Baseline Bt20 Demographic Questionnaire	Continuous data recoded into age categories that are reflective of maternal age range within the sample	13-19 years=1 20-24 years=2 25-29 years=3 30-34 years=4 35-39 years=5 40-49 years=6
Maternal education	Baseline Bt20 Demographic Questionnaire	Original six categories of maternal education included	No schooling/less than grade 5 education =1 Primary =2 Secondary =3 Post-school (i.e. diploma less than 1 year; diploma 2-3 years; 3-4 year degree; masters degree; PhD; university not specified)=4
Maternal marital status	Baseline Bt20 Demographic Questionnaire	The original variable was recoded into a binary variable based on the frequency of distribution of maternal marital status in the sample	single or not living together =0 married (any definition) or living together; =1

has been validated in developing country contexts (26–28). Asset scores were generated through an additive index, by attributing a score of 1 to assets which people owned and a score of 0 to assets which participants did not own. Participant's responses were scored based on their asset scores and ranked as ranging from 1 (lowest) to 5 (highest) SES categories. Asset scores of 0, 1, and 2 fell into the lowest SES category, 3 fell into the low SES category, 4 into medium SES category, 5 into high SES category, and 6 or 7 into the highest SES category. Bivariate logistic regression analyses were conducted to assess the associations between SES, child and maternal socio-demographic variables, and lifetime alcohol use (measured by ever having had a drink in their lifetime) at

both early and late adolescence. Finally, multivariate logistic regression analyses were conducted on the variables found to be significantly ( $p < 0.10$ ) associated with alcohol use in the bivariate logistic regression analyses in order to examine the predictive value of these socio-demographic variables on alcohol use at early and late adolescence.

## Results

Total sample sizes for participants at early and late adolescence on whom socio-demographic and alcohol use data were collected were 1621 and 1735, respectively. Socio-demographic characteristics of the child participants at early and late adolescence are presented in

Table 2. Females comprised just over half the study sample at early (52%) and late (54%) adolescence. The majority of the participants at both early (74%) and late (75%) adolescence had not repeated any schooling years by grade 7. Twenty-two percent of the sample at early adolescence and 66% at late adolescence had ever used alcohol in their lifetime. Regarding household SES, 16 and 15% of the sample at early and late adolescence, respectively, fell within the lowest wealth category (poorest). A total of 13 and 14% of the sample at early and late adolescence, respectively, fell within the highest wealth category (wealthiest). The largest group (33 and 34% at early and late adolescence, respectively) fell into the medium SES category.

The characteristics of the mothers are presented in Table 3. At the time when the children were enrolled into the study, the largest proportion of mothers (53%) was between 20 and 29 years. Seventy-nine percent of mothers had secondary school education, and 62% were unmarried (single or not living together).

Table 4 shows the results of the bivariate logistic regression analyses. In early adolescence, males were more likely than females (OR=1.507; 95% CI=1.187–1.914) to have ever drunk alcohol in their lifetime. The same is true of late adolescence (OR=1.397; 95% CI=1.139–1.714). During early adolescence, those who had repeated 2 years of school by grade 7 were

**Table 2.** Socio-demographic characteristics of the analytical sample at year 13 and year 18

	Analytical sample			
	Early adolescence (n = 1689)		Late adolescence (n = 1735)	
	n	%	n	%
Child gender				
Male	762	48	758	46
Female	839	52	893	54
School years repeated by grade 7 <sup>a</sup>				
0	1116	74	1162	75
1	331	22	337	22
2	55	4	59	4
Lifetime alcohol use	373	22	1140	66
Household SES (wealth category)				
Lowest	230	16	229	15
Low	246	17	257	17
Medium	493	34	496	33
High	304	21	310	21
Highest	194	13	203	14

<sup>a</sup>Totals do not add up to 100% due to rounding.

**Table 3.** Maternal socio-demographic characteristics at the time of the birth of the Bt20 participant

	n	%
Age		
13–19 years	278	18
20–24 years	468	29
25–29 years	386	24
30–34 years	285	18
35–39 years	143	9
40–49 years	34	2
Education		
No schooling/less than grade 5	81	6
Primary	93	6
Secondary	1169	79
Post-school	133	9
Marital status		
Not married	987	62
Married	596	38

significantly more likely that those who had not repeated any school years by grade 7 to have used alcohol (OR=2.518; 95% CI=1.039–6.001). There were no significant associations between the number of school years repeated by grade 7 and alcohol use at late adolescence.

Regarding maternal age, mothers between 20 and 29 years (OR=3.544; 95% CI=1.051–11.94) were significantly more likely than younger mothers (13–19 years old) to have had an adolescent child use alcohol by age 13. However, there were no significant associations between maternal age and alcohol use at late adolescence. Mothers with primary (OR=0.237; 95% CI=0.105–0.537) and post-school education (OR=0.608; 95% CI=0.411–0.898) were significantly less likely than mothers with no/less than grade 5 education to have had a child use alcohol in early adolescence. In late adolescence, mothers with primary (OR=0.308; 95% CI=0.103–0.921), secondary (OR=0.369; 95% CI=0.220–0.617), and post-school (OR=0.473; 95% CI=0.307–0.730) education were significantly more likely than mothers with no/less than grade 5 education to have had an adolescent child use alcohol. Marital status was not significantly associated with alcohol use in early adolescence, while at late adolescence, married mothers were significantly less likely (OR=0.726; 95% CI=0.587–0.897) than non-married mothers to have a child use alcohol.

Household SES was significantly associated with alcohol use at early and late adolescence. Specifically, at early adolescence those participants from low (OR=0.601; 95% CI=0.384–0.940), medium (OR=0.553; 95% CI=0.354–0.863), and high (OR=0.682; 95% CI=0.469–0.993) SES categories were significantly less likely than those adolescents from the lowest SES

**Table 4.** Bivariate logistic regression analyses of lifetime alcohol use, SES, and child and maternal socio-demographic characteristics

Lifetime use of alcohol	Early adolescence			Late adolescence		
	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>
Child gender	1			1		
Male	1.507	1.187–1.914	0.001	1.397	1.139–1.714	0.001
No. of school years repeated by grade 7						
0	1			1		
1	2.249	0.952–5.314	0.065	1.451	0.856–2.459	0.167
2	2.518	1.039–6.100	0.041	1.443	0.824–2.528	0.199
Maternal age at birth of the child						
13–19	1			1		
20–24	3.544	1.051–11.94	0.041	1.222	0.588–2.539	0.591
25–29	3.063	0.918–10.21	0.069	0.958	0.471–1.948	0.906
30–34	3.007	0.898–10.07	0.074	1.115	0.546–2.276	0.765
35–39	2.361	0.695–8.012	0.168	1.103	0.532–2.288	0.793
40–49	2.316	0.658–8.158	0.191	1.158	0.539–2.490	0.707
Maternal education at birth of the child						
No schooling/less than grade 5	1			1		
Primary	0.237	0.105–0.537	0.001	0.308	0.103–0.921	0.035
Secondary	0.594	0.321–1.098	0.097	0.369	0.220–0.617	0.000
Post-school	0.608	0.411–0.898	0.012	0.473	0.307–0.730	0.001
Maternal marital status at birth of the child						
Not married	1			1		
Married	1.047	0.818–1.340	0.716	0.726	0.587–0.897	0.003
Household SES						
Lowest	1			1		
Low	0.601	0.384–0.940	0.026	0.793	0.432–0.975	0.037
Medium	0.553	0.354–0.863	0.009	0.853	0.455–1.008	0.055
High	0.682	0.469–0.993	0.046	0.652	0.382–0.777	0.001
Highest	0.693	0.460–1.044	0.079	1.131	0.665–1.459	0.940

households to have ever drunk alcohol in their lifetime. The same was true for late adolescence (see Table 4).

Table 5 shows the results of multivariate logistic regression analyses. All variables found to be significantly ( $p < 0.10$ ) associated with alcohol use in the bivariate logistic regression analyses were included in the multivariate logistic regression. Gender was predictive of alcohol use. Males were more likely to have ever drunk alcohol in their lifetime at both early (OR = 1.372; 95% CI = 1.054–1.7861) and late adolescence (OR = 1.387; 95% CI = 1.103–1.745) than females. There were no significant associations between maternal age and alcohol use at early or late adolescence.

Regarding maternal education, at early adolescence, children with mothers who had had at least a primary school education (i.e. completed grade 5) were significantly less likely (OR = 0.312; 95% CI = 0.127–0.768) to have ever drunk alcohol, compared to children with mothers with no or less than grade 5 education. In addition, mothers who had post-school education [i.e. diploma (less than 1 year), diploma (2–3 years), 3–4 year degree, master's degree, or a PhD] were significantly less likely (OR = 0.596; 95% CI = 0.387–0.920) to have had children who had ever drunk alcohol in early adolescence than those with mothers with less than grade 5 or no education.

**Table 5.** Multivariate regression analyses of lifetime alcohol use and child and maternal socio-demographic characteristics

Lifetime use of alcohol	Early adolescence			Late adolescence		
	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>
Child gender	1			1		
Male	1.372	1.054–1.786	0.019	1.387	1.103–1.745	0.005
No. of school years repeated by grade 7						
0	1			1		
1	2.261	0.872–5.861	0.093	1.335	0.737–2.418	0.341
2	2.489	0.872–5.861	0.067	0.489	0.737–2.418	0.341
Maternal age at birth of the child						
13–19	1			1		
20–24	3.966	0.872–18.026	0.075	1.040	0.428–2.526	0.931
25–29	3.623	0.811–16.178	0.092	0.682	0.289–1.608	0.382
30–34	3.225	0.726–14.323	0.124	0.778	0.332–1.821	0.563
35–39	2.436	0.543–10.927	0.245	0.741	0.313–1.759	0.497
40–49	2.211	0.475–10.306	0.312	0.745	0.304–1.825	0.519
Maternal education at birth of the child						
No schooling/less than grade 5	1			1		
Primary	0.312	0.127–0.768	0.011	0.381	0.106–1.368	0.139
Secondary	0.771	0.394–1.510	0.449	0.360	0.204–0.633	0.001
Post-school	0.596	0.387–0.920	0.019	0.488	0.306–0.778	0.003
Maternal marital status at birth of the child						
Not married	1			1		
Married	0.984	0.798–1.349	0.922	0.684	0.498–0.844	0.001
Household SES						
Lowest	1			1		
Low	0.681	0.417–1.112	0.125	0.837	0.535–1.309	0.435
Medium	0.596	0.366–0.970	0.037	0.897	0.579–1.389	0.627
Higher	0.672	0.445–1.016	0.059	0.653	0.443–0.963	0.032
Highest	0.728	0.467–1.135	0.161	1.23	0.803–1.893	0.339

At late adolescence, maternal education was also predictive of adolescent alcohol use. Specifically, children with mothers who had secondary (OR=0.360; 95% CI=0.204–0.633) and post-school (OR=0.488; 95% CI=0.306–0.778) education were significantly less likely than children with mothers who had no schooling/less than grade 5 to have ever drunk alcohol. Significant associations emerged between maternal marital status and alcohol use in late adolescence only, with children with married mothers less likely (OR=0.684; 95% CI=0.498–0.844) to have ever used alcohol, compared to children with non-married mothers.

Finally, household SES was predictive of lifetime alcohol use. At early adolescence, participants from

medium (OR=0.596; 95% CI=0.366–0.970) and higher (OR=0.672; 95% CI=0.445–1.016) SES categories were less likely than participants from the lowest SES category to have ever drunk alcohol in their lifetime. The same is true for late adolescence where participants from the higher SES category (OR=0.653; 95% CI=0.443–0.963) were less likely than the participants from the lowest SES adolescents to ever have drunk alcohol in their lifetime.

## Discussion

This paper examined lifetime alcohol use among a birth cohort in Soweto, South Africa, in early (13 years) and late (18 years) adolescence and its association with

household SES as well as child and maternal socio-demographic factors. Specifically, we examined child gender, the number of years the adolescents repeated schooling by grade 7, maternal age, education, marital status, and household SES in association with lifetime alcohol use at these two developmental stages.

Consistent with national and international literature (4, 6, 7), this study found gender differences in rates of alcohol use at both early and late adolescence, indicated by the higher prevalence of adolescent males who drank alcohol in their lifetime and significant associations between gender and alcohol use revealed by bivariate and multivariate analyses, respectively.

The significant association found in early adolescence between the repetition of 2 years of schooling by Grade 7 and lifetime alcohol can be explained by previous research which indicates that poor educational attainment has been associated with substance use (24).

The marginally significant associations found in the multivariate analysis between the repetition of 2 years of schooling by Grade 7 and lifetime alcohol can potentially be confounded by the effect of SES and maternal education (28).

This study also contributes to a body of literature on the relationship between SES and alcohol use. Present findings are consistent with evidence and confirm the study hypotheses that SES is predictive of adolescent alcohol use. Both bivariate and multivariate results corroborate much existing evidence that low SES is related to higher alcohol use (18, 29). In particular, at early adolescence, participants from medium and higher SES categories were less likely to have ever used alcohol in their lifetime than adolescents from the lowest SES category. The latter finding is also true for late adolescence. Similarly, maternal education had consistent predictive value in adolescent alcohol use at early and late adolescence; the higher the maternal education, the less likely adolescents were to have ever drunk alcohol in their lifetime. Potential explanations for these findings are that adolescents from lower SES categories and/or whose mother's education level is lower may be less likely than higher SES categories, with higher maternal education, to be educated about alcohol-related risks and harm (24). They may also have more access to unregulated sale of alcohol than higher SES adolescents (9) and live in areas where alcohol outlet density is higher (30).

The significant associations found between maternal education and alcohol use highlight the protective role of maternal education. At early adolescence, both maternal primary and post-school education were significantly associated with and predictive of alcohol use. At late adolescence, the same was true of the association between mothers with secondary and post-school education and their adolescent children's alcohol use. These findings could be explained by other research, which suggest that

more educated mothers not only engage in healthier behaviour but also have more disposable income to afford more or better health protection (quality food, health care, live in safer neighbourhoods) for their children (31) than mothers who may be less educated with less disposable income. Mothers with higher educational attainment may also, by virtue of their own health education, be better positioned to provide health promotion and education and model more health behaviours than mothers who are less educated (31). Consequently, educating mothers to a higher level may also have benefits for preventing alcohol use by their adolescent children.

Finally, the significant associations between maternal marital status and alcohol use in late adolescence only, partially confirms the study hypothesis that adolescents of unmarried mothers have a higher inclination for alcohol use than adolescents of married mothers. The particular association between maternal marital status and alcohol use among *older* adolescent children may be explained by research which indicates that the lack of a biological father can have negative implications for the socialisation of children (32). Given that more discipline and adolescent social supervision may be required in later adolescence than in earlier adolescence, and single mothers have been found to exert less authority and provide less discipline to their children than married parents (33), the absence of a biological father may have more profound negative effects on children's alcohol use behaviour later, rather than earlier in life.

Taken together, these findings have important implications for planning and programmes. Specifically, programmes targeting risk and protective factors for adolescent alcohol use must take account of the role of gender, SES, and maternal education in adolescent alcohol use. The findings also point to the need for mothers (with low education), boys, and children from lower SES to be targeted (albeit differentially at different stages) as intervention points for adolescent alcohol prevention initiatives. Moreover, future research is required to examine potentially relevant socio-demographic factors in tailoring adolescent alcohol prevention programmes. Finally, maternal education and SES may only partially account for the association between socio-demographic correlates and adolescent alcohol use. The absence of the biological father, coupled with the influence of other determinants (peers, community contexts), may further explain adolescent alcohol use.

There are limitations to this study notably our inability to consider the role of the father in adolescent alcohol use. Low father involvement was due, in part, to the migrant labour system in apartheid South Africa, which disrupted the structure of black families (34). Bearing children outside a marital arrangement was relatively normative in these contexts, resulting in children being born with very low father involvement in the Birth to

Twenty cohort (25). This explains why the majority of mothers were single parents and, therefore, the primary contact for the study. Future research from the birth cohort is required to understand the presence and potential influence of a father figure on adolescent risk behaviours. Furthermore, as with any birth cohort study, loss to follow up is a limitation. Another limitation is the definition of the outcome measure (ever drunk) as a self-reported outcome measure. This is subject to socially desirable responses which potentially result in an over-/underestimation of alcohol use. The recognition of marital status in South Africa under many arrangements, including civil unions and customary unions, and cohabitation makes the standard definition of marriage used in this study a potential limitation.

Additionally, we acknowledge the potential changes that may have occurred in maternal marital status and education from study inception to the survey waves. However, future longitudinal analyses are required to examine the effect of changing maternal socio-demographic characteristics on adolescent alcohol behaviour, as the aim of this paper was to examine the role of child and maternal socio-demographic correlates at birth in adolescent alcohol use. Finally, we recognize that lifetime use of alcohol as the only outcome measure is a limitation. Nevertheless, given that alcohol use is initiated in adolescence, this may be an important marker of future alcohol use. Future studies employing a life course approach to the development of adolescent alcohol behaviours are envisaged to examine the precision of lifetime alcohol use as a measure of later alcohol problems in this birth cohort.

## Conclusion

This study makes a contribution to informing tailored prevention programmes for adolescent alcohol use at important stages in their developmental process. Future research is required to understand the interactions between psychosocial (social support, parenting styles, monitoring) and socio-demographic (age, SES) factors that may play a role in predicting adolescent alcohol use.

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**\*Leane Ramsoomar**

School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road Parktown 2193  
South Africa  
Tel: 27-11-7172608  
Email: leane.ramsoomar@wits.ac.za

# A South African university-practitioner partnership to strengthen capacity in social and behaviour change communication

Nicola J. Christofides<sup>1\*</sup>, Sara Nieuwoudt<sup>1</sup>, Shereen Usdin<sup>2</sup>, Susan Goldstein<sup>1,2</sup> and Sharon Fonn<sup>1#</sup>

<sup>1</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Soul City Institute for Health and Development Communication, Johannesburg, South Africa

Globally, communication plays an integral role in public health strategies, from infectious diseases to diseases related to lifestyles. The evolution of the field of social and behaviour change communication (SBCC), combined with the need for evidence based practice and multi-level interventions to promote health, and human resource gaps in sub-Saharan Africa have led to the imperative to standardise and formalise the field. Moreover, current practitioners come from different disciplinary backgrounds underlining the need to define common core skills and competencies. This paper describes the partnership between the Wits School of Public Health and the Soul City Institute for Health and Development Communication and how the partners responded to this need. It highlights the factors influencing sustainable institutional capacity to provide quality assured, accredited training. We describe an unexpected positive response from a number of practitioner organisations that have chosen to send multiple staff members for training, specifically to build a critical mass within their organisations. Finally, we note the interest from (mostly) southern-based academic institutions in setting up similar programmes and postulate that south-south collaborations can contribute to building sustainable context specific and evidence-informed SBCC programmes in the global south.

Keywords: *SBCC; competency-based curriculum; south-south collaboration; institutional capacity strengthening; Africa; practitioner academic partnership; donor responsiveness*

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Significant resources have been invested to eradicate disease and decrease preventable mortality and morbidity, from communicable and non-communicable causes. These investments have acknowledged that individuals need to act differently to achieve health improvements. Even biomedical interventions, such as voluntary medical male circumcision, invest in communication to drive demand for clinic-based services (1, 2).

Individual change, while important, only impacts on the health profile of a country when there is a significant shift in collective behaviour towards more healthful activities (3). Public health is concerned primarily with this population-level change. Under the umbrella of public health, social and behaviour change communication (SBCC)

develops, implements, and evaluates appropriate, evidence-based interventions to change population health.

SBCC has its origins in, and draws from, a range of academic disciplines including media, communication, and public health. There have been parallel and overlapping approaches that have emerged from these disciplines including communication for development, health communication, and health promotion (Fig. 1). SBCC does not replace any of these fields but draws from all of them. The Ottawa and Bangkok charters on health promotion, outlined changing health outcomes through advocating for supportive policies and supportive environments, community action, preventive and promotive health services, and increased health literacy (4, 5). Health communication programmes are based on 'the scientific

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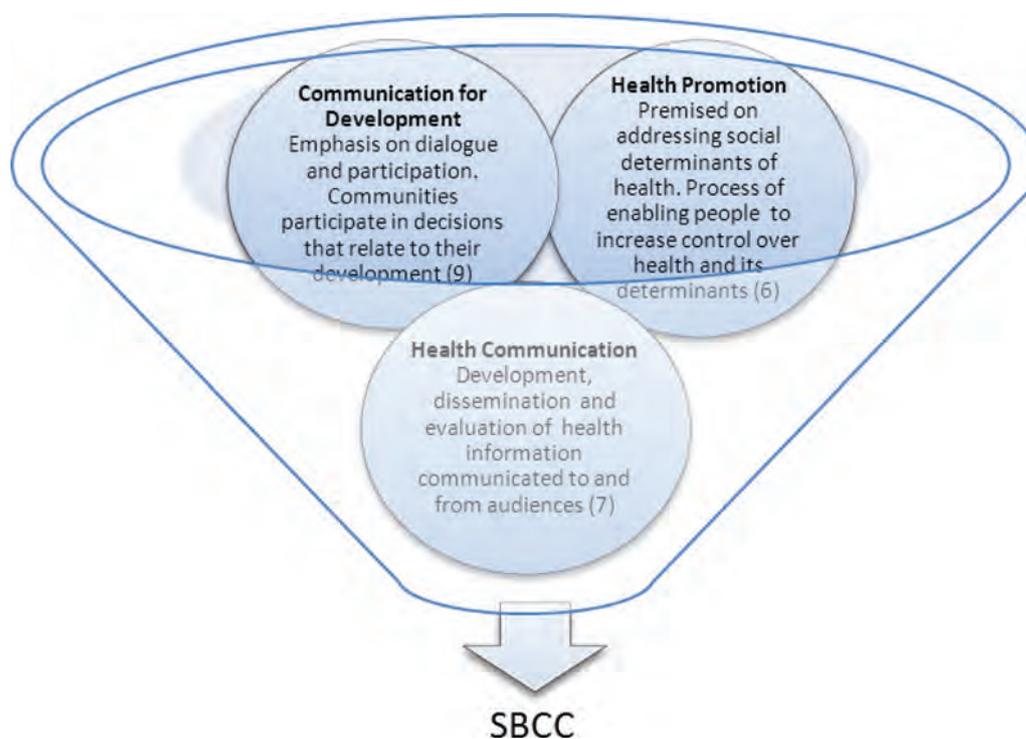


Fig. 1. Disciplines influencing social and behaviour change communication.

development, strategic dissemination, and critical evaluation of relevant, accurate, accessible, and understandable health information communicated to and from intended audiences to advance the health of the public' (p. 2051) (6). Communication for development similarly addressed the need to support two-way communication systems but emphasised dialogue and the participation of communities in the decisions related to their development. It also sought change at different levels including the development of policies that promote development (7). In the late 1990s, the Rockefeller Foundation, in collaboration with a number of organisations from the global south, began looking at communication for social change, moving away from the top down, individual approach to a more engaging and social approach, seeing the individual in the context of their environment and a complex socio-economic system (8). This model of communication, focusing on the political, social, family, and structural issues affecting health, has become the preferred model of many communication programmes (9, 10).

SBCC is premised on the assumption that individual behaviours need to be understood and tackled within an ecological framework, from interpersonal relations to the policies, cultural norms, and values that shape the world in which individuals live. This requires interdisciplinary collaborations to inform interventions and demands greater engagement with policy making and the political and economic context in the African region (11). In the context of such complexity, SBCC must thus draw from those disciplines that engage in this space, including

anthropology, sociology, political science, communication, and marketing, to name a few. To make an impact at the population-level disciplines fundamental to public health such as epidemiology, health policy analysis and health economics make their contribution to SBCC. For example, recently gazette legislation in South Africa addressed the salt content of some processed food, including bread (12). The rationale is that if non-discretionary salt levels can be reduced at the stage of production (creating an enabling environment for decreasing individual salt intake), the country will effectively reduce the salt intake of individuals at risk of developing non-communicable diseases, such as hypertension. This strategy, central to the health promotion concept of making the healthy choices the easier choice, is more cost-effective than attempting to change individuals' eating habits (13).

SBCC, health promotion, and health communication are not without critics. Governments and donors alike are calling for more evidence-informed health communication interventions. The most common critiques of SBCC tend to revolve around limited evidence of health impact (14–18). To address this communication, practitioners have been arguing that evaluation of SBCC interventions requires alternative methods and greater complexity than single-level or clinical interventions (19). SBCC practitioners have promoted alternative evaluation methods, highlighting that using randomized controlled trials (RCTs) to evaluate multi-level communication interventions is often both unfeasible and unethical (20).

This argument may be gaining traction. Recently, some donor agencies have put out calls for alternative ways of evaluating communication interventions. Funding has also been earmarked for continued investment in capacity strengthening for health communication (21).

Thus, SBCC has two challenges to deal with: improving the understanding of interventions to influence population-level changes in behaviour; and developing methods of evaluation to demonstrate the contribution of SBCC to health outcomes and impact. An improvement in the skills of SBCC practitioners in both these areas is required.

SBCC training also needs to account for a great diversity of practitioners, who are employed in a range of institutions, from non-governmental organisations (NGOs) to government health promotion divisions (22). While originating from a range of disciplines, such as marketing, journalism, psychology, education, nursing, medical, or the social sciences, they are all often expected to design, manage, monitor, and evaluate communication initiatives in their workplaces.

The need to strengthen health promotion and SBCC capacity in the global south has been well documented (23, 24). The impact of short-term training or sending a select few individuals to be educated in northern institutions is questionable, as such efforts rarely address the fundamental institutional problems and human retention challenges that underlie capacity gaps in Africa (22, 25–27). The relevance of course content to the challenges faced in the global south has also been under scrutiny. There is growing recognition that capacity strengthening must take place at multiple levels (individual, organisational, sectoral, and institutional), which has led governments and NGOs to explore how universities in the global south can work more closely with networks of other universities, civil society groups, and government to address capacity gaps in the field (22, 25, 28).

The external interest in universities playing a role in SBCC training has been complemented by a university-driven shift to competency-based education (CBE) models (29–31). In the United States of America and Europe, health promotion is an integral part of public health competency frameworks (30, 32). The shift to CBE is a response to a perceived gap between academic training and the practical knowledge, skills, and values required in public health practice, including health communication. Universities have recognised that graduates need to be able to apply their academic skills. This has set the stage for an unprecedented openness to new ways of collaboration for SBCC capacity strengthening within the field of public health.

Defining health communication or SBCC competencies occurred through a parallel process, driven by communication practitioners (4) where academics, government, and civil society actors met in Ica, Peru, in 2001 to develop a competency framework for health

communication (25). Health communication, as framed in Ica, is synonymous with SBCC as described earlier. Obregon and Waisbord describe collaboration with higher education institutions as

a critical dimension of sustained and long-term efforts aimed at creating a critical mass of individuals and organizations with a particular focus on the required competencies in health communication. (p. 560) (25)

Some advantages universities offer over NGO training include accreditation (enabling professional growth), standardisation of competencies, structured longer-term programmes, and a higher likelihood of SBCC training being institutionalised and sustained beyond a particular donor funding stream (25).

While university programmes should not be developed in a vacuum, graduates need to return to work environments that allow them to apply their newly acquired skills or else there is a risk that

capacity activities might unintentionally contribute to promoting a sense of frustration among participants who work in organizations that provide little support to change job performance (22).

Successful academic–practitioner collaborations require several elements to be satisfied. These include institutional cultures supportive of evidence-informed communication, establishing trust within the collaboration, and ensuring that the institutions ultimately responsible for training and employing practitioners (versus donors) own the process (22).

The following case study describes and reflects on a partnership between a southern university, the University of the Witwatersrand (Wits), and Soul City Institute, an NGO, to establish an academic, competency-based SBCC programme serving Southern Africa. While northern donors and collaborators were engaged in the process, this case is notable as a partnership between African institutions, leading a capacity strengthening process in Africa to benefit Africans.

## Case study

### Stakeholders

The Soul City Institute for Health and Development Communication, established in 1992, is a large NGO that develops health and development communication and supports a network of regional partners around Africa. The regional support included capacity strengthening, and by 2008, the Soul City Institute had conducted approximately 100 formal training events in areas such as formative audience research, advocacy, print, radio, and television edutainment drama (33). In 2009, Soul City Institute and their regional partners were also experiencing increasing donor demands to demonstrate

the health impact of their multi-media and multi-level SBCC interventions as well as staff-driven demand for accredited training opportunities.

The Wits School of Public Health (WSPH) has a long history of responding to the context in which it is located. Historically the academic attention of the WSPH focused on exploring the impact of apartheid on health, research to inform policy to improve health equity in a democratic dispensation, and piloting interventions to achieve improved health system performance. This required that academics worked with civil society, community organisations, and NGOs. More recently, its training programmes have successfully sought to fill capacity gaps in public and population health in Africa (25, 26, 34). WSPH comprises staff drawn from a range of disciplines relevant to public health. Interdisciplinary research and innovative teaching approaches and methods are WSPH standard practice.

### *Inception phase of the WSPH–Soul City Institute SBCC training programme*

Over and above the development in competency-based approaches to education and the development of the SBCC field described above, three processes informed the development of a SBCC training programme located at the WSPH: an audit of the needs of potential students; a donor commissioned review of SBCC in the region; and later, a baseline assessment of the expectations and experiences of the first intake of students to ensure that our planned curriculum was appropriate.

The audit developed out of a ‘bottom-up’ appreciation of the need for systematic and accredited training at both an individual and organisational level that Soul City Institute garnered through their partnerships with NGOs in Southern Africa. Academic training was identified as a method to enhance professional growth and to enable organisations to implement programmes more effectively. In late 2008, the Soul City Institute conducted an audit with its staff and partners in its regional capacity strengthening programme to explore the educational backgrounds of staff and determine training priorities. The assessment found that most practitioners relied on short-term training to supplement their ‘on the job’ learning. The Soul City Institute had led some of this training. However, as highlighted by Obregon & Waisbord, they encountered challenges with sustaining longer-term training and were unable to satisfy staff requests for accredited training (25).

There was substantial debate at the time about where a sustainable accredited training programme in the field of health communication in Southern Africa could be housed, and whether there was institutional capacity to create long-term in-country health communication expertise in this region. In response to this debate, donors commissioned a review to explore the rationale for

locating training within a school of public health as opposed to other options (35). This review began with a search of universities with existing SBCC curricula in South Africa and the Southern African region. A number of opportunities to study health communication or health promotion were identified. However, documentation available about the content showed that none of them entirely represented the interdisciplinary training that SBCC requires. The review identified that practitioners needed to understand the theories and approaches of communication for behavioural and social change. They also needed research and operational skills to plan, implement, monitor, and evaluate health communication programmes at regional, national, district, and community levels (35). The review highlighted that SBCC practitioners needed to understand the epidemiology of communicable and non-communicable diseases and other public health issues, as well as the social, cultural, political, and economic contexts of public health in Southern Africa and thus identified ‘compelling reasons’ for locating the initiative at a school of public health. This included noting that knowledge of health issues was considered vital in order to be able to develop specific and accurate health communication and that there would be a greater opportunity for health communication to be mainstreamed if the programme were integrated into a Master of Public Health (MPH) (35). There were also international precedents for health communication to be located within a school of public health (35).

Baseline research carried out with a sample of SBCC masters’ students confirmed that participants expected to gain a broader understanding of public health, the key principles and meaning of public health beyond medical and epidemiological topics, how to apply SBCC theories in their work, how to implement programmes, and how to measure the outcomes. Almost all participants emphasised the desire to develop skills to monitor and evaluate SBCC programmes. This was identified as the most challenging area in their work. The following quote illustrates the common expectations.

I was expecting to get deeper knowledge on SBCC concepts, theories and approaches for application in my work, including skills on how to design and implement SBCC interventions. I was particularly expecting to learn how to monitor and evaluate SBCC interventions, e.g. media. (MPH student, 2010 cohort)

### *The partnership*

On the basis of the audit, and supported by the findings of the donor review, Soul City Institute approached WSPH with the idea of a partnership. Both organisations had a long-standing research and training relationship meeting the requirement of trust as highlighted by Obregon & Waisbord (25). This partnership brought

together practitioners and a tertiary education institution to develop a master's programme and short courses based on praxis and created a competency-based curriculum.

To take the academic-practitioner partnership further, a consultative meeting was held in May 2009 at the WSPH, with the participation of 16 academics and SBCC practitioners from 10 institutions and five countries to develop the programme. It drew on the dual historical processes of defining competencies both within public health and SBCC and the partnership-defined SBCC competencies relevant to the African context (25, 30). These competencies were then translated into a set of learning outcomes, which became the basis for the curriculum, including SBCC-specific formative research, monitoring, evaluation, strategic approaches, behavioural and social theory, and designing and planning programmes.

The final method of securing the partnership between the academy and practitioners was the establishment of an advisory board made up of practitioners from African institutions and academics from the global north and south. Their brief is to keep the curriculum current and to provide a space for critical reflection. The advisory board reflects the interdisciplinary nature of SBCC and includes SBCC practitioners and academics with a background in communication for development as well as in public health.

### *The curriculum*

In response to the immediate short-term need for capacity strengthening in the African region, self-standing certificated short courses as well as a field of study in SBCC within the MPH programme were developed. Currently, certificate courses entail a 5-day face-to-face component and some self-study. The courses utilise adult-education pedagogy, which includes space for participants to reflect on their practice and promotes dialogue and discussion, and application exercises rather than didactic teaching. Table 1 summarises the SBCC courses developed since its inception.

*Table 1.* Social and behaviour change communication (SBCC) courses

Course name	Year of development	Year first run	Method of delivery
Introduction to SBCC	2009	2009	Short course only
Introduction to health promotion	2009	2010	MPH (2010) and short course
Applying social and behaviour change theory to practice	2009	2010	MPH and short course
Planning and implementing SBCC	2009	2010	MPH and short course
SBCC approaches	2009	2010	MPH and short course
Communication, media and society <sup>a</sup>	2009	2009	MPH and short course
Research, monitoring and evaluation for SBCC	2009	2010	MPH and short course
Entertainment education	2011	2011	Short course only

<sup>a</sup>Developed and initially implemented by staff from the Ohio University and University of Roskilde.

To illustrate our approach, we describe how we met the specific need for research and evaluation skills through a course on research, monitoring, and evaluation of SBCC. The course addresses formative research principles and methods; pre-testing of draft material, scripts, and approaches; monitoring of SBCC programmes, including the development and measurement of indicators; and evaluation. The evaluation component grapples with the challenges of using experimental study designs in the context of complex SBCC programmes, especially those that use advocacy or community mobilisation approaches. Students are challenged to consider the strengths and limitations of quasi-experimental, mixed method designs and how some analytic approaches such as propensity score analysis can overcome some of the limitations of non-experimental designs. Students conduct their own research during the course which enhances their skills and allows for real-time feedback through a small research project. This course typifies the approach taken in other SBCC courses that form part of the MPH in SBCC.

The MPH in SBCC is systematically evaluated through extensive internal and standardised university evaluation mechanisms. Early feedback from students suggested that the pedagogical approach was meeting their needs.

... my hopes and expectations have changed greatly, largely because what I have learnt is beyond what I had expected and hoped for. For example, the course had afforded skills to measure situations (trends, prevalence, etc.) before intervening. Previously, I took this as sole responsibility of a researcher and not a program manager. I am now able to advise planners and fellow technical people on areas to assess for evidence first before jumping in with interventions. These are skills I did not have before. (MPH in SBCC student at the end of Year 1).

### *Demand for SBCC training*

The MPH in SBCC was advertised, primarily through Soul City Institute networks and the Communication Initiative website in 2009 (36). Despite this passive form

of recruitment, Wits SPH received over 243 applications for the 2010, 2012, and 2013 intakes.

The educational backgrounds, positions, and geographic representation of the MPH in SBCC students indicate the widespread demand for professional SBCC training. The 14 selected for 2010 represented six countries: South Africa, Malawi, Botswana, Zimbabwe, Ethiopia, and Swaziland. They came from diverse educational backgrounds and held positions in NGOs and government (including national AIDS committees) and worked for donor agencies as well as research institutes. Most of the students enrolled for part-time study and maintained their full-time positions as SBCC practitioners. Many were involved in HIV prevention and management. They stated early on that they were particularly attracted by the location of the specialist field of SBCC within the MPH. The practitioners recognised the interdisciplinary nature of the sector in which they worked. Receiving broad-based training in public health enabled the students to engage more confidently with other public health practitioners who played a critical role in the HIV and AIDS sector.

The short course participants had a similar educational profile to the MPH in SBCC students. However, we were able to accommodate some practitioners with substantial SBCC experience who had less than the required formal tertiary education.<sup>1</sup> The 150 participants who attended one or more of the 14 short courses that ran between December 2009 and March 2012 came from 25 countries mostly in Africa. Interest in attending courses was also received from practitioners in South East Asia including Pakistan and India, the Caribbean, Europe, and the United States of America.

Having a critical mass of staff trained from one organisation can shift the organisational practice. The short courses enabled institutions to send many staff members, often to multiple courses. This has contributed towards building institutional capacity, a need identified in the audit. Some institutions have requested stand-alone or tailored training. Several courses have been run to meet the needs of an international organisation and a UN agency. While the course learning outcomes, structure, and mode of delivery were similar to those routinely delivered, the content was tailored to the needs of the institutions. For example, an agency may request that case studies and in-class exercises focus on reproductive health issues or gender-based violence. Some of this demand has been externally driven or supported; for example, donors have set aside funding for particular types of staff training in SBCC.

<sup>1</sup>The Health Sciences Faculty, which is the academic home of the Wits SPH, sets minimum educational requirements for entry into the master's programme which includes a 4-year degree.

Other universities have also demonstrated interest in SBCC capacity development. WSPH has, on request, hosted study tours by universities from Albania in 2010, Tanzania in 2011, and Nigeria in 2012.

### Funding

The SBCC programme received support from a number of donors, including the UK Department of International Development (DFID), the Centers for Disease Control (CDC), and C-Change, which was a 5-year initiative (2007–2012) supported by the US Agency for International Development (USAID) that aimed to improve the effectiveness and sustainability of communication as a component of development efforts. The South African Government's Department of Health contributed through scholarships for their staff. In addition, both WSPH and Soul City Institute invested substantial resources in this initiative. The external support was invested in developing the competency-based curricula and bursaries to enable students who would otherwise not have been able to enrol. This was especially the case for some of the students who travelled from southern African countries. Sustained funding will facilitate the consolidation of the progress made so far to strengthen SBCC capacity in the region. As was evident in the development of a master's programme in epidemiology and biostatistics at WSPH, initial funding has the potential to leverage additional funding and posts from the university and government (34). This is key because building institutional capacity to provide long-term sustainable training requires sustained investments, and once-off (even though multi-year funding) is only paying lip service to stated intentions to build institutional capacity.

### Conclusion

The need and demand for SBCC capacity strengthening in the global south and beyond is clear. Some of this demand is driven from the bottom-up, while some is donor driven. The bottom-up demand has emerged from individuals and organisations wanting to deliver evidence-based programming and to evaluate their interventions systematically. Donors often are motivated by similar goals, especially in an environment characterised by resource constraints. They too want to ensure that SBCC programmes impact on key health indicators. In addition, there is growing recognition that relying on technical support from the global north is not sustainable and that southern-based institutions have the ability and need to be leading capacity strengthening of southern-based organisations and governments. This is especially true for SBCC, where an understanding of the social context and local environment is critical.

The interest that has been expressed by other academic institutions in the global south underlines the understanding that there is demand for home-grown expertise

in SBCC beyond the United States of America and northern Europe, where this kind of training has been offered for several decades (25). Collaboration between southern-based academic institutions will further enhance south-south capacity strengthening. The interest from southern-based academic institutions has emerged from a range of disciplines, including communication and media studies, social work, and public health. Engaging across disciplines in this way can further enhance the interdisciplinary nature of SBCC. It also enhances the interdisciplinary nature of public health at WSPH, by exposing MPH students in all fields of study and faculty to students who come from a range of disciplinary backgrounds.

Additionally, the involvement of practitioners and civil society institutions in the conceptualisation, delivery, and review of SBCC course content, as has been the case in the WSPH and Soul City Institute partnership, has reduced the gap between academic training and practical relevance. This partnership has been facilitated by donor support. The degree to which donors will have the flexibility to invest for a sufficient period of time to bed down the institutional capacity now developed in southern institutions is unclear. Continued funding to this partnership and, more importantly, the provision of bursaries for practitioners to attend the courses is uncertain. The extent to which funders will follow suit and invest in southern led intuitions also remains a question.

The degree to which the SBCC programme is actually meeting enhanced capacity at an institutional level is yet to be evaluated systematically. The structure of the WSPH programme is ideal for comparing the effects of once-off short courses to a more integrated set of short courses and the MPH degree. Similarly, the programme structure presents opportunities to explore the impact of individual training to that of institutional strengthening as well as the synergies between the two.

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**\*Nicola J. Christofides**

School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road  
Parktown  
South Africa  
Email: nicola.christofides@wits.ac.za

# Analysing post-apartheid gender and racial transformation in medical education in a South African province

Taskeen Khan<sup>1,2\*</sup>, Leena S. Thomas<sup>2,3</sup> and Shan Naidoo<sup>1,2</sup>

<sup>1</sup>Gauteng Health Department, Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Gauteng Health Department, Ekurhuleni, Gauteng, South Africa

**Introduction:** In light of global concerns about insufficient numbers of doctors, midwives, and nurses, the World Health Organization (WHO) has identified the scale-up of the production of medical professionals who are competent and responsive to community needs as urgent and necessary. Coincident with this imperative, South African medical schools have also had to consider redressing apartheid-era inequities in access to medical education and changing the racial and gender profile of medical graduates to be representative of the population. In this article, we explore progress and challenges with regard to transformation, defined as intentional and planned changes aimed at addressing historical disadvantages, in the Gauteng Province of South Africa.

**Methods:** A cross-sectional, descriptive analysis was conducted using data on medical school admissions and graduations from the Health and Education Departments for the period 1999–2011. Admission and graduation statistics of 1999, 2005, 2008, and 2011 were analysed according to race and gender.

**Results:** The results show that there has been progress in transforming the race and gender composition of medical students and graduates, in line with the transformation strategies of the South African government. In 1999, black African enrolments and graduates were conspicuously low in two of the three medical schools in the Gauteng province. By 2011, an almost six-fold increase in black African student enrolments was seen in one medical school that was previously designated as a white institution. In contrast, at the historically black medical school, whites only represented 0.40% of enrolments in 1999 and 7.4% in 2011. Since 1999, the number and proportion of female medical enrolments and graduates has also increased substantially.

**Conclusion:** While there has been progress with redressing historical disparities and inequities in terms of race and gender, further efforts are needed to ensure that student intakes and graduations are in line with the South African population profile.

Keywords: *medical education; transformation; race; gender; inequalities*

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Despite major medical advances and breakthroughs during the 20th century, global inequities in health and access to care still persist (1, 2). The World Health Organization (WHO) estimated that more than a billion people worldwide lack access to quality healthcare, partly due to the major shortages, skill imbalances, and the inequitable distribution of doctors, nurses, and midwives. It is further estimated that 2.4 million more doctors, nurses, and midwives are needed globally to address current and future health needs (3). However, not enough health professionals are being educated, particularly in Africa where they are needed the most, exacerbated by insufficient collaboration between

the health and education sectors (2). For this reason, the WHO has identified the scale-up of medical education as being both necessary and urgent. However, even well-educated graduates may not have the necessary or relevant skills or the content of their education could be unrelated to the epidemiological profile and needs of the populations they serve. In addition, the burden of disease, teaching patterns, and retention of personnel in the public sector play a role in producing health professionals relevant to a country's needs (3). Thus, health workers should graduate with appropriate competencies, thereby meeting population health and health service needs (3).

In many countries, medical education reforms in higher education institutions are often part of broader social transformation efforts. In this article, transformation refers to “an intentional social, political, and intellectual project of planned change aimed at addressing historical disadvantages, inequities, and serious structural dysfunctions” (4). For example, countries in eastern and central Europe, Japan, Brazil, India, Australia, Cameroon, and the United States of America (USA) have introduced various medical education reforms in the past two decades. The aim of these reforms is to address gross disparities and inequities among social classes and minority groups (Brazil, India, Australia, and USA) and/or to overcome histories of repressive regimes (eastern and central Europe) (5). In South Africa, medical schools have also had to consider redressing apartheid-era inequities in access to medical education and changing the racial and gender profile of medical graduates to be representative of the population. It is beyond the scope of this article to address all aspects of transformation. Instead, we explore whether transformation has been achieved in post-apartheid South Africa and if the gender and racial profile of medical students and graduates are in line with the national demographic profile of the country. This article may hold lessons for the transformation of medical education in other societies where disparities or inequalities are still common.

## Background

### South African context

South Africa is home to 51 million people. The ‘racial’ composition of the South African population, a social construct, comprises black Africans (79%), Asians (mainly Indian and a very few Chinese) (2.5%), coloureds (9%), and whites (9%). In the Gauteng province, the focus of this study, there is a higher proportion of whites, compared to the national profile (Fig. 1) (6).

Discrimination and exclusion policies on the basis of race and gender, startling income inequalities, and violence have all formed part of South Africa’s troubled past and have affected all social, political, and economic aspects of South African society (7). Similarly, population health and healthcare challenges have been exacerbated by the legacies of colonialism and apartheid, which have also influenced medical education.

Although black Africans are in the majority, during apartheid they were denied or had limited access to tertiary education. Consequently, they were not represented adequately amongst medical professionals during apartheid. Such discriminatory and exclusive education policies created disparities and inequalities in two ways: first, by ensuring resources were allocated in accordance with the apartheid ideology (unequally based on race), and second, by treating people not classified as white in an

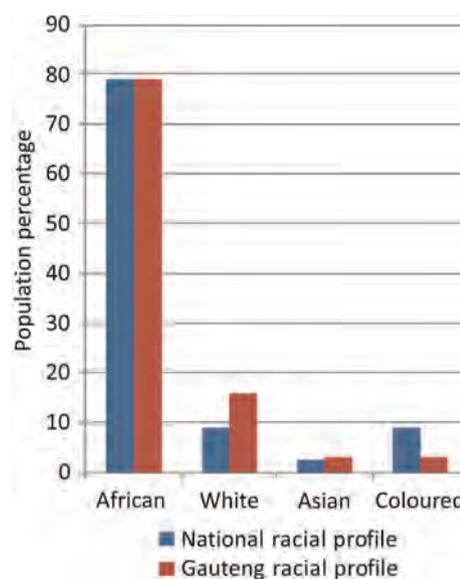


Fig. 1. National and Provincial racial profiles (2011).

inferior and discriminatory manner (8). The distorted state of the medical fraternity in South Africa prior to 1994 is illustrated by the Medical Association of South Africa’s submission to the Truth and Reconciliation Commission, which described the organization as *white, male, elitist, educated and professional* (9).

### Overview of reforms in medical education

Currently there are eight universities in South Africa that train medical doctors (10). Under apartheid, universities with medical schools were designated to train medical professionals of certain race categories. Under apartheid, only three of the medical schools in the country were allowed to train black African students (11). Medunsa (now known as the Health Science Faculty of the University of Limpopo) and Unitra (now known as Walter Sisulu University) catered exclusively for African students, while Natal (now known as the University of Kwazulu Natal) serviced both Indian and African students (11).

Until the late 1980s, apartheid policies dictated that the five historically white universities had stricter admission criteria for black African students and only very few were admitted. During the 1980s, some of the more liberal universities attempted to admit more African students into medicine. However, due to inferior secondary schooling and stringent admission criteria, black African students remained very few in numbers (12). After 1994, the new democratic government introduced profound reform policies and transformation in the health and education sectors to redress historical inequities (9). The National Commission on Higher Education was established in 1995 to advise the minister of education on the restructuring of higher education so as to contribute toward reconstruction and development in South Africa (8).

This led to a number of transformation policies such as the White Paper on Higher Education (8). The latter set out to restructure higher education into a single, nationally coordinated system that would redress the inequities created by apartheid and meet the needs of a new South Africa with fundamentally changed economic, social, and political structures (13).

Restructuring of medical schools in terms of gender and race enrolments as well as curriculum reforms were seen as necessary steps in transforming human resources for health in South Africa. A number of reform measures have been introduced in medical schools to overcome historical disparities, inequalities, and inequities in medical education. Discrimination and exclusion based on race is outlawed in the South African constitution and all medical schools have adjusted their admission policies to admit students regardless of race or gender (10). There is also a significant move toward increasing the number of black African medical students, particularly in historically 'white' institutions. The same applies to the number of female medical student admissions, which has increased considerably. In addition, the curriculum of medical education has been revisited, while problem-based learning now forms a major strategy in some universities. Other initiatives include the development of community education sites and the introduction of a graduate entry medical programme at one university, which admits individuals who have successfully completed an undergraduate degree, thus offering many students who may not have been eligible straight after school an alternative entry route to medical training.

While there is ample information on the history of race in medical education, there is less on the history of gender in the medical profession. Past studies have illustrated the predominance of males in the profession showing notable historical differences in intake, but in recent years an increasing trend of female enrolments is seen (14). In this article, we explore this further.

### Study setting

Gauteng, one of the nine provinces in South Africa, has the highest gross domestic product (GDP) in the country and is known as the 'economic hub' of South Africa. It hosts three medical schools, two of which historically trained white medical students, and the third was exclusively for black African students. These three schools account for almost half of all medical student enrolments and graduates in the country (15). In light of this and because of practical considerations, the Gauteng Province is the focus of this analysis.

### Methods

The focus of the study was the period from 1999 to 2011, and 1999 was used as the base year. A key assumption of the study was that by 1999, that is, 5 years after the onset

of democracy, admission policies would have changed at medical schools and graduation statistics would begin to reflect this change. Using 1999 data as the baseline, consecutive 3-year follow-up data were used for 2005, 2008, and 2011 in an attempt to determine trends over the 12-year period.

A cross-sectional, descriptive analysis was conducted, using enrolment and graduate data for the three medical schools in Gauteng. The data were sourced from the Gauteng Department of Health (GDH) for the period 2008–2011. The GDH data were only available from 2007. For this reason, data for 1999 and 2005 were sourced from the Department of Education (DoE), captured in its Higher Education Management Information System (HEMIS). Race is categorised into black African, Asian, coloured, and white enrolments and graduates, while gender is reflected as female (F) or male (M).

The three medical schools are referred to as A, B, and C, respectively. During the years of apartheid, medical school A catered to the training of African students, medical school B used to train Afrikaans-speaking white students, and medical school C was mainly for English-speaking white students.

The collected data were entered and analysed in Microsoft Office Excel 2007.

Tests of statistical significance were carried out in Epi Info (version 3.5.3) and a Chi-square test was used to determine statistical significance.

### Results

Table 1 shows figures for 1999, 2005, 2008, and 2011 for medical enrolments and graduates. In 1999, the numbers of black African enrolments and graduates were low at medical schools B and C. These numbers have subsequently increased. In 1999, black African students at school B represented 9.7% of all enrolments; in 2011, this proportion had increased to 30.1%. Similarly at school C, black African students represented only 5.8% of enrolments in 1999, which increased to 44% in 2011. At school A, white medical students represented a mere 0.40% of enrolments in 1999, whereas they comprised 7.4% in 2011. A similar pattern can be observed regarding the numbers and proportions of medical graduates among the different race groups, although these numbers are notably smaller. Figure 2 is a graphical representation of percentages of medical graduates, stratified by race and medical school, for the years 1999, 2005, 2008, and 2011. The graph shows that in 1999, medical school A had 74% black African graduates, with 0% white and coloured graduates. In 2011, 87% were African, 1% coloured, and 6% white. During the same period, the proportion of Asian graduates at school A decreased drastically from 25% in 1999 to 6% in 2011. At medical school B, an almost opposite trend is seen: in 1999, a mere 1% of graduates were black African compared to 91% white.

Table 1. MBChB enrolments and graduations at individual Gauteng medical schools by race and gender

Institution	Year	African			Asian			Coloured			White			Grand Total	
		F	M	Total	F	M	Total	F	M	Total	F	M	Total		
Medical school A	Enr	1999*	545	783	1328	121	242	363	8	13	21	2	5	7	1719
	Enr	2005*	536	702	1238	42	52	94	9	7	16	21	30	51	1399
	Enr	2008	442	569	1011	31	25	56	5	3	8	25	35	60	1135
	Enr	2011	520	571	1091	31	29	60	3	6	9	41	52	93	1253
Total A enrolments			2043	2625	4668	225	348	573	25	29	54	89	122	211	5506
Total A graduates	Grad	1999*	77	148	225	23	54	77	2	2	4	0	0	0	306
	Grad	2005*	109	151	260	5	14	19	2	3	5	4	6	10	294
	Grad	2008	74	85	159	9	11	20	1	1	2	3	5	8	189
	Grad	2011	67	79	146	4	7	11	1	1	2	6	4	10	168
Total A graduates			327	463	790	41	86	127	6	6	12	13	15	28	957
Medical school B	Enr	1999*	65	57	122	41	38	79	10	20	30	522	500	1022	1253
	Enr	2005*	212	117	329	62	53	115	34	17	51	468	322	790	1285
	Enr	2008	252	140	392	54	41	95	27	15	42	487	268	755	1284
	Enr	2011	270	131	401	49	33	82	22	22	44	528	276	804	1331
Total B enrolments			799	445	1244	206	165	371	93	74	167	2005	1366	3371	5153
Total B graduates	Grad	1999*	1	1	2	4	9	13	0	3	3	86	93	179	197
	Grad	2005*	18	12	30	11	8	19	5	4	9	79	60	139	197
	Grad	2008	34	13	47	4	11	15	4	1	5	72	61	133	200
	Grad	2011	42	22	64	15	7	22	5	3	8	71	43	114	208
Total B graduates			95	48	143	34	35	69	14	11	25	308	257	565	802
Medical school C	Enr	1999*	74	84	158	286	236	522	12	17	29	332	236	568	1277
	Enr	2005*	204	239	443	226	133	359	17	7	24	294	133	427	1253
	Enr	2008	293	233	526	168	91	259	28	10	38	247	167	414	1237
	Enr	2011	382	199	581	133	90	223	53	25	78	268	171	439	1321
Total C enrolments			953	755	1708	813	550	1363	110	59	169	1141	707	1848	5088
Total C graduates	Grad	1999*	11	11	22	47	25	72	3	6	9	64	49	113	216
	Grad	2005*	16	29	45	56	35	91	3	1	4	70	37	107	247
	Grad	2008	23	24	47	36	19	55	3		3	54	30	84	189
	Grad	2011	31	13	44	35	13	48	2	3	5	44	33	77	174
Total C graduates			81	77	158	174	92	266	11	10	21	232	149	381	826

\*Data obtained from Department of Education, HEMIS, 2007.

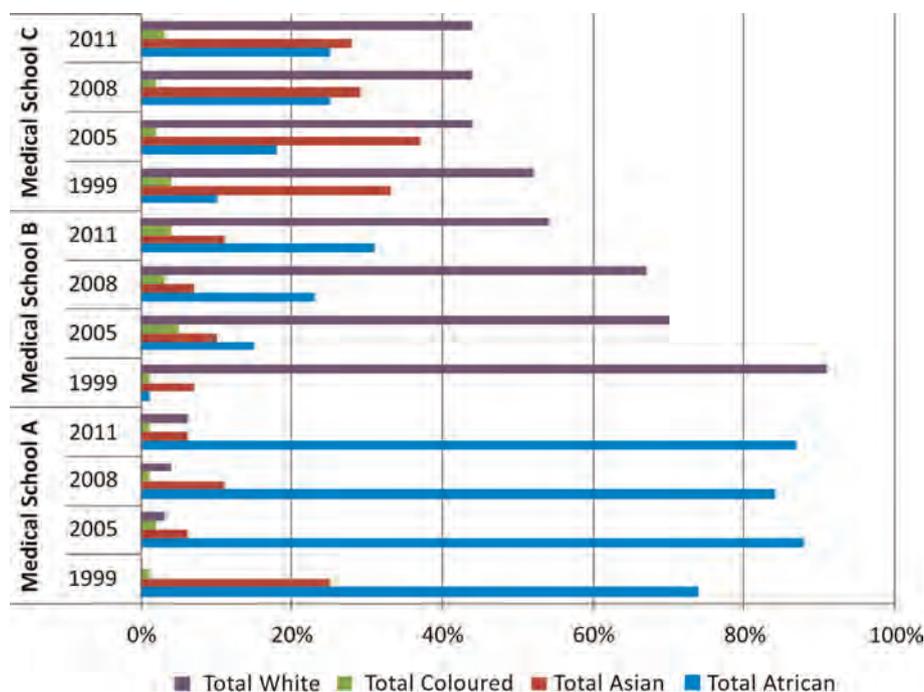


Fig. 2. Medical graduates by race and medical school.

In 2011, black Africans accounted for 31% of medical graduates and whites accounted for 54% at school B. This equates to an almost 50% reduction of white graduates at school B. The number of coloured graduates rose significantly from 1% in 1999 to 4% in 2011, with Asian graduates also increasing in number. At medical school C, black African graduates in 1999 constituted 10% and white graduates 52% of all graduates. In 2011, the proportion of black African graduates has grown to 25%, while white graduates stood at 44%. Asian graduates dropped from 33% in 1999 to 28% in 2011, percentage coloured graduates also dropped slightly.

The other important dynamic analysed was the gender differences in admissions and graduates at the three medical schools for 1999, 2005, 2008, and 2011. All three medical schools have shown rising trends in the proportions of both female enrolments and graduates. In 2011, medical school A was the only institution where less than half of all enrolments and graduates were female. In medical schools B and C, more than half of enrolments and graduates were female since 1999, a large proportion of whom were white.

The differences by 'race' in the different institutions were statistically significant ( $p < 0.0000$ ). These values were the same for both enrolments and graduates.

## Discussion

The results suggest that Gauteng medical schools are implementing government's transformation strategies. This progress is reflected in changing race- and gender-numbers and proportions of medical student enrolments

and medical graduates over the 12-year period. These findings are consistent with the published literature (11, 13).

Medical school B has been particularly active in revising its enrolment policy and aligning itself better with national and provincial population demographics. Medical school A is also not fully representative of the national population but is still more aligned than the other two medical schools though their coloured student intake is still low. In order for the medical schools to be representative of national and provincial demographics (Fig. 1), medical schools B and C – with just 31% and 25% of their graduates being black African in 2011 – need to increase these graduates. Similarly, medical school A needs to increase their white graduates. Coloured student graduates comprise one-fourth of their proportion reflected nationally and need to be increased across the three medical schools. This could be due to the low proportion of coloureds in Gauteng (3%) compared to the national figure (9%) and to the province of the Western Cape where coloureds constitute more than 50% of the population (16). Studies from the Western Cape illustrate that despite higher proportions of coloureds in the province, only a very small proportion of them are accessing undergraduate medical programmes (17). As a marginalised community, it could be argued that there needs to be a more concerted effort from all the stakeholders involved in selecting, supporting, and mentoring coloured students in health science training in Gauteng and other provinces.

The ‘brain drain’ affecting health systems in sub-Saharan Africa has been well documented. In particular, South African doctors are much in demand internationally and the country is one of those severely affected by the ‘brain drain’ (18, 19). A study found that 45% of students who had graduated from medical school C since 1975 were working abroad (20). Price and Weiner also examined graduate data from 1960 to 1994 and found that a large proportion of medical graduates in this period had also worked mainly in the private sector in South Africa, with only their initial work years spent in the public health sector in South Africa (21). The majority of these graduates were found to be white. While the role of race in emigration and public sector retention can only be speculated here, there is no guarantee that if we train more black African students, or more students from disadvantaged backgrounds, that they will not succumb to the attractions of emigration and the private sector. However, the WHO does lean toward supporting such initiatives (3). Nonetheless, other studies conducted on this topic have been inconclusive and the advice is to look at country-specific innovations to deal with public sector staff attrition and retention (22).

Female students (63%) dominate the graduate figures in the Gauteng province and all three medical schools have exceeded the national proportion of females in the population. There has been some discussion in the literature regarding the feminisation of the profession and the implications it poses, particularly for postgraduate surgical studies (14). In addition, females are still viewed as child carers in the traditional society and the medical profession is not adequately resourced to take this into account. South Africa needs to adapt and think of innovative ways to address these challenges (14).

Notwithstanding the importance of context when examining transformation efforts, there are lessons for other countries from this South African case study. A combination of legislation and policies is needed for redressing historical gender and racial inequalities, and to support efforts in curriculum reform and other educational reforms.

At the same time, continuous and systematic monitoring and evaluation of the implementation of the various policies and legislation that intend to facilitate transformation in medical education are needed (8). This could set benchmarks, which in turn could be used to enhance existing policy implementation or inform new policies and/or legislation.

## Limitations

The study has several limitations.

First, the data for the years analysed were limited to the information available from the health and education departments.

Second, as a result of democracy and globalisation, South Africa has experienced an influx of economic and political migrants from other parts of Africa and the rest of the world. After 1994, many of these migrants are now naturalised South Africans, and University admissions do not, and possibly cannot, reflect these nuances. Therefore, a student classified as ‘black African’ may not necessarily be a previously disadvantaged South African individual as they may originally have come from other African countries.

Third, only data from Gauteng institutions were used, which cannot be generalised to the rest of South Africa.

Fourth, enrolments and graduates could not be compared because programme duration varies between 5 and 6 years at the different medical schools.

Finally, the study was limited to an analysis of gender and race dynamics. There was no focus on other aspects of transformation, the perceptions of historically disadvantaged students, or on the impact of curriculum reforms and transformation on population health or service delivery. Further research is needed in these areas.

## Conclusion

There has been encouraging progress on medical student admissions and graduations with respect to gender and race in Gauteng Province, achieved through a combination of enabling legislation, policies, and institutional efforts.

However, further efforts are needed to ensure that student intake and graduations are in line with national and provincial demographic profiles.

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**\*Taskeen Khan**

School of Public Health  
 Faculty of Health Sciences  
 University of the Witwatersrand, Johannesburg  
 7 York Road  
 Parktown 2193  
 South Africa  
 Email: [drtaskeenkhan@gmail.com](mailto:drtaskeenkhan@gmail.com)

# Compensation for environmental asbestos-related diseases in South Africa: a neglected issue

Ntombizodwa Ndlovu<sup>1,2\*</sup>, Jim teWater Naude<sup>3,4</sup> and Jill Murray<sup>1,2</sup>

<sup>1</sup>National Institute for Occupational Health, National Health Laboratory Service, Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Asbestos Relief Trust, Cape Town, South Africa; <sup>4</sup>School of Public Health, University of Cape Town, Cape Town, South Africa

**Background:** Environmentally acquired asbestos-related diseases (ARDs) are of concern globally. In South Africa, there is widespread contamination of the environment due to historical asbestos mining operations that were poorly regulated. Although the law makes provision for the compensation of occupationally acquired ARDs, compensation for environmentally acquired ARDs is only available through the Asbestos Relief Trust (ART) and Kgalagadi Relief Trust, both of which are administered by the ART. This study assessed ARDs and compensation outcomes of environmental claims submitted to the Trusts.

**Methods:** The personal details, medical diagnoses, and exposure information of all environmental claims considered by the Trusts from their inception in 2003 to April 2010 were used to calculate the numbers and proportions of ARDs and compensation awards.

**Results:** There were 146 environmental claimants of whom 35 (23.9%) had fibrotic pleural disease, 1 (0.7%) had lung cancer, and 77 (52.7%) had malignant mesothelioma. 53 (36.3%) claimants were compensated: 20 with fibrotic pleural disease and 33 with mesothelioma. Of the 93 (63.7%) claimants who were not compensated, 33 had no ARDs, 18 had fibrotic pleural disease, 1 had lung cancer, and 44 had mesothelioma. In addition to having ARDs, those that were compensated had qualifying domestic (33; 62.2%) or neighbourhood (20; 37.8%) exposures to asbestos. Most of the claimants who were not compensated had ARDs but their exposures did not meet the Trusts' exposure criteria.

**Conclusions:** This study demonstrates the environmental impact of asbestos mining on the burden of ARDs. Mesothelioma was the most common disease diagnosed, but most cases were not compensated. This highlights that there is little redress for individuals with environmentally acquired ARDs in South Africa. To stop this ARD epidemic, there is a need for the rehabilitation of abandoned asbestos mines and the environment. These issues may not be unique to South Africa as many countries continue to mine and use asbestos.

**Keywords:** *domestic exposure; neighbourhood exposure; pleural plaques; pleural thickening; mesothelioma; South Africa*

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Environmental exposures to asbestos are of concern in many parts of the world. Domestic exposures occur in people living with workers exposed to asbestos, and neighbourhood exposures occur in residents living in the vicinity of asbestos operations. Increased risks of developing mesothelioma (an asbestos related cancer) have been observed in people with no occupational exposures living near asbestos factories (1–3). Neighbourhood exposures to asbestos have been documented in Wittenoom, a former crocidolite mining region of northwest Australia (4), and Libby, Montana,

where asbestos-contaminated vermiculite was mined (5, 6). True environmental asbestos exposures arise from naturally occurring asbestos contamination of the soil and have been documented in China (7), Turkey (8), Greece (9), Corsica (10), Italy (11), and New Caledonia (12), but these are not the subject of this paper.

Asbestos is a generic name for a group of fibrous hydrated silicates with commercial and industrial value because of their physical properties, which include high tensile strength, and heat and chemical resistance. South Africa is unique in that the three main commercial

types of asbestos were mined there: chrysotile (white asbestos), amosite (brown asbestos), and crocidolite (blue asbestos). At the peak of production, it was the third largest producer of asbestos, with crocidolite accounting for more than 97% of global production (13). Asbestos operations generally involved families living close to the mines where men worked, while women and children cobbled, sorted, and packed fibres (14). The waste or tailings were dumped close to villages where, to this day, children play. The tailings were also used for road surfacing and building construction (13, 15). Thus, there is widespread contamination of the environment as a result of asbestos mining operations, which were scattered across rural South Africa (Fig. 1).

It is generally accepted that environmental exposures are much lower, begin at younger ages and continue for longer durations than occupational exposures (17, 18). Although it is known that asbestos levels in South African mines and mills were high, data are not readily available due to poor measurement techniques and record-keeping practices at the time. Workplace amosite fibre levels ranging from less than 1 to 326.7 fibres/ml (f/ml) were measured at Penge mine (Limpopo Province) in the 1970s (19). In the Mafefe villages, to the north of Penge, much lower asbestos concentrations were measured in the 1990s: 0.020 f/ml in school buildings, 0.012 f/ml along village pathways, and 0.016 f/ml during building and gardening activities (15).

Despite the existing body of evidence on the adverse health effects of asbestos, mining continued with little enforcement of regulations until 2002 (13, 14). This has created an ‘invisible epidemic’ of asbestos-related diseases (ARDs), which include diseases of the lung parenchyma, asbestosis and lung cancer, and diseases of the pleura, such as pleural plaques, thickening, and malignant mesothelioma (20). Asbestosis and lung cancer are typically associated with high levels of asbestos exposure, which may occur in occupational settings, while pleural plaques, thickening, and malignant mesothelioma are attributed to lower level exposures. The South African landmark study that established the link between asbestos exposure and mesothelioma also identified 10 cases (30.3%) that were associated with environmental asbestos exposure (21). Other South African studies have shown environmental mesotheliomas to comprise 17–23% of ARDs in the reported study populations (22–24).

South African law compensates all occupational ARDs under the Compensation for Occupational Injuries and Diseases Act (No. 130 of 1993) (25) and, specifically for the mining industry, the Occupational Diseases in Mine and Works Act (No. 78 of 1973) (26). However, statutory redress for miners with occupational lung disease is inadequate, and dissatisfaction with very low payouts (currently ranging from R28,000 to R105,000, approximately 3,500 to 13,000 USD) has resulted in litigation. In 2003 and 2006, court settlements led to the creation

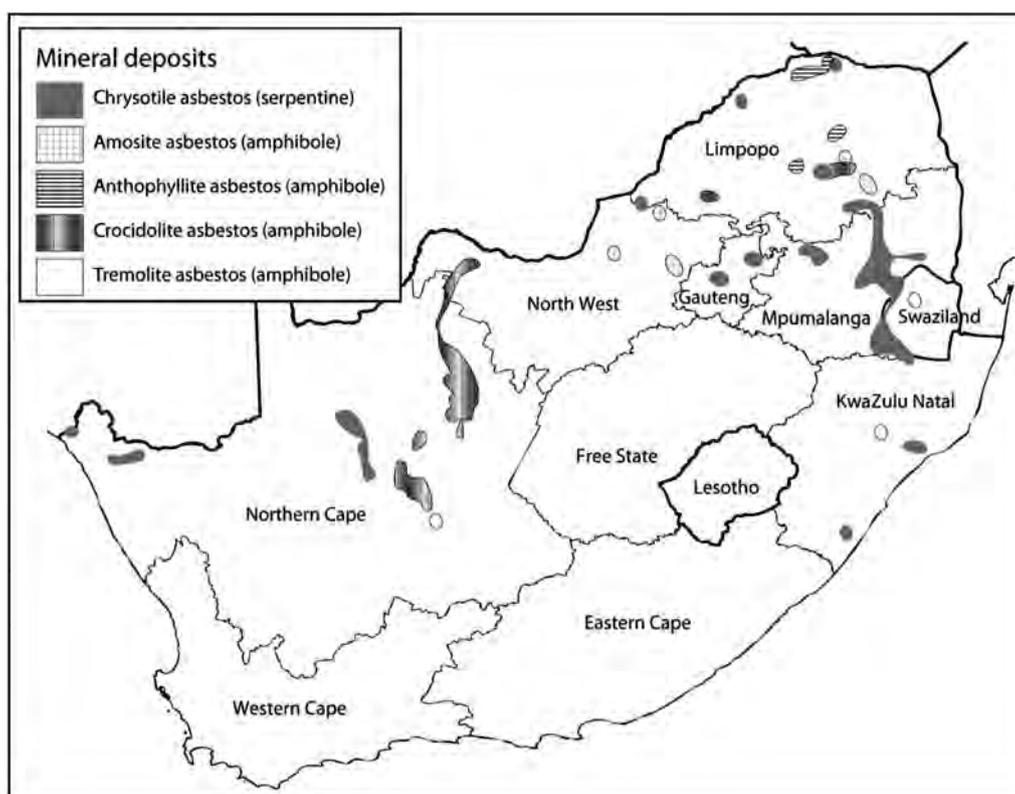


Fig. 1. Distribution of asbestos deposits in South Africa (16).

of two Trusts, the Asbestos Relief Trust (ART) and Kgalagadi Relief Trust (KRT).

The ART administers the Trusts because their administrative claim procedures and benefits are essentially the same with individual claims often made against both Trusts (27). The Trusts were established primarily to compensate former workers of asbestos specific mining operations<sup>1</sup> according to the provisions of their respective Trust deeds. Compensation is awarded on the basis of disease and asbestos exposure. The diseases considered are fibrotic diseases (asbestosis and/or diffuse pleural thickening and pleural plaques) and malignancies (lung cancer and mesothelioma). Fibrotic diseases are divided into those with mild to moderate lung function impairment (FEV1: 79–52% of predicted; FVC: 79–52% of predicted; FEV1/FVC: 75–55%) (ARD1) and those with severe lung function impairment (FEV1: <51%; FVC: <51%; FEV1/FVC: <55%) (ARD2).

There is no statutory compensation for environmentally acquired ARDs in South Africa; the only access to compensation for environmental claimants is through the two Trusts. The claim submission procedures for occupational and environmental claims differ. In the past, the Trusts ran awareness campaigns and actively sought potential occupational claimants throughout South Africa, Lesotho, and Swaziland. In 2011 a passive claims process was introduced, which used accredited doctors to identify and assist potential claimants with compensation submissions (29). For environmental claimants, however, the process has always been passive with the onus on each potential claimant to approach the Trusts and provide medical evidence suggestive of ARDs, including a good-quality chest X-ray obtained at the claimant's own expense (30). Full occupational and residential histories are also required.

A panel of specialist occupational medical practitioners assesses the medical information, and the Trusts pay for any additional tests. The Trusts do not ordinarily consider asbestosis and lung cancer to have been environmentally acquired because these diseases are usually attributable to high asbestos levels seen with occupational exposures (31). However, where there is compelling evidence of high and prolonged environmental exposure, the Trusts may make an award. For both occupational and environmental claimants, after an ARD diagnosis is confirmed, the exposure information is assessed for exposures that meet the Trusts' requirements. The Trustees undertake final review and approval of the claims.

<sup>1</sup>The ART administers compensation on behalf of claimants against Griqualand Exploration and Finance Company (Gefco), General Mining Corporation (Gencor), Msauli, African Chrysotile Asbestos Limited (ACA), Hanova Mining Holdings, and Cape PLC. Similarly, the KRT was established for individuals who worked at the Kuruman Cape Blue (KCBA) and Danielskuil Cape Blue (DCBA) asbestos mines (28).

For environmental claimants, in addition to having a compensable ARD, a claimant must (i) have had domestic or neighbourhood exposure within 10 km of an asbestos work site; (ii) have been exposed during the qualifying period, 1955–2002: specific periods are applicable to each worksite; (iii) have an ARD considered by the Trusts to be caused by such exposures; and (iv) have had no occupational exposure to asbestos (30).

This study sought to determine the proportion of environmental claims submitted to the two Trusts, to describe the ARD diagnosed and, for mesothelioma cases, to document the type of asbestos to which the claimants were exposed. The study also determined the proportion of environmental claims compensated and evaluated and the efficacy of the Trusts in delivering compensation for environmentally acquired ARD.

## Methods

The design of the study is a record review of a compensation database, which employed cross-sectional passive surveillance methodology for environmental cases.

All environmental claims entered on the ART compensation database from the inception of the Trusts in 2003 to April 2010 were included. Personal details, disease diagnoses, and exposure information were obtained from the ART's database and paper records. The numbers and proportions of disease and compensation awards were assessed.

For mesothelioma cases, the likely type of asbestos exposure was assigned according to the area in which the claimant had resided (24). Crocidolite was assigned for exposures that occurred in the Northern Cape and North West Provinces, amosite for those in Limpopo, and chrysotile for those in Mpumalanga.

Ethical approval for the study was obtained from the University of the Witwatersrand Human Research Ethics Committee.

## Results

The Trusts registered a total of 15,463 compensation claims since their inception in 2003 and 2006 to April 2010. Of these, 146 (0.9%) were environmental, comprising 74 women and 72 men in the case series. Their mean ages were similar ( $61.8 \pm 11.9$  and  $56.8 \pm 11.1$  years, respectively) and ranged from 21.1 to 59.3 years.

The year of first exposure to asbestos was available for 128 claimants. The exposure characteristics are summarised in Table 1. Of the 58 (45.3%) that had childhood exposures (mean  $6.0 \pm 5.6$  years), 20 had been exposed from birth. No significant differences in age at first exposure to asbestos, duration of exposure, or time from first exposure (latency) by disease categories were observed (data not shown).

Thirty-three (22.6%) claimants did not have an ARD (Table 2): of these, 17 had no abnormalities visible on a

**Table 1.** Exposure characteristics of environmental claimants

Exposure characteristic ( <i>n</i> = 128)	Mean $\pm$ SD (years)	Range (years)
Age at first exposure	17.1 $\pm$ 12.7	0–59
Total years of exposure	8.4 $\pm$ 8.0	0.1–36
Time since first exposure	43.1 $\pm$ 11.3	21–79

chest radiograph, and the remainder had incidental findings like hyperinflation, sequelae of pulmonary tuberculosis, and scoliosis. ARDs were diagnosed in 113 (77.4%) cases. These included 35 (31.0%) with pleural thickening, most (*n* = 27) of whom had mild to moderate lung function impairment (ARD1). For convenience, three cases of pleural plaques with <10% lung function impairment were added to this category. There were 78 (69.0%) claimants with malignancies of which 1 had lung cancer and 77 had mesothelioma.

Compensation outcomes are summarised in Table 3. Of all the environmental claims submitted, 53 (36.3%) were compensated as they had an ARD as well as qualifying domestic (*n* = 33; 62.2%) or neighbourhood (*n* = 20; 37.8%) asbestos exposures. Ninety three (63.7%) of the total claimants were not compensated. These comprised 37 who did not qualify medically: 33 had no ARD, 3 had pleural disease with <10% lung function impairment, and 1 had lung cancer. The remaining 56 claimants (12 with fibrotic ARD and 44 with mesothelioma) had exposures which did not meet the Trusts' exposure criteria: 2 ARD2 claimants had previous occupational exposures; 4 with mesothelioma had been exposed during non-qualifying periods; 23 had lived more than 10 km from a designated operation (3 with ARD1 and 20 with mesothelioma); and the reason for non-qualifying exposure was not provided for 27 cases.

Mesothelioma was diagnosed in 34 (44.2%) women and 43 (55.8%) men, and their mean ages were similar (60.9  $\pm$  11.1 and 58.2  $\pm$  9.8 years, respectively). Most mesothelioma cases with known exposures had been exposed to crocidolite asbestos (*n* = 70; 90.9%) (Table 4).

**Table 3.** Compensation outcomes for environmental claimants

Disease category	Compensated		Not compensated		Total	
	No.	%	No.	%	No.	%
Fibrotic ARD1	18	34.0	12	12.9	30	20.5
Fibrotic ARD2	2	3.8	3	3.2	5	3.4
Lung cancer	–	–	1	0.1	1	0.7
Malignant mesothelioma	33	62.3	44	47.3	77	52.7
No asbestos-related diseases	–	–	33	35.5	33	22.6
Total	53		93		146	

**Table 2.** Asbestos-related diseases diagnosed in environmental claimants

Disease category	No.	%
Fibrotic ARD1	30*	20.5
Fibrotic ARD2	5	3.4
Lung cancer	1	0.7
Malignant mesothelioma	77	52.7
No asbestos-related diseases	33	22.6
Total	146	

\*Includes 3 cases of pleural plaques with <10% lung function impairment.

## Discussion

This study highlights the contribution of environmental asbestos exposure to the burden of ARDs. The environmental claims reviewed comprised 0.9% of the total claims made to the Trusts. However, this may be an underestimate as the claim process may preclude many potential environmental claimants who are required to provide evidence of disease which may be costly. This case-series under-ascertains the extent of ARD as the analysis was based on submissions made to the Trusts, which have limited geographical coverage, and migration may result in many potential claimants moving out of the Trusts' target areas. The under-diagnosis of ARDs in public health care facilities, where clinicians may be unaware of or ill equipped to diagnose these diseases, also contributes to under-ascertainment (32). In response, the Trusts partnered with the National Institute for Occupational Health and conducted ARD diagnosis workshops for health-care practitioners in affected areas. It can be assumed, therefore, that more extensive awareness campaigns, improved diagnosis, and active case finding will identify many more environmentally acquired ARDs.

Fibrotic pleural ARD accounted for 23.9% and mesothelioma for approximately half (52.7%) of the claims. While lung function impairment associated with fibrotic pleural ARD may cause significant disability, the impact of mesothelioma is particularly devastating as there is no satisfactory clinical treatment and the prognosis is poor,

**Table 4.** Geographic origin and asbestos fibre types of environmental mesothelioma claimants

Province	Likely fibre type	No.	%
Northern Cape	Crocidolite	64	81.8
North West	Crocidolite	6	7.8
Limpopo	Amosite	1	1.3
Unknown	Unknown	6	7.8
Total		77	

with survival typically less than 18 months after diagnosis (17). Almost all of the reported mesothelioma cases had been exposed to crocidolite asbestos. In South Africa, crocidolite has been shown to be the most frequent cause of mesothelioma even after brief or slight exposures (22, 33). It is notable that many exposures had occurred in childhood.

Mesothelioma is an indicator of the ARD burden of a population. The burden is currently borne predominantly by the developed world and varies among countries. A shift in the burden is expected as some developing countries increase their use of asbestos (34). Around the year 2000, high crude annual incidence estimates of 30 cases per million were reported in Australia, Belgium, and Great Britain (35). South Africa reported 2,322 mesothelioma deaths from 1994 to 2008, which accounted for 2.5% of the reported mesothelioma deaths and ranking it ninth among the 83 countries studied (34). In 1984, the age-adjusted mesothelioma incidence rates in South Africa ranged from 3.2 per million/year in black women to 40.5 in white men (23). In 2007, the reported overall mortality rates were much lower than expected at 13 and 3 per million/year for men and women, respectively (36). The decline was attributed to migration, decreased life expectancy due to other causes, and long latency. However, it is projected that the improved life expectancy in Africa will be accompanied by an increase in the burden of diseases with long latency, such as mesothelioma (37).

Compensation payouts for ARDs provide significant financial respite to families and communities in the former asbestos mining areas of South Africa, which are characterised by desperate economic circumstances and high levels of unemployment (38). Approximately two-thirds ( $n=93$ , 63.7%) of the environmental claims reviewed here were not compensated. Many had been exposed to asbestos more than 10 km from designated mining operations, and some had exposures that occurred outside of the qualifying periods. In the absence of complete rehabilitation of the dumps, many more cases of environmentally acquired ARDs that do not meet the Trusts' exposure criteria are to be expected.

The findings of this study support the argument that the Trusts should review their exposure criteria. The mining

operations that led to their creation contributed significantly to contamination of the environment in many regions; for example, in the Kuruman area the Trusts represent companies that generated over 85% of the tonnage of asbestos mined in this area (Jim teWater Naude, personal communication, 10 October 2012). At the time that the environmental compensation criteria were set out by the Trusts, a radius of 10 km from the source of contamination was adopted in the light of preliminary work done by Jones and subsequently published in his thesis on environmental asbestos contamination in South Africa (39). In his discussion, however, Jones makes the point that no clear linear correlation can be drawn between distance from a source point and levels of disease. In addition, there are many asbestos contaminated areas in South Africa where the sources of contamination are not included in the remit of the Trusts because the founders of the Trusts were never active in these regions. The State has a duty to accept responsibility for these areas, and it has been argued that the State should use some of the considerable revenue that it received from asbestos mining to compensate environmentally acquired ARDs and to ensure that contaminated areas are rehabilitated.

## Conclusion

The cessation of asbestos mining and use in South Africa has drastically reduced occupational exposures, but widespread contamination of the environment, from decades of production, suggests an undefined and perhaps extensive ARD epidemic. While compensation systems exist for occupationally acquired ARDs, this study demonstrates that there is very little redress for people with environmentally acquired disease.

This study highlights that contamination of the environment and domestic exposures to asbestos contribute to the burden of ARDs. It is therefore important that workers exposed to asbestos and communities in the vicinity of asbestos operations are made aware of the risks associated with domestic exposures and strategies to prevent contamination of the environment. A recent global policy framework recommends prevention of occupational and environmental cancers through education, standardisation and enforcement of regulations, and disease surveillance (40).

Calls have been made for the South African government to address asbestos-related pollution of the environment (15, 41). Many dumps have been rehabilitated, but erosion of the rehabilitated dumps and exposure to the tailings that were used for road and building construction by nearby communities remain issues that need to be addressed. Improved monitoring and evaluation is required to ensure that exposures remain low and that interventions that are implemented are sustained (42).

Historically, the focus has been on occupationally acquired ARDs in former asbestos mine, mill, and

factory workers. A lesson from this study is that exposure to asbestos outside the workplace contributes to the burden of ARDs and should not be ignored. It is likely that most future ARDs in South Africa will result from neighbourhood exposures as men, women, and children continue to be inadvertently exposed to asbestos. In light of this study, urgent attention needs to be directed towards dealing with compensation for environmental mesotheliomas.

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**\*Ntombizodwa Ndlovu**

National Institute for Occupational Health  
PO Box 4788, Johannesburg  
2000, South Africa  
Tel: +27 11 712 6416  
Fax: +27 11 712 6450  
Email: [zodwa.ndlovu@nioh.nhls.ac.za](mailto:zodwa.ndlovu@nioh.nhls.ac.za)



## Occupational respiratory diseases in the South African mining industry

Gill Nelson\*

Division of Epidemiology and Biostatistics, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** Crystalline silica and asbestos are common minerals that occur throughout South Africa, exposure to either causes respiratory disease. Most studies on silicosis in South Africa have been cross-sectional and long-term trends have not been reported. Although much research has been conducted on the health effects of silica dust and asbestos fibre in the gold-mining and asbestos-mining sectors, little is known about their health effects in other mining sectors.

**Objective:** The aims of this thesis were to describe silicosis trends in gold miners over three decades, and to explore the potential for diamond mine workers to develop asbestos-related diseases and platinum mine workers to develop silicosis.

**Methods:** Mine workers for the three sub-studies were identified from a mine worker autopsy database at the National Institute for Occupational Health.

**Results:** From 1975 to 2007, the proportions of white and black gold mine workers with silicosis increased from 18 to 22% and from 3 to 32% respectively. Cases of diamond and platinum mine workers with asbestos-related diseases and silicosis, respectively, were also identified.

**Conclusion:** The trends in silicosis in gold miners at autopsy clearly demonstrate the failure of the gold mines to adequately control dust and prevent occupational respiratory disease. The two case series of diamond and platinum mine workers contribute to the evidence for the risk of asbestos-related diseases in diamond mine workers and silicosis in platinum mine workers, respectively. The absence of reliable environmental dust measurements and incomplete work history records impedes occupational health research in South Africa because it is difficult to identify and/or validate sources of dust exposure that may be associated with occupational respiratory disease.

Keywords: *gold; platinum; diamond; miners; silica; asbestos; silicosis; migrant labour; autopsy*

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South Africa is a mineral-rich country. Although the mining of these minerals generates wealth for the country, it also causes diseases in the mine workers who are exposed to harmful dust.

Pulmonary silicosis, the disease most commonly caused by exposure to crystalline silica dust, was described in South African gold miners in the early 1900s – not many years after gold-mining commenced. Most studies since then have been cross-sectional, with only one large cohort study being conducted on white miners; long-term trends have not been reported. Currently, South Africa has one of the highest rates of silicosis in the world.

Silica is a component of igneous rock that is found throughout South Africa. Another harmful mineral that occurs commonly in South Africa is asbestos. Although

much research has been conducted on the health effects of silica dust and asbestos fibres in the major mining industries in which exposures to these minerals occur (viz. the gold-mining and asbestos-mining sectors), little is known about their health effects in sectors in which they are accidentally mined. Exposure to these two minerals was the focus of a recent PhD thesis, the themes of which are illustrated in Table 1 (1–4). The first theme addresses trends in silicosis in the South African gold-mining industry over a period of 33 years, and the second explores the potential for occupational respiratory disease in the under-researched platinum- and diamond-mining sectors. This paper is a synthesis of three publications that emanated from the thesis, and it highlights the major findings.

**Table 1.** Summary of major findings from the thesis related publications

	Silicosis in gold miners (1)	Oscillating migration (2)	Asbestos-related diseases in diamond miners (3)	Silicosis in platinum mine workers (4)	Integrating narrative
Trends in silicosis in South African gold miners	The proportion of black miners diagnosed with silicosis increased from 3 to 33% from 1975 to 2007; in white miners it increased from 18 to 22%.	Health care costs were externalised away from the mining companies as a direct result of oscillating migration; this resulted in epidemics of diseases such as silicosis, tuberculosis, and HIV.			Increasing trends are due to the migrant labour system, poor dust control, an inadequate occupational exposure limit, and an ageing workforce with increasing durations of employment.
The potential for respiratory disease in under-researched mining sectors			Diamond mine workers are at risk of developing asbestos-related diseases due to the composition of the rock.	Platinum mine workers are at risk of exposure to crystalline silica and developing silicosis.	The PATHAUT database provides an opportunity for disease surveillance in miners of all commodities, including those in which risks of ill health are considered to be minimal.

### The gold-mining sector

Until the 1990s, there were very few studies on the extent of silicosis in South African gold miners (Table 2) (5–15). The only long-term cohort study, conducted on white miners, provides a clear illustration of the progression of silicosis long after retirement. Not surprisingly, the prevalence of disease in black miners in earlier years (8), when exposure to dust was for relatively short periods, was much lower than in white miners. Three subsequent studies of ex-miners from Lesotho, Botswana, and the Eastern Cape reported proportions of silicosis of up to 36% (10, 11, 13). By 2001, many years after short-term contracts had been phased out, the proportion of black employed gold miners with silicosis was 14 times higher than that reported in 1984 (8, 14).

Most studies have been cross-sectional and have used chest radiography (a relatively insensitive diagnostic tool), and have had small study populations. Studies in current miners underestimate the extent of silicosis because many develop the disease only after they have left the mining industry. This is due to the long latency of disease after dust exposure.

### The diamond-mining sector

There is strong evidence to suggest that diamond mine workers in South Africa are at risk of asbestos exposure. Kimberlite often contains fragments of ultramafic rock that have a low silica and a high magnesium and iron content; these elements form the basis of amphibole min-

erals (16) that can occur as asbestos. Diamond deposits are also found close to asbestos deposits in several provinces (Fig. 1). Two reports, published in 1995 and 2001, respectively, describe airborne asbestos fibres in different diamond mines (18). Crocidolite asbestos was identified around the perimeter of the kimberlite pipe of a diamond mine in the Asbestos Hills in the Northern Cape (PJ Jordaan, unpublished data) and, in 2009, a sample of chrysotile asbestos was sent from a diamond mine in Limpopo province to the National Institute of Occupational Health (NIOH) electron microscopy laboratory for fibre analysis.

### The platinum-mining sector

The platinum group metals (PGMs) are found in the Bushveld Complex in the northeastern part of South Africa (Fig. 2). As an igneous intrusion, the Bushveld Complex contains crystalline silica in addition to many other minerals and compounds. Miners of any of the minerals in the Bushveld Complex are therefore potentially at risk of exposure to silica dust.

There are very few available silica dust measurements from the platinum mines because the silica content of the dust is not routinely measured (20). One study calculated the crystalline silica content of crushed stope rock samples from two platinum mines as 0.45%, compared with 9.9 and 39.1% in two gold mines (21). The silica content of respirable dust samples was less than 0.2%, compared with 4.5% to 57% in the gold mines. A second

Table 2. Studies of silicosis in South African gold miners, 1978–2009

Authors	Study design	Study period	Study population	Study site	Sample size <i>N</i>	Mean/range of employment (years)	Diagnostic tool	Proportion with silicosis	Limitations
White gold miners									
Irwig and Rocks 1978 (5)	Cross-sectional	1968 to 1971	Employed white miners aged 45–54	All areas	1,973	> 10	Chest X- rays	6.8	White miners only*†
Hnizdo and Sluis-Cremer 1993 (6)	Cohort	1968 to 1991	White ex-miners – living and dead	All areas	984	23.5	Chest X- rays	14.0	White miners only†
Murray and Hnizdo 2005 (7)	Cohort	1968 to 2003	Deceased white gold miners	All areas	1,476	23.5	Autopsy	51.6	White miners only
Black gold miners									
Cowie and van Schalkwyk 1987 (8)	Cross-sectional	1984	Employed black miners	Orange Free State, SA	132,765	Not stated	Chest X- rays	1.4	Black miners only; no ex-miners; denominator included new recruits*†
Murray et al. 1996 (9)	Cross-sectional trend analysis	1975 to 1991	Deceased black gold miners	All areas	16,454	4.4–6.9	Autopsy	9.3–12.8	Black miners only; 62% of men employed for <5 years 78% younger than 40*
Steen et al. 1997 (10)	Cross-sectional	1994	Living black ex-miners	Botswana	304	15.5	Chest X- rays	26.6–31.0	Black miners only; selection bias; no current miners*§†
Trapido et al. 1998a (11)	Cross-sectional	1996	Living black ex-miners	Eastern Cape, SA	238	12.2	Chest X- rays	22.0–36.0	Black miners only; no current miners*§†
Meel 2002 (12)	Cross-sectional	1997 to 1999	Living black ex-miners – hospital patients	Eastern Cape, SA	300	Not stated	Chest X- rays	34.0	Black miners only; selection bias (hospital patients); no current miners*§†
Girdler-Brown et al. 2008 (13)	Cross-sectional	1999	Living black ex-miners	Lesotho	624	25.6	Chest X- rays	24.6	Black miners only; no current miners*§†
Churchyard et al. 2004 (14)	Cross-sectional	2000 to 2001	Employed black miners older than 37	North West province, SA	520	21.8	Chest X- rays	18.3–19.9	Black miners only; no ex-miners; healthy worker effect*§†
Park et al. 2009 (15)	Cohort	1999 to 2000	Living black ex-miners	Lesotho	553	26.1	Chest X- rays	27.0	Black miners only; no current miners; short follow-up of 1 year§†

\*cross-sectional study design; §small numbers.; †insensitive diagnostic tool.

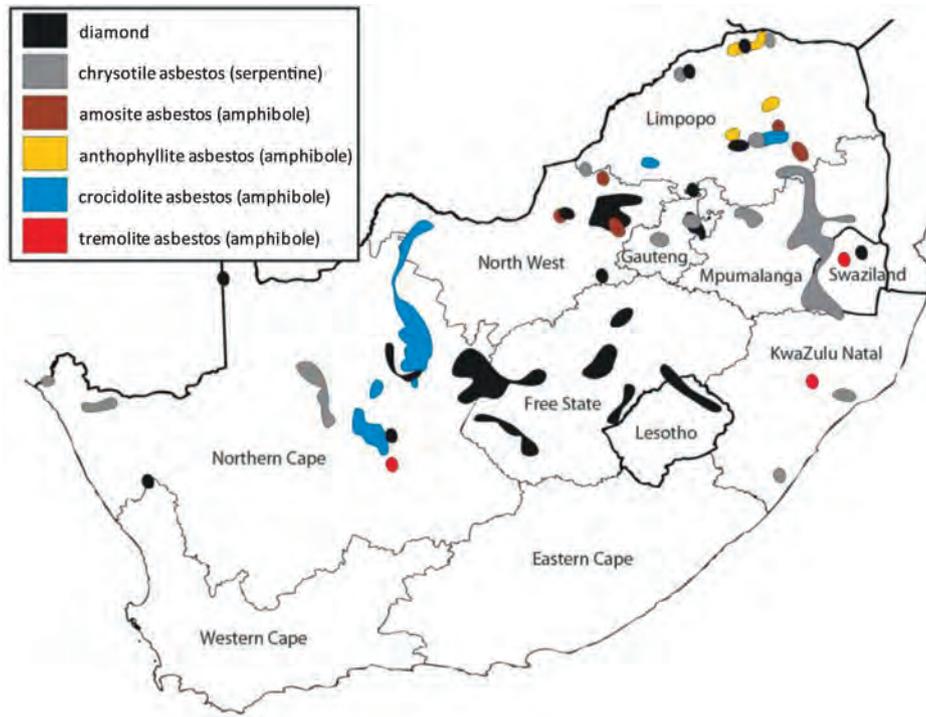


Fig. 1. Map of South Africa showing geographical distribution of diamond and asbestos deposits [generated using ArcExplorer software (17)].

study reported respirable silica dust concentrations ranging from 0.018 mg/m<sup>3</sup> to 0.035 mg/m<sup>3</sup> (22); this is much lower than the South African Occupational Exposure Limit (OEL) of 0.1 mg/m<sup>3</sup> but higher than the American Conference of Governmental Industrial Hygienists (ACGIH) limit of 0.025 mg/m<sup>3</sup>. The only study of silicosis in platinum mine workers was a cross-sectional

survey of 969 miners; silicosis was diagnosed in three, all of whom had a history of gold-mining (18).

The objectives of this PhD thesis were 1) to describe trends in silicosis diagnosed at autopsy in South African gold miners from 1975 to 2007; 2) to explore the possibility of asbestos exposure during the process of diamond-mining; and 3) to explore the

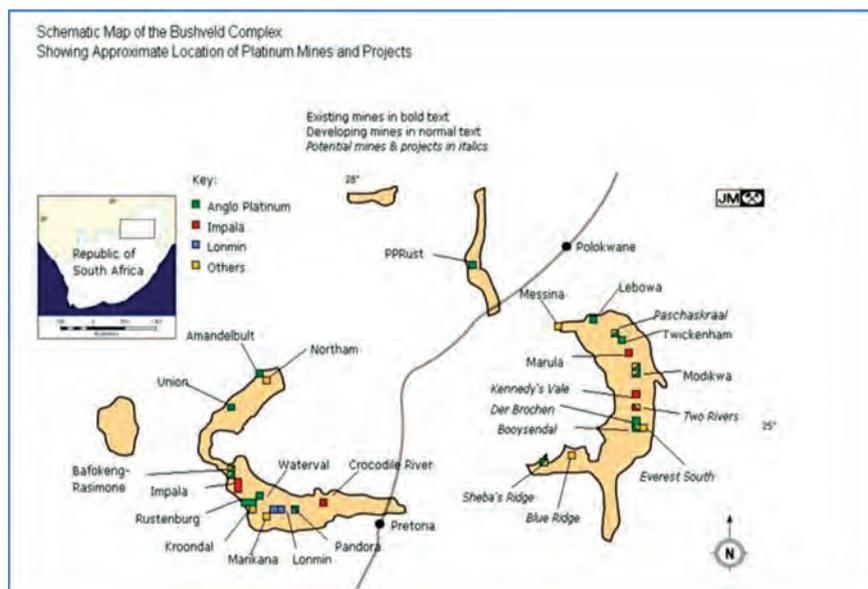


Fig. 2. Map showing the platinum mines in the Bushveld Complex (19).

possibility of developing silicosis during the process of platinum-mining.

## Methodology

### Data sources

There is no single database in South Africa from which comprehensive employment records and exposure data can be extracted. Therefore, a variety of data sources were explored to compile employment histories that were as complete as possible for each section of the thesis.

In terms of the Occupational Diseases in Mines and Works (ODMW) Act, the pathology division of South Africa's National Institute for Occupational Health provides an autopsy service for deceased miners and ex-miners for the diagnosis of compensable disease, regardless of the clinical cause of death or their disease status, provided the next of kin gives consent. Although autopsies have been performed for many decades, until 1975, all reports were paper-based. Details of each autopsied case are recorded in an electronic database that is part of the PATHAUT (Pathology Automation) System. The database provides for the recording of not only disease data but additional information related to demography and exposure (employment in up to five different mining sectors together with the years employed). The PATHAUT database is an important resource for surveillance and research on miners and ex-miners of all commodities. It contains the only data on occupational lung disease in the South African mining industry diagnosed by standard pathological methods that are far more sensitive and accurate than chest radiography. It currently comprises more than 105,000 autopsy records of miners from all population groups, all mining sectors, and all regions of South Africa dating back 37 years to 1975. The PATHAUT database was the primary and common data source used for identifying mine workers with occupational respiratory disease in all three mining sectors (gold, diamond, and platinum).

More comprehensive mining employment histories are recorded by the Medical Bureau for Occupational Diseases (MBOD) in Johannesburg. Until 1994, when the amendments to the ODMW Act were promulgated, examinations of white miners were conducted at the MBOD itself in central Johannesburg or at one of the sub-bureaus located in the vicinity of the gold mines. All records were kept at the MBOD. Black miners, on the other hand, were examined at the mines but their data were not routinely submitted to the MBOD. Nowadays, all examinations are conducted at the mines; data are sent to the MBOD when an occupational disease is suspected. Records are kept for all miners who apply for compensation for an occupational respiratory disease and are linked to the PATHAUT database by a unique MBOD number.

Files of diamond miners with asbestos-related diseases and platinum miners with silicosis were reviewed, specifically for employment histories, to identify those who might have worked in a mining sector other than the one of primary interest. Evidence of potential exposure to asbestos and employment in the gold mines was important to exclude the possibility of miners having contracted the disease of interest in an industry or mining sector other than the diamond or platinum mines, respectively.

Until 2004, when the electronic Mine Workers' Compensation (MWC) system was implemented, the MBOD was entirely paper-based. Since then, all new applications to the MBOD are also recorded electronically. The MWC system consolidates and summarises information on work histories from the autopsy database, the MBOD files, and other sources. The MWC reports were reviewed to corroborate work history information obtained from other sources for diamond and platinum mine workers.

The Employment Bureau of Africa (TEBA) Limited was established in 1902 to assist the gold-mining industry in hiring mine workers. TEBA still deals primarily, but not exclusively, with gold miners. Each miner is assigned a unique industry number that remains his personal number for life even if he is subsequently employed in another mining sector. This number is recorded in the PATHAUT database. The electronic TEBA service history records were reviewed for the diamond and platinum mine workers to confirm that they had not been employed in the asbestos- and gold-mining sector, respectively.

Mining companies archive personnel data (albeit for a limited period and often in paper-based files). Where available, records were reviewed for specific job descriptions and to identify gaps in employment histories. For the studies on diamond miners, tailings and soil samples were collected from three different mines.

### Study designs

Silicosis in gold miners at autopsy was described using a time trend analysis over a 33-year period. The studies to investigate diamond miners with asbestos-related diseases and platinum mine workers with silicosis were both descriptive case series.

### Selection of study populations

Data were extracted from the PATHAUT database for each of the three study populations. For gold miners, all autopsies were included from 1975 to 2007. For the case series of diamond mine workers, cases were identified from 1975 to 2008, and for the case series of platinum mine workers, cases were identified to 2009. All gold miners were included in the trend analysis, regardless of whether they had worked in another mining sector or not. Diamond and platinum mine workers, however, were included in the respective case series only if they had

not worked in another mining sector. Only miners who started working before the age of 24 and those with gaps in their work histories of less than one year were included in order to minimize the chance of including mine workers who had been exposed to asbestos or silica outside of the asbestos- and platinum-mining industries, respectively. The additional inclusion criteria are described in detail elsewhere (1, 3, 4).

### Disease diagnosis

Over the years, diseases have been diagnosed and graded by severity by experienced pathologists at the NIOH according to standardised methods. For the purposes of these analyses, silicosis was defined as the presence of palpable silicotic nodules on macroscopic examination of the lungs, which was then confirmed on microscopic examination. Asbestosis was diagnosed microscopically by the presence of diffuse interstitial fibrosis and two or more associated asbestos bodies. Pleural plaques were defined as circumscribed areas of dense acellular collagenisation with a basket weave appearance involving the parietal, diaphragmatic, and/or visceral pleura and with a minimum diameter of 5 cm.

### Statistical analyses

The relevant data for each aspect of the thesis were extracted from the statistical analysis system (SAS) PATHAUT database and transferred into a Stata IC 10 database for analysis. In each case, a repeat validation of the data was performed for the variables of interest, and the Stata dataset was amended with any additional data (e.g. employment histories) identified from the supplementary sources. Trend analyses on silicosis in gold miners were stratified by race. Trends in the crude proportions of miners with silicosis by year were assessed by means of simple linear regression with weighting by the inverse of the variances of the single year proportions. Binary logistic regression modelling with

silicosis (1 = present, 0 = absent) as a dichotomous outcome was used to estimate associations with the explanatory variables. The three explanatory variables were age at death, duration of employment, and year of autopsy. Direct age and duration of employment standardisation was used to compare proportions of black and white miners with silicosis. The diamond mine workers with asbestos-related diseases and the platinum mine workers with silicosis were described in terms of their demographic characteristics, pathological findings, and occupations.

### Ethical considerations

Consent for autopsy examination can be granted by the next of kin in terms of the Occupational Diseases in Mines and Works Act (ODMWA) of 1973 (23) and the Occupational Diseases in Mines and Works Amendment Act of 2002 (Act no. 60 of 2002). This PhD protocol was approved by the University of the Witwatersrand Committee for Research on Human Subjects (M050228). Permission was obtained from the mining companies for the collection of samples of tailings.

## Results

### Silicosis trends in gold miners

Of the 19,143 gold miners who died from external causes, 16,411 (85.7%) were black and 2,732 (14.3%) were white. The crude proportion of black miners with silicosis increased tenfold from 3 to 32%; the increase in white men was slight, from 18 to 22% (Fig. 3). More white miners had silicosis in 1975 (the proportion was six times higher than that of black miners) but, by 2007, this pattern was reversed (the proportion was 1.5 times higher in black miners). Overall, the proportion of black miners with silicosis was almost double that of white miners for the 33-year period.

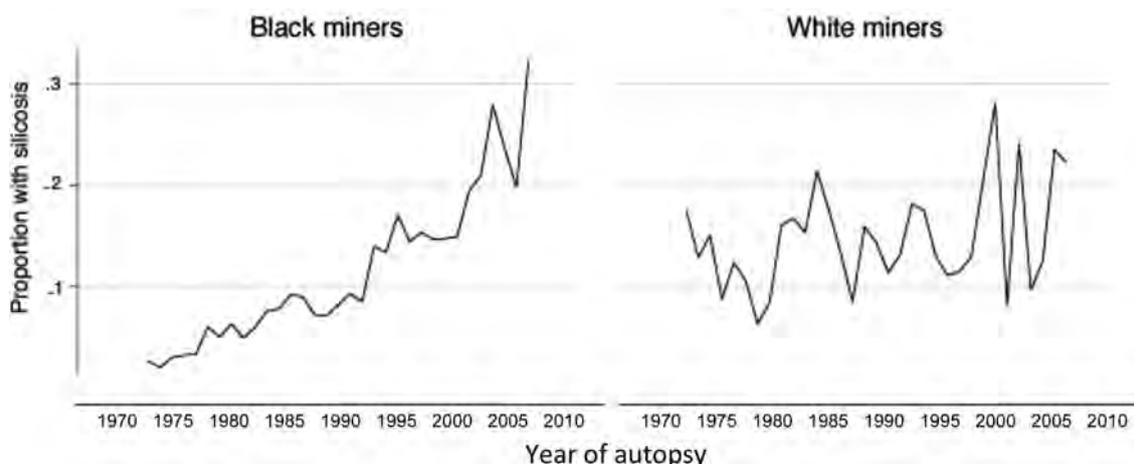


Fig. 3. Crude population group-specific proportions of gold miners with silicosis, 1975–2007.

Increasing age at death and duration of exposure explained much of the increase in silicosis.

The mean age at death of the black and white miners increased by more than 10 years over the study period. For the black miners, the mean age at death rose from 33.0 years in 1975 to 43.4 years in 2007, whereas the mean age at death for the white miners rose from 44.1 years in 1975 to 54.4 years. The mean duration of employment increased by less than 3 years for the white miners (from 17.5 to 20.1 years) but by almost 8 years, from 5.6 to 13.4 years, for the black miners.

The standardised proportion ratio (SPR) by race was 1.70 (95% CI 1.45–1.99); that is, the proportion of black miners with silicosis was 70% higher than that for white miners over the entire period, but this varied over the study period. When the analysis was repeated for miners dying from natural causes, the SPR increased to 2.27 (95% CI 2.12–2.43), most likely due to the association of tuberculosis with silicosis.

The overall age and employment duration-adjusted proportion of black miners with silicosis was higher than that of white miners for all years of autopsy other than 1975–1979 suggesting that a factor(s) other than increasing age and duration of employment was associated with the increase in disease. It is likely that black miners had higher intensities of exposure than white miners due to the dustier jobs in which they were (and still are) employed. This is supported by the fact that more black than white miners developed silicosis after relatively short periods of employment and at younger ages. The proportion of black miners with silicosis reached 2% after fewer years than it did for white miners (15–19 years versus 20–24 years), and the proportion of black miners with silicosis below the age of 50 years was almost double that of white miners (0.07 versus 0.04). These results have been reported elsewhere (1).

#### *Asbestos-related diseases in diamond mine workers*

Of all the deceased mine workers who came to autopsy from 1975 to 2008, 1,887 had a record of having worked in the diamond-mining sector. Five hundred and fifty-nine (29.6%) had worked only in the diamond-mining sector – an exhaustive search of the multiple data sources showed no employment in any other mining sector or elsewhere – and fulfilled the study inclusion criteria (3); 24 (4.3%) had one or more asbestos-related diseases at autopsy. After a comprehensive review of all data sources to ascertain possible exposure to asbestos outside of the diamond-mining industry, only six diamond miners with one or more asbestos-related diseases were included in the case series. Four had asbestosis, one had pleural plaques, and one had malignant mesothelioma and pleural plaques.

The stored lungs of an additional 11 diamond mine workers were analysed under scanning electron micro-

scopy (SEM). Tremolite asbestos fibres or fibres in the tremolite–actinolite amphibole asbestos series were identified in five. No chrysotile asbestos fibres were identified even though four of the five workers had worked in a diamond mine close to a chrysotile asbestos deposit. None had an asbestos-related disease.

Tailings samples from a diamond mine near a crocidolite asbestos deposit contained tremolite-actinolite series fibres. The tailings samples from the diamond mine near a chrysotile deposit contained chrysotile fibres and tremolite-actinolite series fibres. Tailings samples and dust collected from a crusher located above ground from a diamond mine near anthophyllite and chrysotile deposits contained tremolite-actinolite series fibres. A sample of pure chrysotile asbestos was also collected from between the kimberlite pipe and the country rock in this mine.

#### *Silicosis in platinum mine workers*

A total of 12,241 men in the PATHAUT database had worked in the platinum-mining industry from 1975 to 2009. As for the diamond mine workers, a thorough search of all available data sources produced no evidence of employment in another mining sector for 6,490 (53%) of the platinum mine workers; 85 (2.2%) had silicosis at autopsy. Fibrotic nodules, a recognised precursor of silicosis, were identified in the lymph nodes of 490 (12.7%). After reviewing all available data sources, five mine workers with pulmonary silicosis (four of whom also had fibrotic nodules in the lymph nodes), plus an additional 25 with fibrotic nodules in the lymph nodes but without silicosis, were identified. There was enough evidence to suggest that these pathological changes occurred in the course of the miners' employment in the platinum mines giving a crude autopsy prevalence of 5/6490 (0.06%) definite and 25/6490 (0.39%) potential silicosis at autopsy in platinum miners (4).

#### **Discussion**

The high rates of silicosis are of major concern in the gold-mining industry largely because of the association of silicosis and tuberculosis (24); South African gold miners have one of the highest incidence rates of pulmonary tuberculosis in the world (25).

The alarming increase in the proportion of gold miners with silicosis at autopsy reflects the failure of the mining companies to reduce silica dust to safe levels. There is no evidence to believe that silicosis levels have decreased since the 1940s (14, 26), and this is supported by these findings. As miners continue to age and work for longer periods, the burden of silicosis and other diseases will continue to rise. This has far-reaching implications for health services that need to be prepared for increasing morbidity and mortality in current and ex-miners.

South Africa is committed to the World Health Organization/International Labour Organization initiative to

eliminate silicosis by 2030. The Department of Mineral Resources (DMR) set targets to reduce 95% of all respirable crystalline silica measurements to below  $0.1 \text{ mg/m}^3$  by December 2008 and, after December 2013, to have no new cases of silicosis among previously unexposed individuals (27). However, the 2008 target was not met: the proportion of mines reaching 95% compliance decreased from around 94% in 2006 to less than 85% in 2010 (28). Consequently, the second milestone is also unlikely to be met. Nevertheless, silicosis rates need to be monitored by the DMR on an ongoing basis to evaluate the success of this and any other similar programmes.

The migrant labour system, together with employment practices, played a major role in the development of silicosis (29–31). Migrant labour-related problems are deep-seated within the mining industry (32), and mine occupational health professionals need to become actively engaged with management on these issues. Oscillating migration is a risk factor for work-related disease and falls within the scope of occupational health services. Oscillating migration has diluted community and organised labour pressures on mine management to reduce dust levels and control disease and has enabled mining companies to limit disease-associated costs, thereby reducing the financial incentive to control dust and disease. Policies need to be instituted to assure that ex-miners, in particular, have access to health care and compensation services. A more comprehensive discussion on this subject was published as part of the thesis (2).

The need for regional and national policies that acknowledge the economic value of migrant workers and that provide for infrastructure, such as strengthening health services where migrant workers are employed or live, and in labour-sending areas, is vital (2). As the South African mining industry shrinks, health services in labour-sending areas are becoming even more overstretched by returning migrants. Even though policies to address these and other issues might be in place, the translation into action is fraught with obstacles. This is discussed in depth in a recent paper by Murray et al. (33).

Diseases previously undocumented in diamond and platinum mine workers were found to be associated with exposure to mineral dusts and fibres. The evidence for the risk of asbestos-related diseases in diamond miners is provided by the mineralogy of kimberlite, the diagnosis of asbestos-related disease in diamond mine workers, and the identification of asbestos fibres in the lungs of diamond mine workers and diamond mine tailings. The diagnosis of silicosis and fibrotic nodules in the lymph nodes of platinum miners, as well as silica dust measurements in some of the mines, point to a risk of silicosis in platinum mine workers. Although mines are required by law to establish and maintain disease surveillance programmes (34), occupational health practitioners need to be

aware that diseases other than those recognised as risks in the mining sector in which the employee works may also occur.

This work needs to be extended to identify and quantify risks in other mining sectors where occupational respiratory research has not been conducted. Many mines worldwide are ‘contaminated’ with asbestos mineral tailings (35–40). Asbestos has been reported in a vermiculite mine in South Africa (41), and there are anecdotal reports of asbestos in other mines such as the iron and manganese mines in the Northern Cape province and in chrome/platinum mine tailings dumps (James I Phillips, NIOH, personal communication). The Bushveld Complex is a mineral-rich area that is being extensively mined. The potential for exposure of mine workers in this region to associated minerals and, hence, the risk of respiratory disease, needs to be investigated in other mining sectors such as tin, vanadium, feldspar, and so forth.

The two major hindrances to this research were poorly documented work histories and lack of exposure measurements.

All mining companies should record comprehensive work histories from the time the worker is first employed including jobs outside of the mining industry. Aside from the benefits for families seeking compensation for occupational disease, this information will enable more rigorous analysis of disease associations related to different exposures during mining processes as well as during employment in different industries unrelated to mining.

Although the DMR requires all mines to conduct occupational hygiene surveillance on a regular basis, according to prescribed guidelines, many of the mines do not follow the regulations. In some platinum mines, silica levels are believed to be too low to measure, and they are commonly reported as ‘below the detectable limit’ (20). Silica dust measurements reported by gold mines are estimated, rather than measured directly, and are based on a number of extrapolations. The reliability of the data is affected by the fact that the dust measurements are collected for risk assessment in accordance with the ODMW Act for purposes of calculations of levies that the mines pay. The measurements are not validated by the DMR or any other external agency. Asbestos is also not measured routinely in most mines although there are anecdotal reports of its presence in many mine environments. Because both silica and asbestos occur throughout South Africa, it is likely that they will be present in many mines. Dust measurements should be regularly conducted by all mines and audited and validated by the DMR.

These recommendations are not restricted to South Africa. Platinum and diamond deposits are mined in Zimbabwe, Angola, the Democratic Republic of Congo, Ghana, Tanzania, Lesotho, and Botswana – in many cases by large multinationals. The recording of

work histories and exposure measurements should be mandatory.

In South Africa, the quality of future research on the health of mine workers hinges on the DMR putting legislation in place regarding the documentation of comprehensive work histories and the measurement, reporting, and validation of dust levels and dust measurement procedures. Such legislation will go a long way towards protecting the health of mine workers.

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**\*Gill Nelson**

Division of Biostatistics and Epidemiology  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Email: [gill.nelson@wits.ac.za](mailto:gill.nelson@wits.ac.za)

# “Even if I were to consent, my family will never agree”: exploring autopsy services for posthumous occupational lung disease compensation among mineworkers in South Africa

Audrey V. Banyini<sup>1,2\*</sup>, David Rees<sup>2,3</sup> and Leah Gilbert<sup>4</sup>

<sup>1</sup>Chamber of Mines, Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>National Institute for Occupational Health, National Health Laboratory Service, Johannesburg, South Africa; <sup>4</sup>Department of Sociology, University of the Witwatersrand, Johannesburg, South Africa

**Context:** In the South African mining sector, cardiorespiratory-specific autopsies are conducted under the Occupational Diseases in Mines and Works Act (ODMWA) on deceased mineworkers to determine eligibility for compensation. However, low levels of autopsy utilisation undermine the value of the service.

**Objective:** To explore enablers and barriers to consent that impact on ODMWA autopsy utilisation for posthumous monetary compensation.

**Methods:** In-depth interviews were conducted with mineworkers, widows and relatives of deceased mineworkers as well as traditional healers and mine occupational health practitioners.

**Results:** A range of socio-cultural barriers to consent for an autopsy was identified. These barriers were largely related to gendered power relations, traditional and religious beliefs, and communication and trust. Understanding these barriers presents opportunities to intervene so as to increase autopsy utilisation.

**Conclusions:** Effective interventions could include engagement with healthy mine-workers and their families and re-evaluating the permanent removal of organs. The study adds to our understanding of utilisation of the autopsy services.

Keywords: *mineworker autopsy; posthumous compensation; South Africa; consent for autopsy*

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South Africa has a statutory system for the post-mortem examination (autopsy) of cardiorespiratory organs of deceased mineworkers to determine their eligibility for compensation. The procedures (family consent, removal and transporting of organs) and benefits (which are largely financial) are governed by the Occupational Diseases in Mines and Works Act (ODMWA) (1). The actual pathological examinations and certification (the determination of the nature and severity of occupational disease) are centralised in Johannesburg, a city in Gauteng Province, which is distant from most mines and areas in which former mineworkers and their families live. Consequently, the organs are permanently removed and, after a period of storage, destroyed in Johannesburg. The organs are stored for a maximum of 2 years for

re-examination in cases of appeal on the certification categories by the families. ODMWA certifications are categorised into either ‘no compensable disease’, ‘first degree’ or ‘second degree’, with the latter being the more severe occupational disease which carries a larger compensation payment.

The provisions of this Act are important as a large number of former mineworkers are not compensated in life (2–5). During 2001–2010, 311 deceased mineworkers who were not compensated while alive were found to have first-degree occupational lung disease and 2,426 second-degree disease. Additionally, 59 cases were upgraded from first to second degree. Applying the salary range used to calculate compensation payments (\$3,340.50–\$4,912.50), the 311 families were eligible for

\$1,038,895.50–\$1,527,787.50 compensation in the first-degree category with an average of \$4,126.50 per family. Similarly for those categorised as having second-degree disease, the 2,426 families were eligible for \$24,260,000–\$26,537,407.50 with an average of \$10,469.38 per family. During the 10-year period, the 311 cases in the first-degree category and the 2,426 in the second degree were 2% and 18%, respectively, of all the autopsies performed.

Of particular poignancy in the South African context of impoverished rural communities is that despite the potential financial benefits for the families of deceased mineworkers, there is underutilisation of the autopsy service by black mineworkers. For example, during 2001–2010, The Employment Bureau of Africa (TEBA), which annually registers 71% of the total mine employees, recorded 28,265 in-service mineworkers' deaths, all of whom were eligible for an autopsy (Herbet G, unpublished data, 2011). Yet, only 13,201 autopsies (i.e. 46.7% of TEBA-recorded deaths) were performed during this period (5). Assuming that the same 10-year average proportions of first- (2%) and second-degree (18%) certifications would have been applied to the 15,064 TEBA-recorded deaths, an additional 355 and 2,769 families would have been eligible for \$1,185,869.62–\$1,743,926 in the first-degree and \$20,598,076.13–\$30,291,695.50 in second-degree categories, respectively. It should be noted that these calculations of financial loss due to underutilisation of the autopsy underestimate the true losses because the number of deaths in non-TEBA-registered (in-service mineworkers) and retired mineworkers is unknown and are excluded from the calculations. Although money is only one aspect of defining poverty, the compensation award is up to 11 times the mineworkers' monthly salary (6), and the award has been shown to offer a short-term financial relief to families of the deceased mineworkers (7).

For various reasons, the number of autopsies continues to fall despite the potential benefits of the procedure to families and medical science (8, 9). Some of the reasons for the decline include fear of mutilating the body, maintaining the body in the best condition possible, lack of knowledge about autopsy, belief that the examination during an autopsy inflicts further suffering to the body, the treating physician's lack of rapport with the deceased's family, lack of consensus among family members regarding the procedure, concern about funeral delays, dying at home as opposed to hospital or preference to preserve the dignity of the deceased over knowing the cause of death (10–14).

In South Africa, the ODMWA autopsies are declining especially among retired mineworkers. For example, of the total 4,255 ODMWA autopsies of black mineworkers during 2007–2010 (noting that there were 11,512 TEBA-recorded deaths), 19.6% were performed on retired mineworkers and the rest on in-service mineworkers (Ndlovu

N, unpublished data, 2010). Insufficient knowledge of ODMWA provisions by the mineworkers, their relatives and health personnel in rural hospitals has been postulated as one of the causes of underutilisation (15). There is a dearth of research on this underutilisation. The aim of this paper is to fill this gap by exploring the enablers and barriers affecting ODMWA autopsy of black mineworkers and their families.

## Methods

This descriptive study used an exploratory, qualitative approach to obtain in-depth information from respondents. Such an approach is usually associated with the social constructivist paradigm which emphasises the socially constructed nature of reality. It is about recording, analysing and attempting to uncover the deeper meaning and significance of human behaviour and experience, including contradictory beliefs, attitudes and emotions. This approach was used with the aim of discovering the meanings that respondents attach to their choices, how they interpret situations, and what their perspectives are on autopsy-related issues. Qualitative studies provide an understanding of complex psychosocial issues (16), and the enquirer seeks insights into the meaning(s) attached to events by seeking disparate views, rather than looking to determine the most commonly held view (17). The advantage of qualitative methods in exploratory research is the use of open-ended questions and probing which gives respondents the opportunity to respond in their own words, rather than forcing them to choose from fixed responses, as quantitative methods do. Open-ended questions as used in this study have the ability to evoke responses that are meaningful and culturally salient to the participant, unanticipated by the researcher, and rich and explanatory in nature.

## Respondents

The respondents were former miners, relatives and widows of the deceased miners, in-service miners and others (traditional healers and occupational health practitioners). These categories of respondents were selected because of the particular perspective they were likely to bring. Miners and their families have a direct influence on autopsy utilisation, and traditional healers were thought to be able to offer a shared cultural perspective on attitudes towards autopsy and may also be in a position to influence behaviour. Occupational health practitioners were considered to be capable of offering a shared experience on the mineworkers' attitudes towards autopsy as they had contact with miners and families during illness and death. In the main, informants were selected on the basis of their availability and accessibility. Individual informants were identified through community workers, other mineworkers and representatives of organised labour, except for traditional healers who were considered

popular among mineworkers and each of whom represented a different cultural tradition.

The majority of retired mineworkers, relatives and widows were from Nongoma, a district of KwaZulu-Natal Province, which has a high density of mineworkers (Herbet G, unpublished data, 2011). Additionally, retired mineworkers living in five urban townships around Free State Province gold mines and in-service mineworkers from a Randfontein gold mine west of Johannesburg were selected on the basis of convenience, being relatively close to the base of the researchers.

### Data collection

The in-depth interview approach was selected for the study to explore individual or group meaning and experiences since human phenomena such as psychosocial responses are embedded in cultural patterns, and the inter-relationships among its components are complex, necessitating a flexible enquiry that allows concepts to emerge from the data being collected (16, 17). A semi-structured questionnaire was used to guide the interviews. Using open-ended questions, the researcher probed initial responses to gain in-depth insights. The questionnaire was piloted with three retired mineworkers and four in-service mineworkers and thereafter refined for content clarity. All of the interviews were conducted and audio taped by the first author, a medical doctor who speaks the vernacular languages of the respondents, in the respondents' preferred language. Additional handwritten notes were also taken. Informants were free to stop and discontinue the interviews.

The issues covered in each interview were: labour history; mine medical surveillance and mine exit

medical information; compensation legislation knowledge, ODMWA processes and benefits; and autopsy knowledge, perception and attitudes.

### Conceptual framework

In the absence of adequate literature on barriers to an autopsy for the compensation or what encourages its utilisation, the literature on general clinical autopsy was used to formulate a conceptual framework for the study (Fig. 1). The identified potential factors playing a role in clinical autopsy utilisation were found to be at individual, institutional and community/societal levels. Factors at individual and socio-cultural levels were used to develop the semi-structured questionnaire to guide the interviews and the thematic analysis of the transcripts.

### Data analysis

All interview data were transcribed into English within 3 days of the interviews by the first author who speaks the vernacular languages and English to ensure recollection of discussions. Handwritten notes taken during the interviews were also included in the analysis. Key ideas generated were noted at the end of each interview. The notes for each informant were uploaded in MAXqda PC (2003), coded and grouped into thematic categories. Emerging themes were identified using the conceptual framework and their meaning interpreted.

### Number of respondents

The maximum number of respondents was set at 70 or whenever saturation of information was reached.

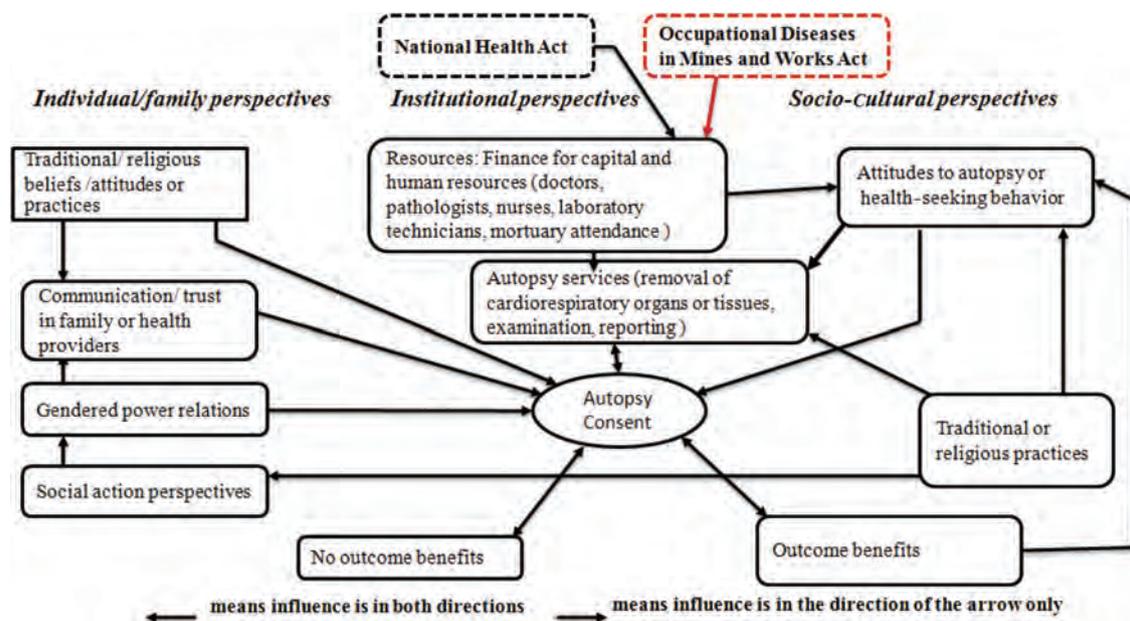


Fig. 1. Conceptual framework of factors influencing clinical autopsy utilisation.

### Ethics

Informed consent was obtained from all respondents, and confidentiality was maintained. Relatives and widows who experienced the death of a mineworker within two years prior to the study were excluded to reduce psychological and emotional reactions invoked by discussing the death of their loved one. The study was approved by the Faculty of Humanities' Human Research Ethics Committee (non-medical) in 2007, Ethical clearance number H070618.

### Results

Seventy respondents were interviewed as shown (Fig. 2). Almost all of the mineworkers, their relatives and widows were unaware of the benefits and processes of ODMWA autopsy.

The results on the enablers and barriers impacting on autopsy utilisation were largely related to gendered power relations, traditional and religious beliefs, and communication and trust. For this reason, the findings are presented under these headings.

#### Gendered power relations

According to respondents, during the bereavement period, widows observed a period of mourning and were excluded from funeral and burial rituals and decision-making. During this period of mourning, a widow's communication and contact with other family members would be limited until a pre-determined period and the person will be ritually cleansed. Some female respondents argued that even if they agreed to an autopsy, they would miss an opportunity to consent because of the cultural restrictions and taboos surrounding mourning. They articulated that a man's body belonged to his birth family and not to his wife or adult children. This implied that a man's patrilineal relations were stronger than to his wife. While the wives did not have decision-making power to give consent, patrilineal powers extended to paternal aunts who can communicate with ancestors. On the contrary,

matrilineal relations in the absence of paternal relatives were conducive to autopsy. In addition, the absence of the deceased mineworker's family created an opportunity for the widow to give consent.

A widow from Nongoma said:

Autopsy, I will agree to find the cause of death ... however, in my situation, he belongs to his family who has a final say .... I had no power around the death. You are only shown his body after the elder family women dressed him and they show you only his face. You are told not to look at face for long ... you are mourning. You will know what is happening or get updates only if you have someone who really loves you .... You still don't have any power to question anything. My husband died in hospital and I took him there (silence) .... He died the following day and I was sent home to mourn him ... yes as a wife you mourn. We used to hear about mineworkers who had autopsy at the mines ... this will be discussed, but their wives did not know about it ... they did not see the scars.

A paternal aunt of the deceased mineworker in Nongoma articulated:

My brother's son died at the age of 31 years leaving a small child. He came back ill .... If I had knowledge about the autopsy, I will consent ... If I know where the parts from autopsy went, I would have agreed .... I would inform him and the ancestors through the sacrificial killing. I will consent because of the purpose and there is possibility that his kids, who are currently suffering financially, get a chance of compensation ... It is now the issue of the person not discussing the laws with the family and the doctors not talking. It is the current myth of young ones to believe that they will live longer than ugo (grandparents) .... They do not communicate.

The respondents' view on the widow's lack of decision-making power relating to her deceased husband was corroborated by traditional healers. According to them,

Former mineworkers (21)	Relatives (10)	Widows (21)	In-service mineworkers (8)	Other participants (10)
<ul style="list-style-type: none"> <li>• Urban (8)</li> <li>• Lesotho (3)</li> <li>• Eastern Cape (2)</li> <li>• Mozambique (1)</li> <li>• Free State (2)</li> <li>• Rural (13)</li> <li>• Nongoma</li> </ul>	<ul style="list-style-type: none"> <li>• Nongoma (9)</li> <li>• Mothers (5)</li> <li>• Daughters (3)</li> <li>• Paternal aunt (1)</li> <li>• Virginia (1)</li> <li>• Sister in law</li> </ul>	<ul style="list-style-type: none"> <li>• Nongoma (18)</li> <li>• Lesotho (2)</li> <li>• Welkom (1)</li> </ul>	<ul style="list-style-type: none"> <li>• Males (6)</li> <li>• Urban</li> <li>• From Mozambique (1)</li> <li>• Urban (1)</li> <li>• Migrant</li> <li>• Eastern Cape (3)</li> <li>• Kwa-Zulu Natal (1)</li> <li>• Females (2)</li> <li>• Urban</li> </ul>	<ul style="list-style-type: none"> <li>• Others (10)</li> <li>• Traditional healers (3)</li> <li>• Mine health practitioners (5)</li> <li>• Community leader (1)</li> <li>• Organised labour (1)</li> </ul>

Fig. 2. Key informants by category and number.

the role of a wife during mourning is considered by the family to be a minor one. They explained that wives were alien to ancestral communication.

A traditional healer (from Gauteng) articulated:

If I die my family tradition and what is required is known by my family ... they can inform my wife. They (my family) know which songs must be sung, the messages to be communicated to my ancestors and the rituals that must be performed in line with the family tradition and culture. The wife will not be able to sing this song for me, as she will not know the song. My wife would join after my family has completed the task ...

The gendered supremacy of the collective over the widow was reversed in the absence of the mineworkers' family of origin and for those who live in a modern nuclear family structure.

A widow from the Welkom, Free State noted:

He was 53 years. He died of cancer of the lungs and breathed through a tracheotomy before he died. No autopsy was requested ... he worked underground for many years. His parents passed on before him. I will consent to autopsy ... you see I was alone and his family died earlier. I made all the decision surrounding his funeral and mourned him observing the family tradition.

### *Traditional and religious beliefs*

There were respondents who accepted autopsy because they believed that the soul dissociates from the body at death, and there were those who disagreed with the dissociation of the soul from the body. According to those who disagreed, cardiorespiratory organs were an engine that were crucial for the individual's existence in afterlife, resurrection, reincarnation and for becoming a good ancestor. They also believed that being buried without cardiorespiratory organs was similar to burying 'an empty box', and this will anger the ancestors and cause the deceased's soul to be rejected by them. The respondents described their fear of wrath and misfortunes from the ancestors and the deceased which included fear of their own deaths. Some respondents detailed their fear about their inability to meet the ancestral demands to return the cardiorespiratory organs for burial.

A former mineworker from Virginia, in the Free State, who was worried about the 'empty box', explained:

I don't agree with the autopsy ... a person is these organs. They can be checked where he died ... why send them away ... my cardiorespiratory can't be sent away ... because as people we have our cultural laws and beliefs. When we have our culture and you are buried apart from these organs ..., the ancestors will not like it. Even if I can agree, the family won't agree that I am buried without these organs ... If the family consents when the person has died, he will come back to haunt them, cause them mis-

fortune ... while looking for his scattered parts. Traditionally we suffer from these decisions ...

The 'empty box' was corroborated by traditional healers.

Autopsy is not in our vocabulary as people. We believe that when a person dies, there should be no organs/parts removed. The person should be buried whole, so that when we reunite his body with his spirit ... We believe that when a person dies, he wakes up.

Some respondents argued that autopsy further inflicts pain on the deceased and disturbs their peace. This perception deterred the believers from accepting autopsy, as illustrated in the following citation.

An in-service mineworker from Mohlakeng and originally from Mozambique said:

My belief is that this (resurrection) will not be possible as this person was buried without complete parts ... I don't like this autopsy and will not agree to ... when a person is dead, is asleep and autopsy is disturbing his/her peace ... it is troubling the person and I will therefore not agree to this.

Some respondents argued that the soul and spirit were independent of the body. (The words soul and spirit were used interchangeably to denote a similar meaning.) According to respondents, once the soul and spirit departs from the body at death, the body and its parts are useless because the soul becomes 'a complete being' capable of conducting all functions. They expressed the view that the spirit is able to protect the living members of its family against misfortunes and advise them when consulted, and become a good ancestor and be reincarnated irrespective of the status of the body at death or burial. This is in contrast to the 'empty box' concerns of some respondents.

An in-service migrant mineworker from the Eastern Cape articulated:

I personally believe that 'flesh' is soil. Once spirit (umoya) leaves the flesh, the flesh has nowhere to go other than back to the soil. The soul of an ancestor does not go with flesh ... The ancestors are a soul/spirit. To me this same spirit is similar to that which is religiously preached ... It does not mean that when the flesh is incomplete, so is the spirit. The flesh is dead, there is nothing much that will be done by the flesh, it is dead and stone dead, it will never come back and what remains is to bury it.

A former mineworker from Nongoma expressed the following:

I can consent to autopsy because the body rots and is buried. My family may disagree with my acceptance of the autopsy ... I believe that the soul and spirit are complete, even if the person is maimed one way or the other. This has never changed in our tradition; it has always been known that once the

person dies and the soul leaves the body, the soul can't draw back the flesh (body) and vice versa. This is a belief rooted in traditional values more than the born-again Christian concept which may vary ... I am not a born again. For an example, you die beheaded, you can't glue the pieces together, but the spirit is complete, not beheaded.

Some respondents believed the organ retention and autopsy were similar to commodification of the body parts. According to them, their role is caring for the body during life and up to the time of burial, as the soul can take care of itself. They were concerned that giving consent to ODWMA autopsy would be considered as sacrificing that responsibility.

A former mineworker from Nongoma's view was:

This autopsy is not correct, whether it is for compensation or not. It is like selling your body parts for money. I would not be motivated by money. Money finishes. It is like I sold my family, my child, never! ... So the doctor explains why autopsy should be done, to find the cause of death or there is disease and so what about it! Religion motivates one to take care of the soul more than the body ... and rationalise that autopsy is ok ... Only modernised people agree to autopsy.

However, some respondents believed that autopsy would benefit them by elucidating the presence or absence of disease, confirm the cause of death and provide financial support for their families. Some believed that autopsy will provide closure on the mystery surrounding the cause of death and argued this mainly when the deceased were young.

An in-service mineworker from Mhlabeng, Randfontein said:

I am hearing about autopsy for the first time and I don't have any problems as it is ok to find out the cause of my death. I believe that it is right for the law to check whether I had disease ... This may benefit my family. I was told about chest pick up for compensation when I was working at another mine ... ever since I started here, I was never told anything. A deceased body has no further purpose in life and whatever can be done on my body to assist my family I can consent.

An in-service mineworker from Eastern Cape expressed:

I don't believe that being buried without lungs affects the position of an individual to be an ancestor ('indlhozi'). The flesh rots; however, the spirit of that person remains alive and comes back to give the light to the family. The person can also appear during family dreams as a complete person and that body is no longer the flesh that was buried.

### **Communication and trust**

Respondents reported that the gendered power relations, family, traditional and religious fears to consent may be

mitigated through proper communication with ancestors. Some respondents believed that communication will address the 'empty box' concern, deceased's anger and rejection by ancestors of an incomplete body and the suffering inflicted by the procedure. For the communication to be acceptable, the required rituals should be performed following autopsy acceptance by the mineworker and communication of this intention to the family while being healthy. According to respondents, communication to the ancestors is not acceptable if only carried out when the mineworker is ill.

An in-service mineworker from Eastern Cape said:

In my family culture, this autopsy may not be acceptable because they (ancestors) know that the person was complete when he died, and now he is buried being incomplete and tormented by this autopsy ... The ancestors will not recognise him ... This scenario changes if he has expressed his intention for autopsy in life because the family and he would have communicated this intention to ancestors in a proper way known to the ancestors. The ancestors will not disagree with him because they were consulted earlier about it ... However, if they consent without my prior knowledge and acceptance ... I will come and harass them (whoever gave consent).

A grandmother (from Nongoma) of deceased mineworker reiterated:

I don't like this autopsy (as you explain it). If I know, I can consent, and I will also remind the ancestors and him through the sacrificial killing. He will not cast a bad spell compared to him being buried only to be informed by the ancestors who do not welcome him due to missing parts that he was not aware of. If he told me about the autopsy and I did not inform the ancestors, he will trouble me.

Some respondents noted that for communication to be effective, trust among families and in the communities is required. They reported instances when men and their families mistrusted wives. According to them, there is a traditional belief that some husbands die because their wives killed them.

A former mineworker from Nongoma articulated:

I can consent to autopsy ... With regard to discussing autopsy with my wife for possible compensation, do I have to discuss this with her? The family can know about the autopsy but not my wife ... (silence) ... it is a problem. This law can also be told to the magistrate who can then implement it. I know of a friend of mine whose son died of stomach ulcers, do stomach ulcers kill? I believe the wife poisoned him so that she can get the money. The family found that he has been poisoned by his wife. How can an ulcer kill? This law must use the office of the magistrate. Women will finish the men and consent to autopsy if they know that there is

going to be possible compensation .... In my culture, women do not have power to decide on this, only men have power for decisions. Women carry them out.

A former mineworker from Welkom said:

I believe that women are witches and that should they know that you have consented to ODMWA autopsy which has potential compensation, they can do anything sinister. You see, even when I was working ... and now that I have retired due to ill health, I have never discussed anything with women, including money issues .... I am the breadwinner and her role is to receive any money I give her.

Some respondents expressed that autopsy should be treated the same way as items listed in an individual's will to ensure that the spouse and other members of their family are able to carry out the request if other family members questioned the procedure.

An in-service mineworker from Mohlakeng, Randfontein, explained:

I will consent to autopsy. I told my family that when I die, my wife must inform the mine that my cardiorespiratory organs can be removed for examination to check for occupational diseases and other organs if healthy be donated to help those who need them .... If my relative wrote in a will that he consents to autopsy I will carry it out because it is his wish and I would not want to disagree with his spirit and soul. His beliefs are not the same as mine. I would not want to disagree with his soul as an ancestor.

Some respondents said that there was a traditional belief that discussing death-related matters is challenging, and it may actually invite death to occur in their families. They noted that the fear to invite death limited individuals from discussing their post-death wishes. Respondents discussed their experiences with families that missed out on potential death benefits because of limited communication.

An in-service mineworker from Randfontein reiterated:

This autopsy is unusual. There are many people who will miss this compensation. It is in our culture that discussing matters relating to death is not a good thing as one could be calling for it (meaning inviting death) .... I don't believe that discussing it is challenging it. There are many people that I know who lost so much because their wives knew nothing and they had no information to argue their cases ... they did not talk to their families .... There are many people I know who have lost everything they owned, which the family did not know or if they know, do not have the means of accessing these 'materials' or doing follow-up because the person told them nothing. This is what we pick up when we are in the villages during a funeral.

## Discussion

South African mineworkers have a high burden of occupational lung diseases (2–4), but many do not receive occupational compensation in life. Consequently the ODMWA autopsy provision is important, yet under-utilisation of autopsy is substantial. The aim of this study was to explore the enablers and barriers affecting ODMWA autopsy utilisation by black mineworkers and their families to understand them so that effective interventions can be designed.

The study found that the enablers and barriers affecting ODMWA autopsy utilisation are diverse, complex and multifaceted and these were entrenched in cultural, religious or societal domains. The respondents rationalised their acceptance or rejection of autopsy within their own individual cultural or religious belief system, and these varied according to the individual's experiences, family beliefs and societal practices. The prerequisites to increase utilisation autopsy are significant and varied. Foremost, ODMWA autopsy process and the potential compensation benefits need to be empathetically communicated to all mineworkers, their families and communities while the mineworkers are still healthy to alleviate cultural barriers to consent. Trust concerning the ODMWA process must be established among the mineworkers, their families and society, and the purpose and the potential benefits must be understood by all parties. This finding suggests that central to building public and family trust, communication, awareness and knowledge should occur when mineworkers are healthy so that consent can be obtained easily at death. This perception presents an opportunity for policy makers and the mines to develop and implement intervention awareness and communication strategy, as this strategy would enable mineworkers and their families to perform rituals and would reduce the potential for a wife to be accused by the family and community of the murderer of her husband.

The requirement for consent is one reason for the decline in non-forensic autopsies (9). Although obtaining informed autopsy consent is to elicit the family's (and deceased patient's) religious, cultural and ethical sensitivities and determine what information is significant to decision making (19–22), the study found that family consent was deemed important to appease ancestors so that misfortunes are associated with causes other than the wrath of their ancestors. This finding is similar to other low-income settings that found that the initial decision making for informed consent was vested in the community rather than in the individual (20, 23).

This study established that retention of cardiorespiratory organs for re-examination in case of an appeal by families poses a major challenge. Burial without cardiorespiratory organs ('empty box') was not culturally acceptable to many respondents. Returning the organs to the body after examination was deemed culturally acceptable.

Although this would address those that believed in the 'empty box', this intervention requires mobilisation of resources to ensure that examinations pose no delays to burial arrangement, as this may damage the trust by the family and community. Similar cultural beliefs were found in another study: burial with body parts missing or receiving an organ transplant ('foreign') was believed to prohibit an individual's transition to the realm of the ancestors by some black South Africans (23).

This study also found that the autopsy organ retention process in order to obtain the potential benefits was akin to commodification of body parts.

The various African religious and cultural beliefs found to be barriers to clinical autopsy; organ donation and this study are not unique. In Islam, autopsy and dissection of body parts for research are generally prohibited because of pre-destination belief and are akin to violation of human body sanctity (18, 22, 24). Unlike in Catholic and most Protestant religions, where autopsies are generally accepted, Hindu religion forbids it because of the belief in reincarnation (20). One study found that Judaic and Muslim families of the deceased gave consent to autopsy if it would benefit the family and communities' lives or find the cause of death (24). In Muslim communities, post-mortem needle biopsy was accepted at a family and community level if it provided community benefits without violating family and cultural beliefs (24).

This study found that building awareness and increasing knowledge of families and communities while the mineworker was healthy to allow for ancestral ritual communication on the process rendered organ removal for examination acceptable to some, while others accepted only on-site examination and return of the organs for burial.

The findings from this study highlight that cultural factors present both barriers and opportunities for ODMWA autopsy. Unequal power relations control autopsy decisions and lead to exclusion of potential beneficiaries (widows and children). The fact that the cultural beliefs are not static or uniform suggests that increasing autopsy consent requires comprehensive communication and awareness intervention strategies aimed at an individual, family and community levels. The intervention strategies should not be once-off, but long term, and should address the cultural beliefs.

### **Study limitations**

Although respondents represented heterogeneous groups in three provinces affected by autopsy and saturation was reached in each group, the confined study settings may have limited the comprehensiveness of the issues identified and the generalisation of the findings to other groups. The respondents were selected by someone they knew and trusted. They may have said what they thought

their contact and researcher would want to hear. While this bias could be real, the traditional healers and health practitioners corroborated the responses from the respondents, and this suggests that the responses were genuine.

### **Policy implications**

First, the findings that cultural beliefs influence ODMWA autopsy consent – and within the culture itself there are various interpretations – provide an opportunity to ensure that mineworkers, their families and the communities they come from or live in understand the purpose of autopsy in a manner that addresses these beliefs. The high burden of undiagnosed occupational lung diseases in life warrants this intervention and should be considered as a method to secure informed consent.

Second, decentralisation of autopsy examination so that organs can be examined and replaced before burial, thus removing the 'empty box' barrier, warrants consideration. However, replacing the organs for burial would remove the opportunity for re-examination during an appeal by families, and this issue needs consideration if decentralisation of autopsy is to be advocated. Additionally, the ODMWA autopsies' data are comprehensive and have been the resource for both mineworkers' occupational lung disease surveillance and research over many decades (25–28). Steps to preserve the ODMWA autopsy database would have to be put in place if decentralisation was to happen. Also, centralisation allows for a uniform and standardised pathological assessment of disease and the extent of disease. Steps to preserve these advantages would have to be implemented in a decentralised system.

### **Conclusion**

The study found not only barriers to autopsy but also cultural beliefs that may enable these barriers to be overcome. These findings may be generalisable to similar socio-cultural environments outside South Africa. Chief among the barriers was the requirement to obtain formal consent for autopsy within a biomedical framework, which clashed with certain socio-cultural beliefs. However, respondents reported that consent could be facilitated, for example, by mineworkers making their agreement to autopsy clear while being alive and by communicating this intention to ancestors – thus providing consent consistent with their belief system. ODMWA autopsy awareness and education should be geared towards families and communities of mineworkers. The enablers of autopsy could be used in campaigns to improve autopsy utilisation. More education for the mineworkers, their families and mining communities is required, while the mineworker is still alive to increase awareness and discussion of ODMWA autopsy's purpose and benefits.

Amending the ODMWA should be considered so that the current requirement of formal consent after

death by the family is moderated, but ethical and legal aspects need to be taken into account. The current centralised autopsy procedure defined by ODMWA is a barrier to autopsy. The advantages and disadvantages of decentralising ODMWA autopsy to obviate a permanent removal of cardiorespiratory organs need investigation.

Further research is required to investigate the attitude of health care providers (nurses, traditional healers and medical practitioners) towards autopsy; to investigate the process of decentralising the autopsy examination and the impact it will have on appeals, standardisation and resources; and to examine the legal framework which would make ODMWA autopsy permissible without the current consent requirement, possibly under conditions similar to forensic medicine.

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**\*Audrey V. Banyini**

Chamber of Mines  
PO Box 61809  
Marshalltown, 2107  
Johannesburg, South Africa  
Tel: (+2711): 498 7100  
Email: [abanyini@chamberofmines.org.za](mailto:abanyini@chamberofmines.org.za)

# Moving towards universal coverage in South Africa? Lessons from a voluntary government insurance scheme

Veloshnee Govender<sup>1\*</sup>, Matthew F. Chersich<sup>2,3</sup>,  
Bronwyn Harris<sup>2</sup>, Olufunke Alaba<sup>1</sup>, John E. Ataguba<sup>1</sup>,  
Nonhlanhla Nxumalo<sup>2</sup> and Jane Goudge<sup>2</sup>

<sup>1</sup>Health Economics Unit, School of Public Health and Family Medicine, Faculty of Health Sciences, University of Cape Town, South Africa; <sup>2</sup>Centre for Health Policy, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Department of Obstetrics and Gynaecology, International Centre for Reproductive Health, Ghent University, Ghent, Belgium

**Background:** In 2005, the South African government introduced a voluntary, subsidised health insurance scheme for civil servants. In light of the global emphasis on universal coverage, empirical evidence is needed to understand the relationship between new health financing strategies and health care access thereby improving global understanding of these issues.

**Objectives:** This study analysed coverage of the South African government health insurance scheme, the population groups with low uptake, and the individual-level factors, as well as characteristics of the scheme, that influenced enrolment.

**Methods:** Multi-stage random sampling was used to select 1,329 civil servants from the health and education sectors in four of South Africa's nine provinces. They were interviewed to determine factors associated with enrolment in the scheme. The analysis included both descriptive statistics and multivariate logistic regression.

**Results:** Notwithstanding the availability of a non-contributory option within the insurance scheme and access to privately-provided primary care, a considerable portion of socio-economically vulnerable groups remained uninsured (57.7% of the lowest salary category). Non-insurance was highest among men, black African or coloured ethnic groups, less educated and lower-income employees, and those living in informal-housing. The relatively poor uptake of the contributory and non-contributory insurance options was mostly attributed to insufficient information, perceived administrative challenges of taking up membership, and payment costs.

**Conclusion:** Barriers to enrolment include insufficient information, unaffordability of payments and perceived administrative complexity. Achieving universal coverage requires good physical access to service providers and appropriate benefit options within pre-payment health financing mechanisms.

Keywords: *health insurance; civil servants; health-finance reforms; universal coverage; South Africa*

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In 2005, member states of the World Health Organization (WHO) committed themselves to developing health financing systems that would enable universal coverage (UC) by ensuring access to adequate health care at an affordable cost for all citizens (1). Although there is no one clear path to UC, the World Health Report 2010 describes several strategies for expanding access to care. These include the removal of direct payments, particularly user fees, and the

introduction of pre-payment schemes with tax-based funding or compulsory or voluntary health insurance contributions (2).

Given the limits of, and competing demands on, tax-based funding (3), the focus in many low- and middle-income countries, has been on contributory health insurance schemes (where employees contribute toward the premium). Nonetheless, there is the recognition that for some groups, these contributions will need to be

partially- or fully-subsidised by government (2). Some countries such as Iran are expanding coverage through voluntary, contributory insurance schemes (4), while Ghana is opting for mandatory insurance (5). Countries with existing insurance schemes, have attempted to expand coverage through the provision of lower cost alternatives with similar benefit packages, but possibly with limited choice of providers. The Seguro Popular Programme in Mexico and the UC scheme in Thailand, are examples where the contributions of low-income individuals and families are subsidised by government (6, 7).

In South Africa the tax-funded public health system, with free primary health care and minimal charges for inpatient care, provides some form of UC. However, despite substantial transformation of the public health system post-apartheid (8, 9), perceptions and experiences of poor quality of public health care persist (10). These arise from a range of factors, including the quadruple disease burden (11), poor stewardship, and inefficient use of resources (8). This has led to increased utilisation of private providers for primary health care. However, only the wealthiest 16% of the population can afford private health insurance to cover the costs of private-sector services (12). For the uninsured, direct payments are often catastrophic in nature (above 10% of household expenditure) (13), contributing to household poverty (14, 15). Therefore, despite a tax-funded public health care system available to all, marked inequalities in health care access persist (8, 16).

It is against this backdrop that the goal of UC has taken centre stage in several health-financing reform policy proposals and initiatives since democracy in 1994. Box 1 shows a timeline of policy initiatives and proposals (17–26).

As indicated in these timelines, the earlier debates considered the option of a NHI scheme which, by definition ‘covers the entire population irrespective of whether they have personally contributed to the scheme or not’ (12, p. 73). Around 2005 strategies for insurance coverage of low-income households were considered in the country (24). In 2005, the government (as an employer) implemented a health insurance scheme (27), restricted to government employees, that aimed to achieve greater pooling of funds across this segment of the employed population. Post 2009 the debate has shifted to the implementation of a NHI system, that aims to strengthen the public health care system and ensure adequate provision of funding (26).

South Africa’s government employees’ scheme intends to pool resources from a broad range of civil servants and aims to attract members from all income groups. The intention of a designated network of private general practitioners and private hospitals is to expand access to benefits for low-income government employees.

*Box 1.* Timeline of health-financing policy initiatives and proposals since 1994

**1994:** African National Congress (ANC) National Health Plan recommended that a Commission of Inquiry be appointed to investigate the feasibility of a National Health Insurance (NHI) Fund (17).

**1994:** National Department of Health’s Health Care Finance Committee put forward three possible mandatory insurance options, including NHI (18).

**1995:** Hospital Strategy Project, initiated by the National Ministry, tasked with setting out a framework for the development and restructuring of the public hospital sector (19).

**1995:** Committee of Inquiry into a NHI System (20).

**1997:** National Department of Health releases policy document on Social Health Insurance Scheme for formal sector employees (21).

**1997:** White Paper on the transformation of the health system in South Africa built upon the ANC’s 1994 Health Plan (22).

**2002:** The Committee of Inquiry into a Comprehensive System of Social Security for South Africa recommends that South Africa move toward a NHI system (23).

**2004:** Ministerial Task Team on SHI recommended implementation of SHI for the formally employed, since it did not consider NHI feasible in the short term.

**2005:** Ministerial Task Team commissioned an investigation into low-income medical schemes (24).

**2005:** Introduction of the Government Employee Medical Scheme (referred to as the government scheme in the article), restricted to public-sector employees.

**2007:** A policy resolution committed the ANC to introduce NHI (25).

**2011:** NHI Green Paper released by government detailing a 14-year plan towards NHI (26).

The scheme is heavily subsidised, particularly for low-income members, to encourage enrolment and so extend coverage.<sup>1</sup> Employees appointed from 1 July 2006 onwards were only eligible for the government subsidy if they joined the government scheme and not another health insurance scheme.<sup>2</sup>

<sup>1</sup>The lowest cost benefit option is fully subsidised for those in the two lowest salary categories; for the other four benefit options, the government pays 75% of the employee’s total monthly contribution, subject to an upper-limit.

<sup>2</sup>Employees appointed prior to 2006 still received a subsidy for membership of any insurance scheme.

This study analysed coverage of the government health insurance scheme, the population groups with low uptake, and the individual-level factors, as well as characteristics of the scheme that influenced enrolment.

The study findings are used to highlight lessons for other contributory schemes which aim to encompass both high- and low-income population groups.

## Methods

### *Sampling and data collection*

In 2008–09, 1,329 currently employed civil servants were interviewed across four of South Africa's nine provinces.<sup>3</sup> Health and education, two of the largest public sectors, were selected for the survey. Provinces were chosen on the basis of being urban, having a greater distribution of private providers as well as relatively well-resourced public health care facilities (Gauteng and Western Cape), and being predominantly rural with few private facilities and less-resourced public facilities (KwaZulu-Natal and North West) in order to assess variation in enrolment related to geographical access. The minimum sample size per province was 245 and this was increased to 309 to allow for possible incomplete questionnaires.

Multi-stage random sampling was used. First, the number of health and education employees to be sampled in each salary category was determined by their relative proportion in each province. Second, districts in each province were selected with a probability proportionate to number of employees, following which 15 schools and four hospitals within each of the selected districts were randomly selected. Finally, within the selected schools and hospitals, a sampling frame was constructed of all employees, stratified by salary category, to allow specific quotas of interviews to be conducted across the different salary categories. These employees were then invited for an interview until the required number in each salary category was reached. Study procedures received ethics clearance from the Universities of Cape Town and the Witwatersrand, as well as relevant Provincial Departments of Health. All respondents provided informed signed consent.

### *Study variables and data management*

Information was collected on health insurance uptake, including membership of the government and other schemes, factors influencing membership of the government scheme, choice of benefit option and the reasons for such choice. Those who transferred to the government scheme from another medical scheme were classified as 'previously-insured', while 'newly-insured' referred to

those who were uninsured prior to joining the government scheme. The survey questionnaire included questions to assess possible consumer inertia, arising from the transaction costs of either switching from one scheme to another (28) or from joining a scheme having not been previously insured. The questionnaire also included reasons underlying inertia, specifically the lack of a perceived need for insurance and administrative complexity of the scheme.

Adverse selection, arising from the tendency for people with perceived low risk (younger, healthier, low-income) to avoid insurance coverage is another challenge for voluntary schemes (29). In recognition of this, age, health status and income (indicated by salary) were assessed as key potential determinants of the decision to take insurance. The choice of socio-demographic (age, sex, race, location, education, marital status and housing), economic (income) and health status variables was guided by previous research examining determinants of health insurance ownership in voluntary schemes in South Africa (30) and internationally (31–34).<sup>4</sup> Civil servants were classified by skill level into five categories (lower skilled, skilled, highly-skilled, supervisory and senior management); these categories determine salary levels within the civil service.

Data were double-entered by an independent survey company, cross-checked by the research team and then analysed using Stata<sup>®</sup> 10 (Stata Corporation, College Station, TX, United States). In addition to descriptive statistics of the uninsured and insured populations, the respondent's decision to enrol in the government scheme was modelled using multivariate logistic regression. The dichotomous dependent variable was enrolment in the government scheme (combining the 'previously-insured' and 'newly-insured') and the explanatory variables were categorical and included socio-demographics, salary level and health status. Variables associated with government scheme membership in univariate analysis ( $p < 0.1$ ) were included in the initial multivariate model in addition to important potential confounders such as gender, and retained if their removal markedly altered the model fit. Education level was excluded as one of the independent variables since it correlated closely with salary level.

## Results

### *Description of study population*

Two-thirds of respondents worked in the education sector, and one third in health. More than half (58.6%) were female. A third of respondents were 30–39 years and

<sup>3</sup>Retired civil servants were not included in the study sample. This population was initially excluded from participation in the government scheme, but later included.

<sup>4</sup>As brokers could not make any financial gains from enrolling civil servants in the government scheme, we considered them unlikely to have any role or influence on the decision to enrol. Hence they were not considered in this study.

a similar proportion was 40–49 years (35.2%). Approximately two-thirds had tertiary-level education, while 12.5% had only primary or no education. Median total monthly household expenditure was US\$533.3.<sup>5</sup> Half the respondents were classified as highly skilled employees (53.3%); almost a third (31.1%) as being low skilled; and only 3.1% were senior managers. Only 2.6% reported their health as being poor or very poor, but almost a third was taking chronic medication.

### *Insurance status of public-sector employees*

Three-quarters of respondents (74.3%) were insured (with either the government or another insurance scheme Table 1) and 25.7% are uninsured. Less than half (41.9%) of the insured are members of the government scheme; more than half of the insured (58.1%) belonged to another scheme. Of the members of the government scheme, 29.5% had insurance prior to joining the government scheme, while 12.4% were newly-insured. Of the 9.2% of the respondents who joined the civil service after 2006, only 18.9% had enrolled in the government scheme. A further 16.4% were members of another scheme, considerably fewer than amongst civil servants employed before 2006 where almost half were enrolled in another scheme (46.0%); the remainder (64.7%) were uninsured.

The insured (those belonging to the government or other schemes) were more likely to be above 40 years, women, educated at tertiary level, living in formal housing, Indian/Asian or white, in the higher salary categories (highly skilled to senior management) and living in a household with an individual on chronic medication. Self-assessed health status was not a predictor of health insurance. In univariate analysis, all socio-economic and demographic variables, besides gender, were associated with uptake of the government scheme (either newly or previously insured).

Taking up insurance for the first time (newly insured) was highest amongst those aged 20–29, females, single people, black Africans, and those living in informal housing or with a lower-income (salary categories lower skilled and skilled) (Table 1). In contrast, factors associated with switching from a previous scheme to the government scheme were having a skilled job, age 50–59 years, being divorced, separated or widowed, secondary education level, living in formal housing and in an urban province (i.e. Gauteng or the Western Cape).

Multivariate analysis allowed for the simultaneous examination of the effect of several demographic, socio-economic and health status factors on the uptake of the government insurance scheme by both the previously and newly insured (Table 2). Multivariate analysis showed that employees who were female, no longer married or cohabiting (i.e. divorced, separated, widowed), or in the

lowest salary category were more likely to have enrolled in the government scheme (Table 2). Enrolment in the government scheme was 72% lower among those >60 years and 43% lower in those 40–49 years, compared with those aged 20–29 years. Similarly, those living in the relatively rural provinces (KwaZulu-Natal and North West) were less likely to be insured under the government scheme than the urban provinces.

### *Choice of benefit option under the government scheme*

The government scheme has five benefit packages ranging from low-cost options, which are fully subsidised for those in the lower income categories, to high-cost packages that are increasingly comprehensive in the range of services covered. The two lower-cost options (options 1 and 2) offer members outpatient benefits through a limited network of private healthcare providers (general practitioners, dentists or optometrists). These two options differ with respect to hospital benefits; in option 1, members have access to a network of state hospitals and option 2 to a limited private hospital network.<sup>6</sup> Options 3, 4 and 5 allow access to any private hospital.

Option 4 was the most popular benefit option, with the proportion selecting this option rising as salary increased (Table 3). However, a substantive proportion (28.3%) of those in the highest salary category selected comprehensive option 5. Of the two low-cost options, the fully subsidised option 1 was more popular amongst the lowest salary employees (19.4%).

### *Factors affecting uptake of the government scheme*

For the insured, the most important reasons for joining the government scheme across all salary categories were the affordability of member contributions (67.4%), perceptions that it had better benefits and covered more dependents (37.9%) (Table 4).

Amongst the uninsured, 40.2% of those in the lower-salary categories (lower skilled and skilled) cited lack of affordability as a reason for not joining and almost a third of all the uninsured across the three lower-salary categories noted that they would join if the scheme was made more affordable. Among respondents, 28.9% of those in the lower skilled and 21.7 in the skilled categories stated perceived administrative complexities had deterred them from joining the scheme, while 23.7% of lower skilled and skilled) stated lack of information about the scheme as important obstacles to enrolment. Among the uninsured, 26.7% of those in the higher-salary grades, did not join because they believed they did not need health insurance. However, more than a third of them said they would join if they had a health need.

<sup>5</sup>1US\$ = 7.5 South African Rand.

<sup>6</sup>Networks refer to designated health-care providers contracted through the government scheme to provide services to members.

**Table 1.** Associations between health insurance, demographic characteristics and income level among public-sector employees in South Africa

Variable (n)	Insured% (n)	Insurance scheme (%)			p
		Government scheme			
		Newly insured	Previously insured	Other schemes	
<b>Age (years)</b>					
20–29 (141)	53.9 (76)	39.5	19.7	40.8	<0.001
30–39 (402)	74.4 (299)	18.7	26.4	54.9	
40–49 (468)	78.6 (368)	6.3	31.3	62.5	
50–59 (268)	76.5 (205)	5.9	35.1	59.0	
≥60 (46)	80.5 (37)	2.7	27.0	70.3	
<b>Sex</b>					
Female (778)	78.8 (613)	13.4	28.2	58.4	0.317
Male (548)	67.7 (371)	10.8	31.8	57.4	
<b>Marital status</b>					
Married/cohabiting (806)	77.8 (627)	7.3	30.6	62.1	<0.001
Div./sep./widow (149)	77.2 (115)	8.7	38.3	53.0	
Single (375)	65.6 (246)	26.8	22.8	50.4	
<b>Education level</b>					
None/prim. comp (168)	48.8 (82)	18.3	30.5	51.2	<0.001
Incomp. secondary (102)	66.7 (68)	14.7	33.8	51.5	
Comp. secondary (184)	63.0 (116)	23.3	39.7	37.0	
Diploma (360)	79.2 (285)	14.7	27.7	57.6	
Degree (516)	84.7 (437)	6.4	27.2	66.4	
<b>Housing</b>					
Formal (1272)	75.9 (966)	11.8	29.8	58.4	0.003
Informal (50)	40.0 (20)	40.0	20.0	40.0	
<b>Race</b>					
Black African (858)	71.1 (610)	16.1	27.9	56.0	<0.001
Coloured (253)	70.7 (179)	10.0	33.0	57.0	
Indian/Asian (77)	87.0 (67)	6.0	34.3	59.7	
White (132)	93.9 (124)	0.8	31.5	67.7	
<b>Salary category</b>					
Lower skilled (168)	42.3 (71)	31.0	22.5	46.5	<0.001
Skilled (246)	60.6 (149)	27.5	37.6	34.9	
Highly-skilled (709)	81.2 (576)	9.6	28.3	62.1	
Supervisory and Senior Management (206)	92.7 (191)	2.1	29.8	68.1	
<b>Province</b>					
Gauteng (344)	70.4 (242)	17.7	32.3	50.0	<0.001
KwaZulu-Natal (310)	72.6 (225)	17.3	24.9	57.8	
North West (329)	82.4 (271)	5.9	29.2	64.9	
Western Cape (343)	72.6 (249)	9.6	31.8	58.6	
<b>Self-assessed health status</b>					
Excellent (320)	71.3 (228)	17.6	29.8	52.6	0.021
Good (633)	75.8 (480)	10.2	31.0	58.8	
Average (342)	74.5 (255)	11.0	25.5	63.5	
Poor (34)	73.5 (25)	20.0	40.0	40.0	
<b>Individual on chronic medication</b>					
Yes (385)	86.7 (334)	8.1	32.3	59.6	0.013
No (923)	69.5 (641)	14.4	27.9	57.7	
<b>Total</b>	<b>74.3 (988)</b>	<b>12.4</b>	<b>29.5</b>	<b>58.1</b>	

**Table 2.** Multivariate logistic regression analysis of factors associated with uptake of the government insurance scheme (newly insured and previously insured by other schemes)

	Adjusted odds ratio	(95% CI)
<b>Age</b>		
20–29	1.0	
30–39	0.83	0.47–1.48
40–49	0.57*	0.32–1.03
50–59	0.62	0.33–1.17
≥60	0.28*	0.11–0.74
<b>Sex</b>		
Female	1.0	
Male	0.69*	0.51–0.93
<b>Marital status</b>		
Married/cohabiting	1.0	
Divorced/separated/widowed	1.60*	1.03–2.48
Single	1.35	0.97–1.90
<b>Housing</b>		
Formal	1.0	
Informal	1.73	0.63–4.72
<b>Salary category</b>		
Lower skilled	1.0	
Skilled	1.51	0.82–2.75
Highly-skilled	0.48**	0.28–0.81
Supervisory and Senior Management	0.39**	0.22–0.71
<b>Province</b>		
Gauteng	1.0	
KwaZulu-Natal	0.69*	0.46–1.01
North West	0.58**	0.40–0.85
Western Cape	0.76	0.52–1.11
<b>Individual on chronic medication</b>		
Yes	1.0	
No	0.94	0.69–1.27

CI, confidence interval.

\**p* < 0.1; \*\**p* < 0.05.

In order to assess affordability, we examined employees’ contribution as a percentage of the lowest monthly income for each income category. As noted earlier, the government scheme contributions are income-based, with the monthly contributions varying according to the employee’s salary, choice of benefit option and number of dependents. Despite the subsidy for low-income employees, on average those in the lower-salary categories still paid a higher percentage of their salaries for health insurance than those with greater income (with the exception of the fully subsidised option) (Table 5). For example, in the low-cost option 2, the health insurance payment constitutes 7.6% of income for someone in the lowest salary category 1 who earns \$475 per month, while this option is only 1.7% of monthly income for someone in category 5 who earns \$6,000 per month.

### Discussion

In 2003, prior to the government scheme, insurance coverage among South African civil servants was 56% (35). Our analysis shows that two years after the government scheme was initiated in 2006, 74.3% of civil servants were insured, and 41.9% of these belonged to the government scheme. Although evidence suggests that membership has increased, with 53.8% of civil servants enrolled in the government scheme in 2012 (27), other studies on enrolment in health insurance schemes in Ecuador, Ghana, Mali, Senegal and Uganda, have found similar low levels of enrolment (36–40).

The newly-insured group included those from population groups who commonly experience financial and other access barriers, such as younger employees, women, unmarried single people, black Africans, and those living in informal housing or with lower-incomes. Therefore, in contrast to private health insurance in the general population, where 71% of members are located in the richest 20% of the population (41), the government scheme is comparatively pro-poor. Nevertheless, a considerable portion of socio-economically vulnerable groups remained uninsured (more than half of the lowest salary category for example), including men, black African or

**Table 3.** Choice of government scheme’s benefit options

Benefit option chosen	Salary category (%)				
	Lower skilled	Skilled	Highly-skilled	Supervisory and Senior Management	Total
Option 1: Low cost	19.4	9.4	0.5	1.7	4.4
Option 2: Low cost	13.9	7.3	0.5	0.0	3.2
Option 3: Mid-range savings	11.1	5.2	11.1	5.0	8.8
Option 4: Comprehensive	55.6	75.0	80.6	65.0	74.8
Option 5: Comprehensive	0.0	3.1	7.4	28.3	8.8
Total	100 (36)	100 (96)	100 (216)	100 (60)	100 (408)

**Table 4.** Factors influencing the decision to join the subsidised government scheme

Factors	Salary category (%)				Overall (%)
	Lower skilled	Skilled	Highly-skilled	Supervisory and Senior Management	
Affordability					
Insured joined because scheme affordable	57.9	65.0	70.2	67.2	67.4
Uninsured did not join because scheme expensive	40.2	40.2	27.1	33.3	34.8
Uninsured would join if scheme more affordable	34.0	32.0	34.6	13.3	32.8
Benefit options and coverage					
Insured joined as scheme offered better benefits and covered more dependents	36.8	41.2	33.5	49.2	37.9
Uninsured would join if more dependents were covered	2.1	2.1	0.0	0.0	1.2
Administrative complexity of scheme					
Insured joined as administrative procedures easy	2.6	10.3	6.0	11.5	7.5
Uninsured did not join as administrative procedures complex	28.9	21.7	17.3	20.0	21.9
Information about scheme					
Uninsured did not join scheme as lacked information	23.7	23.7	15.8	6.7	19.9
Uninsured would join if more information provided	2.1	2.1	0.0	0.0	1.2
Need for health insurance					
Uninsured did not join as insurance not needed	10.3	15.5	17.3	26.7	15.2
Uninsured would join if there was a health need	41.2	44.3	31.6	33.3	38.0

Multiple-response questions.

coloured race groups,<sup>7</sup> less educated and lower-income employees, and those living in informal housing. This is despite membership for the lowest salary tier being fully subsidised.

Factors discouraging or deterring enrolment included affordability, the perceived administrative complexity of joining the scheme, and difficulties in obtaining information about the benefit options. Moreover, the comparatively poorer uptake of the government scheme in the more rural North West and KwaZulu-Natal provinces, may reflect underlying variations in geographical access to services (Table 2). Proximity of a primary care provider contracted with the scheme is likely an important factor influencing a potential member's decision to join the scheme. Transport costs have been shown to be an important barrier to accessing care in the South African setting (42), and the distance to a scheme-contracted provider may increase problems of affordability. This was likely an important issue in some provinces at the time of the survey. As argued in a recent review of UC in Thailand, 'Financing reform must go hand in hand with ensuring physical access to services.' (7, p. 17). In 2009, to improve access to primary health care services, the government scheme in South Africa expanded the

network of primary healthcare service providers and geo-mapped members' homes and workplaces against the provider in order to improve availability (43). In 2010, the scheme reported reaching a target of having at least 90% of members within 10 km from the nearest network provider (43). At a provincial level, this target was achieved in four of the country's nine provinces (Free State, Gauteng, KwaZulu-Natal and the Western Cape); in the rural North West province 84.8% of members were within 10 km of a registered provider. It will be important to document whether these changes have diminished the differentials between membership across provinces.

Affordability (or lack thereof) of member contributions was an important factor encouraging (or discouraging) enrolment in the government scheme. As Carrin et al. observe (44, p. 803), 'Affordability of premiums or contributions is often mentioned as one of the main determinants of membership.' The South African Ministerial Task Team commissioned investigation of low-income medical schemes found that '... the fundamental obstacle to expanding coverage to low-income households in South Africa remains affordability' (24, p. 124). Several other studies have pointed to premiums being unaffordable as a factor discouraging demand for insurance in West Africa (45), Kenya (46) and India (47). Of note, a similar scheme to that studied here was implemented in Botswana in 1990, with all government employees entitled to a 50% subsidy from the government for

<sup>7</sup>In this paper, racial categories structured through apartheid are used in recognition that race remains an important social and economic fault line in the post-apartheid context.

**Table 5.** Employee contributions (percent of monthly salary) towards monthly insurance contributions

Benefit option	Salary category (%)				
	Lower skilled	Skilled	Highly-skilled	Supervisory	Senior Management
Low-cost option 1	0.0	0.0	3.5	1.6	0.5
Low-cost option 2	7.6	6.5	4.1	2.7	0.9
Mid-range savings option 1	13.0	10.2	7.0	5.2	1.7
Comprehensive option 2	13.5	10.5	8.0	5.8	1.9
Comprehensive option 3	34.5	27.0	16.9	10.7	3.4

1US\$ = 7.5 South African Rand.

Financial contributions calculations assume a family of three (member, and an adult and child dependant). Percent monthly contribution is calculated as a proportion on the lowest level in each salary category. Income from other household members is unknown, and hence not included in the calculation.

health insurance. Nearly 70,000 members had enrolled by 2010 (48).

Preferences and expectations of the range of services and approved providers within benefit options can encourage (or deter) enrolment. Earlier research among households in South Africa indicated dissatisfaction and poor perceptions of public health services (10, 24), creating a preference for private health care, including primary and inpatient care. This might explain the relatively poor uptake of low-cost option 1, despite a full subsidy for those in the lower-salary categories. The ‘free’ low-cost option only provides members with access to basic outpatient services at pre-specified facilities and public hospitals, which may conflict with their strong preference for private primary and inpatient care. This might also explain the popularity across all salary categories of comprehensive option 4, which provides access to any private hospital.

The study identified perceptions and understandings of insurance, particularly among low-income employees, as a barrier to enrolment in the government scheme. These point to peoples’ underlying understandings of the potential role that insurance might play in either reducing or averting health care costs. This suggests a need for effective communication strategies to enhance knowledge about concepts of insurance to encourage enrolment in a health insurance scheme. The findings also suggest that older people (i.e. 60 years and older), whites, those in higher salary categories and tertiary education who probably have been with their current scheme for a long time may have ‘brand loyalty’ and consumer inertia, even if the new scheme offers better value for money due to the subsidy. Further research could more clearly define reasons and preferences for this.

Previous research exploring low enrolment in a community health insurance (CHI) scheme in Uganda identified ‘a mixed understanding on the basic principles of CHI and on the routine functioning of the schemes’, lack of information, affordability, poor quality of care,

enrolment complexities and issues of trust as barriers to enrolment (38, p. 172). Similarly, in Ghana, a household study of the National Health Insurance Scheme identified premiums, registration fees and administrative arrangements as key factors influencing enrolment and retention (49). In Uganda (38) and Tanzania (50), lack of familiarity with community insurance schemes, particularly insurance principles of pooling and prepayments, contributed to low levels of enrolment. However, as Basaza et al. (38, p. 182) caution, ‘... a good understanding of CHI principles, per se, will not directly translate into increased enrolment.’ Qualitative research can improve understanding of the ways in which quality of care, benefit options, contributions and information shape peoples’ knowledge and views of health insurance and their decision to enrol.

Being a cross-sectional survey of existing civil servants, the study was unable to examine the period prior to the government scheme (i.e. pre 1993 when enrolment in one of a few pre-determined schemes was mandatory for some employees, or the period 1993 to 2005, where employees were free to choose which scheme they joined). The cross-sectional design cannot examine the institutional context within which insurance for civil servants has operated, changes that occurred in the scheme and how these may impact on participation. The ability to draw conclusions is also limited by the timing of the survey, which was only about three years after introduction of the scheme. The frequent changes made to the scheme in the period preceding this study and thereafter, restrict our ability to compare the study findings with outcomes of schemes in other countries or contexts. Also, it is possible that factors influencing enrolment in the long-run vary from those described here in the relatively early stages of the scheme. Moreover, data on the influence of perceptions and experiences of public health services on the decision to join the government medical scheme was not collected.

## Conclusion

Introduction of low-cost options which are fully subsidised resulted in an increase in membership among low-income public-sector employees. However, uptake of membership particularly by young, black African or coloured groups, men, lower-income employees, those with no, or only primary education and in rural provinces was sub-optimal, suggesting that barriers remain. Importantly, these are the same population groups that have limited access to care within the existing publicly funded system. Lower-income employees were found to contribute a higher percentage of their salaries towards health insurance than higher-income employees indicating inequity in the government insurance scheme. The findings suggest that financing reforms intended to move towards UC must also take into account geographical and administrative access. Improving quality of care within public facilities is critical for improving public perceptions and encouraging the uptake of insurance especially among low-income households. Moreover, reforms need to consider the benefit options carefully, and must pay attention to the choice and geographical location of providers.

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**\*Veloshnee Govender**  
 Health Economics Unit  
 School of Public Health and Family Medicine  
 Faculty of Health Sciences  
 University of Cape Town  
 South Africa  
 Tel: +27 21 4066752  
 Fax: +27 21 4488152  
 E-mail: veloshnee.govender@uct.ac.za

# Building consensus on key priorities for rural health care in South Africa using the Delphi technique

Marije Versteeg<sup>1</sup>, Lilo du Toit<sup>1\*</sup> and Ian Couper<sup>1,2</sup>

<sup>1</sup>Rural Health Advocacy Project, Centre for Rural Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg

**Background:** South Africa is currently undergoing major health system restructuring in an attempt to improve health outcomes and reduce inequities in access. Such inequities exist between private and public health care and within the public health system itself. Experience shows that rural health care can be disadvantaged in policy formulation despite good intentions. The objective of this study was to identify the major challenges and priority interventions for rural health care provision in South Africa thereby contributing to pro-rural health policy dialogue.

**Methods:** The Delphi technique was used to develop consensus on a list of statements that was generated through interviews and literature review. A panel of rural health practitioners and other stakeholders was asked to indicate their level of agreement with these statements and to rank the top challenges in and interventions required for rural health care.

**Results:** Response rates ranged from 83% in the first round ( $n = 44$ ) to 64% in the final round ( $n = 34$ ). The top five priorities were aligned to three of the WHO health system building blocks: human resources for health (HRH), governance, and finance. Specifically, the panel identified a need to focus on recruitment and support of rural health professionals, the employment of managers with sufficient and appropriate skills, a rural-friendly national HRH plan, and equitable funding formulae.

**Conclusion:** Specific policies and strategies are required to address the greatest rural health care challenges and to ensure improved access to quality health care in rural South Africa. In addition, a change in organisational climate and a concerted effort to make a career in rural health appealing to health care workers and adequate funding for rural health care provision are essential.

Keywords: *rural health; priorities; challenges; Delphi technique; health systems; leadership; management*

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South Africa has a sizeable rural population, comprising 43.6% of its 49 million inhabitants (1). The majority of rural people are poor and rely almost entirely on the public health system (2). The current health system is curative in focus, high but inequitable spending on health, the country is facing a quadruple disease burden (consisting of HIV & AIDS and tuberculosis (TB), chronic diseases, injuries, and maternal and child mortality), and health outcomes are poor. These are the main factors that have led the South African Government to embark on a 'total overhaul' of the system (3) to meet its constitutional mandate to provide access to quality health care for all South Africans (4).

Rural communities are amongst the most disadvantaged in terms of accessing quality health care. A child living in the Eastern Cape province (predominantly rural)

is more than twice as likely to die in its first year of life than a child from the Western Cape (containing large urban areas), while a person with TB in the Gauteng province (predominantly urban) has a 19.9% higher chance of being cured than a person with TB in the North West province (predominantly rural) (5). In 2007, South African infant mortality rates were found to be 71.2 per 1,000 live births in rural areas compared to 43.2 in urban areas (6). Other developing countries show similar inequities in urban-rural health outcomes (7). In the same year (2007), India reported 62 deaths per 1,000 live births in rural areas compared to 39 in urban areas (8). The United Nations notes that, globally, children in rural areas are at greater risk of dying, even where overall child mortality is low (9).

Recent policy developments in South Africa include the primary health care (PHC) re-engineering strategy (10),

a new national human resources for health plan (11), and the proposed introduction of a national health insurance (NHI) (12), all of which aim to achieve quality health care access for all. They have been received with much positive anticipation by rural health practitioners. However, experience has made these practitioners cautious in their optimism. This stems from past policy decisions which, unintentionally, impacted negatively on or were difficult to implement in rural settings. Specific examples in the South African context include the closing of rural hospital-based nursing colleges and the introduction of a salary structure for public sector health professionals that rewards specialisation in urban centres (13).

A special focus on rural health has not been the norm in the South African health policy landscape. Yet, globally, there is a trend among countries with large rural populations to develop targeted interventions for rural health care. For instance, the Indian government established a rural health mission which aims to improve access to quality health care for people residing in rural areas (8), while Australia adopted a rural health strategy in 1994 (14). The UK government introduced the concept of ‘rural-proofing’ of all domestic policies, including health policies, and made it a mandatory part of the policy-making process (15). This concept of ‘rural-proofing’ involves ensuring that all relevant policies are examined to determine whether they would or could have a different impact in rural areas from elsewhere, because of the unique characteristics of rural areas, and are adjusted, where necessary, to reflect rural needs and to ensure that public services are equally accessible to a rural community (16).

The rationale for arguing that special policy attention be given to rural health care is based on the disparities in access and health outcomes between rural and urban settings (2). A World Bank report on geographical imbalances in the distribution of health workers indicated that rural health facilities lack the required numbers and skills mix needed in most sub-Saharan countries (17). Although the situation is worse in other African countries, it is nevertheless true for South Africa. The WHO recommends a health worker density of 2.28 health workers per 1,000 population as a minimum to achieve health-related Millennium Development Goals (9). South Africa is below this minimum nationally and even more so in rural areas; in 2010 in the public sector there were 0.29 doctors and 1.35 nurses per 1,000 population nationally, compared to 0.24 doctors and 0.81 nurses per 1,000 in the North West province (predominantly rural) (18).

The design of health policies can (intentionally or unintentionally) leave out the interests of certain groups. The formulation of public health policy is often a complex issue, and the groups influencing it in particular contexts may not necessarily represent the interests of the margin-

alised (19). In South Africa, there has been insufficient lobbying for the needs and interests of rural populations. This is reflected not only in past policy decisions, such as those referred to earlier, but also in the critical issue of budget allocations. Although South Africa spends 8.6% of its gross domestic product (GDP) on health, more than any other African country, the majority of this is spent in the private health care sector, which is accessible only to 14% of citizens. Only 3.5% of GDP is spent in the public health sector, of which rural areas remain the most under-resourced. Health expenditure per capita is highest in the two most urban provinces Gauteng and Western Cape (108.9% and 106.0% of the average), and as low as 81.6% in the rural North West province (20). Health expenditure on PHC in 2010/2011 was R404 per person (about US\$45) in the most deprived districts, which are all rural, versus R584 (about US\$66) in the least deprived districts, which are mostly urban (21). Thus, provinces with the greatest burden of disease and the least economic resources, yet still with large populations, receive the smallest share of funds for public health care (22). Health care workers in rural areas have also commented that their interests, and those of the communities they serve, are not sufficiently heard (23).

Given this background of inequity, a health system in transition and past experiences of policy-making that was not rural-proofed, we sought to understand what rural health workers believe to be the key challenges and priority interventions required for rural health care. The intention was thus to give rural health care workers a voice to influence policy discussions.

For the purpose of this research, we defined rural health care as provision of health services to areas outside of metropolitan centres where there is not ready access to specialists, intensive and/or high technology care, and where resources, both human and material, are lacking. This service may be within hospitals, health centres, clinics, within homes in communities, or independent practices. It is best provided by a team of health care workers and is based on the principles of PHC (24).

## Objectives

The aim of the research was to obtain consensus among a group of people involved in rural health care regarding the biggest challenges and most important priorities for rural health care delivery in South Africa. The purpose of this article is to make this information available to policy makers to advocate for equitable access to health care as well as improved health outcomes for rural citizens.

## Methods

The Delphi method was used to obtain consensus from a panel of experts with a wide variety of opinions and views on the challenges and priorities for rural health care.

### Rationale

Key characteristics of the Delphi process include (a) structuring information flow with the aim of focusing on relevant content; (b) facilitating regular feedback by allowing participants to revise their opinions at any given time; and (c) guaranteeing anonymity, thus allowing participants the privacy to express opinions that may be contrary to the group's or leader's view. Participants can also suggest new issues for consideration at any stage (25). Although it originated as a predictive methodology, it is often used in exploring issues in a more normative sense (how *should* it be, apart from how it *is*) (25). The method is particularly useful within the rural context. As time and distance were not limitations for participation, participants from a variety of groups and contexts took part (26), and it enabled the research team to obtain consensus from a range of stakeholders with differing backgrounds and perspectives, from all over South Africa.

### The Delphi panel

Fifty-three panellists across seven out of nine provinces in South Africa consented to participate in the Delphi process. Participants were selected purposively on the basis of either frontline or policy level expertise in relation to rural health care delivery and included senior representatives from provincial departments of health, hospital managers, clinical managers, family physicians, medical officers, nursing professionals, rehabilitation professionals, medical specialists, such as an obstetrician and paediatrician, policy experts, and activists in the field of human rights and health. Most respondents were identified directly by the researchers. In addition, suitable health care workers in remote areas were approached on the basis of recommendations from other rural health care workers.

### Data collection

Two steps were followed to generate a list of issues to be considered by the Delphi panel. We conducted in-depth interviews with three rural health experts, who were involved in rural practice in three different provinces, namely KwaZulu-Natal, Western Cape, and Mpumalanga. This information provided the content and scope for a literature review. Combining these, a list of statements was drawn up, organised into six themes aligned to the WHO health system building blocks: service delivery; health workforce/HRH; information; medical products, vaccines and technology; financing; and leadership and governance (27).

In a process comprising three questionnaire rounds, participants were asked to:

- 1) Indicate their level of agreement with 153 statements, representing challenges or priority interventions, on a Likert-scale from 1 to 5 (strongly disagree to strongly agree);

- 2) Introduce new challenges and priorities if applicable; and
- 3) Rank the top five challenges and priorities.

In the second and third round, a weighted scoring system was applied (i.e. a statement that was ranked as the top priority received a score of 5 and the one ranked as the fifth priority was assigned a score of 1). In the final (third) round, the top 10 challenges and the top 10 priorities were listed, and participants were asked to arrange them in their preferred order of importance. Figure 1 illustrates the research process.

The protocol was approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand. Participation was voluntary and consent forms were signed prior to participation. The confidentiality of participants was maintained.

### Results

Participation in this process was good, with response rates ranging from 83% in the first round ( $n=44$ ) to 64% in the final round ( $n=34$ ) (Table 1). Participants frequently provided lengthy motivations for their choices, indicating a high level of engagement.

Table 2 presents the top five challenges that were identified through this process and puts them alongside the top five priorities.

The appointment of people to senior positions without the requisite knowledge and skills was the highest ranked challenge identified by the panel, followed by the maldistribution of health care workers. The remainder of the top challenges were the weak role of provincial health departments in dealing with urgent human resource (HR) matters such as recruitment of health professionals, budget cuts, and frozen medical posts that do not take into account the fragile positions of already under-resourced rural hospitals, and the lack of a work ethic and value systems among health care workers and management, hampering a motivating climate in health facilities.

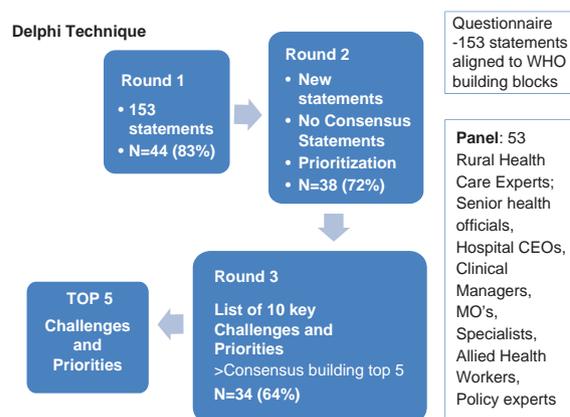


Fig. 1. Delphi process to determine key challenges and priorities for rural health care.

**Table 1.** Participation of respondents by sector

Position	Round 1		Round 2		Round 3	
	Number	%	Number	%	Number	%
Academic	6	14	5	12	5	15
Allied health	6	14	6	14	6	18
Civil society	6	14	6	14	3	9
Manager	6	14	6	14	5	15
Medical officers	19	43	19	44	14	41
Nurse	1	2	1	2	1	3
Total	44	100	43	100	34	100

The interrelatedness of some of the challenges and their impact on delivery of rural health care was reflected in the comment of one panellist:

Senior and managerial posts should be filled based on suitability of the candidate in terms of knowledge, experience and vision. Placing inappropriate

people in senior posts just to fill a gap leads to demoralisation of people having to work with/under them, a breakdown of service standards, inefficiency and poor service delivery.

The intervention that was ranked as the highest priority was to focus on recruiting and retaining health care

**Table 2.** Top five challenges alongside top five priorities

Theme	Statements and their rankings under ‘challenges’			Statements and their rankings under ‘priorities’		
	Statement	Ranking round 2	Ranking round 3	Statement	Ranking round 2	Ranking round 3
Governance & leadership	People are appointed to senior posts in hospitals, district offices, and provincial departments of health without requisite knowledge, skills, and experience.	3rd	1st	Hospital/medical managers should be employed based on the appropriate skills and experience.	1st	2nd
HR for health	Comprehensive and equitable rural health care is hampered by the mal-distribution of health workers between urban and rural sectors, private and public sectors, and at different levels (tertiary hospital to PHC clinic).	1st	2nd	There is a need to focus on how to recruit, retain, and support senior health care professionals in rural hospitals for the long term.	2nd	1st
HR for health	Provincial HR departments are often weak, causing a variety of problems such as a lack of a sense of urgency in dealing with important matters, namely recruitment of professionals, including advertising of posts.	4th	3rd	There is a need for the development and implementation of a national HR plan that is relevant to the rural health care context.	3rd	3rd
Finance	Budget cuts and frozen medical positions take place across the board and do not take into account the often fragile positions of already under-resourced rural hospitals.	2nd	4th	Equitable funding formulae need to be designed for the financing of hospitals based on the local burden of disease, staffing needs, the costing of services, and equity principles.	7th/8th	4th
Governance & leadership	There is a lack of work ethic and value systems among health care workers and management that hamper a motivating climate in health facilities.	5th/6th	5th	District managers should be employed based on the appropriate skills and experience.	4th	5th

workers in rural hospitals. Appointing people to senior posts in hospitals, district offices, and provincial departments of health with the requisite knowledge, skills, and experience was the second highest priority, linking well with the challenges identified above. The remaining priority interventions ranked in the top five were the need to develop and implement a national HRH plan that is relevant to rural health, the need to design equitable funding formulae, and the need to employ district managers based on appropriate skills and experience.

In terms of the critical skills required by health managers (priorities three and five), many respondents argued that people skills are of equal importance to health management skills. A respondent stated this as follows:

There is a very impressive middle manager at a little hospital in my area. (...) He notices issues that are happening on the ground. And he listens to people. We had a crisis in finding a bed for a lady with MDRTB [Multiple Drug Resistant TB]. The nurses had tried to do their best. He called the whole team in, got everyone to discuss how best to solve this problem, then instructed the matron to turn an empty antenatal care ward into a temporary MDR ward. The whole team felt so supported. He thanked the nurses who had made some temporary plans (and didn't bomb on them!) and told them that they were showing true compassion for their patients. He is also prepared to move into the not-the nicest office, in order to make more clinical space!

As part of the solution to the HRH shortage and challenges at management level, a panellist made the following suggestion:

We are not using doctors enough in management to plan and oversee the health systems issues. ... If nurses are well trained and well supported, they are able to take over many of the basic clinical roles of doctors. On the other hand, we need to rely more on doctors with their good overview and understanding of the whole health system in planning and prioritising care.

## Discussion

It is evident that the top five priority interventions for rural health care presented in Table 2 largely reflect the top five challenges: the opinions of the panel coalesce around governance, leadership, and HRH. Three of the priorities identified were introduced by participants in round 1, and their importance was confirmed in subsequent rounds. Although there were variations in the ranking of the top challenges and priorities, the themes were common. These are discussed below.

### Human resources for health

Human resource issues, in the opinion of the expert panel, emerged as the biggest challenge to improve comprehensive, quality health care for rural citizens.

This is in line with the assertion by the WHO that the failure to mobilise an effective health workforce is the most important obstacle to improving the performance of health systems and, in turn, achieving key health objectives (27). Although three different WHO building blocks (health workforce, finance, leadership and governance) feature in the top five challenges, it is notable that they all have links to human resources for rural health.

Given the low doctor-to-population ratio in the rural provinces of South Africa, Limpopo being worst affected, followed by Mpumalanga, the Eastern Cape, and North West (28), it is not surprising that the Delphi panel identified the mal-distribution of health care workers as the second greatest challenge. While this problem is a global one, there are strategies that can increase access to health workers in rural and remote areas; as outlined in the 2010 WHO global policy recommendations. These include educational strategies (for which there is the most evidence), regulation, financial incentives, and personal and professional support (29). Appropriate selection of students and training of health professionals in rural areas have been shown to be interventions that can redress the inequitable distribution of health workers (30). In the Philippines, the Zamboanga School of Medicine in rural Southern Mindanao province provides a successful example; more than 90% of its graduates are continuing their training and clinical practice within the region, in a context where the majority of medical graduates leave the country (31).

This mal-distribution of the health workforce is also found *within* rural districts, which results from the lack of effective recruitment and retention strategies as well as the lack of staffing norms and needs-based HRH allocations (28). This is further compounded by weak provincial HR departments (third greatest challenge). Although it is difficult to fill posts in rural areas, this is aggravated by the long delays in filling posts even when interested and suitable candidates are available (28).

It is interesting that the financial compensation of health care workers did not arise as a key challenge, rather the underfunding and rationalisation of health spending without regard to the often fragile situation of rural health facilities (fourth greatest challenge) was considered a key challenge. This links to the fourth priority, which refers to the underfunding of rural health care and the need for equitable formulae. Here, it is important to note that rural hospitals are often more expensive to run than urban hospitals due to their lower economy of scales (less dense population being serviced), with the great distances between people and services raising both demand and supply costs. Indeed, many hospitals in remote areas exist to improve access to services and to redress inequity rather than the high population numbers in the area (which would bring down the average cost per population). The argument that rural

health services need to be treated differently in relevant aspects to ensure equitable outcomes (32) forms the basis for policy making that include a specific rural health focus in a number of countries, such as the United States (33), Canada (34), and Australia (35).

The biggest losers as a result of staff shortages, low morale, frozen posts, and poor governance in rural areas are rural health care users. One testimony to this is the high number of avoidable and modifiable factors in maternal and child mortality ratios at health system level, with 22% of child deaths related to administrator action, such as lack of senior doctors and nurses, and 53% related to health care provider action, such as poor assessment and management in hospitals (36).

### *Governance and leadership*

The first and the fifth greatest challenges are inter-related and concern governance and leadership matters that have a direct bearing on the recruitment and retention of the rural health workforce, namely the quality of management and the organisational culture in health facilities. Although weak HR management affects the public health system across the board, the impact on rural facilities is most devastating due to their disproportionate state of fragility. According to various Delphi panellists, the appointment of senior managers that do not have the requisite training and skills within such systems can lead to uninformed decision-making, a lack of urgency in dealing with crisis situations, a poor work ethic, poor work relations, and low staff morale.

Globally, poor management and a lack of leadership skills are understood to be key drivers of HR problems in the broader health system, both in the developed and developing world (37–40). It is well-documented that good leadership inspires good performance by junior staff and vice versa. This is important because poor work ethic was identified by the panellists as a problem not only among management but also among health care workers. Good leadership includes the development of a joint vision; building adherence; strengthening accountability; planning, implementing, and monitoring HRH policies; and transparency in decision-making (41).

The South African government has recently announced plans for academic programmes to improve management and leadership skills. Although this is one important part of the solution, such programmes will have limited success when implemented within hierarchical organisational structures that discourage accountability (42). A negative organisational climate discourages skilled and committed people from staying in their positions over the longer term. Ultimately, the link between a system that fails to respond to contextual health care needs and an organisational culture that does not support visionary leadership and responsiveness needs to be made explicit (43). In various contexts, the argument is being made for

decentralisation and deconcentration of health care services as a means of creating more flexible and contextually responsive health systems (44). This should be paired with local accountability. As a Delphi participant commented:

Hospital and medical managers should be able to spend their budgets without central approval at every step of the way, and then be held accountable for what they spend.

Rural health care needs vision-driven, capable managers who act with a sense of urgency, who are not only role models to their own staff but who also get the support from their superiors to effect changes on the ground that are specific to their districts, facilities, and communities (45). Such examples do exist in rural hospitals and these managers need to be nurtured and celebrated. This demands a change in organisational culture in many health settings, towards a climate where advocacy for patients' rights is rewarded and acted on, and where the vision of the Department of Health of a caring and humane society in which all South Africans have access to affordable, good quality health care is the common goal of all working in the health system.

### *Limitations*

There were some limitations to this study. The panel was dominated by rural doctors, with fewer facility managers or nurses. This was both a result of the response rate and the sampling strategy and may have introduced some bias. Although the researchers sought to include health professionals of different backgrounds, our access to insightful, practising rural doctors resulted in this group being over-sampled. Furthermore, during the recruitment stage, many people were approached but only 53 respondents consented to take part. At the same time, analysis of the responses by doctors compared to the other categories revealed a large degree of consensus. For instance, 93% of respondents in round 1 felt that an HRH plan relevant to the rural context was either a 'key priority' or a 'priority to a large extent'. Because of the small numbers of individuals in this study, a more detailed analysis by different professional groups could not be undertaken.

The Delphi technique is often criticised as the results may be biased towards the views of the facilitator (who ultimately collates feedback from participants) and that opinions, even if shared by many, may not be based in fact (26). In this particular study, it is possible that people with similar problems gave their opinions, though we sought to make the panel as diverse as possible. Such a study could be more useful if all provinces and all levels of health workers had an equal chance of being sampled. However, the findings were also consistent with issues that have been well described in the current policy dialogue in South Africa and give voice to front-line

rural practitioners who are not always consulted on policy-making.

## Conclusion

Many rural health workers fear that there is little scope for positive change in rural facilities, which are at risk of remaining understaffed and poorly managed, thus entrenching existing inequities. This highlights the need, globally, for public health policy developments to be reviewed in terms of their possible impact on rural areas. The goal of this article was to present the consensus views of key informants and health experts on priority issues in rural health care. It is hoped that it can be used as an advocacy and lobbying tool to promote focussed policy development for rural health care.

To respond to the greatest rural health challenges, governments need to develop well-targeted rural health strategies that address HR distribution, financing, and governance issues and also ensure rural-proofing of new policy initiatives to prevent any negative impact on rural health care. In the 2011 HRH plan for South Africa (11), the National Department of Health identified the issue of management and leadership in the health sector as the first priority and also, for the first time, included a detailed chapter on HRH for rural health. Promising as these developments are, the underlying conditions for change must include equitable financing for rural health care provision, management appointments based on appropriate skills and experience, and transforming the organisational culture.

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**\*Lilo du Toit**  
 Centre for Rural Health  
 Faculty of Health Sciences  
 University of the Witwatersrand, Johannesburg  
 7 York Road, Parktown 2193  
 South Africa  
 Email: [Lilo.Dutoit@wits.ac.za](mailto:Lilo.Dutoit@wits.ac.za)

# Comparing the job satisfaction and intention to leave of different categories of health workers in Tanzania, Malawi, and South Africa

Duane Blaauw<sup>1\*</sup>, Prudence Ditlopo<sup>1</sup>, Fresier Maseko<sup>2</sup>,  
Maureen Chirwa<sup>2</sup>, Aziza Mwisongo<sup>3</sup>, Posy Bidwell<sup>4</sup>,  
Steve Thomas<sup>4</sup> and Charles Normand<sup>4</sup>

<sup>1</sup>Centre for Health Policy, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Department of Community Health, College of Medicine, University of Malawi, Blantyre, Malawi; <sup>3</sup>National Institute for Medical Research, Dar es Salaam, Tanzania; <sup>4</sup>Centre for Global Health, Trinity College, University of Dublin, Dublin, Ireland

**Background:** Job satisfaction is an important determinant of health worker motivation, retention, and performance, all of which are critical to improving the functioning of health systems in low- and middle-income countries. A number of small-scale surveys have measured the job satisfaction and intention to leave of individual health worker cadres in different settings, but there are few multi-country and multi-cadre comparative studies.

**Objective:** The objective of this study was to compare the job satisfaction and intention to leave of different categories of health workers in Tanzania, Malawi, and South Africa.

**Methods:** We undertook a cross-sectional survey of a stratified cluster sample of 2,220 health workers, 564 from Tanzania, 939 from Malawi, and 717 from South Africa. Participants completed a self-administered questionnaire, which included demographic information, a 10-item job satisfaction scale, and one question on intention to leave. Multiple regression was used to identify significant predictors of job satisfaction and intention to leave.

**Results:** There were statistically significant differences in job satisfaction and intention to leave between the three countries. Approximately 52.1% of health workers in South Africa were satisfied with their jobs compared to 71% from Malawi and 82.6% from Tanzania ( $\chi^2 = 140.3, p < 0.001$ ). 18.8% of health workers in Tanzania and 26.5% in Malawi indicated that they were actively seeking employment elsewhere, compared to 41.4% in South Africa ( $\chi^2 = 83.5, p < 0.001$ ). The country differences were confirmed by multiple regression. The study also confirmed that job satisfaction is statistically related to intention to leave.

**Conclusions:** We have shown differences in the levels of job satisfaction and intention to leave between different groups of health workers from Tanzania, Malawi, and South Africa. Our results caution against generalising about the effectiveness of interventions in different contexts and highlight the need for less standardised and more targeted HRH strategies than has been practised to date.

Keywords: *health worker; job satisfaction; intention to leave; Tanzania; Malawi; South Africa*

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Inadequate human resources are a major constraint to improving global health (1, 2). The insufficient numbers, skill imbalances, maldistribution, low motivation, and poor performance of health workers in low- and middle-income countries (LMICs) compromise the delivery and expansion of priority health programmes (3, 4). Addressing the human resources for health (HRH)

crisis is now a major component of health systems strengthening initiatives in LMICs.

The job satisfaction of health workers has become an important topic of HRH research (5, 6). Job satisfaction is the degree to which employees have a positive affective orientation towards employment by an organisation (7). Job satisfaction has been conceptualised both *globally*

(general satisfaction with a job) and *dimensionally* (satisfaction with specific dimensions of a job such as remuneration, promotion, and relationships with colleagues) (7). Job satisfaction is of interest because it is an important determinant of the performance of health professionals. Job satisfaction has been linked to health worker motivation (8), stress (9, 10), burnout (11), absenteeism (12, 13), intention to leave (14–16), and turnover (17, 18). Intention to leave refers to an employee's expressed intention of leaving their current job in the near future (19) and is used as a proxy indicator of turnover in cross-sectional surveys, which are not able to measure turnover directly (15).

The job satisfaction of health professionals has been shown to be influenced by a range of individual and organisational factors (5, 20–23), including personality, the work itself, work organisation, remuneration, workload, interactions with colleagues, training opportunities, recognition, and leadership styles. Importantly, job satisfaction depends not only on the characteristics of a job but also on employees' expectations of what their job should provide (5).

Job satisfaction studies have now been conducted in a number of different countries with different categories of health workers using a range of tools. The vast majority of research on health worker job satisfaction has been conducted in high- and upper middle-income countries (5, 6), and there are only very few studies from lower income countries (24–32). Nurses are, by far, the most researched group (5), but there are also a number of studies with doctors, dentists and pharmacists (6, 33–35). Research on other allied health workers has been less common (36). The job satisfaction of nurse practitioners in high-income countries has been investigated (37, 38) but we were only able to find one study relating to the job-satisfaction of mid-level workers in Africa (39).

Most job satisfaction data derives from small-scale surveys conducted with a single category of health worker from one country. There are few job satisfaction studies formally comparing different countries (25, 40–45) or different health worker cadres (46–50), and we were not able to find any studies that do both. Comparative research would help elucidate the specific needs of different health workers in specific contexts and inform the design of more effective HRH interventions (51).

Intention to leave is an intervening variable between job satisfaction and actual turnover (19) and is therefore affected by similar individual and organisational factors. The literature on intention to leave among health workers suffers from the same limitations highlighted above. There are very few studies from low-income and lower middle-income countries (30) and only a handful from upper middle-income countries (52–56). We were only able to find one relevant comparative study, a

comparison of organisational commitment in Malaysian and English nurses (45).

The objective of this study was to measure and compare the job satisfaction and intention to leave of different categories of health workers in Tanzania, Malawi, and South Africa.

## Methods

### Study context

This research was part of a broader study, *The Motivation Project*, that investigated issues of motivation and retention of health workers in Tanzania, Malawi, and South Africa (57). Table 1 compares some key demographic, health expenditure, health status, and HRH indicators from the three countries. These three countries were selected for the larger study because of differences in health professional cadres, regulatory environments, health labour market, resource availability, and recent HRH policy interventions. Tanzania and Malawi are low-income countries with large rural populations and high levels of poverty, whereas South Africa is a middle-income country that is more urbanised. South Africa has higher health expenditure per capita than Tanzania and Malawi, and significantly more health workers, although the health outcomes of the three countries are similar. The HRH crisis in Malawi and Tanzania is particularly severe, even in comparison to other countries in sub-Saharan Africa. Both countries have very low numbers of health professionals, depend on mid-level clinical officers and

**Table 1.** Comparison of key indicators in study countries – 2010

Indicator	Tanzania	Malawi	South Africa
Population (Million)	42.5	14.8	49.7
Population in rural areas	75%	81%	39%
GNP per capita (PPP)	\$1,230	\$830	\$9,780
Population living on < \$1 (PPP) per day	88.5%	73.9%	26.2%
Total expenditure on health (% GDP)	5.3%	9.9%	8.6%
Per capita total expenditure on health (PPP)	\$22	\$50	\$819
Life expectancy at birth	53 yrs	53 yrs	53 yrs
IMR (per 1,000 live births)	67	65	48
MMR (per 100,000 live births)	950	1,100	400
HIV prevalence	6.2%	11.9%	18.1%
Number of nurses	9,440	3,896	184,459
Nurses per 10,000 population	2	3	41
Number of doctors	300	257	34,829
Doctors per 10,000 population	<0.5	<0.5	8

Source: WHO World Health Statistics (58).

nurses to provide health care services, and have documented problems with health worker motivation (59, 60). The South African national HRH statistics are better in comparison, but obscure significant problems in retaining and motivating health workers in the public health sector and rural areas (61). All three countries have on-going HRH interventions to address these problems which would be informed by better information on job satisfaction.

### Data collection

As detailed below, multi-level stratified sampling strategies, customised for each country, were used to select a reasonably representative sample of health workers. We aimed to include approximately 150 respondents from each of the main cadres of health workers in each country to allow comparisons between groups and countries. The study included health workers from both public sector and non-governmental health facilities but not from the private-for-profit sector.

The study was based in three regions of Tanzania. Two districts were randomly selected from each region and data were then collected from the regional and district hospitals, as well as two health centres and three dispensaries selected at random from each district. In each of the selected facilities, random samples of health workers from the predetermined categories present on the day of the study were selected: 100 participants from each regional hospital, 40 from each district hospital, 8 from each health centre, and 3 from each dispensary. In Malawi, 11 of the 27 districts were selected at random, and all health workers from the predetermined categories in the selected districts were included in the sample. In South Africa, the study was based in two provinces (one urban and one rural) selected for the broader study. A random sample of five district hospitals and one referral hospital were randomly selected from each province, and then four wards in each district hospital and six wards in each referral hospital were randomly selected. The survey sample included all doctors and six nurses chosen at random from personnel lists in the selected wards.

To enable comparisons, we intended to include the most important health worker cadres in each country. The targeted groups in Tanzania and Malawi were nursing auxiliaries (1 year training), enrolled nurses (2 years), registered nurses (4 years), clinical officers (3 years), and allied health staff. Medical officers were included if they were present in the sampled facilities at the time of the survey, but they make up a very small proportion of the health workforce in these two countries. Although South Africa has begun to train small numbers of mid-level workers (62), none had graduated by the time of the study, so the survey concentrated on nursing auxiliaries, enrolled nurses, registered nurses, and doctors (medical officers and specialists) in the study facilities.

The study was explained to the selected health workers and they were invited to participate. Those that agreed completed a self-administered questionnaire which included basic socio-demographic information, a 10-item job satisfaction scale, and one question on intention to leave (19). The job satisfaction scale was derived from Bennett et al. (63) who undertook an extensive review of organisational measurement scales and validated their tools in studies in Georgia and Jordan (64). These tools have successfully been used in other African settings (65). Respondents were asked to indicate their agreement with statements about their satisfaction with their job in general and with nine different aspects of their jobs, using a five-point Likert scale from 'strongly disagree' to 'strongly agree'. The job attributes covered both intrinsic and extrinsic job satisfaction (63) and focused on important aspects highlighted in our previous review (57). The question on intention to leave asked health workers how strongly they agreed with the statement that they were actively seeking other employment.

### Data analysis

Data from the questionnaires in each country was entered into an Epi-Info database and then transferred to Stata v12.0 (StataCorp, College Station, TX) for cleaning, merging, and analysis.

Statistical differences in socio-demographic characteristics between the three countries were evaluated by means of a Chi-squared test for categorical variables and analysis of variance (ANOVA) for numerical variables. Post-hoc analysis of the ANOVA results used the Bonferroni test to identify which differences between countries were significant. 95% confidence intervals (95% CI) were calculated using standard methods, including exact binomial intervals for proportions.

Two methods were used for the analysis of the Likert scale responses. Firstly, the answers were coded on a scale from 1 (strongly disagree) to 5 (strongly agree) and analysed numerically. Secondly, we calculated the proportion of respondents agreeing with each statement by combining those that 'strongly agreed' and those that 'agreed' with each statement. Differences between countries were tested using ANOVA of the numerical data.

We used principal component analysis (PCA) to construct a job satisfaction index combining all ten questions on job satisfaction. The reliability of this scale was evaluated by calculating Cronbach's alpha and by inspection of the results of the PCA.

Finally, to formally test for differences between the three countries while adjusting for other socio-demographic determinants, we used multiple linear regression for job satisfaction and multiple logistic regression for intention to leave. For job satisfaction, we used the job satisfaction index from the PCA. For intention to leave we used the Likert response recoded as a binary variable indicating

those health workers who agreed that they were actively seeking alternative employment. A cut-off of 0.05 was used to determine statistical significance in all the statistical tests.

### Ethical considerations

National and international ethical standards were followed throughout the research. The study protocol was reviewed by the human research ethics committees of the National Institute for Medical Research in Tanzania, the University of the Witwatersrand in South Africa, the University of Malawi in Malawi, and Trinity College Dublin in Ireland. Prior to data collection, permission to conduct the research was also obtained from the relevant governmental and health authorities in each country. Written informed consent was obtained from all participants.

## Results

### Study participants

A total of 2,335 respondents were selected to participate in the survey. We excluded non-health workers and blank questionnaires from those that indicated they did not want to participate. This left a total of 2,221 questionnaires for analysis: 567 from Tanzania, 937 from Malawi, and 717 from South Africa, giving response rates for the study of 91.7%, 95.1, and 98.0%, respectively.

Table 2 summarises the basic demographic characteristics of the study sample. The health workers in this study were predominantly female, half were married, and most had children. The mean age of the participants

was 38.2 years, and they had been working in their current jobs for an average of nearly 8 years. All of these variables showed statistically significant differences between the three study countries (Table 2). In particular, the Malawian sample had a higher proportion of males, was relatively younger, had fewer children, and had been in a post for a much shorter period of time, in comparison to study participants from South Africa and Tanzania.

Table 3 provides a breakdown of the participants by cadre. In Tanzania, nursing staff (medical attendants, nurse midwives, trained nurses) made up 61.6% of health workers, 18.3% were clinical officers or assistant medical officers, and there were only 25 (4.4%) doctors. The main categories in Malawi were nurse midwife technicians and enrolled nurses (45.2%), and medical assistants and clinical officers (30.4%). Reflecting their relative scarcity, registered nurses were only 10.4% of the sample, and there were only five medical officers in total in the sampled facilities. Allied health workers (therapists, radiographers, pharmacists, laboratory technologists) made up a small proportion of participants from Malawi and Tanzania. Finally, in South Africa, the sample was more or less evenly divided between nursing auxiliaries, registered nurses and doctors.

### Job satisfaction and intention to leave

The results of the job satisfaction survey by country are summarised in Table 4. Overall, 82.3% [95% CI: 78.9–85.4] of respondents in Tanzania were satisfied with their jobs, compared to 71.0% [95% CI: 68.0–73.9] in Malawi, and 52.1% [95% CI: 48.3–55.8] in South Africa.

Table 2. Characteristics of study participants

Variables	Total	Tanzania	Malawi	South Africa	<i>p</i>
N	2,221	567	937	717	
Sex					
% Female	62.5	68.2	47.9	77.0	<0.01 <sup>†</sup>
Age					
Mean ± SD	38.2 ± 11.4	41.0 ± 9.4	35.9 ± 12.5	39.3 ± 10.5	<0.01 <sup>‡</sup>
Marital status					
% Single	35.0	23.2	37.7	40.7	<0.01 <sup>†</sup>
% Married	54.7	66.6	52.0	48.8	
Any children					
% Yes	70.5	82.7	60.9	73.4	<0.01 <sup>†</sup>
Facility type					
% Clinic	21.0	14.2	41.3	0.0	
% Public hospital	72.3	85.8	42.7	100.0	<0.01 <sup>†</sup>
% Mission hospital	6.8	0.0	16.1	0.0	
Years in current post					
Mean ± SD	7.7 ± 8.5	12.1 ± 9.4	4.0 ± 5.3	9.3 ± 9.3	<0.01 <sup>‡</sup>

<sup>†</sup>Chi-squared test; <sup>‡</sup>ANOVA.

**Table 3.** Breakdown of health worker cadres in each country

Category	Tanzania		Malawi		South Africa		Total	
	N	%	n	%	n	%	n	%
Auxiliary/enrolled nurse	163	28.8	424	45.2	258	36.0	845	38.0
Registered nurse	186	32.8	97	10.4	270	37.7	553	24.9
Medical assistant/clinical officer	104	18.3	285	30.4			389	17.5
Medical officer/specialist	25	4.4	5	0.5	189	26.3	219	9.9
Allied health workers	89	15.7	126	13.5			215	9.7
Total	567	100.0	937	100.0	717	100.0	2,221	100.0

These differences were statistically significant ( $\chi^2 = 138.6$ ,  $p < 0.001$ ). The mean scores for each question were compared to evaluate satisfaction with different job attributes. In all three countries, health workers were most satisfied with their job variety and the opportunity to fully utilise their abilities. The lowest mean satisfaction scores in all three countries were for the educational and training opportunities and the availability of drugs and equipment. Although the rankings were reasonably consistent, the actual scores differed significantly between the three countries (Table 4). For all job attributes, satisfaction was generally highest in Tanzania, intermediate in Malawi, and lowest in South Africa. Post-hoc analysis of the ANOVA results showed that differences between all three countries were significant for most of these results, except that the mean scores for satisfaction with manager handling of staff and the availability of drugs were not statistically different between Malawi and South Africa, and that Malawi and Tanzania did not have statistically different scores for the question about jobs allowing health workers to perform at high levels (Table 4).

In terms of intending to leave their current job, only 18.8% [95% CI: 15.6–22.2] of health workers in Tanzania and 26.5% [95% CI: 23.7–29.5] in Malawi indicated that they were actively seeking employment elsewhere, compared to 41.4% [95% CI: 37.3–45.1] in South Africa (Table 4). These differences between the three countries were also statistically significant ( $\chi^2 = 83.5$ ,  $p < 0.001$ ).

The scores for satisfaction with different job components correlated well with each other and with general job satisfaction. The Cronbach's alpha for the satisfaction scale derived from all 10 items was 0.829 (0.823, 0.808, and 0.838 in Tanzania, Malawi, and South Africa, respectively). The question on job variety had the lowest correlation with the scale although this was still 0.435 and its exclusion did not improve Cronbach's alpha significantly. The first component in the PCA explained 40.8% of the total variance (39.6%, 37.5, and 42.4% in Tanzania, Malawi, and South Africa, respectively). The loadings indicated that an index derived from the first component was close to an average of all ten items (results not shown) and the correlation between a simple additive

sum of the ten items and the first component was 0.997 ( $p < 0.001$ ). The job satisfaction index obtained from the first component of the PCA was used in subsequent regression analyses.

### *Determinants of job satisfaction and intention to leave*

Table 5 shows the results of the multiple regression used to evaluate differences in job satisfaction between the three countries while adjusting for differences in other socio-demographic determinants (Table 2). The model was statistically significant ( $p < 0.001$ ) but only explained 10.7% of the total variation in job satisfaction. Female health workers were less satisfied than males but this difference was not significant in the multiple regression. Job satisfaction was significantly higher in the age group over 50 years of age compared to those under 30 years. Workers in public hospitals were significantly less satisfied than workers in clinics and health centres, they were also less satisfied than workers in mission hospitals but this difference was not statistically significant ( $p = 0.440$ ). Differences between different health worker cadres were also not significant. However, the differences between countries persisted in the multiple regression after adjusting for other available predictors. Job satisfaction in South Africa was significantly lower than Malawi, while Tanzania scored significantly higher than Malawi.

Table 6 shows that the multiple regression model of predictors of intention to leave. Gender, marital status, type of facility and health worker category were not significantly associated with actively seeking alternative employment. However, intention to leave decreased significantly with age – the odds of leaving in the over 50 age group was half that of those under 30 years. Intention to leave was statistically higher in South Africa than in Malawi ( $p < 0.001$ ) and in Tanzania ( $p < 0.001$ ), with South African health workers more than twice as likely to report on intending to leave than those from Malawi and Tanzania, but there was no significant difference between Malawi and Tanzania ( $p = 0.871$ ). Intention to leave was negatively correlated with job satisfaction in the multiple regression, so that health workers with higher job

Table 4. Satisfaction with job characteristics and intention to leave by country

Job attribute	% Agreeing			Satisfaction score (Mean $\pm$ SD)			Significance (ANOVA)	
	Tanzania	Malawi	South Africa	Tanzania	Malawi	South Africa	Overall	Post-hoc comparison
In general, I am satisfied with this job	82.3	71.0	52.1	4.03 $\pm$ 0.91	3.72 $\pm$ 1.23	3.22 $\pm$ 1.19	F=82.28, $p$ <0.001	a, b, c
I feel that I am able to use my abilities to their full potential	88.9	78.2	62.7	4.22 $\pm$ 0.83	3.94 $\pm$ 1.1	3.56 $\pm$ 1.15	F=64.1, $p$ <0.001	a, b, c
I have a variety of duties, tasks and activities in my job	88.5	93.5	86.7	4.19 $\pm$ 0.83	4.33 $\pm$ 0.78	4.04 $\pm$ 0.87	F=25.3, $p$ <0.001	a, b, c
I find that my opinions are respected at work	72.9	63.1	48.0	3.76 $\pm$ 0.97	3.49 $\pm$ 1.13	3.22 $\pm$ 1.1	F=39.64, $p$ <0.001	a, b, c
I am satisfied with the recognition I get for the work that I do	77.2	51.2	38.8	3.8 $\pm$ 0.93	3.16 $\pm$ 1.26	2.98 $\pm$ 1.17	F=87.1, $p$ <0.001	a, b, c
I am satisfied with the personal relationship between my manager and myself	75.6	65.6	55.1	3.82 $\pm$ 0.98	3.55 $\pm$ 1.16	3.35 $\pm$ 1.17	F=28.4, $p$ <0.001	a, b, c
I am satisfied with the way my manager handles staff	62.8	46.8	43.2	3.53 $\pm$ 1.07	3.11 $\pm$ 1.21	3.02 $\pm$ 1.22	F=32.9, $p$ <0.001	b, c
I feel that my job conditions allow me to perform at high levels	60.0	55.9	43.3	3.47 $\pm$ 1.18	3.35 $\pm$ 1.25	3.03 $\pm$ 1.2	F=22.8, $p$ <0.001	a, c
I am satisfied with the availability of drugs and equipment	46.2	39.9	36.7	3.11 $\pm$ 1.18	2.85 $\pm$ 1.2	2.78 $\pm$ 1.24	F=12.7, $p$ <0.001	b, c
I am satisfied with the educational/training opportunities that I get	41.0	29.9	39.2	2.98 $\pm$ 1.17	2.53 $\pm$ 1.28	2.8 $\pm$ 1.29	F=24.7, $p$ <0.001	a, b, c
I am actively seeking other employment	18.8	26.5	41.4	2.42 $\pm$ 1.13	2.64 $\pm$ 1.31	3.05 $\pm$ 1.34	F=39.9, $p$ <0.001	a, b, c

Bonferroni post-hoc comparisons: a: Malawi and South Africa significantly different; b: Malawi and Tanzania significantly different; c: South Africa and Tanzania significantly different.

**Table 5.** Multiple linear regression of predictors of job satisfaction

Variable	Coefficient	95% CI	p
Constant	-0.215	[-0.686; 0.256]	0.371
Female	-0.146	[-0.377; 0.086]	0.217
Age group			
<30 years	-	-	-
30-50 years	0.177	[-0.081; 0.435]	0.178
>50 years	0.751	[0.409; 1.093]	<0.001
Marital status			
Single	-	-	-
Married/living together	-0.015	[-0.249; 0.220]	0.901
Separated/divorced/widowed	0.405	[0.049; 0.761]	0.026
Number of children	0.005	[-0.256; 0.266]	0.970
Facility type			
Clinic/health centre	-	-	-
Public hospital	-0.440	[-0.693; -0.187]	0.001
Mission hospital	-0.180	[-0.567; 0.208]	0.363
Years in current post	0.002	[-0.011; 0.016]	0.730
Health worker cadre			
Auxiliary/enrolled nurse	-	-	-
Registered nurse	-0.087	[-0.328; 0.153]	0.476
Medical assistant/clinical officer	-0.219	[-0.514; 0.075]	0.144
Medical officer/specialist	0.062	[-0.317; 0.442]	0.748
Allied health workers	-0.021	[-0.367; 0.325]	0.905
Country			
Malawi	-	-	-
South Africa	-0.461	[-0.76; -0.161]	0.003
Tanzania	0.923	[0.657; 1.189]	<0.001

F = 14.9, p < 0.001, R<sup>2</sup> = 0.107.

satisfaction indices were significantly less likely to want to leave their jobs.

### Discussion

We have used a cross-sectional survey to compare the job satisfaction and intention to leave of different categories of health workers in Tanzania, Malawi, and South Africa. We have found statistically significant differences in job satisfaction and intention to leave between the three countries. The lowest job satisfaction and highest intention to leave were found in South Africa where 47.9% of those surveyed were dissatisfied with their jobs and 41.4% were actively seeking other jobs (Table 4). The differences between countries were confirmed by multiple regression while adjusting for other potential predictors. Differences between health worker cadres were not significant but

**Table 6.** Multiple logistic regression of predictors of intention to leave

Variable	OR	95% CI	p
Constant	0.420	[0.239; 0.737]	0.003
Female	0.954	[0.722; 1.26]	0.741
Age group			
<30 years	-	-	-
30-50 years	0.726	[0.535; 0.985]	0.039
>50 years	0.495	[0.318; 0.770]	0.002
Marital status			
Single	-	-	-
Married/living together	0.838	[0.634; 1.107]	0.214
Separated/divorced/widowed	0.847	[0.537; 1.336]	0.475
Any children	1.244	[0.91; 1.701]	0.171
Facility type			
Clinic/health centre	-	-	-
Public hospital	0.895	[0.650; 1.231]	0.493
Mission hospital	1.085	[0.675; 1.743]	0.738
Years worked at this facility	0.989	[0.971; 1.007]	0.224
Health worker cadre			
Auxiliary/enrolled nurse	-	-	-
Registered nurse	1.088	[0.811; 1.461]	0.574
Medical assistant/clinical officer	1.063	[0.741; 1.526]	0.739
Medical officer/specialist	0.849	[0.543; 1.326]	0.471
Allied health workers	0.950	[0.614; 1.472]	0.820
Country			
Malawi	-	-	-
South Africa	2.158	[1.501; 3.103]	<0.001
Tanzania	1.029	[0.725; 1.461]	0.871
Job satisfaction index	0.733	[0.693; 0.776]	<0.001

LR  $\chi^2 = 240.9$ , p < 0.001, Pseudo R<sup>2</sup> = 0.106.

the multiple regression model analysis did show that health professionals working in public hospitals were less satisfied than those in clinics and health centres, younger health workers were significantly more dissatisfied and more likely to want to quit their jobs, and that lower job satisfaction was significantly associated with intention to leave (Tables 5 and 6).

This article adds to the very small comparative literature on job satisfaction and intention to leave. A few studies have directly compared job satisfaction in different countries. For example, a classic study which compared nursing in different countries, Aiken (44) found that 41.0% of American nurses were dissatisfied with their job, compared to 32.9% in Canada, 37.7% in Scotland, 36.1% in England, and only 17.4% in Germany. Chirwa et al. (25) noted differences in job satisfaction between nurses caring for HIV patients in Lesotho, Malawi, South Africa, Swaziland, and Tanzania. In research comparing nurses working in Malaysia and England, it was found

that English nurses were significantly more satisfied with their jobs, although Malaysian nurses showed lower intention to leave (45). Studies comparing doctors from Norway and Germany found significantly higher job satisfaction among Norwegian doctors which was attributed to better working hours, higher salary, and more control over clinical work in Norway (41, 43).

A few comparative studies have explored differences in job satisfaction or intention to leave between different categories of health workers (46–50). Although differences have been noted in these studies they have not always been evaluated statistically. We were not able to confirm significant differences in job satisfaction or intention to leave between different health worker cadres using multiple regression models. Similar findings have been reported elsewhere (66) but a number of authors have shown nurses to be significantly more satisfied with their jobs than doctors (47, 49, 50). Although they did not compare levels of satisfaction, Krogstad et al. (48) demonstrated that the job satisfaction of doctors, nurses and auxiliaries in Norway were influenced by different determinants.

The finding that younger nurses have lower levels of job satisfaction and higher intention to leave has been confirmed in a number of previous studies (5, 44, 67–69) and in a meta-analysis of variables related to job satisfaction (21). Other authors have found lower job satisfaction in public sector health workers in both lower and higher-income countries (27, 31, 40, 70, 71) and the association between job satisfaction and intention to leave has been demonstrated before (14–18).

This article also contributes to the limited research on job satisfaction and intention to leave in the three study countries. South African health professionals had the lowest levels of satisfaction in our study but Chirwa et al. (25) found that nurses from South African and Tanzania had higher mean job satisfaction scores than those from Malawi, Swaziland, and Lesotho. The low levels of job satisfaction among public sector nurses in South Africa has been confirmed in a number of studies (70, 72–74) and a survey of primary health care nurses in rural South Africa also found high turnover intentions as 51.1% planned to leave their current job within 2 years (56). A cross-sectional survey of nurses from Tanzania, Kenya, and Uganda found lower levels of job satisfaction when compared with a European reference group and also that satisfaction was lower among public hospital nurses than those working the private sector (24). In one of the few studies from Malawi, McAuliffe et al. (39) showed that job satisfaction was correlated with elements of organisational justice among a mixed group of mid-level workers.

This survey was a small component of a larger study and suffers from a number of limitations. First, although this is one of the largest health worker job satisfaction surveys to date, the samples were not designed as

nationally-representative samples. Resource constraints required regionalised sampling strategies in all three study countries although we were careful to select provinces and regions that were typical. Also, we did not show statistically significant differences between different categories of health workers which may be due to the lower power of these analyses, even though the numbers of respondents in each category were not small. These problems are not unique to this study, since most of the available literature on health worker job satisfaction is based on very small samples of health workers (57). More representative studies will require a significant investment of resources in HRH research in LMICs.

Second, although job satisfaction measurement tools have been validated for use in many different settings (75), local construct validation does not necessarily ensure direct comparability of tools for comparative research. Nevertheless, it is encouraging that measurement equivalence of job satisfaction scales have been demonstrated between different countries (76), and between nurses and doctors (77).

Third, the objective of this study was to measure and compare job satisfaction and intention to leave in the three countries, so we did not collect detailed data on possible determinants, actual working conditions or remuneration. Therefore, the available variables only explained a small proportion of the variation in job satisfaction and intention to leave in the multiple regression models. Also, like similar health worker surveys, we did not investigate if differences in expressed job satisfaction had any real impact on health worker performance or patient care. Further research will be required to properly explain some of the patterns that we have observed and investigate their significance for health service delivery.

Finally, like much of the existing HRH literature, this analysis is based on cross-sectional rather than longitudinal data. As a result, we were not able to measure actual turnover although there is significant empirical evidence linking intention to leave with actual leaving in other settings (78, 79). Cross-sectional studies may also be biased because they only capture the views of health workers that have remained in service. More longitudinal HRH research is an important priority to address these limitations, particularly in LMICs (15, 30).

There are important implications of the findings reported here. This preliminary study demonstrates the need for more detailed comparative HRH research. We have shown differences in the levels of job satisfaction and intention to leave between different groups of health workers from different countries but research is also needed on the relative importance of different determinants of job satisfaction and retention for different health professionals in different contexts. Current HRH interventions are based on fairly standardised generalisations

about what is important to health workers but more targeted HRH strategies, based on more differentiated research, may be more important than has been recognised to date.

Better working conditions may not result in higher health worker job satisfaction and retention. We found the lowest levels of satisfaction and highest turnover intentions among South African health professionals which is surprising considering that the health system in South Africa is much better resourced than either Malawi or Tanzania. General living standards are better, per capita public health expenditure is many times higher, and staffing ratios are better (Table 1). The lower satisfaction of health workers in the public sector, compared to the non-governmental or private sector, is also not always attributable to significantly worse resources or remuneration (27, 31, 70). There is a significant affective component to job satisfaction and intention to leave which suggests that the observed differences between countries or sectors are not simply related to differences in job characteristics or working conditions but are influenced by other cultural, economic and political factors such as health worker expectations, organisational culture, labour market conditions, as well as the organisation and militancy of health professionals (5, 80). HRH interventions need to take these dynamics into account since good strategies may be ineffective, or even have contradictory effects, when introduced in a general climate of dissatisfaction. More attention also needs to be given to identifying HR interventions and strategies that improve the general morale and attitudes of health workers.

The observation here, and in other studies, that younger health professionals have lower job satisfaction, and express higher turnover intentions is also cause for concern. There are generational differences between health workers that appear to have less to do with ageing than with significant changes in the underlying motivations, needs, expectations and opportunities of newly qualified health workers. Corresponding changes are required in the selection, training, deployment, and remuneration of health professionals to address the disaffection of young health workers and prevent further deterioration of the HRH crisis.

Suggested interventions to improve job satisfaction have mostly been extrapolated from the organisational factors known to be associated with job satisfaction, so include improving remuneration, workload, physical working conditions, work organisation, supervision, and leadership (5, 23). However, there are very few studies that have rigorously evaluated the impact of such HRH interventions on the job satisfaction of health professionals (81–83), and none from lower income countries. In the absence of such evidence, our results caution against simplistic assumptions about the effectiveness of these interventions. More rigorous intervention research

is clearly needed if the existing descriptive studies are to be translated into practical HRH strategies.

## Conclusion

Improving the motivation, performance and retention of health workers are essential steps in addressing the HRH crisis facing LMICs. Job satisfaction is an important determinant of the performance and turnover of health professionals. We have shown differences in the levels of job satisfaction and intention to leave between different groups of health workers from Tanzania, Malawi, and South Africa. Moving from description to intervention requires a better understanding of the different determinants of job satisfaction and intention to leave for different sub-groups of health workers in different countries. Our findings highlight the need for less standardised and more targeted HRH strategies than has been the practice to date.

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**\*Duane Blaauw**

Centre for Health Policy  
 School of Public Health, Faculty of Health Sciences  
 University of the Witwatersrand, Johannesburg  
 7 York Road, Parktown 2193  
 South Africa  
 Tel: +27-11-717-3422  
 Fax: +27-11-717-3422  
 Email: duane.blaauw@wits.ac.za

# Policy implementation and financial incentives for nurses in South Africa: a case study on the occupation-specific dispensation

Prudence Ditlopo<sup>1\*</sup>, Duane Blaauw<sup>1</sup>, Laetitia C. Rispel<sup>2#</sup>, Steve Thomas<sup>3</sup> and Posy Bidwell<sup>3</sup>

<sup>1</sup>Centre for Health Policy, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Centre for Health Policy and Management, Trinity College, Dublin, Ireland

**Background:** In 2007, the South African government introduced the occupation-specific dispensation (OSD), a financial incentive strategy, to attract, motivate, and retain health professionals in the public sector. Implementation commenced with the nursing sector, but there have been unintended negative consequences.

**Objective:** First, to examine implementation of the OSD for nurses using Hogwood and Gunn's framework that outlines 'perfect implementation' pre-conditions. Second, to highlight the conditions for the successful implementation of financial incentives.

**Methods:** A qualitative case study design using a combination of a document review and in-depth interviews with 42 key informants.

**Results:** The study found that there were several implementation weaknesses. Only a few of the pre-conditions were met for OSD policy implementation. The information systems required for successful policy implementation, such as the public sector human resource data base and the South African Nursing Council register of specialised nurses were incomplete and inaccurate, thus undermining the process. Insufficient attention was paid to time and resources, dependency relationships, task specification, and communication and coordination.

**Conclusion:** The implementation of financial incentives requires careful planning and management in order to avoid loss of morale and staff grievances.

Keywords: *financial incentives; occupation specific dispensation; nurses; policy implementation; South Africa*

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Financial incentives are a commonly used strategy to improve health worker motivation and retention (1, 2). However, there is limited evidence of their impact in low- and middle-income countries (3, 4) or in rural and remote areas (1, 3). Rigoli and Dussault have cautioned that the failure of many incentive schemes to achieve expected results is due to poor design (5). The problems of inappropriate or poorly designed policies are exacerbated by policy implementation challenges, which in turn may determine the impact of financial incentive policies (6, 7). In most countries, policy makers have

limited guidance on how to implement financial incentive strategies so that they can achieve their intended policy objectives. For example, inequities, or perceived inequities in the manner in which incentive strategies are designed and implemented have been documented as a source of demotivation (4). Increasing attention has thus been paid to understanding the problems of policy implementation in order to identify key contributing factors to the failure to achieve the desired impact (8).

In South Africa, several authors have analysed the disjuncture between policies or plans, on the one hand,

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and implementation, on the other hand. These have included studies on mental health (9–11), HIV and AIDS (12–15), hospital rationalisation and restructuring (12, 14), municipal health services (16), social inclusion (17), and user fees (18). A few studies have looked at policies on remuneration or incentives (19–21). Several problems have been identified. Stack and Hlela, and Khosa found that the challenges included hurried policy implementation; limited consultation with the implementing actors; lack of prioritisation, insufficient time, and a lack of co-ordination between different government departments (12, 14). Rispel et al. found that inadequate administrative and implementation capacity, insufficient resources, corruption, and lack of involvement of civil servants beset the implementation of various social policies (17), while challenges of varying technical capacity at different government levels influenced the implementation of mental health policy (11).

Although these studies provide important insights into the factors that plague policy implementation, there is a dearth of studies that analyse the implementation of policies on remuneration or financial incentives (19–21). In light of the global human resource crisis, analysis of policy implementation of financial incentives is important to guide policy makers, as these are the most commonly used staff retention strategies.

In South Africa, public sector conditions of service (issues such as remuneration or working hours) are determined on the basis of a central collective bargaining process between the employer (government) and recognised labour representatives (unions or professional associations), in line with provisions of the Labour Relations Act (22).

In 2007, the South African government introduced the occupation-specific dispensation (OSD), a financial incentive strategy to attract, motivate, and retain health professionals in the public health sector (23). The OSD policy defines the remuneration structure, frequency of pay progression, grade progression opportunities, career pathing, recognition of appropriate experience and required levels of performance (23, 24). Implementation commenced with all categories of nurses, as they are the majority of health care providers in South Africa and because of the shortages of and high turnover among nurses in clinical specialties, especially in critical care wards and operating theatres.

Existing evidence suggests numerous problems with the implementation of the OSD policy, ranging from inadequate planning, budget overruns (25) and some unintended negative consequences (26). These consequences included unmet nurses' expectations, inequities in the amounts received, perceived unfairness, and dissatisfaction and divisions among the different categories of nurses (26).

The article draws on the Hogwood and Gunn policy implementation framework to analyse the implementation of OSD and seeks to determine whether the manner in which OSD was implemented caused these unintended negative consequences. The article concludes with lessons for South Africa and other countries, which could be used to guide future financial incentive policies.

### *Conceptual framework*

Although there are several theories and frameworks to analyse policy implementation, this article uses Hogwood and Gunn as an analytical framework (Table 1) to analyse the implementation of OSD (7, 27). Hogwood and Gunn make a distinction between 'non-implementation' and 'unsuccessful implementation'. With 'non-implementation', policies are not put into effect as intended because those involved in the implementation are inefficient or because it was not possible to overcome obstacles despite their best efforts. 'Unsuccessful implementation' refers to a situation where the policy is fully implemented but fails to produce the intended outcomes (7). Although the framework is idealistic in that it suggests the notion of 'perfect' implementation, it is useful to consider the preconditions and key features necessary for the successful policy implementation of complex financial incentives.

### *Methods*

The study was approved by the University of the Witwatersrand Committee for Research on Human Subjects and the Provincial Health Research Ethics Committees in the two provinces that participated in the study. Hospital managers were also asked for permission to access their facilities. All participants provided informed consent after receiving a study information sheet.

### *Study design*

A descriptive case study design was used, combining a review of policy documents and in-depth interviews with key informants who were knowledgeable on OSD policy design and/or implementation. The document review included relevant government documents including policy directives (23, 24) and media releases (28–30) in order to understand the context and content of the OSD implementation.

### *Study sites and setting*

The study was conducted in North West and Gauteng provinces between 2008 and 2010. North West is a predominantly rural province with a population of 3.2 million (6.4% of the total South African population) while Gauteng is an urban province with a population of 11.1 million (22.4% of the total population). We selected a total of 10 hospitals in the two provinces. Out of 30 hospitals in

**Table 1.** Conceptual framework

Hogwood and Gunn's 10 preconditions for implementation (27)	
Stage	Description of the practice
External constraints	Circumstances external to the implementing agency do not impose crippling constraints
Time and resources	Adequate time and sufficient resources are made available to the programme
Resource combination	The required combination of resources is available
Theory-based policy	The policy to be implemented is based on a valid theory of cause and effect
Cause/effect relations	The relationship between cause and effect is direct and that there are few, if any intervening links
Dependency relationships	The dependency relationships are minimal
Agreements of objectives	There is agreement of, and understanding on, objectives
Events sequencing	The tasks are fully specified in correct sequence
Communication/coordination	There is perfect communication and coordination
Total compliance	Those in authority can demand and obtain perfect compliance

North West province, three were purposively selected<sup>1</sup> to ensure inclusion of those hospitals that were part of the hospital revitalisation programme and two were selected randomly. Similarly, in Gauteng province, one hospital was purposively selected while four were selected at random.

### Study participants and data collection

Forty-two key informants were selected purposively on the basis of their influence or knowledge of the OSD policy or their involvement with OSD implementation, using a snowballing sampling technique. The key informants consisted of the following groups of stakeholders: national government (7), provincial government ( $n=12$ ), academics ( $n=7$ ), statutory body ( $n=1$ ), nursing organisations ( $n=4$ ), nursing unions ( $n=3$ ), and hospital managers who were available at their facilities on the day of data collection ( $n=8$ ).

The selected key informants were interviewed using a semi-structured interview guide. The questions focused on the background and context of OSD for nurses, actors and their responsibilities, implementation of OSD, successes of the OSD implementation, challenges experienced, and recommendations.

### Data analysis

A thematic content analysis of the documents and transcripts was conducted (31) using ATLAS.ti. To ensure coding consistency, two researchers (one being the first author) independently read at least seven transcripts and discussed discrepancies until agreement on the codes was reached.

<sup>1</sup>The purposive selection was done to ensure that hospitals undergoing revitalisation were included, as it constituted the focus of the broader study.

## Results

Table 2 shows the extent to which OSD implementation met the preconditions and key features necessary for successful policy implementation, proposed by Hogwood and Gunn. Although these conditions overlap, each is elaborated below for the sake of clarity.

### Precondition 1: external constraints

External obstacles 'may be political in that either policy or the measures needed to achieve it are unacceptable to interests (such as party activists, trade unions, or in some societies, the military) which have the power to veto them'(27).

Although OSD was part of ongoing government efforts to recruit and retain health care professionals in the public sector, intense lobbying by organised labour, particularly by the Democratic Nursing Organisation of South Africa (DENOSA), for improved remuneration and a protracted public servants strike during 2007 accelerated its implementation (32). However, the strike influenced the ability of government to plan adequately.

A key external constraint was contestations regarding the prioritisation of nurses over other health care professionals in the OSD implementation, especially among the recognised labour organisations in the central bargaining chamber. One informant commented as follows:

At that time, government said I have got X amount of money to improve the salaries of health professionals, but it is not enough to improve the salaries of everybody. Now all of us as health professionals had to say 'start with us' so it was so difficult. So when we thought that we had convinced the government to start with the nurses, when it went to the Bargaining Chamber with other trade unions, we were seen as people that were promoting elitism. We were asked 'why only nurses, what about cleaners?' (KII 18, Nursing Union)

**Table 2.** Assessment of occupation-specific dispensation (OSD) implementation against Hogwood and Gunn conditions for success

Hogwood and Gunn's criteria	OSD assessment
External constraints	Widespread public sector strike accelerated implementation, contributing to insufficient planning before implementation Some contestation over prioritisation of nurses as the first health provider category to benefit from OSD
Adequate time and resources	OSD implementation was rushed Insufficient financial resources Limited human resources Inadequate training of the implementers
Required combination of resources	OSD policy guideline in the form of Resolution 3 of 2007 Poor human resource information system
Policy based on valid theory	Philosophy of OSD policy supported Policy not evidence based
Clear cause and effect relationship	OSD would provide clear career paths and salary progression for nurses Increase in salary will increase motivation and retention
Minimal dependency relationships	Complex series of events Dependent on nurses submitting proof of Nursing Council qualifications
Agreement of objectives	The objective of OSD was to retain nurses within clinical areas Vagueness in the definition of what constitutes specialisation
Sequencing of events	Roles of implementation stakeholder not made explicit Announcement made prior to ensuring sufficient and combination of resources
Communication and coordination	Weak communication to frontline nurses Poor coordination amongst key actors
Total compliance	Varied interpretation at institution and provincial level Overpayments and underpayments

**Preconditions 2 and 3: adequate time and resources**

Both Gauteng and North West provinces reported using the OSD policy for implementation. Task teams were established at some hospitals, and these hospital managers reported fewer implementation challenges.

One of the reasons for the success of the OSD process was the formation of the task teams prior to implementation. (Assistant Nursing Manager, Central Hospital, Gauteng)

A combination of resources is required according to the Hogwood and Gunn framework, which assumes that if one or more of the resources is delayed, the project is set back by several months (27). Although the intention was for OSD to be implemented by March 2008 (23), actual implementation was delayed until September 2008; and even then, not all provinces implemented it at the same time. There were inconsistencies in the benefits nurses received among the different provinces and institutions. This led to confusion and disgruntlement.

Insufficient time was allocated for the training of the implementers at institution level, there was no reference made in the OSD policy to who would be trained on OSD implementation or the length of the training (23), so this aspect was neglected. Thus reinforcing, a common reason

why policies do not achieve the stated intentions is that too much is expected too soon (27). There was consensus amongst hospital managers that OSD was implemented in a rushed and pressured manner.

I think the way OSD was implemented, it was in a rush, there were deadlines to say on a certain date implementation must start. It was putting a lot of people under pressure. I think it would have been done smarter if it was done at a natural pace and everybody has been comfortable with the implementation. (Hospital Manager 4, District Hospital, Gauteng Province)

In terms of financial resources, around R1, 5 billion (equivalent to US\$ 200 million; 1\$ = 7.5 South African Rands) was allocated for OSD for nurses for the 2007 financial year (Department of Health, 2007). This amount was insufficient for several reasons. Firstly, a sub-optimal human resource information system resulted in an undercount of the total number of nurses in the public health sector by 10,000 individuals. Although this was a policy design problem, it had ramifications during implementation. Hence, the implementation of the OSD proved to be more expensive than previously planned, illustrated by the comment from one key informant.

It became clear that the government doesn't know how many nurses they actually have. I remember they were even roughly quoting figures, only to find that they under-budgeted around 10,000 nurses. (KII 18, Nursing Union)

A second key challenge was that financial resources were not made available immediately at the hospital level, resulting in problems for individual hospital managers.

The people who planned it [OSD] are wrong because you can't plan to give people money whilst you don't have that money at hand. In our case, we had to pay the nurses even though we didn't budget for OSD. It was said that the budget for OSD will come from the province, but it never came at that time. (Hospital Manager 9, District Hospital, North West Province)

Lastly, insufficient financial resources were exacerbated by problems of overpayment of some nurses, and this meant that hospitals could not fill vacant posts.

People were paid more than they were supposed to be paid, so that's why now we can't even fill vacant posts. (Hospital Manager 9, District Hospital, North West)

#### ***Preconditions 4 and 5: valid theory, clear cause, and effect relationship***

The study found that Hogwood and Gunn's preconditions 4 and 5 were met. There was general agreement amongst respondents that OSD was a 'good' policy, which was informed by the human resource problems in the public health sector, illustrated by the following comments:

Well, in theory it [OSD] was a brilliant idea and it should have gone a long way to solve some of the problems. (KII 7, Gauteng Department of Health)

The nurses' OSD remains the best possible policy to address the issues within nursing. (KII 20, Nursing Union)

The OSD also attracted nurses from overseas back into the country and from the private to the public health sector.

But I have realised that when I was in PE, just before I came here, the introduction of the OSD attracted a lot nurses from the private sector ... when I came here in 2008 February, we employed about 160 nurses from the private sector. (KII 10, Eastern Cape Department of Health)

... turnover was high ... there was a time when we were really struggling to recruit nurses, but I must say the OSD made a huge difference because we are able to recruit people from private sector and we also got two nurses from overseas. (Hospital Manager 4, District Hospital, Gauteng Province)

Key informants were also of the opinion that OSD encouraged nurses to improve their qualification or to specialise in critical care or operating theatre technique.

Nevertheless, some respondents pointed out that OSD was not based on research evidence and were of the opinion that formative research should have been conducted to shape this policy.

I think before they could implement it [OSD], they were supposed to do thorough research and correct calculations. (Hospital Manager 9, District Hospital)

For precondition 5, it can be argued that the causal chain was direct (7). This is because there was an expectation from policy makers that an increase in salary would increase recruitment and retention of nurses.

#### ***Precondition 6: minimal dependency relationships***

Minimal dependency relationships imply that there should be a single implementing agency or if other agencies are involved, that the dependency relationships are minimal both in number and importance (27). However, in terms of the South Africa constitution, health is a concurrent function (or joint responsibility) of the national and provincial governments, with national government responsible for overall policy development, while the nine provincial health departments are the implementing agencies. Invariably, this decentralisation resulted in different interpretations and variations in policy implementation.

OSD implementation was also dependent indirectly on other agencies such as the South African Nursing Council (SANC), as nurses were required to submit proof of their registration and specialised qualifications with the SANC. Nurses were also required to produce their length of service record. Consequently, an informant from a nursing union blamed the SANC for failure to record the relevant nursing qualifications.

I must say SANC nearly failed the [nurses] on OSD, there are things in SANC that we must correct, around the registration of certain courses, accreditation of courses and so forth because we have a large chunk of nurses who were left out of the OSD because they are not regarded as speciality. (KII 20, Nursing Union)

On the other hand, SANC shifted the blame on the nurses for their tardiness in registering their qualifications and only doing so when these were required as part of the OSD implementation.

#### ***Precondition 7: agreement of objectives***

The document review suggests that the policy makers did not take into account the complexities of the various nursing specialities. One respondent remarked as follows:

Nursing is a complicated profession, there are different specialities. So nursing OSD is not as straight forward as any OSD. I think there were grey areas in the implementation of OSD or no clarity (KII 27, Nursing Manager)

For example, the OSD policy lacked clarity on how nurses with more than one speciality were to be rewarded. Furthermore, a grandfather clause was introduced that allowed nurses who worked in a speciality area, but without the formal qualification, to benefit from OSD. On the other hand, those with the formal qualification, but not working in the specialised area could not benefit. This resulted in unhappiness among those nurses and movement of some nurses out of managerial positions back to the specialised area, where OSD was paid. A document review of a letter by the Principal Specialist and Head of one Gauteng hospital to SANC chairperson noted some of these concerns:

Fewer registered nurses are choosing to work in medical wards following the implementation of the Occupational Specific Dispensation (OSD). This is because medical nurses do not qualify for OSD as there is not a recognised post-basic qualification in medical nursing. Consequently, there are fewer registered nurses in medical wards and care of medical inpatients is severely compromised. (Principal Specialist and Head, Regional Hospital, Gauteng Province)

#### **Precondition 8: sequencing of events**

The announcement on the OSD was made by the then Minister of Health, Dr Manto Tshabalala-Msimang prior to ensuring that sufficient financial and human resources were in place. This on its own created a lot of confusion and dismay among nurses when the implementation was delayed at provincial level.

Another important element of sequencing is that the role of each stakeholder involved in the implementation process should be made explicit (27). The OSD policy did not state the responsibilities of provincial or hospital managers explicitly nor the steps required for effective implementation. This resulted in variations in implementation across the nine provinces. One hospital manager commented as follows:

Provinces did as they wish, that's why a nurse in here can be paid differently from a nurse in Eastern Cape or a nurse in Limpopo province. For me, the current system does not work because provinces are independent entities; national [government] usually can say here is a guideline and provinces can decide on how they implement it. (Hospital Manager 7, Provincial Hospital, North West Province)

In the study provinces, the OSD implementation was the responsibility of the Human Resource divisions of the provincial health departments. However, they were not familiar with nursing training and specialities. This

challenge was exacerbated by the unavailability of uniform instructions and inadequate training to support these managers. It was left to these human resource managers to define their role, liaise with the hospital or provincial managers and fulfil these undefined roles to the best of their abilities.

#### **Precondition 9: communication and coordination**

The OSD policy clearly stipulated that its fundamental underpinnings are 'career pathing', 'pay and grade progression', 'specialty' as well as 'competencies' and 'performance'. For instance, one of the objectives noted in the policy reads as follows:

To provide adequate and clear salary progression and career pathing opportunities based on competencies, experience and performance. (OSD Policy, Resolution 3 of 2007)

However, there were many mixed messages sent out to nurses, who either received information from the media or their labour organisations. In the media, OSD was promoted as a general nurses' salary increase and one informant commented as follows:

Unfortunately in the eyes of the nurses, it [OSD] was more about the salary increment. Nurses look at their salary and say 'no, but this thing [OSD] did not benefit me'. (KII 2, Nursing Union)

Hence, the communication did not emphasise the fundamentals of OSD, resulting in disappointment and unrealistic expectations among nurses. Communication and coordination between the National Department of Health and provinces were also inadequate, and it was not clear what support was given to provinces during implementation or how the provinces in turn supported the districts and hospitals. It was also not clear whether and how coordination happened between the SANC and the provinces or health facilities.

#### **Precondition 10: total compliance**

This precondition suggests that those in authority can demand and obtain perfect compliance. However, the authority for implementation was diffused as the nine provinces and different categories of health facility (primary care centre vs. hospital) interpreted the OSD guidelines differently. Key informants pointed out that in both study provinces, implementation varied across health facilities at the same level, and also between primary health care facilities and hospitals. Inadvertently, OSD contributed to further 'imbalances' in the distribution of nurses between hospital and primary health care facilities as well as between provinces.

Lastly, because there was not 'total compliance' in terms of policy implementation, accountability was also diffused, and no one took responsibility for implementation challenges. Instead, it became a vicious cycle of

blame: the National Department of Health blamed the provinces, the provinces blamed the hospital management, the hospital management blamed the unions, and the unions blamed the SANCO, that ironically does not have a mandate for any implementation or participation in financial incentives.

## Discussion

This study used Hogwood and Gunn's 10 preconditions for 'perfect implementation' (27) to assess the implementation process of the OSD. Although the framework has been criticised for being idealistic and impossible to achieve (33), it provides useful insights into the challenges of implementing financial incentive policies. The framework is particularly useful in identifying the strengths and weaknesses of the policy implementation process, thus contributing to knowledge on the implementation processes of financial incentives.

The study found that very few of the preconditions were met, namely that the policy was based upon a valid theory of cause and effect and that the relationship between cause and effect is direct (27).

The study found that a number of preconditions were not met, and this resulted in sub-optimal implementation (34). The challenges included time and resources, dependency relationships, task specification, and communication and coordination. For instance, problems with OSD policy implementation that were demonstrated by other policy implementation studies in South Africa (11, 12, 14) included rushed implementation, lack of consultation with or orientation of provincial health departments of health facility managers, lack of proper time scales, and insufficient resources. Because OSD is a financial incentive, with long-term financial implications, these challenges have to be addressed in the planned revision of OSD policy (35).

The implementation of OSD was decentralised, meaning that the responsibility for implementation, including funding was delegated from national to provincial health departments and from the province down to district, sub-district and hospital levels. As was found in other studies (14, 36), this decentralisation resulted in insufficient coordination among different stakeholders and different interpretations and variations in OSD policy implementation. As Jeppson rightly pointed out, policy implementation in a decentralised system is complex and must be understood in a misdirected translation process (37). Consistent with existing policy implementation studies (12, 14, 19, 32), we also found that there was insufficient communication between the different levels of the health departments. Improved communication might have facilitated better implementation (32).

There are several limitations in this study. The use of Hogwood and Gunn's framework limits a detailed analysis of the actors that were involved in policy processes or

the identification of intended and unintended impact. This framework further assumes that policy implementation is a linear progression. In practice, this is not the case and it is unlikely that all 10 preconditions of Hogwood and Gunn would be in place prior to implementation of most government policies. Also, the framework does not take into account that setbacks in policy making and implementation are opportunities for revisions, redesign, and self-correction (38). The study was done in two provinces, which limits its generalisability, and the use of key informants reflects their opinions at a point in time.

Nonetheless, there are important lessons to be learned from this case study that could inform the planned revision of the OSD policy. These lessons include the need for better planning and management of the implementation process, careful communication, and change management to ensure that unrealistic expectations are not created, as well as the development of detailed guidelines for implementers and extensive training of these implementers. There is also the need for clear monitoring and evaluation indicators that will allow problems to be picked up at an early stage. This will allow for remedial action to be taken. These lessons are also useful in light of the planned implementation of major health care reforms, notably the National Health Insurance System, thus avoiding a repeat of these mistakes on a much bigger scale.

## Conclusion

The success of financial incentives depends on the manner and process of implementation. Implementation weaknesses can be overcome by paying attention to the conditions needed for successful implementation, namely better planning and management of the implementation process, improved communication and coordination, detailed guidelines for implementers, and clear monitoring and evaluation indicators. However, in acknowledging that 'perfect implementation' is rarely achievable, setbacks in implementation of financial incentives should be taken as an opportunity for revisions, redesign, and self-correction.

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**\*Prudence Ditlopo**

Centre for Health Policy  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Email: [prudence.ditlopo@wits.ac.za](mailto:prudence.ditlopo@wits.ac.za)

# Developing a new mid-level health worker: lessons from South Africa's experience with clinical associates

Jane Doherty<sup>1\*</sup>, Daphney Conco<sup>1</sup>, Ian Couper<sup>2</sup> and Sharon Fonn<sup>1#</sup>

<sup>1</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Division of Rural Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** Mid-level medical workers play an important role in health systems and hold great potential for addressing the human resource shortage, especially in low- and middle-income countries. South Africa began the production of its first mid-level medical workers – known as clinical associates – in small numbers in 2008.

**Objective:** We describe the way in which scopes of practice and course design were negotiated and assess progress during the early years. We derive lessons for other countries wishing to introduce new types of mid-level worker.

**Methods:** We conducted a rapid assessment in 2010 consisting of a review of 19 documents and 11 semi-structured interviews with a variety of stakeholders. A thematic analysis was performed.

**Results:** Central to the success of the clinical associate training programme was a clear definition and understanding of the interests of various stakeholders. Stakeholder sensitivities were taken into account in the conceptualisation of the role and scope of practice of the clinical associate. This was achieved by dealing with quality of care concerns through service-based training and doctor supervision, and using a national curriculum framework to set uniform standards.

**Conclusions:** This new mid-level medical worker can contribute to the quality of district hospital care and address human resource shortages. However, a number of significant challenges lie ahead. To sustain and expand on early achievements, clinical associates must be produced in greater numbers and the required funding, training capacity, public sector posts, and supervision must be made available. Retaining the new cadre will depend on the public system becoming an employer of choice. Nonetheless, the South African experience yields positive lessons that could be of use to other countries contemplating similar initiatives.

**Keywords:** *mid-level medical workers; human resource policy and production; district hospitals; South Africa; policy analysis*

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Achieving universal coverage requires strong district health systems that reach even the most disadvantaged and remote communities (1). However, attracting staff to work in such settings is a perennial problem (2). The international experience suggests that mid-level health workers have played an important role in addressing human resource shortages and improving health care access and equity, especially in low- and middle-income countries (3–5). A review of mid-level workers found that they are a world-wide phenom-

enon, playing a variety of roles in both developed and developing countries, from augmenting the work of doctors to independent practice (6). They are present in large numbers in Southeast Asia and are the backbone of the primary care system in East Africa, with more than 10,000 clinical officers trained in Uganda, Tanzania, and Kenya alone. They are being introduced, or their roles are being expanded, in the United Kingdom, Canada, and Australia. There is evidence that, 'with appropriate and adequate training ... and provided with continued

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support and supervision, [mid-level workers] can indeed provide care comparable to medical professionals' (6: 305). However, some mid-level worker programmes have failed, not because the concept is flawed, but as a result of '... weaknesses relating to poor teamwork, competing market forces, [poor] production processes and employment opportunities as well as a lack of synergy between involved role players and the processes of regulation, production and employment' (7, p. 7).

This article describes how South Africa embodied the international experience in the way it conceptualised and introduced a new mid-level medical worker known as a clinical associate. The creation of this new cadre forms part of a broader strategy to strengthen district health systems and extend health care coverage by dealing with South Africa's own human resource shortages. These shortages are considerable when compared to other middle-income countries, with 60,000 additional doctors required to reach ratios equivalent to those in Brazil (8, 9). The article draws lessons from South Africa's early implementation of the clinical associate programme to inform the efforts of other countries seeking to expand the range of mid-level workers deployed in their health systems.

## Methods

This article is based on a rapid assessment that used a qualitative approach and was conducted in 2010 (10). Prior to commencement, ethics approval was obtained from the University of the Witwatersrand Committee for Research on Human Subjects (clearance certificate M090674).

The study consisted of a document review and a set of semi-structured interviews. The document review was purposive in nature and looked at 19 local policy documents, reports of government and university planning meetings, preparatory studies, and published opinion pieces that reflected on the development of the clinical associate strategy and were easily accessible. Eleven interviews were conducted with a purposive sample of stakeholders integrally involved in the mid-level medical worker programme through policy development, planning, or training (i.e. national and provincial ministries of health, the national Treasury, training institutions, and professional councils).

The issues that were investigated through both the document review and interviews included the reasons for the programme and its objectives; the history of the programme, including the process of stakeholder engagement; the roles and attitudes of the various stakeholders; the key design features of the programme and the reasons for these; the successes and challenges of early implementation and the reasons for these; and future problems anticipated. These themes were developed on the basis of lessons from international literature as well as the

authors' personal knowledge of South African and international mid-level worker programmes.

Prior to the interview, each key informant was provided with an information sheet and consent forms. Two senior researchers using semi-structured interview guides and a recorder conducted interviews. All interviews were transcribed. The anonymity of key informants was protected by using number codes for interview transcripts.

A thematic analysis was conducted on the document reviews and interview transcripts based on the pre-identified themes. Information that could be triangulated because it appeared in several sources (whether documents or interviews) formed the basis of our findings, although sometimes we had to formulate findings on the basis of single sources of information (in which case these findings are indicated as tentative). During write-up, Walt and Gilson's Policy Analysis Triangle (11) was used to group themes: this approach makes explicit the complex interaction between actors (at the centre of the triangle) and context, process and policy design (at the points of the triangle), aiding understanding of why and how a policy has an impact.

The final draft of the study report was sent to key informants who were given several months to provide feedback. Seven people submitted comments, providing another opportunity for triangulation, and these were incorporated into the final version of the report.

A limitation of the study was that not all of the stakeholders who were initially identified by the researchers were available for interview during the study's timeframe. However, the most relevant stakeholders were interviewed and key informants provided some information on other stakeholders' positions. Very little new information came to light during the final interviews, which suggested that some measure of saturation had been achieved and that the interviews were able to capture the main dimensions of policy-makers' and implementers' experience.

## Results

### *Key features of the clinical associate programme*

The overall purpose of South Africa's clinical associates is to strengthen health care at district hospitals<sup>1</sup> as integral members of the health care team, in the context of revitalising primary care at district level. They take over some of the tasks of doctors so that their time is freed up to perform higher-level functions. Some of these tasks are currently being performed by nursing staff though they are outside of their scope of practice, a form of task-shifting that is common in resource-poor

<sup>1</sup>In South Africa, district hospitals are staffed by generalist doctors and operate at sub-district level, providing support to primary health care services.

settings (12). By allowing other cadres to focus on their own roles and fulfil them better, and strengthening a level of hospital care that suffers severe staff shortages in South Africa, clinical associates will provide better access to care for marginalised communities and reduce the need for referral.

Clinical associates are required to work under the supervision of doctors. Their scope of practice includes patient consultation and physical examination, routine diagnostic and therapeutic procedures, assisting with emergencies and inpatient care, and counselling. Their skills are generalist rather than specialist. It is anticipated that clinical associates may develop more specialised skills as they gain clinical experience but this will depend on the particular needs of the hospital, the interests of the supervising doctor, and the capabilities of the individual clinical associate.

Three main features distinguish the clinical associate from nurses who have developed specialised clinical competencies (traditionally known in South Africa as primary health care nurses). First, these nurses are registered nurses who have completed basic training through a 4-year degree (or diploma) and then obtained a post-basic diploma. Therefore, their training takes at least 5 years compared to the 3 years it takes to train a clinical associate. Second, unlike clinical associates, these nurses are independent practitioners and therefore do not have to work under the supervision of a doctor. Their competencies also include prescribing and issuing drugs on the primary health care essential drugs list (schedules one to four) (13). Finally, these nurses are trained to diagnose and treat patients who are appropriately seen in an outpatient setting and do not have significant training in conducting the diagnostic and therapeutic procedures typically required of an inpatient setting.

Training of the first cohort of clinical associates began in 2008. The bachelor's degree course is offered by three of the country's eight medical schools. A national curriculum framework guides participating universities and ensures a common standard while allowing local differences and protecting university autonomy.

Students are mainly recruited by the four provincial health authorities participating in the programme (and, more recently, the South African Military Health Services), with a special emphasis on identifying students from remote areas. Students are offered provincial bursaries in return for undertaking to work in the provincial health services immediately after qualifying for as many years as they received the bursary.

The teaching approach is small-group learning with maximum practical experience. Class sizes began relatively small, ranging from the mid-twenties to mid-fifties, although more recently one medical school has settled on a class size of 80. Students receive some early training on the main university campus but within weeks spend most

of their time in selected district hospitals that have received some physical upgrading for training purposes.

Training is coordinated locally by small teams of two to three staff who mostly have 'joint appointments' (where the incumbent has both academic responsibilities towards a university and service responsibilities towards the public health sector). In one province, the aim is to have 12 clinical associate students per district hospital in each year of study (so that there are 36 students at each hospital at any one time), with two training staff for every 12 students and one administrative person for all 36 students. District Training Complexes are evolving at some sites: these allow for the training of medical and other undergraduates, medical interns, family medicine registrars, and primary health care nurses alongside clinical associates.

Thus far, training has proceeded relatively smoothly and is reportedly of good quality. Pass rates for the first student cohorts were approximately 95% or more and new graduates have demonstrated confidence and competence in their new workplaces. There are anecdotal accounts that staff in training facilities appreciated the contribution made by students in relieving their workload, and there appears to be a demand for new graduates. However, a formal evaluation of the quality of graduates has still to be performed as well as an assessment of the manner in which the first graduates have been received by the wider health workforce since their entry into the job market in 2011.

### *Factors accounting for the early success of the clinical associate programme*

The initial success of the clinical associate programme was due to savvy policy-making and training implementation processes, underpinned by favourable contextual factors. These enlisted the support of key stakeholders (or at least diffused resistance from potential antagonists) and resulted in a clinical associate programme tailored to the country's needs.

Thus, for example, the political context supported the introduction of clinical associates. The African National Congress, the majority party in government since the first democratic elections, had always endorsed the concept of mid-level workers while one minister of health was particularly instrumental in driving the implementation of the clinical associate programme.

Initial opposition to the concept from some quarters was dissipated through a process of consultation with a range of stakeholders, including primary health care nurses and their trainers, rural doctors and family physicians, provincial and national ministries of health and politicians, the ministry of education, medical schools, professional organisations of doctors and nurses, and professional councils. Accommodating stakeholder concerns in the formulation of the new cadre's scope of

practice (e.g. through focusing on procedures and requiring a doctor's supervision) was important to achieving stakeholder buy-in, especially among doctors and nurses. Growing awareness of the human resource crisis facing South Africa helped in this regard.

Committed and technically expert family physicians were carefully identified to support government planners. Together they reviewed international evidence, conducted country visits, determined the nature of health conditions that could be dealt with by a mid-level medical worker at district hospital level, developed the clinical associate concept, and produced the national curriculum framework. During this process, a Ministerial Task Team was formed to provide guidance and impetus to policy formulation and early implementation: this provided stability in the early years of the programme. Further, some members were also responsible for developing the clinical associate course at their home universities, lobbying for support among their colleagues, and developing a sense of ownership among university faculty. The health authorities and professional council encouraged this by allowing each university to develop its own course within the overall national framework.

Implementers' viewpoints were incorporated in the early stages of policy development. This happened partly through working closely with university-based course developers who were very familiar with the needs of remote district hospitals and the challenges of providing training in these settings, and had already established good working relationships with some district hospital staff. Further, provincial-level health officials were involved in all stages of the process: this developed a sense of commitment to the programme in the provinces and led to them becoming instrumental in advertising, selecting students, awarding bursaries, assisting in the refurbishment of sites, creating 'joint appointment' posts for training staff, and weathering implementation obstacles, especially funding shortages.

Table 1 provides more detail on how the design of the clinical associate programme accommodated contextual factors, stakeholders' concerns, and implementers' advice whilst retaining the original objectives of the clinical associate programme and wider human resource policy, namely the extension of health care coverage and improvement of the quality of care at the district level, especially in rural communities (9).

### **Challenges to the sustainability of the clinical associate programme**

While key informants felt that the early curriculum development and training of clinical associates had been successful, many pointed out that these achievements were precarious. One government respondent ascribed this to 'rapid implementation which, in my

opinion, overwhelmed our administrative capacity to actually manage that implementation'.

For example, start-up funding for course development and training the first cohorts of students was expected from donor sources but was never properly secured because of the difficult economic climate faced by donor countries and banking delays in transferring funds. This was aggravated by an apparent miscommunication between the ministry of health and Treasury around planning and releasing special allocations for the start-up of the clinical associate programme.

The funding shortfall meant that universities largely had to draw on their existing resources, leaving teaching faculty stretched to the maximum. Hospital managers also found it difficult to pay for new training posts and other related training costs out of their existing budgets; provincial directors faced the same problem with funding bursaries. This raises questions about the prospects for expansion of the clinical associate programme. The currently low levels of production will not have a substantial impact on the health care needs of the country and considerable scaling up is required to meet the minimum target of 1,350 clinical associates, equivalent to five per district hospital (9), let alone the 16–20 clinical associates per hospital that some key informants estimated are actually required.

While regular ministry of education subsidies to universities kick in as students begin to graduate, there will inevitably be a mismatch between these subsidies and training costs as class sizes expand, new student cohorts are added, and more universities participate in the programme. This threatens the ability of universities to preserve the high quality of training that was made possible in the early days of implementation through the participation of a few highly committed and skilled teaching faculties and the availability of adequately resourced district training sites.

The first cohorts of graduates are still working back their bursaries in the public sector but soon their obligations will be met. Poor working conditions and management systems in the public sector contribute to poor staff retention, especially in rural areas (14). These conditions may be expected to impact on the aspirations of clinical associates also, although it is hoped that the rural origin of clinical associates, and their training in rural facilities, will equip them better for rural practice (15). Nonetheless, several key informants felt that the private sector would 'snap up' clinical associates once they are free to leave the public sector.

Insufficient posts in the public sector could hasten this brain drain, as has been the experience with other forms of mid-level workers in South Africa who have migrated to the private sector. Until now, participating provinces have used vacant posts for other health professionals to

**Table 1.** Design features of the clinical associate programme that contributed to initial successes

Design feature	Potential value*
<b>Linkage to training and regulation of doctors</b>	
Training of clinical associates is located within medical schools as a 3-year degree course	Confers status on the new cadre
Regulation of the cadre is through the medical and dental board	Fosters synergy between clinical associates and doctors who have to work closely together
	Training is quicker and less costly than for a doctor, and there will not be a brain drain overseas as the degree is not recognised internationally
	Enables post-graduate training which supports career progression
<b>National curriculum and exam</b>	
A national curriculum framework guides the courses at different universities	Ensures comparable training and maintains standards
Students face both a local and national final exam	Allows local flexibility and innovation
<b>Clearly defined position within the district hospital health care team</b>	
The clinical associate is conceptualised as part of a collaborative district-level clinical team that includes the doctor working with a primary health care nurse at the clinic and health centre level, and the doctor working with the clinical associate at the district hospital level	In tandem with policies to improve district management capacity, supports the development of a particularly weak level of the district health system (i.e. the district hospital) and relieves the workloads of nurses and doctors
The scope of practice of the clinical associate is tailored to the specific context and needs of the district hospital	Responds to the patient profile at district hospitals (district hospitals do not have enough patients with complex conditions that warrant full-time specialist clinical associates, such as an anaesthetic assistant)
There is an emphasis on generalist skills and flexibility in response to the particular situation of the individual hospital and health worker	Clarifies differences in scopes of practices and reporting lines and avoids overlap of roles with primary health care nurses
	Diffuses concerns of other health professionals
	Encourages a sense of belonging to a team
	Creates a 'pluri-potential' person who is not locked into specific tasks and is able to adapt to different tasks during their working day and longer-term career
<b>Rural recruitment and training</b>	
Students are recruited from rural and other disadvantaged areas	Creates a new route of entry into the medical field, especially for students from marginalised communities
The bulk of training is in rural facilities	Produces health workers who can communicate with patients in their home language
	Enhances retention in rural areas
<b>Supervision by doctors</b>	
Adequate supervision and support is ensured through making the presence of a doctor integral to the functioning of a clinical associate	Strengthens quality of care
	Alleviates concerns about the ability of clinical associates to deliver quality care
<b>Service-based learning</b>	
Service-based learning	Provides plenty of opportunities for practical learning
Creation of District Training Complexes	Allows students to become familiar with local circumstances, the district hospital setting and community in which they will one day work
	Students demonstrate their usefulness to other staff by immediately relieving their workload
	Helps to realise the goal of decentralised, multi-disciplinary training that makes health workers better equipped for, and more responsive to, community needs
	Allows the development of teaching approaches that can be applied to other categories of health professional
	Provides additional motivation and support for staff, improving recruitment and retention

\*This is the value identified by key informants. Whether the potential has been fully realised needs to be determined by a more comprehensive evaluation.

accommodate new clinical associate graduates, but this will become increasingly difficult as production continues.

Confrontations between the new cadre and existing health professionals around the boundaries of scopes of practice and prescription competencies are also looming. In the meantime, clinical associates have been stopped from prescribing by the Pharmacy Council, at least until new regulations are promulgated, while recently qualified clinical associates are beginning to challenge their salary scales, given the extensive amount of work they are taking over from doctors. It is the international experience that it is difficult to clarify and protect the boundaries between the scopes of practice of different health professional categories, especially in settings that are hugely under-resourced, as tasks have to be shared by whoever is on duty (12). It is also likely in South Africa that clinical associates in some hospitals will be expected to perform their duties without the required supervision as doctors are not always available, as has been the experience with newly graduated doctors working through their community service commitments (16). These trends may undermine the carefully negotiated support of this new cadre by health professional associations and create aspirations for greater recognition and remuneration among clinical associates in a context where the impact on the quality of care – whether positive or negative – remains unmeasured.

### *Immediate priorities for securing the future of the clinical associate programme*

Treasury and the ministries of health and education will have to find mechanisms to expand and stabilise funding for the training of clinical associates. The elements of the training programme requiring funding are summarised in Box 1. Short-term funding solutions are required at the start-up of new training programmes and during rapid expansion, such as special allocations by Treasury, but a long-term solution would be something like a national training grant combined with contributions from provinces' regular budgets, although these are highly constrained in the current economic climate. To reach this point, the ministry of health needs to present Treasury with clear documentation that puts the case for clinical associates, sets targets, and lays out in detail the plans for scaling up production and deployment: these negotiations are quite urgent given the long lead time involved in the annual budgeting cycle. Another possible response to the funding crisis is to improve the efficiency of the current training programmes which one respondent characterised as using 'models of teaching [that] tend to be very expensive'.

Equally importantly, posts need to be created in the public sector to absorb new graduates. This is not purely a technical exercise. There is much professional sensitivity involved in the issue, relating to how different lengths and

#### *Box 1. Costs associated with mounting a new clinical associate training programme*

Salary package for course coordinator.  
 Salary and other costs related to the design and approval of the new curriculum and the development of new teaching materials.  
 Salary packages for teaching staff (mainly joint appointees based at district hospitals).  
 Associated office costs and overheads.  
 Salary packages for administrative staff.  
 Infrastructure development, including refurbishment of district teaching hospitals and district-based teaching sites.  
 Accommodation and food for students.  
 Transport for students.  
 Bursaries for marginalised students to cover student fees. (including materials, access to services such as libraries, etc.)

sophistication of training and clinical experience are recognised and remunerated. This means involving the ministry of public service administration, one of the few stakeholders that was not an integral part of earlier consultations.

More 'joint appointment' training posts are also required. Respondents identified these as critical in sustaining the quality of clinical associate training at district hospitals, especially as the number of hospitals involved in the training programme expands. Partnerships between rural facilities and universities also help to attract good calibre staff (thereby helping to strengthen the district health system as a whole) and are integral to realising decentralised training of many other categories of health worker (17).

Tensions between the different members of the health care team also need to be actively managed. Whilst a considerable amount of effort was put into this initially, there still remains a risk that clinical associates will be received with suspicion, especially in facilities that were not involved in training. Orienting managers and other health professionals to the role of the new cadre, and advertising the fact that successful relationships have already emerged between students, staff, and patients in training facilities, are strategies that may alleviate anxiety about clinical associates. Clarifying opportunities for the career progression of clinical associates – including post-graduate training, becoming trainers, and entry into management echelons – is another strategy. A wide array of interventions to improve staff recruitment and retention for all staff categories, including clinical associates, is also required to improve the attractiveness of district-based practice, especially in disadvantaged areas (3, 15).

**Table 2.** Lessons from South Africa's experience of clinical associates for introducing a new mid-level worker

	Positive lessons	Cautions
Taking account of contextual issues	<p>Support advocacy for a new mid-level worker programme by drawing on previous policy documentation, where this exists, and taking advantage of political moments that are favourable to change.</p> <p>Seize the opportunity provided by an influential policy champion to drive through the implementation of the programme.</p>	<p>Sometimes policy documents pay lip-service to mid-level workers, which mean that continued advocacy is required to popularise the concept. Highlight the relevance of the concept to new policies as they emerge.</p> <p>As policy champions may move on with time, make sure to build broad-based support for the concept over time.</p>
Managing actor concerns	<p>Consult widely at the early stages of policy formulation and allay fears through advocacy and adjusting the design of the new mid-level worker programme to take account of stakeholders' views and interests without sacrificing important policy objectives.</p> <p>Build strong channels of communication with key implementation agencies. In particular, ensure that Treasury and the ministry of public service administration are brought on board and participate at critical moments in the planning process. Involve local health authorities closely with the process of student selection and development of training sites.</p> <p>Where resistance to the new cadre is encountered (for example, on the part of health authorities, training institutions and other health professionals), allow phased introduction of the programme to build support on the basis of demonstrable benefits.</p>	<p>As implementation proceeds, consensus will erode as unexpected problems emerge. Address this through continued consultation and feedback, modifying the policy or implementation approach if appropriate.</p> <p>Other government ministries have their own timelines and information requirements. Ensure these are met in order to ensure a smooth flow of activities, such as the release of funding and creation of new post structures, levels and staff complements.</p> <p>Strong national leadership is required to withstand pressure from other health professionals where this is based on narrow self-interest. Complementary measures to bolster the status of the new cadre may be required.</p>
Building a strong process of policy formulation and implementation	<p>Take time to study the international experience, including visiting best practice sites, and incorporate these lessons into local policy.</p> <p>Understand health system needs properly, conducting exploratory studies and consulting widely.</p> <p>Create a committed team of experts and other key stakeholders who will drive policy formulation, consultation and implementation, as well as ensure continuity.</p> <p>Include implementers' concerns from the early stages of policy formulation.</p>	<p>Re-visit these lessons over time, especially when preparing for the entry of new graduates into public service, as this is a high-risk moment in the development of a mid-level worker programme.</p> <p>Monitor the programme closely in both the initial years of production and deployment, including through consultation, in order to check progress against objectives and detect unexpected problems.</p> <p>Sustain this 'task team' into the early phases of deployment of new graduates so that unintended problems can be addressed before they spark resistance. Thereafter, sustained effort is required to ensure that the scaling up of training – and the hiring of new graduates into the public sector – proceeds as planned in order to make a substantial difference to the functioning of the district health system.</p> <p>The intense energy required to implement a new policy often dissipates once there have been early achievements. Maintain close links with implementers throughout the policy development and implementation process in order to anticipate problems that may derail these early successes.</p>

Table 2 (Continued)

	Positive lessons	Cautions
	<p>Develop a short-term and long-term funding strategy that will secure the start-up of training, allow scaling up of the programme and ensure posts are available for new graduates.</p> <p>Develop an active strategy for incorporating new graduates into the public health system.</p>	<p>Promised funding does not always materialise or is released out of synchrony with training and service needs. This requires contingency planning and negotiation of interim measures.</p> <p>This is one of the most challenging components of implementation and, if not handled properly, can lead to the collapse of a programme. While the creation of new posts is very important, do not neglect 'softer issues' such as developing appropriate management systems and teamwork. In particular, strong supervision and support systems are required to realise the potential of the new cadre, which in turn is essential for establishing the cadre as a permanent feature of the health system. Active recruitment and retention strategies, including career pathing, are required to prevent brain drain to the private sector.</p>
Designing an appropriate policy	<p>Take care to describe and delineate the scope of practice well, paying particular attention to meeting well-defined health care gaps and differentiating the new cadre from other health professionals with whom they will work closely.</p> <p>Link the curriculum closely to the scope of practice and health system needs. Create a professional that is flexible and adaptable so that he or she may work effectively in typically under-resourced settings.</p> <p>Conceptualise the new cadre as part of a team whilst also clarifying lines of reporting.</p> <p>Recruit students from rural and disadvantaged areas. This is an important strategy for retention.</p> <p>Employ service-based and small-group learning. This requires the appointment and nurturing of locally based training coordinators, including through joint appointments between universities and health authorities.</p>	<p>Assess how the scope of practice plays out in practice and adjust it where appropriate. Efforts to strengthen the health system may need to occur in tandem as it is difficult to realise ideal scopes of practice under sub-optimal conditions.</p> <p>Implement efforts to standardise training, such as a national curriculum framework, national exams and independent evaluations of courses. Allow some local flexibility in training. In order to prevent brain drain overseas, tailor training specifically to local conditions. Implement on-going efforts to build teamwork, such as better management and communication processes.</p> <p>Develop mechanisms to support these students e.g. bursaries, mentorship to support adjustment to the experience of tertiary training.</p> <p>This is a resource-intensive option but can be used to strengthen district health systems at the same time as producing the new cadre. For example, the creation of District Training Complexes can be used to galvanise improved training for the full range of health professionals and act as a spur to recruiting high calibre staff.</p>

Finally, it is unclear whether national-level support for the clinical associate concept is as enthusiastic now as it was previously. The ministry of health is absorbed in implementing two other massive and challenging reforms (i.e. primary health care re-engineering and national health insurance). Policy-makers and planners have not highlighted the part that clinical associates could play in realising the objectives of these reforms, even though the latest national human resource policy states very clearly that the production of more clinical associates is a priority (9).

### *Lessons learnt from the clinical associates programme*

The specific findings described above yield some general lessons around how to take contextual factors into account when developing a mid-level medical worker programme, manage actor concerns, build a strong process of policy formulation and implementation, and design an appropriate policy. Using the policy analysis approach of Walt and Gilson (11), we group these lessons for other countries in Table 2. Also included in the table are cautions around issues that, in our analysis of the

interviews and documents, seem to have been dealt with less adequately in the South African context. Some of these were raised as concerns in the early days of formulating the clinical associate policy (18) and many resonate with accounts in the international literature (4, 19–21). This suggests that internationally, and in South Africa, strong national leadership and action are required to preserve the gains made by mid-level medical programmes. These lessons and recommendations remain tentative, however, until a more formal and comprehensive evaluation of the South African clinical associate programme can be conducted.

## Conclusion

South Africa has introduced a new form of mid-level medical worker to contribute to the quality of district hospital care. Only small numbers have entered the health system to date, and it is too soon to tell whether this new category of health professional will achieve its full potential. Immediate and significant challenges are scaling up production, creating funded public sector posts to absorb new graduates, dealing with tensions between different members of the health care team around scopes of practice, managing the career aspirations of the new cadre as they gain experience, and preventing a brain drain to the large and attractive private sector. Assessing the impact of the new cadre on the quality of care will soon become a new priority, given general concerns about the quality of management and clinical supervision at district hospitals.

The mid-level medical worker programme has made a strong start, however. Technical experts and policy-makers drew on international experience in the development and implementation of the new health worker programme in order to pre-empt some of the problems encountered in other settings. They also investigated South Africa's own experience of the introduction of other types of mid-level worker to learn from past mistakes. This led to buy-in from other health professionals, integral support and involvement by participating provincial health authorities, the recruitment of good quality students from disadvantaged areas, standardised and good quality training, and possibly alleviation of other health professionals' workloads. Central to the success of the programme was a clear definition and understanding of the interests of various stakeholders.

This experience adds to the considerable international evidence on the strengths and challenges of developing mid-level workers and yields some additional lessons that could be of use to other countries contemplating similar initiatives.

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**\*Jane Doherty**

School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Email: [dohertyj@telkomsa.net](mailto:dohertyj@telkomsa.net)

# Administrative integration of vertical HIV monitoring and evaluation into health systems: a case study from South Africa

Mary Kawonga<sup>1\*</sup>, Sharon Fonn<sup>2#</sup> and Duane Blaauw<sup>3</sup>

<sup>1</sup>Gauteng Health Department, Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>3</sup>Centre for Health Policy, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** In light of an increasing global focus on health system strengthening and integration of vertical programmes within health systems, methods and tools are required to examine whether general health service managers exercise administrative authority over vertical programmes.

**Objective:** To measure the extent to which general health service (horizontal) managers, exercise authority over the HIV programme's monitoring and evaluation (M&E) function, and to explore factors that may influence this exercise of authority.

**Methods:** This cross-sectional survey involved interviews with 51 managers. We drew ideas from the concept of 'exercised decision-space' – traditionally used to measure local level managers' exercise of authority over health system functions following decentralisation. Our main outcome measure was the degree of exercised authority – classified as 'low', 'medium' or 'high' – over four M&E domains (HIV data collection, collation, analysis, and use). We applied ordinal logistic regression to assess whether actor type (horizontal or vertical) was predictive of a higher degree of exercised authority, independent of management capacity (training and experience), and M&E knowledge.

**Results:** Relative to vertical managers, horizontal managers had lower HIV M&E knowledge, were more likely to exercise a higher degree of authority over HIV data collation (OR 7.26; CI: 1.9, 27.4), and less likely to do so over HIV data use (OR 0.19; CI: 0.05, 0.84). A higher HIV M&E knowledge score was predictive of a higher exercised authority over HIV data use (OR 1.22; CI: 0.99, 1.49). There was no association between management capacity and degree of authority.

**Conclusions:** This study demonstrates a HIV M&E model that is neither fully vertical nor integrated. The HIV M&E is characterised by horizontal managers producing HIV information while vertical managers use it. This may undermine policies to strengthen integrated health system planning and management under the leadership of horizontal managers.

**Keywords:** *integration; vertical programme; disease-specific intervention; health system strengthening; monitoring and evaluation; district health system; South Africa*

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Efforts to improve health in low- and middle-income countries (LMIC) are often characterised by tensions between horizontal approaches, which seek to tackle health problems 'on a wide front, through the creation of a system of permanent institutions commonly known as general health services' (1), and vertical approaches, which tackle one specific health problem

through targeted delivery, coordination, financing, or information mechanisms (2, 3). While vertical approaches increase the coverage of targeted interventions, their parallel mechanisms undermine and fragment health systems (4). For example, a vertical approach to the scale-up of antiretroviral treatment (ART) attracts staff away from general services and establishes parallel drug

<sup>#</sup>Supplement Editor Sharon Fonn has not participated in the review and decision process for this paper.

supply mechanisms that bypass and undermine national systems, whereas a horizontal approach strengthens capacity of general services and existing health system drug-delivery systems which include catering for ART scale-up needs (5). Thus, approaches that maximise synergies between health systems and programmes are recommended, including the diagonal approach to strengthen health systems through pursuing specific disease priorities (6, 7), or full integration of vertical programmes within health systems (8).

Integration is most commonly described as providing two or more vertical services at the same point of care (9–11). Increasingly it is understood as integrating policies, management (administrative integration) or implementation activities (operational integration) of vertical programmes within health system functions such as governance, service delivery, financing, or monitoring and evaluation (M&E) (12, 13). Data relating to policy and operational integration are becoming more available (12, 14, 15), but less so for administrative integration (16). Unger et al. (13) conceptualise administrative integration as: integrating the middle management of disease-specific programmes within general service management, giving general service (horizontal) managers administrative authority over disease-specific activities, and disease-specific (vertical) managers providing technical advice. This implies a shift in day-to-day administrative responsibility over disease-specific interventions from vertical to horizontal managers. For example, for the health system M&E function (which entails data collection, collation, analysis, and use (17)), administrative integration might mean that horizontal managers exercise authority in coordinating collection and collation of disease-specific data and refer to vertical managers for technical advice on how to use these data for management. Whether this model of administrative integration is happening in South Africa has not been documented.

### *Vertical programmes and the health system in South Africa*

In South Africa, integration is a health sector reform priority, while several vertical programmes exist, notably for HIV, tuberculosis (TB), and maternal and child health (MCH) (18). For example, the HIV programme was introduced soon after 1994 with earmarked funding (19) and later a conditional grant (20), as well as a dedicated M&E system (21). Initially focussed on prevention, it has evolved over time to include ART; HIV services have been progressively integrated within general health services (22, 23). However, historically a national HIV/AIDS directorate and HIV managers at provincial and district levels have controlled the programme. Furthermore, HIV programme managers account for the HIV conditional grant by submitting data and financial reports to the National Treasury through dedicated reporting

mechanisms. Also, several sub-programmes (e.g. for HIV counselling and testing [HCT], prevention of mother-to-child HIV transmission [PMTCT], and ART) have been established within the HIV programme and are coordinated in separate silos, indicating further verticalisation (24). This is at odds with current health sector decentralisation reforms that envisage integrated health management under the control of horizontal managers at district level. South Africa's decentralisation reforms entail: the devolution of political and administrative authority from national level to nine semi-autonomous provincial governments (25), and the establishment of a district health system (DHS) by shifting health management responsibility from provincial to district health clusters (deconcentration) (26, 27). A nationally standardised district health information system (DHIS) has been established to support DHS management (28).

If the DHS is to be the foundation of the health system as envisaged, then district managers need to exercise authority over DHS functions, including disease-specific interventions (i.e. administrative integration). This study examines whether this is happening. We use the HIV programme as a case study given its traditionally vertical approach, and focus on the M&E (information) function as a tracer for analysing administrative integration (24). Our study therefore aims to: describe the extent to which horizontal managers exercise authority over HIV M&E coordination, determine factors associated with exercised authority, and explore vertical managers' roles in HIV M&E coordination. We hypothesise that vertical managers and those with higher management capacity and HIV M&E knowledge exercise more authority.

## **Method**

### *Study design and setting*

We conducted a cross-sectional study during 2010–2011 in two of South Africa's nine provinces (one rural [Site A], one urban [Site B]). Each province comprises several districts, each with sub-districts further divided into local areas (clusters of health facilities). In both sites, horizontal managers at district, sub-district, local area, and facility levels coordinated general health services. Both HIV programmes were coordinated by a senior HIV manager, 3–4 sub-programme HIV managers and several assistant sub-programme managers at provincial level, assisted by one HIV manager each at district, sub-district (Site A only), and district hospital levels. Horizontal information managers coordinated the DHIS. At the time of this study, HIV data recording and reporting were integrated within the DHIS in Site B (though HIV data were recorded by dedicated staff and coordinated by a HIV M&E manager). In Site A, HIV prevention data were fully integrated within the DHIS, while ART data were coordinated separately by a HIV M&E manager (24).

**Study population and sampling**

We purposively selected sites where we have on-going research. We included only public sector services. We selected one of three districts in Site A, and one of six in Site B, and within each district selected one sub-district and one local area per sub-district. All primary care facilities within a local area, as well as the district hospital HIV service were included (representing the full spectrum of HIV services: those initiating patients on ART; those to which patients started on ART who are referred for on-going care; and those providing HIV prevention only [HCT, PMTCT, and HIV/TB]). Our inclusion criteria

were: i) manager works at any level from facility to provincial; ii) manager is primarily responsible for general health services or information (horizontal manager) or for vertical services or information (vertical manager); iii) manager coordinates the production of HIV information (data collection, collation, analysis) and/or uses HIV information. Of 53 managers selected, 51 participated (Fig. 1).

**Approach for measuring ‘exercised authority’**

There are no existing tools to measure ‘exercised authority’ over programme administration. Bossert’s

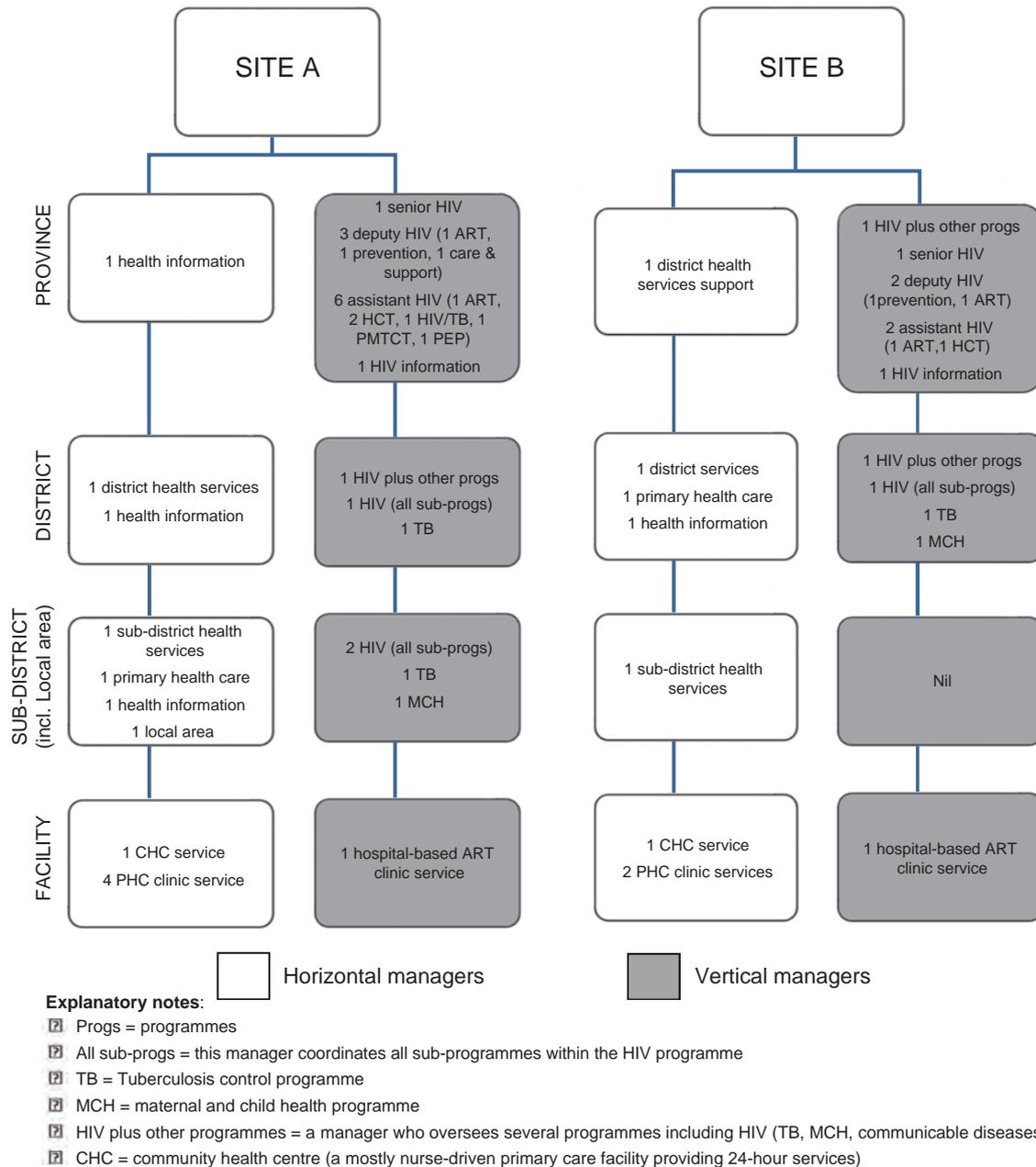


Fig. 1. Study participants at each level of the health system.

‘decision-space’ approach however provides a useful frame (29). Bossert’s tool collects data to rate the degree to which sub-national officials exercise decision-making authority over health system functions after decentralisation as ‘narrow’, ‘moderate’ or ‘wide’. As it has never been applied to either the health system M&E function or to other programmes, we could not use it as is. However, we followed a similar approach to measure ‘exercised (administrative) authority’.

We defined exercised authority over the HIV M&E function as: *a manager undertakes tasks to oversee HIV data collection, collation and analysis, and uses HIV data to review the programme and take action*. To measure this, we first identified the M&E tasks that managers are reasonably expected to perform within each M&E domain (collection, collation, analysis, use) by consulting the M&E literature and using information from an expert informant (senior provincial manager). We then defined

which were ‘routine administration’, ‘problem identification’, or ‘problem solving’ tasks (Figure 2). Finally, we designed, pilot-tested, and administered a semi-structured questionnaire to collect data on participants’ performance of these tasks. Our face-to-face interviews also collected data on: participant characteristics (age, sex, duration in current job, health system level); management capacity (training in human resource, financing, and health information management; duration of management experience); and M&E knowledge (defines common HIV indicators, differentiates counts and proportions, and understands the utility of three HIV indicators listed on the DHIS). Ethical approval was obtained from the University of the Witwatersrand Committee for Research on Human Subjects and both Provincial Health Departments. Participants gave written informed consent. Interviews were recorded and transcribed if separate consent to record was granted.

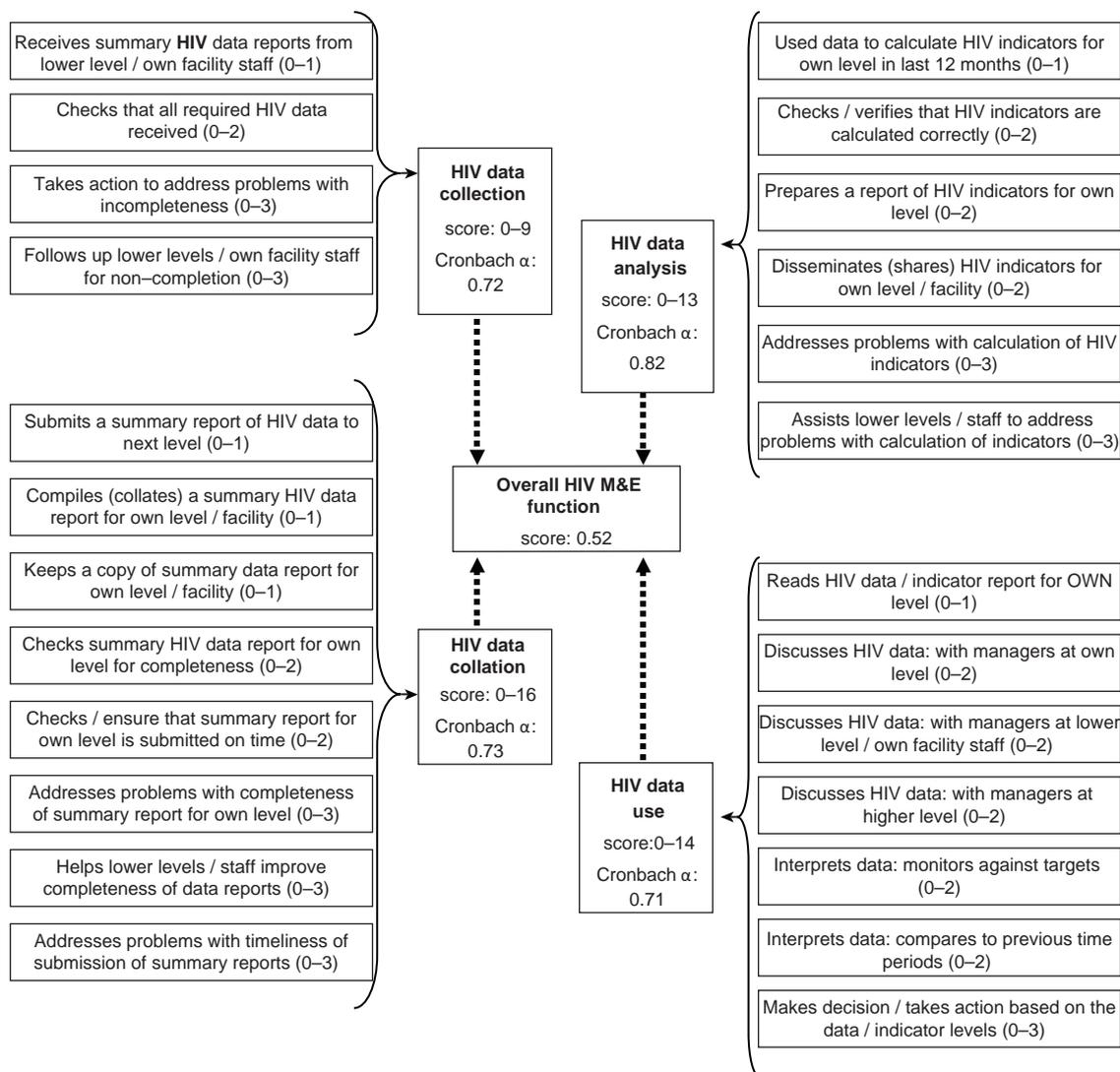


Fig. 2. Sub-scales and items for measuring the extent to which managers performed HIV programme M&E tasks.

Otherwise, detailed notes were taken and later typed in full.

We developed four sub-scales to measure the degree of exercised authority for each M&E domain. Sub-scales comprised several items (M&E tasks), which we coded 'no' if a respondent did not perform the task (score = zero) or 'yes' if s/he did. Tasks were weighted relative to their importance, so 'yes' responses were scored one for 'routine administration', two for 'problem identification' or three for 'problem solving' tasks. Item scores summed to a sub-scale score, and sub-scale scores summed to an overall HIV M&E score (Fig. 2). Cronbach's  $\alpha$  coefficients for sub-scales ranged from 0.7 to 0.8. Scale structure was confirmed by principal component analysis (PCA). Extracted components were very similar to our sub-scales, so we used our sub-scales in the analysis. We also developed two composite scores for manage-

ment capacity (7 items, score 0–13) and M&E knowledge (7 items, score 0–13).

### Data analysis

Data were analysed in SPSS 20.0 for Windows. We performed *t*-tests, Chi-square, and Mann–Whitney U tests to compare participant characteristics between the two sites, and mean scale and sub-scale scores between vertical and horizontal managers (alpha level of 0.05 for all tests). To determine the degree of exercised authority, we computed an ordinal dependent variable for each HIV M&E domain by categorising the maximum total score for each sub-scale into thirds. We then coded observed scores in the bottom, middle, and top third as 'low', 'medium', and 'high', respectively. We compared the distribution of dependent variables between horizontal and vertical managers (Chi-square test). We

**Table 1.** Participant demographic and professional characteristics

Variable	All (n = 51)	Site A (n = 31)	Site B (n = 20)	Significance
Age (years) <sup>+</sup>				
Mean (SD)	48.5 (7.5)	47 (6.9)	51 (7.9)	0.060
Sex				
Female <sup>#</sup> No. (%)	42 (82.4)	23 (74.2)	19 (95.0)	0.057
Disciplinary background <sup>#</sup> No. (%)				
Nursing	41 (80.4)	24 (77.4)	17 (85.0)	0.239
Non-health	7 (13.7)	6 (19.4)	1 (5.0)	
Medical	3 (5.9)	1 (3.2)	2 (10.0)	
Actor type <sup>#</sup> No. (%)				
General manager	20 (39.2)	12 (38.7)	8 (40.0)	0.927
Programme manager	31 (60.8)	19 (61.3)	12 (60.0)	
Level of health system <sup>#</sup> No. (%)				
Facility	10 (19.6)	6 (19.4)	4 (20.0)	0.185
Sub-district (includes local area)	9 (17.6)	8 (25.8)	1 (5.0)	
District	12 (23.5)	5 (16.1)	7 (35.0)	
Province	20 (39.2)	12 (38.7)	8 (40.0)	
Highest qualification attained <sup>#</sup> No. (%)				
Undergraduate diploma	9 (17.6)	4 (12.9)	5 (25.0)	0.007**
Undergraduate degree	31 (60.8)	24 (77.4)	7 (35.0)	
Postgraduate qualification	11 (21.6)	3 (9.7)	8 (40.0)	
Whether had management training <sup>#</sup> No. (%)				
Human resources	38 (74.5)	20 (64.5)	18 (90.0)	0.041*
Financial management	45 (88.2)	25 (80.6)	20 (100.0)	0.036*
Information management	43 (84.3)	25 (80.6)	18 (90.0)	0.370
Duration in current job <sup>@</sup> (months)				
Median (IQR)	56 (22–66)	38 (60–148)	60 (24–66)	0.389
Management experience to date <sup>@</sup> (months)				
Median (IQR)	82 (60–139)	95 (60–139)	73 (60–148)	0.685

<sup>+</sup> *t*-test, <sup>#</sup> Pearson Chi-square test, <sup>@</sup> Mann–Whitney U test.

\**p* < 0.05.

\*\**p* < 0.01.

also performed ordinal logistic regression to investigate which explanatory variables (actor type [horizontal vs. vertical], health system level, study site, highest qualification, duration of management experience, management capacity score, and M&E knowledge score) were predictive of higher degrees of exercised authority. Finally, to determine vertical managers' roles in HIV M&E coordination, we thematically analysed our narrative data, and also determined the proportion who undertook 'routine administration' versus 'problem-solving' tasks.

## Results

More than 75% of participants were female, with an undergraduate degree or higher, and had some management training. Site B managers had higher educational qualifications (Table 1). Participant characteristics were similar between vertical and horizontal managers (data not shown), except fewer horizontal managers had a postgraduate qualification (5% vs. 23%,  $p=0.02$ ) and fewer were at provincial level (10% vs. 58%,  $p=0.02$ ). Table 2 shows that horizontal managers attained higher mean scores for HIV data collection ( $p<0.05$ ) and

collation ( $p<0.01$ ), but lower for HIV data use ( $p<0.01$ ) and M&E knowledge ( $p<0.05$ ).

### Degree of exercised authority

A pooled analysis showed that 65% of all managers exercised a 'medium' degree of authority on the overall HIV M&E function, with no significant differences between vertical and horizontal managers. Disaggregating the data into collection, collation, analysis and use revealed differences between horizontal and vertical managers: more horizontal managers (60% vs. 19%;  $p=0.003$ ) exercised a high degree of authority over HIV data collation, but fewer exercised a high degree over HIV data use (25% vs. 61%;  $p=0.003$ ) (Fig. 3). Since four of the six information managers (whose primary role is to coordinate data) were horizontal managers, we performed Chi-square analysis excluding information managers. However, differences between horizontal and vertical managers persisted for HIV data collation (50% vs. 14%;  $p=0.001$ ) and data use (31% vs. 71%,  $p=0.011$ ).

We performed ordinal logistic regression only for the HIV data collation and data use domains (where Chi-square analyses showed associations). As Table 3 shows,

**Table 2.** Capacity, M&E knowledge and HIV M&E scale and sub-scale scores

Scales and sub-scales	All managers ( $n=51$ )	Horizontal managers ( $n=20$ )	Vertical managers ( $n=31$ )	Significance <sup>#</sup>
Data collection (sub-scale score: 0–9)				
Mean (SD)	5.24 (3.2)	6.50 (2.6)	4.42 (3.4)	0.016*
Mean score as % of maximum possible score	58.2	72.2	49.1	
Data collation (sub-scale score: 0–16)				
Mean (SD)	8.24 (4.2)	10.10 (3.0)	7.03 (4.4)	0.005**
Mean score as % of maximum possible score	51.5	63.1	43.9	
Data analysis (sub-scale score: 0–13)				
Mean (SD)	3.43 (3.6)	4.60 (1.0)	2.68 (0.5)	0.098
Mean score as % of maximum possible score	26.4	35.4	20.6	
Data use (sub-scale score: 0–14)				
Mean (SD)	8.59 (3.12)	6.75 (5–10)	9.77 (9–12)	0.002**
Mean score as % of maximum possible score	61.4	48.2	69.8	
Overall M&E function (scale score: 0–52)				
Mean (SD)	25.49 (8.8)	27.95 (8.6)	23.90 (8.6)	0.108
Mean score as % of maximum possible score	49.0	53.8	46.0	
Management capacity (scale score: 0–13)				
Mean (SD)	6.12 (2.4)	5.85 (2.0)	6.29 (2.7)	0.534
Mean score as % of maximum possible score	47.1	45.0	48.4	
HIV M&E knowledge (scale score: 0–13)	( $n=47$ )	( $n=19$ )	( $n=28$ )	
Mean (SD)	8.11 (3.4)	6.58 (3.2)	9.14 (3.3)	0.011*
Mean score as % of maximum possible score	62.4	50.6	70.3	

SD, standard deviation.

<sup>#</sup>Two-sided *t*-test.

\* $p<0.05$ .

\*\* $p<0.01$ .

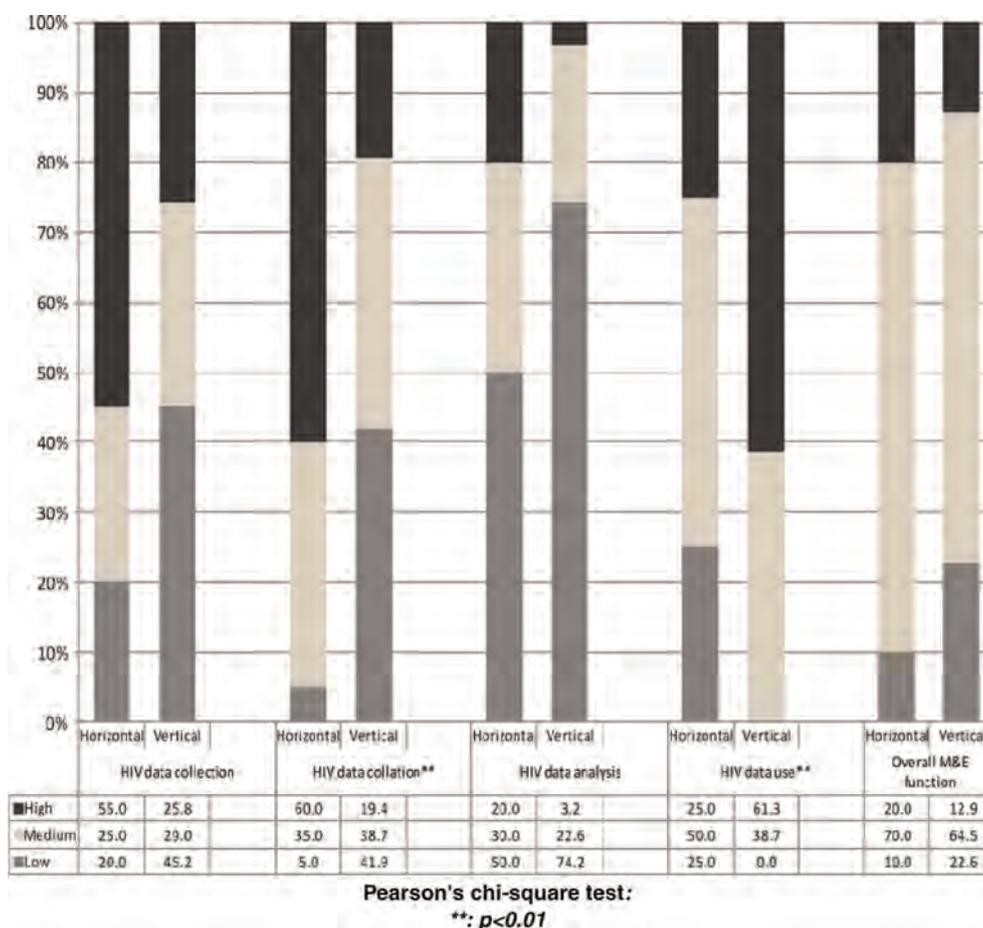


Fig. 3. Degree of exercised authority: comparing distributions between horizontal and vertical managers.

horizontal managers, facility managers, and managers in Site A exercised higher degrees of authority over HIV data collation, while being a vertical manager, working at provincial level, having a postgraduate qualification or a higher M&E knowledge score were associated with exercising a higher degree of authority over HIV data use. Individual management capacity was not associated with exercised authority for either domain. Multivariate logistic regression revealed that being a horizontal manager was predictive of higher degrees of authority over HIV data collation (OR 7.26; CI: 1.9, 27.4). Being a vertical manager (OR 0.19; CI: 0.05, 0.84) and having a higher HIV M&E knowledge score (OR 1.22; CI: 0.99, 1.49) were predictive of higher degrees of authority over HIV data use (Table 3).

#### Vertical managers' roles in HIV M&E coordination

Vertical managers generally coordinated data that was specific only to their respective programme (HIV, MCH, TB) or HIV sub-programme (PMTCT, ART, HCT, TB/HIV). There were some overlaps, for example, MCH managers as well as PMTCT sub-programme managers coordinated PMTCT data, with no clarity about who was ultimately accountable. HIV data were largely used

collectively in groups, for example, during district meetings attended by horizontal managers and district-based vertical managers (who formally reported to the head of the district health department). Provincial HIV managers belonged to separate management structures and discussed HIV data during HIV programme meetings (often including district-based HIV managers but excluding district horizontal managers). Even in site B where all HIV data were operationally integrated in the DHIS, HIV managers coordinated and used sub-sets of HIV data in their separate sub-programmes, exclusive of horizontal managers.

Senior provincial HIV managers reportedly relied on sub-programme managers and district-based HIV managers for day-to-day HIV M&E coordination. Our quantitative data showed few provincial HIV managers playing a technical support role. Only a third or less, for example, helped horizontal managers at district or lower levels to address HIV M&E problems (Fig. 4).

#### Discussion

This study adapted and applied an existing methodology to explore the measurement of administrative

**Table 3.** Predictors of higher degrees of exercised authority: HIV data collation and data use

Variable	HIV data collation		HIV data use	
	Crude OR (95% CI)	Adjusted OR (95% CI)	Crude OR (95% CI)	Adjusted OR (95% CI)
<b>Actor type</b>				
Horizontal manager	7.5 (2.3, 24.8)	7.26 (1.9, 27.4)	0.15 (0.04, 0.51)	0.19 (0.05, 0.84)
Vertical manager	1		1	1
<b>Study site</b>				
Site A	2.0 (1.7, 5.6)	2.23 (0.63, 7.94)	0.86 (0.29, 2.52)	–
Site B	1	1	1	
<b>Level of health system<sup>#</sup></b>				
Facility	7.9 (1.6, 40.3)	–	0.10 (0.02, 0.53)	–
Sub-district	1.3 (0.3, 5.5)		0.26 (0.05, 1.25)	
District	1.0 (0.3, 3.9)		0.72 (0.17, 3.07)	
Province	1		1	
<b>Highest qualification</b>				
Undergraduate diploma	3.1 (0.6, 16.7)	2.28 (0.4, 13.1)	0.35 (0.05, 2.17)	1.02 (0.12, 8.42)
Undergraduate degree	6.3 (1.6, 25.3)	2.44 (0.5, 12.5)	0.21 (0.05, 0.93)	0.57 (0.10, 3.38)
Postgraduate qualification	1	1	1	1
Management experience (duration in months)	1.0 (1.0, 1.0)	–	1.00 (0.99, 1.01)	–
Management capacity score	0.9 (0.7, 1.1)	–	1.12 (0.89, 1.40)	–
M&E knowledge score	1.0 (0.9, 1.2)	–	1.26 (1.06, 1.51)	1.22 (0.99, 1.49)

<sup>#</sup> ‘Level of health system’ not included in multivariate analyses due to its high correlation with ‘actor type’.

OR, odds ratio; CI, confidence interval.

integration for the first time. Our discussion first addresses the application of decision space analysis in this study and related strengths and weaknesses. We then discuss our findings, taking into account the limitations of the study, and the implications of our findings for DHS strengthening. Based on this, we propose some recommendations.

### Applying decision space analysis

Given that this technique has never been used before in the way it was applied in this study, we must consider the validity of our measurements. We observed some unexpected findings, that is, general managers exercise greater authority than programme managers and management capacity was not associated with exercised authority. These could signify problems with our: a) measures or b) hypothesis (30). Regarding the latter, we formulated hypotheses premised on the assumption that the programme was completely vertically managed. However, the HIV M&E turned out to be a ‘hybrid’ model, and this may explain the unexpected observation. Regarding the former, two important considerations to note are: whether our scales comprehensively reflect the variables of interest (content validity), and the degree to which our tool measures the concept of exercised authority in relation to existing ideas (construct validity). For measuring ‘exercised authority’: in the absence of

previously researched tools and formal delegation rules, we optimised content validity by devising sub-scales that we deemed comprehensively described HIV M&E domains, based on our knowledge of the M&E literature, consultation with an expert informant and pilot-testing. However, to measure management capacity, we only assessed whether participants had received training. Assessing the nature of this training may have revealed different results. The lack of previous similar studies limited our ability to test our scoring against a ‘gold standard’. However, having confirmed our scale structure with PCA, we are quite confident that our sub-scales are fairly robust.

Other potential limitations need to be considered. This technique requires that we describe and ascribe value to respondent’s activities. We relied on and could not objectively verify respondent reported activities and despite attempts to limit them, we cannot preclude socially desirable responses. While we interviewed almost all (96%) relevant managers in the selected districts for our study, this nonetheless resulted in a small sample size, that is, the study lacked sufficient power to develop a more comprehensive multivariate model. We also had to group together health service and information managers. Choosing one district and sub-district in two provinces out of nine in South Africa limits generalisation to other provinces.

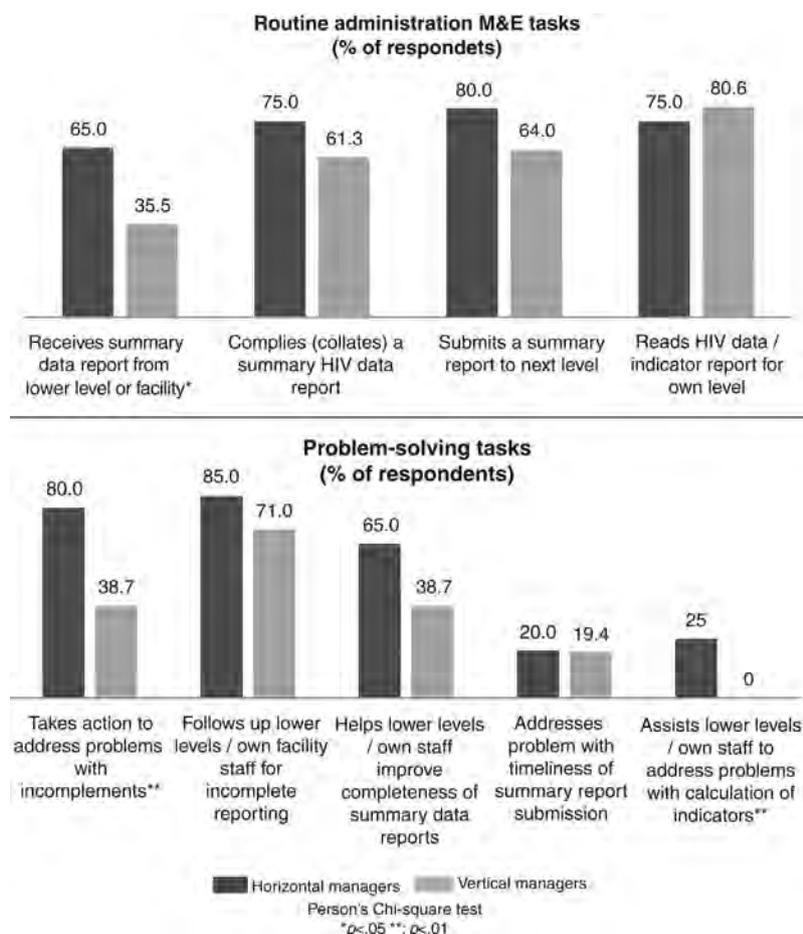


Fig. 4. Managers' roles in HIV M&E coordination.

#### A 'hybrid' indirect M&E programme with horizontal production and vertical use of HIV data

Our study reveals several key findings. First, horizontal and vertical managers exercise similar degrees of authority over the HIV M&E function overall, though horizontal managers exercise more authority over HIV information production, while the use of HIV information is largely under the control of vertical managers. Second, HIV managers largely function outside the district management structure and use HIV data in even smaller sub-programme specific silos, usually excluding horizontal managers. This represents a more extreme form of verticalisation than the usual models in the literature. In considering these two findings in conjunction with our previous work which showed that the HIV M&E system is predominantly operationally integrated with the DHIS (24), we find that the HIV programme M&E is partly operationally and partly administratively integrated within the health system M&E function. This concurs with the discourse regarding a 'false dichotomy' between horizontal and vertical approaches (31), and observations that programmes tend to lie along a

continuum from integrated to fully vertical (32). According to Unger et al. (13), disease specific programmes can be: a) *vertical*, that is, no integration; b) *fully integrated*, that is, operational and administrative integration, or; c) *indirect*, that is, operationally integrated but administratively vertical. The HIV M&E system in our study does not fit neatly into any of these categories, but is closest to the indirect model (as it is largely operationally integrated and largely administratively vertical). We therefore refer to it as a *hybrid indirect* programme.

Third, despite the top-heavy HIV management structure at provincial level, vertical and horizontal managers play similar roles, mostly performing the same HIV M&E tasks but only on discrete sub-sets of the HIV dataset. This suggests duplication, overlapping roles and thus inefficiency. It needs to be established whether this is because of a lack of clarity regarding division of roles. Related research on decentralisation shows poor role clarity limits managers' ability to exercise their delegated management authority (19, 33). Finally, vertical managers possess higher HIV M&E knowledge scores

(70% vs. 51%) and HIV data use scores (70% vs. 48%) than horizontal managers. The gap between these manager groups indicates that investment is required to support horizontal managers' capacity to use data. Or alternatively it could describe a particular clearly defined role that some HIV programme managers could play as technical experts and still leave space to deploy some HIV programme managers to other roles in particular in resource-constrained environments. Conversely horizontal managers exercise higher degrees of authority over HIV data collection and collation domains. This could be because they systematically over-estimated their practice or more likely because good knowledge of HIV indicators may not be essential for coordinating these domains.

#### *Horizontal production and vertical use of HIV data: drivers and health system implications*

Funding arrangements in health systems are context-specific and have been found to be determinants of integration (30). This may drive the vertical use of HIV data in our study as most HIV funding is given through a conditional grant which is different to regular funding that comes through the provincial health budget (20). There are also views that because of DHIS weaknesses and horizontal managers' limited knowledge of disease control issues, vertical M&E systems should be maintained (24) and vertical programmes retained under the control of vertical managers (19). Such attitudes may perpetuate vertical managers' dominance in using HIV data rather than improving the capacity of horizontal managers. In South Africa, conditions attached to the HIV conditional grant require HIV managers to submit a separate report on HIV expenditure (20). In this way, vertical managers are forced to monitor nationally defined HIV programme indicators. In contrast, this is not required of horizontal managers who have wide ranging and poorly defined performance measures that in many instances ignore data and health outcomes (34).

An M&E system characterised by horizontal production and vertical use of programme information perpetuates the idea that horizontal managers should merely produce and submit programme data 'upwards'. This contradicts DHS strengthening ideals, which are about improving horizontal managers' capacity to use information for management. As information use is the ultimate purpose of M&E (35), it is not beneficial for horizontal managers to play a key role in information production and then not use it optimally. In settings pursuing DHS strengthening or decentralisation, managerial reforms to ensure horizontal managers are the primary users of health (including disease-specific) information are imperative.

A well-functioning DHS is however a necessary foundation if district managers are to assume authority over

programmes. That a functional DHS is not fully established in South Africa (34) could hinder administrative integration. Similarly, a functioning middle management is important for successful administrative integration (13), as poor managerial capacity can limit the extent to which managers exercise authority over newly allocated roles (36). Arguing that horizontal managers should not manage programmes because of limited capacity is circular and simply reinforces their incapacity. It may discourage agency in managers who should be leading the development of their districts. Rather, investments to equip them with technical skills are imperative.

#### *Recommendations*

In the absence of conclusive evidence on the most effective integration models (37), countries are advised to adopt context-specific arrangements that optimise health system benefits (8). In this section, we draw on our findings to propose actions for South African policy-makers. Our case study findings are unlikely to be unique to the HIV programme. We anticipate broader relevance for other disease-specific programmes in South Africa which are managed by parallel bureaucracies, and particularly those with dedicated M&E systems.

In policy contexts like South Africa where DHS strengthening is a priority, the continuing role of vertical programme management structures warrants revision as silo structures could undermine DHS development. However, as we have shown, programme models can be quite complex and any decisions to revise existing arrangements, for example, by shifting authority from vertical to horizontal managers or integrating governance structures, need to consider the context. If integration is to be pursued in a weak health system, a phased incremental process, while building horizontal management capacity, is advised to avoid undermining local absorptive capacity (2, 8). In the interim, decision-makers could ensure that horizontal and vertical managers engage in dialogue and joint planning and monitoring (30). Linked to this should be clarity in allocation and application of their respective roles, as ignoring this can exacerbate confusion about how vertical managers should engage with horizontal management structures (18). Clarity regarding district managers' delegated authority over vertical programme functions is also important.

Finally, we recommend further research to evaluate integration of other disease-specific programmes with the M&E as well as other health system functions and to also understand whether and how clarification of roles, individual management capacity, and health system funding models influence administrative integration. Considering our methodological limitations, we recommend further research to test our scales on larger samples using more precise definitions of management capacity, in order to produce more robust measurement scales.

That programmes rarely fit within prevailing conceptualisations of 'integrated' or 'vertical' and that formal delegated authority may vary across settings adds complexity in that measurement tools may have to be quite context-specific to capture nuances. This may limit applicability in cross-country studies.

## Conclusion

In light of the increasing focus on health system strengthening and integration, our research makes a contribution by providing a method and scales for measuring and monitoring administrative integration. We anticipate that these will be strengthened further by empirical testing on larger samples and varied settings. In applying this method to South Africa's public sector HIV programme, we find that HIV M&E coordination is generally not administratively integrated, characterised by horizontal managers exercising little authority in using HIV data, and vertical managers using HIV data in sub-programme silos. We argue that this programme model should not be sustained as it potentially undermines aims of integrated district health management.

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## Conflict of interest and funding

We declare that we have no competing interests.

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**\*Mary Kawonga**

Department of Community Health  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Tel: +27 11 717 2575  
Fax: +27 11 717 2084  
Email: [mary.kawonga@wits.ac.za](mailto:mary.kawonga@wits.ac.za)

# Predictors of loss to follow-up among children in the first and second years of antiretroviral treatment in Johannesburg, South Africa

Mazvita Sengayi<sup>1,2\*</sup>, Ntabozuko Dwane<sup>2</sup>, Edmore Marinda<sup>2</sup>,  
Nosisa Sipambo<sup>1</sup>, Lee Fairlie<sup>1</sup> and Harry Moultrie<sup>1,2</sup>

<sup>1</sup>Wits Reproductive Health and HIV Research Institute, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** Ninety percent of the world's 2.1 million HIV-infected children live in sub-Saharan Africa, and 2.5% of South African children live with HIV. As HIV care and treatment programmes are scaled-up, a rise in loss to follow-up (LTFU) has been observed.

**Objective:** The aim of the study was to determine the rate of LTFU in children receiving antiretroviral treatment (ART) and to identify baseline characteristics associated with LTFU in the first year of treatment. We also explored the effect of patient characteristics at 12 months treatment on LTFU in the second year.

**Methods:** The study is an analysis of prospectively collected routine data of HIV-infected children at the Harriet Shezi Children's Clinic (HSCC) in Soweto, Johannesburg. Cox proportional hazards models were fitted to investigate associations between baseline characteristics and 12-month characteristics with LTFU in the first and second year on ART, respectively.

**Results:** The cumulative probability of LTFU at 12 months was 7.3% (95% CI 7.1–8.8). In the first 12 months on ART, independent predictors of LTFU were age <1 year at initiation, recent year of ART start, mother as a primary caregiver, and being underweight ( $WAZ \leq -2$ ). Among children still on treatment at 1 year from ART initiation, characteristics that predicted LTFU within the second year were recent year of ART start, mother as a primary caregiver, being underweight ( $WAZ \leq -2$ ), and low CD4 cell percentage.

**Conclusions:** There are similarities between the known predictors of death and the predictors of LTFU in the first and second years of ART. Knowing the vital status of children is important to determine LTFU. Although HIV-positive children cared for by their mothers appear to be at greater risk of becoming LTFU, further research is needed to explore the challenges faced by mothers and other caregivers and their impact on long-term HIV care. There is also a need to investigate the effects of differential access to ART between mothers and children and its impact on ART outcomes in children.

Keywords: *HIV; antiretroviral treatment; children; loss to follow-up; South Africa*

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Sub-Saharan Africa is home to 90% of the world's 2.1 million HIV-infected children. Of all the people living with HIV in sub-Saharan Africa, 10% are children (1). In South Africa at the end of 2009, 330,000 children were infected with HIV and the prevalence of HIV in children aged between 2 and 14 years was 2.5% (1.9–3.5%) (2, 3). The number of patients receiving antiretroviral treatment (ART) at PEPFAR-supported government sites in South Africa increased nearly 20-fold in 5 years from 33,500 in 2005 to 632,000 in 2009 (4).

In the same period, paediatric ART programmes in South Africa have seen an over 50-fold increase in average monthly patient enrolments from 2 to 106 (5). The impact of this rapid expansion of ART programmes on quality of care is a cause of concern.

The study of loss to follow-up (LTFU) and other treatment outcomes in HIV care has been used to monitor and improve programme effectiveness, using patient retention as a measure of quality of care (6). While children in HIV care programmes have a much

higher retention than adults, a rise in LTFU has been observed as paediatric HIV care programmes scale-up (7–9). A trend of increasing LTFU over time was observed in a pooled analysis of the 16 paediatric HIV care programmes in sub-Saharan Africa which form the Kids' Antiretroviral Treatment in Lower-Income Countries (KIDS-ART-LINC) Collaboration. The risk of LTFU was 2.8% (95% CI 1.9–4.1) at 6 months, 4.6% (95% CI 3.4–6.2) at 1 year, and 8.4% (95% CI 6.5–10.7) at 2 years (7).

Most children initiating ART in resource-poor settings start treatment at advanced stages of illness leading to high mortality rates especially in the first 3 months of ART initiation (1, 10–12). These early deaths if unreported may be misclassified as early LTFU. The risk factors of LTFU in the first year and second year of ART may differ. It is therefore important to examine the risk factors of LTFU in the first year on ART and explore whether these differ with predictors of LTFU after surviving the first year on ART. This is potentially useful in making recommendations for patient retention in paediatric HIV care programmes.

The aim of the present study was to determine the rate of LTFU in children receiving ART and to identify baseline characteristics associated with LTFU in the first year on treatment. We also explored the effect of patient characteristics at 12 months on LTFU in the second year on treatment.

## Methods

### Study population

The study is an analysis of prospectively collected routine data of HIV-infected children at the Harriet Shezi Children's Clinic (HSCC) in Soweto. The HSCC is a large urban paediatric HIV treatment clinic situated at the Chris Hani Baragwanath Academic Hospital, a referral hospital in Johannesburg. Since 1 April 2004, HSCC has treated children with government-funded ART. All children enrolled at HSCC are HIV-infected and ART is started based on current South African national guidelines. The 2004 national guidelines recommended ART for HIV-positive children with recurrent (two admissions per year) or prolonged (4 weeks) hospitalization, WHO clinical stage 3 and 4, or CD4 cell percentage <20% in children under 18 months and <15% for older children (13). The 2010 treatment guidelines recommend ART initiation for all HIV-positive children aged <1 year, for children aged 1–5 years with clinical stage 3 or 4 or CD4  $\leq$ 25% or absolute CD4 count <750 cells/mm<sup>3</sup>, and for children >5 years with clinical stage 3 or 4 or CD4 <350 cells/mm<sup>3</sup> (14). Ethical approval for this study was granted by the University of Witwatersrand Committee for Research on Human Subjects.

All children <12 years of age who started ART at HSCC between 1 April 2004 and 30 October 2011 were included in the study. Twelve years was used as a cut-off because older children might have unique predictors of LTFU compared to younger children, and may be able to attend clinic visits on their own. Only children with a minimum follow-up time of 6 months before date of database closure were included in the study. The date of database closure was 30 April 2012. Children with follow-up time of <1 day (who never returned to the clinic after the day of initiation) were excluded from the analysis.

### Procedures

A child was defined as LTFU if their last date of contact with the clinic was >6 months before the date of database closure (30 April 2012), and they were not known to have died or transferred. Baseline exposure variables were as follows: age, sex, year of ART initiation; primary caregiver relationship; anthropometric measures (weight-for-age Z score (WAZ); height-for-age Z score (HAZ) and weight-for-height Z score (WHZ)); WHO clinical stage; CD4 cell percentage; immune suppression (as defined by the 2006 WHO classification of HIV-associated immunodeficiency in children using CD4 cell count and age) (15); log<sub>10</sub> of plasma HIV viral load; and ART regimen. Age was categorised into the following categories: <1 year, 1 to <3 years, 3 to <5 years, and 5 years to 12 years. Updated 12-month characteristics were used to investigate LTFU in the second year on ART. The United Nations General Assembly Special Session (UNGASS) on HIV/AIDS recommends reporting of 12-month outcomes of patients on ART and yearly thereafter as indicators of programme retention (16). This guided the selection of the 12-month cut-off in the analysis.

### Statistical analysis

Continuous variables were tested for the assumption of normality using histograms and normal quantile plots. Categorical variables were described using frequencies; normally distributed continuous variables in terms of mean and standard deviation; non-normal continuous variables in terms of median and inter-quartile range.

Time-to-event analysis was the primary method of analysis. In the analysis for LTFU in the first year on ART, person-time accrued from date of ART initiation to the earliest of (1) date of last visit, or (2) date at 12 months from ART initiation, or (3) date of database closure (30 April 2012). Cumulative probabilities of LTFU and period incidence rates were calculated. Kaplan–Meier curves were plotted and were compared using log rank tests. Cox proportional hazards models were fitted to investigate associations between baseline characteristics and LTFU. Global tests (using Schoenfeld

and scaled Schoenfeld residuals) were used to test for validity of the proportional hazards assumption. Similarly, in the analysis of LTFU in the second year on ART, person-time accrued from 12 months post ART initiation to the earliest of (1) date of last visit, or (2) date at 24 months from ART initiation, or (3) date of database closure (30 April 2012). Variables included in the multivariate models were age, year of ART start, primary caregiver relationship, WAZ, and CD4 cell percentage. These variables were selected based on findings of other studies (5, 7, 8, 17), WHZ and HAZ were excluded for collinearity with WAZ, and regimen was excluded because the age at initiation determined regimen selection (13, 14).

Stata version 11 (Stata Corporation, College Station, Texas, USA) software package was used for all statistical analyses.

## Results

### Cohort description

A total of 4,266 children enrolled between 1 April 2004 and 30 October 2011 were included in the study. A flow chart of children included in the study is shown in Fig. 1. Characteristics at baseline and at 12 months on treatment and the proportion of missing data for each variable are presented in Table 1. The median age was 4.2 years (IQR 1.4–7.4), and 48.7% (2078) of them were female. The majority of children (52.2%) had mothers as their primary caregivers at ART initiation. More than two-thirds of children had advanced/severe immunodeficiency (68.6%) at the start of treatment, and 73.7% had WHO clinical stage 3 or 4 disease. The mean CD4 cell percentage was 14.5% (SD 9.3) at baseline, and the mean  $\log_{10}$  of HIV plasma viral load was 11.4 copies per millilitre (SD 2.6). Baseline regimens had either a protease inhibitor (PI) backbone (47.4%) or a non-nucleoside reverse transcriptase inhibitor (NNRTI) backbone (44.2%). At 12 months after starting treatment, 49.1% of the children in care were female and 52% had mothers as their caregivers. The proportion of children with advanced/severe immune suppression dropped to 48.1%, the mean  $\log_{10}$  of plasma viral load dropped to 5.8 copies/mL (SD 3.6), and the mean CD4 cell percentage was 23.6 (SD 9.5).

### LTFU in the first year on ART

In the first year on ART, a total of 323 children were lost to follow-up (7.6%). There were a total of 3832.8 child-years of follow-up, and the overall incidence of LTFU in the first 12 months was 8.4 per 100 child-years (95% CI 7.6–9.4). The incidence of LTFU was highest in the first 3 months on ART with a period incidence rate of 13.6 per 100 child-years (95% CI 11.6–16.1). The cumulative probability of LTFU at 12 months was 7.3% (95% CI

7.1–8.8). There were 113 reported deaths and 202 known transfers in the first year (Fig. 1).

Age group, year of ART initiation, primary caregiver relationship, WAZ, and CD4 cell percentage were included in the multivariable Cox model to identify independent predictors of LTFU in the first year (Table 2). Older children were less likely to become LTFU than infants [HR 0.5 (95% CI 0.3–0.8) and HR 0.6 (0.4–0.9) for children aged 3 to <5 years and 5–12 years, respectively]. Children initiating ART in 2006–08 were twice as likely to become LTFU as those who initiated in 2004–05 [HR 2.1 (1.2–3.5)], and those initiating ART between 2009 and 2011 were five times more likely to become LTFU [HR 4.9 (2.9–8.2)]. Children whose biological mother was their primary care giver had the highest risk of LTFU. Having a grandmother [HR 0.1 (0.04–0.3)], other relatives [HR 0.6 (0.4–0.9)], or non-family caregivers [HR 0.4 (0.2–0.8)] as primary caregivers at baseline was significantly associated with a lower risk of LTFU than being cared for by the child's mother. Kaplan Meier plots also showed the increased risk of LTFU in children cared for by their mothers (Fig. 2). Severely underweight children (WAZ < -3) were over three times more likely to become LTFU than well-nourished children [HR 3.6 (2.5–5.3)]. CD4 cell percentage had no effect on risk of LTFU in the first year [HR 1.0 (0.99–1.0)].

### LTFU in the second year on ART

At the end of 12 months from the start of ART, 3,460 children (81.1%) were still in care at HSCC. These children contributed a total of 3,064.4 child-years and the overall incidence of LTFU in the second year on ART was 5.0 per 100 child-years (95% CI 4.2–5.8). The cumulative probability of LTFU at the end of the second year was 4.9% (95% CI 4.2–5.7). There were 32 reported deaths and 294 known transfers in the second year (Fig. 1).

Table 3 shows adjusted and unadjusted hazard ratios for the effect of characteristics at 12 months treatment on LTFU in the second year. Age group at 12 months was not significantly associated with LTFU in the second year on ART. Children initiating ART in 2006–08 were twice as likely to become LTFU as those who initiated in 2004–05 [HR 1.9 (1.1–3.1)], and those initiating ART between 2009 and 2011 were nearly three times more likely to become LTFU [HR 2.7 (1.6–4.5)]. Children cared for by their grandmothers [HR 0.3 (0.1–0.6)] and other relatives [HR 0.6 (0.3–0.8)] had a lower risk of LTFU than those cared for by their biological mothers. Children who were still severely underweight after 1 year on ART were three times more likely to become LTFU than those who were well-nourished [HR 2.9 (1.9–4.5)]. The hazard of LTFU decreased by 3% for every unit increase in CD4 cell percentage [HR 0.97 (0.96–0.99)].

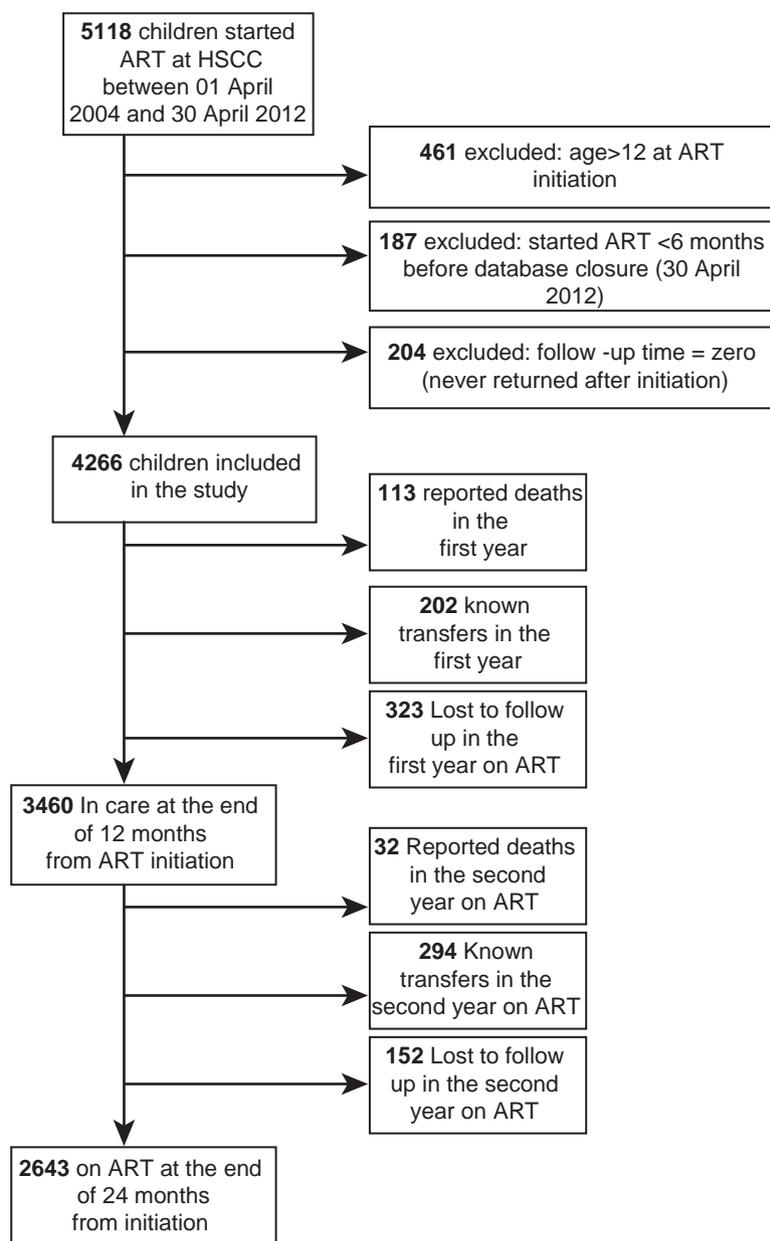


Fig. 1. Flow chart of HIV-infected children initiating ART at HSCC between 01 April 2004 and 30 April 2012.

### Sensitivity analyses

Missing CD4 cell percentage values at baseline were imputed using the multivariate normal method, and the multivariate Cox model for the first year was re-run using the imputed values and compared with the multivariate Cox model using the original data, and similar results were obtained (Table 4). The multivariate Cox models were also re-run using age and year of start as continuous variables and compared with the Cox models with categorised age and year of start using likelihood ratio tests (Tables 4 and 5). There were no significant differences in models. Tests for linear trend confirmed a linear relationship between year of ART start and LTFU in the first and second year (Tables 4 and 5). Age group

had a linear relationship with LTFU in the second year on ART (Table 5).

### Discussion

As in other paediatric HIV care programmes in sub-Saharan Africa (8, 10), the majority of children initiated ART at advanced stages of disease having WHO stage 3 or 4 and advanced or severe immune suppression. Incidence of LTFU in this study was 8.4 and 5.0 per 100 child-years in the first and second year of ART, respectively.

In the first year on ART the incidence rate of LTFU was highest in the first 3 months. This mirrors the previously reported high rate of death in the first

**Table 1.** Overall cohort characteristics at baseline ( $N=4,266$ ) and at 12 months on treatment ( $N=3,640$ )

Characteristic	Baseline		12-month characteristics	
	<i>N</i>	%	<i>N</i>	%
Sex				
Male	2188	51.3	1760	50.9
Female	2078	48.7	1700	49.1
Age				
<1 year	823	19.3		
1 to <3 years	949	22.3	998	28.8
3 to <5 years	634	14.9	587	17.0
5 to 12 years	1860	43.6	1875	54.2
Median age, years (IQR)	4.2 (1.4–7.4)		5.2 (2.4–8.5)	
Year of starting ART				
2004–05	969	22.7	865	25.0
2006–08	1742	40.8	1548	44.7
2009–11	1555	36.5	1047	30.3
Primary caregiver				
Mother	2226	52.2	1800	52.0
Grandmother	641	15.0	594	17.2
Other family	827	19.4	741	21.4
Foster/institution/neighbour/guardian	301	7.1	256	7.4
Data missing	271	6.4	69	2.0
Weight-for-age Z score				
> –2 (not underweight)	3112	73.0	2430	70.2
–2 to –3 (moderately underweight)	461	10.8	543	15.7
< –3 (severely underweight)	369	8.7	426	12.3
Data missing	324	7.6	61	1.8
Mean WAZ (standard deviation)	–0.1 (2.6)		–0.8 (2.1)	
Height-for-age Z score				
> –2 (no stunting)	2911	68.2	2850	82.4
–2 to –3 (moderate stunting)	90	2.1	126	3.6
< –3 (severe stunting)	39	0.9	46	1.3
Data missing	1226	28.7	438	12.6
Mean HAZ (standard deviation)	2.7 (3.2)		1.9 (2.8)	
Weight-for-height Z score				
> –2 (no wasting)	1273	29.8	1145	33.1
–2 to –3 (moderate wasting)	421	9.9	406	11.7
< –3 (severe wasting)	832	19.5	841	24.3
Data missing	1740	40.8	1068	30.9
Mean (standard deviation)	–2.2 (2.2)		–2.2 (2.1)	
Immune suppression <sup>s</sup>				
Mild	263	6.2	1639	47.4
Advanced/severe	2927	68.6	1663	48.1
Data missing	1076	25.2	158	4.6
WHO clinical stage				
1/2	621	14.6	558	16.1
3/4	3144	73.7	2815	81.4
Data missing	501	11.7	87	2.5
CD4 cell percentage				
≥ 15%	1327	31.11	2701	78.1
< 15%	1883	44.14	617	17.8

Table 1 (Continued)

Characteristic	Baseline		12-month characteristics	
	N	%	N	%
Data missing	1056	24.75	142	4.1
Mean (standard deviation)	14.5 (9.3)		23.6 (9.5)	
Log <sub>10</sub> of plasma viral load (copies/mL)				
Data missing	1158	27.1	177	5.1
Mean (standard deviation)	11.4 (2.6)		5.8 (3.6)	
Initial regimen				
NNRTI-based	1884	44.2	1251	36.2
PI-based	2024	47.4	1405	40.6
Data missing	350	8.4	804	23.2

<sup>§</sup>Definitions of immune suppression according to the 2006 WHO classification of HIV-associated immunodeficiency in children by age and CD4%: (*children <1 year*: mild = CD4% of 30–35%, advanced = CD4% of 25–29%, severe = CD4% <25%; *children 1 to <3 years*: mild = CD4% of 25–30%, advanced = CD4% of 20–25%, severe = CD4% <20%; *children 3 to <5 years*: mild = CD4% of 20–25%, advanced = CD4% of 15–19%, severe = CD4% <15%; *children >5 years*: mild = CD4 cell count 350–499 cells/mm<sup>3</sup>, advanced = CD4 cell count 200–349 cells/mm<sup>3</sup>, severe = CD4 cell count <200 cells/mm<sup>3</sup> or CD4% <15%) (14).

WHO: World Health Organization; NNRTI: non-nucleoside reverse transcriptase inhibitor (efavirenz or niverapine); PI: protease inhibitor (lopinavir/ritonavir).

90 days on ART (18) and may be partly attributable to unreported early mortality. The cumulative probability of LTFU at 12 months was 7.3% (95% CI 7.1–8.8). This is comparable with the 1-year LTFU rate of 7% reported by the International epidemiologic Databases to Evaluate AIDS in Southern Africa (IeDEA-SA) study in a pooled analysis of 10 paediatric ART programmes from South Africa, Malawi, Mozambique, and Zimbabwe (10). The incidence of LTFU in Asian children on ART with an average follow-up time of 3 years was found to be lower at 4.2 per 100 person-years (19). In the first 12 months on ART, independent predictors of LTFU were age <1 year at initiation, recent year of ART, having one's biological mother as a primary caregiver, and being underweight (WAZ ≤ -2). The risk of LTFU increased progressively

in successive enrolment calendar periods with those initiated between 2009 and 2011 having the highest LTFU. This increase in LTFU in children enrolled in more recent years is consistent with findings of studies of ART outcomes in similar settings (8, 17). This might reflect the effect of rapid scale-up and subsequently higher workloads on quality of care. A study of temporal trends in four South African provinces which comprised smaller, rural paediatric cohorts did not demonstrate the same progressive increase in LTFU in subsequent calendar cohorts as shown in this study (5). This suggests that the increase in LTFU might be related to rapid ART scale-up in large urban cohorts where the impact of high workloads on quality of care would be significant.

Haitian children who were LTFU had lower baseline median WAZ (-3, IQR -3.7 to -1.8) than those retained in care (20). WAZ is a marker of disease severity associated with mortality in the HSCC cohort (18). Among children who were still in care at 12 months since ART initiation, 12-month characteristics which predicted LTFU were recent year of ART, having one's biological mother as a primary caregiver, and being underweight (WAZ ≤ -2). The hazard of LTFU in the second year decreased by 3% for every unit increase in CD4 cell percentage. Baseline CD4 cell percentage had no effect on LTFU in the first year on ART, but children who still had a low CD4% after 12 months on ART were more likely to get LTFU in the second year. This may be explained by possible suboptimal adherence and consequent higher risk of death in children with a poor immune response at 12 months.

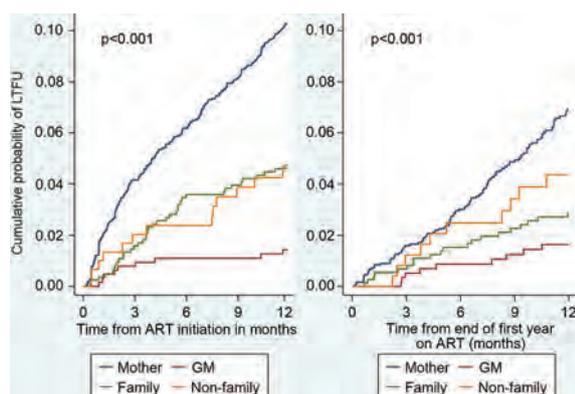


Fig. 2. Kaplan-Meier estimates of cumulative probability of LTFU by caregiver relationship during the first year and second year on ART.

**Table 2.** Baseline characteristics associated with LTFU in the first year on ART

Characteristic	Unadjusted HR (95% CI)	<i>p</i>	Adjusted HR* (95% CI)	<i>p</i>
<b>Sex</b>				
Male	1		–	
Female	0.94 (0.76–1.17)	0.580		
<b>Age at ART initiation</b>				
<1 year	1		1	
1 to 3 years	0.79 (0.61–1.04)	<0.093	1.15 (0.79–1.69)	0.458
3 to <5 years	0.30 (0.19–0.45)	<0.001	0.47 (0.27–0.83)	0.009
5 to 12 years	0.31 (0.24–0.42)	<0.001	0.61 (0.41–0.93)	0.020
<b>Year of starting ART</b>				
2004–05	1		1	
2006–08	2.48 (1.56–3.93)	<0.001	2.05 (1.21–3.49)	0.008
2009–11	6.28 (4.05–9.75)	<0.001	4.90 (2.92–8.20)	<0.001
<b>Primary caregiver</b>				
Mother	1		1	
Grandmother	0.13 (0.07–0.26)	<0.001	0.12 (0.04–0.31)	<0.001
Other family	0.45 (0.32–0.63)	<0.001	0.57 (0.37–0.88)	0.011
Foster/institution/neighbour/guardian	0.43 (0.25–0.76)	0.003	0.38 (0.18–0.82)	0.013
<b>Weight-for-age Z score</b>				
> –2 (not underweight)	1		1	
–2 to –3 (moderately underweight)	3.38 (2.52–4.53)	<0.001	2.71 (1.90–3.88)	<0.001
< –3 (severely underweight)	4.83 (3.61–6.49)	<0.001	3.64 (2.51–5.27)	<0.001
<b>Height-for-age Z score</b>				
> –2 (no stunting)	1		–	
–2 to –3 (moderate stunting)	11.10 (7.28–16.93)	<0.001		
< –3 (severe stunting)	15.17 (8.52–27.02)	<0.001		
<b>Weight-for-height Z score</b>				
> –2 (no wasting)	1		–	
–2 to –3 (moderate wasting)	0.89 (0.58–1.37)	0.592		
< –3 (severe wasting)	0.43 (0.28–0.67)	<0.001		
<b>Immune suppression<sup>§</sup></b>				
Mild	1		–	
Advanced/severe	0.49 (0.33–0.71)	<0.001		
<b>WHO clinical stage</b>				
1/2	1		–	
3/4	1.37 (0.95–1.98)	0.090		
CD4 cell percentage	1.04 (1.02–1.05)	<0.001	1.01 (0.99–1.02)	0.212
Log <sub>10</sub> of plasma viral load (copies/mL)	1.10 (1.04–1.16)	<0.001		
<b>Initial regimen</b>				
NNRTI-based	1		–	
PI-based	2.45 (1.88–3.21)	<0.001		

\**N* = 3078 for adjusted model.

<sup>§</sup>Definitions of immune suppression according to the 2006 WHO classification of HIV-associated immunodeficiency in children by age and CD4%: (*children <1 year*: mild = CD4% of 30–35%, advanced = CD4% of 25–29%, severe = CD4% <25%; *children 1 to <3 years*: mild = CD4% of 25–30%, advanced = CD4% of 20–25%, severe = CD4% <20%; *children 3 to <5 years*: mild = CD4% of 20–25%, advanced = CD4% of 15–19%, severe = CD4% <15%; *children >5 years*: mild = CD4 cell count 350–499 cells/mm<sup>3</sup>, advanced = CD4 cell count 200–349 cells/mm<sup>3</sup>, severe = CD4 cell count <200 cells/mm<sup>3</sup> or CD4% <15%) (14).

WHO: World Health Organization; NNRTI: non-nucleoside reverse transcriptase inhibitor (efavirenz or niverapine); PI: protease inhibitor (lopinavir/ritonavir).

**Table 3.** The effect of 12-month characteristics on LTFU in the second year on ART

Characteristic	Unadjusted HR (95% CI)	<i>p</i>	Adjusted HR* (95% CI)	<i>p</i>
<b>Sex</b>				
Male	1		–	
Female	1.15 (0.83–1.8)	0.399		
<b>Age at 12 months on ART</b>				
1 to <3 years	1		1	
3 to <5 years	0.82 (0.53–1.29)	0.397	1.19 (0.74–1.91)	0.471
5 to 12 years	0.58 (0.41–0.83)	0.003	0.88 (0.58–1.35)	0.566
<b>Year of starting ART</b>				
2004–05	1		1	
2006–08	1.91 (1.19–3.08)	0.007	1.85 (1.12–3.07)	0.017
2009–11	2.84 (1.73–4.66)	<0.001	2.68 (1.58–4.55)	<0.001
<b>Primary caregiver</b>				
Mother	1		1	
Grandmother	0.23 (0.12–0.46)	<0.001	0.30 (0.15–0.59)	0.001
Other family	0.41 (0.26–0.67)	<0.001	0.49 (0.30–0.82)	0.006
Foster/institution/neighbour/guardian	0.63 (0.33–1.20)	0.155	0.59 (0.28–1.21)	0.150
<b>Weight-for-age Z score</b>				
> –2 (not underweight)	1		1	
–2 to –3 (moderately underweight)	2.09 (1.37–3.18)	0.001	1.97 (1.28–3.04)	0.004
< –3 (severely underweight)	3.51 (2.38–5.18)	<0.001	2.93 (1.91–4.47)	<0.001
<b>Height-for-age Z score</b>				
> –2 (no stunting)	1		–	
–2 to –3 (moderate stunting)	5.05 (2.60–9.81)	<0.001		
< –3 (severe stunting)	13.52 (6.19–29.55)	<0.001		
<b>Weight-for-height Z score</b>				
> –2 (no wasting)	1		–	
–2 to –3 (moderate wasting)	0.55 (0.28–1.09)	0.081		
< –3 (severe wasting)	0.64 (0.39–1.03)	0.068		
<b>Immune suppression<sup>§</sup></b>				
Mild	1		–	
Advanced/Severe	1.74 (1.23–2.46)	0.002		
<b>WHO clinical stage</b>				
1/2	1		–	
3/4	1.46 (0.88–2.43)	0.140		
CD4 cell percentage	0.98 (0.96–0.99)	0.007	0.97 (0.96–0.99)	0.004
Log <sub>10</sub> of plasma viral load (copies/mL)	1.17 (1.12–1.21)	<0.001	–	
<b>Regimen at 12 months</b>				
NNRTI-based	1		–	
PI-based	1.43 (0.93–2.20)	0.099		

\**N* = 3,283 in adjusted model.

<sup>§</sup>Definitions of immune suppression according to the WHO classification of HIV-associated immunodeficiency in children by age and CD4%: (*children <1 year*: mild = CD4% of 30–35%, advanced = CD4% of 25–29%, severe = CD4% <25%; *children 1 to <3 years*: mild = CD4% of 25–30%, advanced = CD4% of 20–25%, severe = CD4% <20%; *children 3 to <5 years*: mild = CD4% of 20–25%, advanced = CD4% of 15–19%, severe = CD4% <15%; *children >5 years*: mild = CD4 cell count 350–499 cells/mm<sup>3</sup>, advanced = CD4 cell count 200–349 cells/mm<sup>3</sup>, severe = CD4 cell count <200 cells/mm<sup>3</sup> or CD4% <15%) (14).

WHO: World Health Organization; NNRTI: non-nucleoside reverse transcriptase inhibitor (efavirenz or niverapine); PI: protease inhibitor (lopinavir/ritonavir).

Table 4. Sensitivity analyses: LTFU in the first year

Characteristic	Model A (original)		Model B (imputed CD4% missing values)		Model C (age and year of start as continuous)	
	HR (95% CI)	<i>p</i>	HR (95% CI)	<i>p</i>	HR (95% CI)	<i>p</i>
Age at HAART initiation						
<1 year	1		1			
1 to <3 years	1.15 (0.79–1.69)	0.458	0.89 (0.66–1.21)	0.452		
3 to <5 years	0.47 (0.27–0.83)	0.009	0.39 (0.24–0.63)	<0.001		
5 to 12 years	0.61 (0.41–0.93)	0.020	0.49 (0.35–0.69)	<0.001		
Age (as continuous variable)					0.93 (0.88–0.97)	0.002
Year of starting ART						
2004–05	1		1			
2006–08	2.05 (1.21–3.49)	0.008	2.08 (1.27–3.39)	0.003		
2009–11	4.90 (2.92–8.20)	<0.001	4.67 (2.90–7.50)	<0.001		
Year of starting ART (as a continuous variable)					1.36 (1.26–1.47)	<0.001
Primary caregiver						
Mother	1		1		1	
Grandmother	0.12 (0.04–0.31)	<0.001	0.18 (0.09–0.37)	<0.001	0.12 (0.04–0.31)	<0.001
Other family	0.57 (0.37–0.88)	0.011	0.64 (0.45–0.93)	0.018	0.57 (0.37–0.87)	0.010
Non-family	0.38 (0.18–0.82)	0.013	0.49 (0.27–0.87)	0.015	0.40 (0.19–0.86)	0.019
Weight-for-age Z score						
> –2	1		1		1	
–2 to –3	2.71 (1.90–3.88)	<0.001	2.96 (2.19–4.00)	<0.001	2.75 (1.92–3.93)	<0.001
< –3	3.64 (2.51–5.27)	<0.001	4.06 (3.01–5.49)	<0.001	3.57 (2.48–5.18)	<0.001
CD4 cell percentage	1.01 (0.99–1.02)	0.212	1.01 (0.99–1.02)	0.443	1.01 (0.99–1.02)	0.383

Likelihood ratio test between Model A and Model C showed that there was no difference between the model ( $p=0.449$ ).

Tests for linear trend for age group were significant ( $p<0.001$ ) and so were tests for departure from linear trend ( $p<0.001$ ) suggesting a more complex relationship between age group and LTFU in the first year.

Tests for linear trend for year of ART initiation were significant ( $p<0.001$ ) and those for departure from linear trend were not significant ( $p=0.935$ ), hence there was a linear relationship between year of ART start and LTFU.

Those who had higher CD4 cell percentage at 12 months were probably more adherent and less likely to suffer opportunistic diseases that may lead to death and LTFU.

The finding that children with their biological mothers as primary caregivers at baseline and at 1 year were more likely to be LTFU can be explained by the possibility that a number of these mothers may have died during the follow-up period resulting in the children becoming LTFU. Keeping HIV-positive mothers alive by effective ART has been shown to reduce under-five childhood mortality to levels seen in children of HIV-negative mothers (21). While it is likely that these mothers were enrolled in ART programmes themselves, it is possible that they might not be accessing ART due to the differences in the eligibility criteria for ART in adults and children in South Africa (13, 14, 22). At the time of

the study, women would be initiated on ART if their CD4 count were  $\leq 200$  cells/mm<sup>3</sup> or if they had a WHO stage 4 condition according to the 2004 guidelines (13). According to the 2010 ART guidelines women can access treatment at CD4  $\leq 200$  cells/mm<sup>3</sup> except in pregnancy and active tuberculosis, where therapy is started at CD4  $\leq 350$  cells/mm<sup>3</sup> (22). The paradox becomes that children are eligible for ART in South Africa at earlier disease stages than their non-pregnant mothers, with possible negative consequences on children's treatment outcomes. The adoption of the WHO Option B plus for prevention of mother to child transmission (PMTCT), which offers the best protection of maternal health by starting all pregnant HIV-infected women on ART for life (23), may positively impact children's outcomes.

Another explanation could be misclassification of mothers as caregivers since the caregiver status might

**Table 5.** Sensitivity analyses: LTFU in the second year

Characteristic	Model D (original)		Model E (age and year of start as continuous)	
	HR (95% CI)	<i>p</i>	HR (95% CI)	<i>p</i>
Age at 12 months				
1 to <3 years	1			
3 to <5 years	1.19 (0.74–1.91)	0.471		
5 to 12 years	0.88 (0.58–1.35)	0.566		
Age (as continuous variable)			0.94 (0.89–0.99)	0.047
Year of Starting ART				
2004–2005	1			
2006–2008	1.85 (1.12–3.07)	0.017		
2009–2011	2.68 (1.58–4.55)	<0.001		
Year of starting ART (as a continuous variable)			1.21 (1.10–1.34)	<0.001
Primary caregiver				
Mother	1		1	
Grandmother	0.30 (0.15–0.59)	0.001	0.32 (0.16–0.64)	0.001
Other family	0.49 (0.30–0.82)	0.006	0.54 (0.32–0.89)	0.017
Foster/Institution/Neighbour/Guardian	0.59 (0.28–1.21)	0.150	0.63 (0.30–1.29)	0.206
Weight-for-age Z score				
> –2 (Not underweight)	1		1	
–2 to –3 (Moderately underweight)	1.97 (1.28–3.04)	0.004	1.97 (1.29–3.04)	0.002
< –3 (Severely underweight)	2.93 (1.91–4.47)	<0.001	2.65 (1.74–4.04)	<0.001
CD4 cell percentage	0.97 (0.96–0.99)	0.004	0.97 (0.95–0.99)	0.001

Likelihood ratio test between Model D and Model E showed that there was no difference between the model ( $p=1.000$ ). No imputation of missing CD4% was done for the LTFU in the second year model since only 4.1% had missing CD4% at 12 months.

Tests for linear trend for age group at 12 months were significant ( $p=0.003$ ) and those for departure from linear trend were not significant ( $p=0.525$ ), hence there was a linear relationship between age group at 12 months and LTFU in the second year.

Tests for linear trend for year of ART initiation were significant ( $p<0.001$ ) and those for departure from linear trend were not significant ( $p=0.559$ ), hence there was a linear relationship between year of ART start and LTFU in the second year.

not have been updated promptly on the HSCC database. A recent study of paediatric ART adherence in Gugulethu, Cape Town, showed that children cared for by their mothers were more adherent than those cared for by other relatives or foster parents, contradictory findings to those in our study (24).

This study draws its strength from a large sample size of children accessing care at the same site. The data was prospectively collected in an electronic format and includes social factors such as caregiver relationship which other cohorts elsewhere may not be able to collect adequately. Sensitivity analyses yielded similar results with the main analyses.

Our study had some limitations. The study was observational and key variables at baseline such as CD4 cell percentage, and  $\log_{10}$  viral load had high proportions of missing data. Additionally, the quality of care at a referral academic hospital such the HSCC

is likely to differ from that of lower levels of care or in rural areas. We used data from only one non-randomly selected urban site; therefore, these results cannot be generalised to children accessing care in non-urban settings.

### Conclusion

Increased roll-out of ART for HIV-infected children, particularly in recent years, has led to an increase in LTFU, especially in infants and strategies to retain infants and children in care need investigation. There are similarities between predictors of LTFU and known predictors of death. Unreported mortality possibly inflates LTFU in the first and second year of ART. Family-based care models improving maternal access to ART and reducing mortality need further exploration. The holistic care of HIV-positive children should emphasise linkage of caregivers to adult HIV care programmes.

There is need to investigate the effect of differential access to ART between mothers and their children in South Africa and its impact on ART outcomes in children. There is need to strengthen ART roll-out programmes with resources to cope with rapid increases in enrolled patients.

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## Conflict of interest and funding

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**\*Mazvita Sengayi**

National Cancer Registry  
National Health Laboratory Service  
47 de Korte Street  
Braamfontein  
Johannesburg, 2001  
South Africa  
Email: mazvita.sengayi@nhls.ac.za

# Self-reported health and health care use in an ageing population in the Agincourt sub-district of rural South Africa

Francesc Xavier Gómez-Olivé<sup>1,2\*</sup>, Margaret Thorogood<sup>1,2,3</sup>, Benjamin Clark<sup>4</sup>, Kathleen Kahn<sup>1,2,5</sup> and Stephen Tollman<sup>1,2,5</sup>

<sup>1</sup>MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>INDEPTH Network, Accra, Ghana; <sup>3</sup>Warwick Medical School, University of Warwick, Coventry, UK; <sup>4</sup>Centre for Population Studies, London School of Hygiene and Tropical Medicine, London, UK; <sup>5</sup>Centre for Global Health Research, Epidemiology and Global Health, Umeå University, Umeå, Sweden

**Background:** South Africa is experiencing a demographic and epidemiological transition with an increase in population aged 50 years and older and rising prevalence of non-communicable diseases. This, coupled with high HIV and tuberculosis prevalence, puts an already weak health service under greater strain.

**Objective:** To measure self-reported chronic health conditions and chronic disease risk factors, including smoking and alcohol use, and to establish their association with health care use in a rural South African population aged 50 years or older.

**Methods:** The Study on Global Ageing and Adult Health (SAGE), in collaboration with the INDEPTH Network and the World Health Organization, was implemented in the Agincourt sub-district in rural northeast South Africa where there is a long-standing health and socio-demographic surveillance system. Household-based interviews were conducted in a random sample of people aged 50 years and older. The interview included questions on self-reported health and health care use, and some physical measurements, including blood pressure and anthropometry.

**Results:** Four hundred and twenty-five individuals aged 50 years or older participated in the study. Musculoskeletal pain was the most prevalent self-reported condition (41.7%; 95% Confidence Interval [CI] 37.0–46.6) followed by hypertension (31.2%; 95% CI 26.8–35.9) and diabetes (6.1%; 95% CI 4.1–8.9). All self-reported conditions were significantly associated with low self-reported functionality and quality of life, 57% of participants had hypertension, including 44% of those who reported normal blood pressure. A large waist circumference and current alcohol consumption were associated with high risk of hypertension in men, whereas in women, old age, high waist-hip ratio, and less than 6 years of formal education were associated with high risk of hypertension. Only 45% of all participants reported accessing health care in the last 12 months. Those who reported higher use of the health facilities also reported lower levels of functioning and quality of life.

**Conclusions:** Self-reported chronic health conditions, especially hypertension, had a high prevalence in this population and were strongly associated with higher levels of health care use. The primary health care system in South Africa will need to provide care for people with non-communicable diseases.

**Keywords:** *health care use; older population; self-reported health; non-communicable disease; WHODAS; WHOQOL; rural; South Africa*

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**H**ypertension in developing countries has been an area of concern for many years (1) and several reviews have called attention to this public health problem (2, 3). In 2000 a study in South Africa

showed that high blood pressure was responsible for 9% of all deaths and 2.4% of all Disability Adjusted Life Years (4). A recent research article has described the impact on health care demand of the increase in

non-communicable diseases in South Africa (5). The United Nations General Assembly addressed this global problem, proposing new global interventions to attend to the increasing world-wide burden of non-communicable diseases, promote prevention and strengthen health services (6). In September 2010, the South African Summit on the Prevention and Control of Non-communicable diseases acknowledged the impact that the coming epidemic of non-communicable disease will have in South Africa (7).

African populations are ageing and undergoing demographic and health transition (8). The resulting South African demographic and health changes have led to an increasing older population with some 15% of the population aged 50 years and older and 7.7% aged 60 years and older in 2011 (9). Older age groups are known to experience a high prevalence of non-communicable diseases, and so an increasing burden of these conditions can be expected (5, 10). Although a study in 1998 found high levels of hypertension in South Africa, particularly in urban areas (11), there is no routine measurement of the prevalence of non-communicable diseases in South Africa that could help measure this change (12). The annual District Health Barometer included diabetes and hypertension for the first time in its 2010/2011 annual report, recognising both the lack of morbidity data and the importance of non-communicable diseases in South Africa (13).

The primary health care system in South Africa is inadequately prepared to meet new demands for care of non-communicable diseases in addition to up-scaling antiretroviral therapy for HIV and AIDS patients (14). In recognition of these challenges, the South African Ministry of Health has started to re-engineer the primary health care system including addressing issues of integrated chronic disease care (8), accessibility (15, 16), and acceptability. However, more information on the health care needs of older people and their current use of health care systems is needed.

The data for this study were collected before the recent health care reforms. This cross-sectional study aims to describe self-reported non-communicable diseases, and self-reported smoking and alcohol use, measures of blood pressure and body size, together with health care use of an older population living in a rural South African area.

## Methods

The Study on Global Ageing and Adult Health (SAGE) is a collaboration between the INDEPTH Network and the World Health Organization (Department of Health Statistics and Informatics). The study was run at national level in six countries (India, China, Russia, Ghana, South Africa, and Mexico) and at three INDEPTH Health and Demographic Surveillance System (HDSS)

sites in India (Vadu HDSS), Ghana (Navrongo HDSS), and South Africa (Agincourt HDSS). This article presents an analysis of SAGE data collected in the Agincourt HDSS site.

## Setting

The study was based in the Agincourt sub-district of Mpumalanga Province, South Africa. Since 1992, the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) has collected data on the sub-district population, with vital events (pregnancy outcome, deaths, and migrations) updated yearly by trained local fieldworkers (17). Additional data (labour participation, household assets, education status, and union status) are collected at different time intervals to complement demographic data and give contextual information. The total population under surveillance in 2006 was approximately 72,801 people distributed in 21 villages and 11,734 households, of which 8,224 (11.3%) were aged 50 years or older.

Since 1992, there has been substantial socio-economic development in the area. However, the unemployment rate remains high with 60% labour migration among men aged 35–54 years and an increasing proportion of labour migrants among young men and women (17). The gender distribution of people permanently living in the area is affected by this migration, resulting in a higher proportion of resident females.

The public health system in the sub-district consists of six clinics and one health centre. Hospital services are covered by three hospitals situated between 25 and 45 km from the study site (18). At the time that the data described in this article were collected, clinics did not have specific services for chronic diseases and the registration and follow up of patients was erratic, with no system for identification and recall of patients who did not attend monthly routine appointments to get medication. Although primary health care services are free, the cost of transport may reduce the attendance at health facilities. Private doctors practice in the area and there is an active network of traditional healers (15, 19). At the time of the study, voluntary counselling and testing (VCT) services for HIV/AIDS were available in local clinics but antiretroviral treatment was only available in the district hospitals, and only a small proportion of the sub-district population was accessing this service.

The SAGE study was embedded within the Agincourt HDSS routine operations and the sample was selected from the population database. Information collected in this study could therefore be linked with existing socio-demographic variables.

## Sample

A random sample of 575 people was drawn from the 2005 update of the population database. The size of the sample

was determined by the requirements of the larger WHO-INDEPTH international study. Inclusion criteria were residence in the study site for 12 months prior to the 2005 update round and being 50 years old or more at the beginning of the study on 1 May 2006. Men and women were selected separately reflecting the unequal proportions of men and women in the population aged 50 years and over.

### *Quality control and training*

A week of training for the principal investigators and researchers involved in multi-country SAGE studies was organised by WHO a few months before implementation of the study. Training focused on using and understanding the questionnaire manuals, standardising data collection, anthropometric measurements, and performance tests. Thereafter, the field supervisors, quality checkers, and fieldworkers on-site in Agincourt received 2 weeks training.

A quality control system was established with three control points in the field and validation checks in the data entry process.

### *Data collection*

The SAGE questionnaire (20) was translated to the local language (Xitsonga) and translated back to English. Additional demographic data, including gender, age, marital status, nationality, and level of education were extracted from the Agincourt HDSS 2005 database.

### *Data entry, data cleaning, and analysis*

Data were double-entered using CPro 3.1 (U.S. Census Bureau) using an application provided by WHO which included validation checks. The data cleaning process included checking for completeness, identification and correction of outliers, and ensuring individual consistency on all ID codes. Data were then extracted to Stata11 (Stata Corp, College Station, Texas, USA) for analysis.

### *Variables*

We calculated age as of May 2006 and assigned participants to 5-year age groups. Years of formal education were obtained from the 2005 Agincourt HDSS database and categorised according to WHO levels of education: 6 years or more; less than 6 years, and no formal education. Marital status was categorised into two groups:

1. Current partnership: currently married or in an informal union; and
2. Single: those who had never married or those who were separated, divorced, or widowed.

We used data on employment status from the 2004 HDSS database since these were the most recent data available.

Socio-economic status (SES) was derived from the 2005 household asset survey. An SES indicator was constructed giving equal weight to each asset and rescaling it so that values of a given asset variable fall within the range [0, 1]. The assets were then categorised into five groups: 'quality of housing', 'water and sanitation', 'power supply', 'modern assets', and 'livestock assets'. These rescaled asset values were added up for each household and asset group and rescaled again to give a specific value in the range [0, 1]. Finally, these five group-specific scaled values were totalled for each household, providing an overall asset score with a value in the range of [0, 5] (21). Household asset scores were grouped into quintiles for the entire Agincourt sub-district population. Participants in this study are not equally distributed across the five quintiles because they are a sub-sample of the whole population (50 years and older).

Before 1993, the Agincourt sub-district received a high number of refugees from Mozambique fleeing the civil war. Mozambican residents are separately identified in the HDSS database and differ from the host South African population in measures, such as education, household assets, and child mortality (22). The variable nationality of origin (South African/Mozambican) records the different origins of the study population.

The physical and social functioning of each participant was measured using the WHODAS II scale (World Health Organization Disability Assessment Schedule II) which assesses daily functioning. Ten questions on the difficulty experienced by the respondent when performing certain activities in the last 30 days were used to create the WHODAS II scale. The score ranges between 0 and 100 with a high score indicating severely impaired physical function. The World Health Organization Quality of Life (WHOQOL) scale of 8 to 40 (where 8 is the best quality of life) was used. It includes questions on self-rated general health and on satisfaction with life. Both scales are explained in more detail elsewhere (23–26). We used two single questions to measure self-reported health and function. Participants were asked 'In general, how would you rate your health today?' with the options of very good, good, moderate, bad, and very bad; and 'Overall in the last 30 days, how much difficulty did you have with work or household activities?' with options being none, mild, moderate, severe, and extreme/cannot do.

Two life-style behaviours, cigarette smoking and consuming alcohol, are known to be associated to the occurrence of several chronic diseases. We defined 'currently smoking' as presently using any tobacco product even if not daily. We defined 'currently drinking' as having drunk any alcoholic beverage in the last 30 days.

Weight and height were measured and used to calculate the body mass index (BMI) using the formula: Weight in kilograms/height in metres<sup>2</sup>. A normal scale was used and weight was recorded to the nearest 0.1 kg. Height was measured using a stadiometer and measures were recorded to the nearest 0.1 cm.

Waist/hip ratio was calculated by dividing waist circumference in centimetres by hip circumference in centimetres. Waist circumference was measured at the navel level and the hip at the hip joint level. Both measures were taken using an inelastic tape and recorded to the nearest 0.1 cm.

Blood pressure was calculated by the average of the second and third blood pressure measurements taken. Hypertension was classified as follows:

1. Normal (SBP <120 mmHg and DBP <80 mmHg) and Pre-hypertension (SBP 120–139 mmHg or DBP 80–89 mmHg);
2. Stage 1 Hypertension (SBP 140–159 mmHg or DBP 90–99 mmHg); and
3. Stage 2 Hypertension (SBP ≥160 mmHg or DBP ≥100 mmHg) (27).

When blood pressure is presented as a binary variable, Stage 1 and Stage 2 Hypertension are combined as Hypertension.

Participants were asked whether they had ever been told that they had any of the following health conditions: arthritis, back pain, pain or swelling around joints, stroke, angina, diabetes, respiratory diseases, depression, and hypertension. We created a composite variable termed ‘musculoskeletal pain’ to include self-reported:

1. arthritis;
2. pain, aching, stiffness or swelling in or around the joints not related to an injury and that lasted for more than a month; and
3. back pain during the last 30 days.

We asked participants when was the last time they needed health care; if they had used care in the last 12 months; what type of health facility they used; and the reason for the visit.

### Statistical analysis

We explored factors associated with the presence of hypertension by constructing logistic regression models separately for men and women.

We entered age group *a-priori* into the multivariate regression model and then tested for the effect of all potential risk factors: BMI, waist circumference, waist–hip ratio, tobacco use, alcohol use, union status, education level, household asset status, nationality, physical

function, and quality of life. Risk factors were sequentially introduced into the model and retained in the model if their inclusion had a significant effect at  $p < 0.05$ .

### Results

We obtained completed questionnaires from 425 (73.9%) participants. We were unable to contact 118 (20.5%) participants who had out-migrated or were not available on the three occasions we visited them. In addition, 22 (3.8%) individuals had died and 10 (1.7%) declined to participate.

Women were significantly more likely to be single ( $p < 0.001$ ) (Table 1), report greater levels of disability ( $p = 0.001$ ) and lower quality of life ( $p = 0.029$ ) than men. There was weaker evidence that women rated their health as poorer ( $p = 0.069$ ) and reported more difficulty in performing daily activities ( $p = 0.07$ ) (Table 1). Men reported higher levels of smoking ( $p < 0.001$ ) and higher levels of alcohol intake ( $p < 0.001$ ) (Data not shown).

Overall, 42% of participants reported musculoskeletal pain, 31% hypertension, and 6% diabetes. Men reported respiratory diseases significantly more than women ( $p = 0.039$ ) and women reported hypertension significantly more than men ( $p = 0.001$ ) (Table 2).

We compared self-reported hypertension with measured blood pressure. Of the 255 participants who did not report that they had hypertension, high blood pressure levels compatible with hypertension were present in 112 (43.9%) ( $p < 0.001$ ). Half of the 20 participants who reported hypertension but were normotensive when their blood pressure was measured were on treatment for hypertension. The positive predictive value of a self-reported diagnosis of hypertension was 91.9%, but the negative predictive value of a self-reported normal blood pressure was only 43.9%. Awareness of diagnosis of hypertension varied with gender. Of the 262 women who had measured hypertension, 81 (30.9%) reported that they had hypertension, while of the 116 men with measured hypertension only 22 (19%) reported that they had hypertension ( $p = 0.025$ ).

We found that in all cases, individuals reporting one of the three most commonly reported diagnoses (musculoskeletal pain, hypertension, and diabetes) were significantly more likely to report bad or very bad functional ability (measured by WHODAS) and quality of life (measured by WHOQOL) (data not shown).

Table 3 shows the measures of body size and blood pressure in men and women. Women had a significantly higher mean BMI ( $p < 0.001$ ) and waist circumference ( $p < 0.001$ ) but the difference in waist/hip ratio was not significant ( $p = 0.081$ ). Despite the difference in body size, men and women had similar levels of blood pressure and similar proportions of participants with measured high

**Table 1.** Socio-demographic measures, quality of life, function and life style by gender in the Agincourt sub-district in 2006

	Male	Female	Total	$\chi^2$ p-value (degree of freedom)
<b>Five year age group</b>				
50–54	20 (14.7)	64 (22.2)	84 (19.8)	0.525
55–59	27 (19.9)	46 (16.0)	73 (17.2)	(6 d.f.)
60–64	20 (14.7)	39 (13.5)	59 (13.9)	
65–69	26 (19.1)	42 (14.6)	68 (16.0)	
70–74	13 (9.6)	31 (10.8)	44 (10.4)	
75–79	16 (11.8)	39 (13.5)	55 (13.0)	
80 plus	14 (10.3)	27 (9.4)	41 (9.7)	
<b>Union status*</b>				
Currently married	98 (72.1)	102 (35.3)	200 (47.1)	<0.001
Single	38 (27.9)	187 (64.7)	225 (52.9)	(1 d.f.)
<b>Years of education**</b>				
No education	79 (59.9)	193 (68.7)	272 (65.9)	0.207
Less than 6 years	33 (25.0)	56 (19.9)	89 (21.6)	(2 d.f.)
Six years or more	20 (15.2)	32 (11.4)	52 (12.6)	
<b>Employment status<sup>&amp;</sup></b>				
Employed	35 (29.7)	34 (18.0)	69 (22.5)	0.058
Unemployed	7 (5.9)	13 (6.9)	20 (6.5)	(2 d.f.)
Retired/sick/family supported	76 (64.4)	142 (75.1)	218 (71.0)	
<b>Nationality of origin</b>				
South African	109 (80.2)	207 (71.6)	316 (74.4)	0.061
Mozambican	27 (19.9)	82 (28.4)	109 (25.7)	(1 d.f.)
<b>Household asset score (2005)<sup>#</sup></b>				
Lowest	17 (12.6)	44 (15.3)	61 (14.5)	0.385
Middle low	23 (17.0)	49 (17.1)	72 (17.1)	(4 d.f.)
Middle	24 (17.8)	69 (24.0)	93 (22.0)	
Middle high	33 (24.4)	64 (22.3)	97 (23.0)	
Highest	38 (28.2)	61 (21.3)	99 (23.5)	
<b>WHO Disability Adjusted Score (WHODAS II)<sup>†</sup></b>				
Very good	48 (35.3)	59 (20.4)	107 (25.2)	0.001
Good	28 (20.6)	40 (13.8)	68 (16)	(4 d.f.)
Mild	22 (16.2)	58 (20.1)	80 (18.8)	
Bad	19 (14)	71 (24.6)	90 (21.2)	
Very bad	19 (14)	61 (21.1)	80 (18.8)	
<b>WHO Quality of life (WHOQOL)<sup>††</sup></b>				
Very good	47 (34.6)	65 (22.5)	112 (26.4)	0.029
Good	28 (20.6)	53 (18.3)	81 (19.1)	(4 d.f.)
Mild	23 (16.9)	48 (16.6)	71 (16.7)	
Bad	19 (14)	67 (23.2)	86 (20.2)	
Very bad	19 (14)	56 (19.4)	75 (17.7)	
<b>Rate health today<sup>‡</sup></b>				
Very good	13 (9.6)	17 (5.9)	30 (7.1)	Fisher exact test
Good	63 (46.3)	114 (39.5)	177 (41.7)	0.069
Moderate	50 (36.8)	113 (39.1)	163 (38.4)	
Bad	10 (7.4)	44 (15.2)	54 (12.7)	

Table 1 (Continued)

	Male	Female	Total	$\chi^2$ p-value (degree of freedom)
Very bad	0 (0)	1 (0.4)	1 (0.2)	Fisher exact test 0.07
Difficulty work/household activities <sup>xy</sup>				
None	50 (37)	71 (24.6)	121 (28.5)	
Mild	36 (26.7)	80 (27.7)	116 (27.4)	
Moderate	26 (19.3)	82 (28.4)	108 (25.5)	
Severe	18 (13.3)	47 (16.3)	65 (15.3)	
Extreme	5 (3.7)	9 (3.1)	14 (3.3)	

\*Union status: currently married includes official and traditional unions. Single includes never married, divorced, and separated; \*\*Years of education: completed years of schooling; <sup>z</sup>Employment status: employment situation for those who worked in the past. Employed are currently working. Unemployed are those not currently working but looking for a job; <sup>#</sup>Household asset score: household weighted measured in quintiles used as a proxy to calculate socio-economic status. Data are from 2005; <sup>†</sup>WHODAS II (World Health Organization Disability Assessment Schedule II) is a self-rated measure of functionality presented in quintiles; <sup>††</sup>WHOQOL (World Health Organization quality of life) is self-rated general health and questions on life satisfaction presented in quintiles; <sup>‡</sup>Rate health today: is a self reported measure of health answering the question ‘in general how would you rate your health today?’; <sup>xy</sup>Rate difficulty work/household activities: is a self reported measure of functionality answering the question ‘overall in the last 30 days, how much difficulty did you have with work or household activities?’

blood pressure (Table 3). Mean systolic blood pressure (SBP) was 134.2 in both genders with 95% CI 129.8–138.5 for men and 95% CI 131.4–137.0 for women. When blood pressure levels were analysed by age group and sex, there was little evidence of a trend of increasing blood pressure with age in men, but a significant increase with age in women (data not shown).

Reported use of health care facilities (See Table 4) was associated with a number of factors although, contrary to our expectations, we did not find any significant association between old age and use of health facilities. Women ( $p=0.041$ ), those who were single ( $p=0.012$ ), and those who were South African rather than Mozambican ( $p=0.005$ ) were all more likely to use primary health care facilities. A higher level of education was also associated with greater use of health care facilities but this difference was not significant ( $p=0.066$ ). Individuals

reporting that they had a non-communicable disease were more likely to have used a health facility, as were those reporting a greater level of disability ( $p=0.001$ ) or a lower quality of life ( $p=0.001$ ).

Those participants who reported being told they had a health condition were asked if they had used any medication for the condition in the last 12 months. Of those reporting having diabetes, 98.3% said they had used medication at some time in the last 12 months, with slightly lower figures for other conditions (80.9% of those reporting lung disease; 87.0% of those reporting depression; 80.3% of those reporting hypertension). When asked about their use of health care, 86 participants (20.3%) reported that they had never needed care, and a further 96 (22.7%) reported that they had not needed care within the last 12 months. Twenty eight (32.5%) of those who reported never needing care

Table 2. Prevalence of self reported health conditions by gender

	Male	Female	Total	
	Prevalence (N)	Prevalence (N)	Prevalence (N)	p
Musculoskeletal pain	38.52 (52)	43.21 (124)	41.71 (176)	0.362** (1 d.f.)
Stroke	1.48 (2)	1.74 (5)	1.65 (7)	0.604*
Angina	5.19 (7)	3.47 (10)	4.02 (17)	0.403** (1 d.f.)
Diabetes	6.67 (9)	5.9 (17)	6.15 (26)	0.76** (1 d.f.)
Respiratory disease	8.15 (11)	3.47 (10)	4.96 (21)	0.039** (1 d.f.)
Depression	6.67 (9)	4.86 (14)	5.44 (23)	0.445** (1 d.f.)
Hypertension	20.74 (28)	36.11 (104)	31.21 (132)	0.001** (1 d.f.)

\*Fisher’s exact test; \*\*Chi square test.

**Table 3.** Anthropometric measurements and clinical measures by gender in the Agincourt sub-district in 2006

	Male	Female	<i>p</i>
	N (%)	N (%)	
<b>Categories of BMI</b>			
Underweight <18.5	11 (8.87)	4 (1.49)	<0.001*
Normal weight (18.5–24)	54 (43.55)	69 (25.65)	
Overweight (25–29.9)	37 (29.84)	82 (30.48)	
Obese class I (30–34.9)	19 (15.32)	67 (24.91)	
Obese class II (35–39.9)	1 (0.81)	24 (8.92)	
Obese class III ( $\geq 40$ )	2 (1.61)	23 (8.55)	
<b>Waist/hip ratio category (WHO)</b>			
Normal	36 (26.47)	55 (19.03)	0.081**
Substantially increased	100 (73.53)	234 (80.97)	1 d.f.
<b>Waist circumference (WHO)</b>			
Normal	73 (53.68)	28 (9.69)	<0.001**
Increased	25 (18.38)	47 (16.26)	1 d.f.
Substantially increased	38 (27.94)	214 (74.05)	
<b>Blood pressure JNC7<sup>#</sup></b>			
Normal BP, no treatment	50 (43.1)	114 (43.35)	0.117**
Normal BP on treatment	7 (6.03)	23 (8.75)	5 d.f.
Stage 1 hypertension	22 (18.97)	46 (17.49)	
Stage 1 hypertension on treatment	0 (0)	12 (4.56)	
Stage 2 hypertension	32 (27.59)	52 (19.77)	
Stage 2 hypertension on treatment	5 (4.31)	16 (6.08)	

\*Fisher exact test; \*\*Chi square test; <sup>#</sup>JNC7: classification was done using US Department of Health and Human Services. Seventh report of the Joint National Committee on prevention, detection, evaluation and treatment of high blood pressure. 2004.

nevertheless reported that they had a chronic health condition, including musculoskeletal pain ( $n=16$ ), diabetes ( $n=6$ ), and hypertension ( $n=6$ ).

Information was available for 222 of the 241 people who reporting needing health care in the previous 12 months. Of the 222, 191 (86.0%) had received care. Of these 191, 19% received care in private facilities of various kinds, 22% in public hospital outpatient departments, and 59% in public clinics.

The 191 participants who had used a health facility in the last year accounted between them for 448 visits. Many had used health facilities only once, but 25 participants (13.0% of 191) were responsible for 45.9% of all reported visits. Table 5 shows the risk factors of hypertension separately for men and women. In men, a larger waist circumference (increased waist circumference odds ratio [OR] 4.3; 95% CI 1.3–14.2, substantially increased waist circumference OR 3.7; 95% CI 1.2–11.4) and currently

drinking alcohol (OR 5.2; 95% CI 1.5–18.1) were associated with a higher risk of hypertension. In women, age had a U-shaped association with hypertension (OR aged 55–59 years 3.1, 95% CI 1.3–7.5; OR aged 70–74 years 1.6, 95% CI 0.6–4.2; and OR aged 80 years plus 5.0, 95% CI 1.7–14.9). Other factors associated with hypertension in women were a higher waist–hip ratio (OR 2.7; 95% CI 1.4–5.2) and level of education where those with less than 6 years of formal education were at higher risk than those without any formal education (OR 2.3; 95% CI 1.1–4.8).

## Discussion

In general, this group of older people reports a good quality of life and good or moderately good health. Nevertheless, there was a high prevalence of self-reported health conditions, most notably hypertension (31%) and musculoskeletal pain (42%). Although nearly a third of participants reported being previously diagnosed with a non-communicable disease, around two fifths (43%) reported that they had not needed any health care in the last 12 months.

An important limitation of this study is that apart from blood pressure, we have not been able to confirm the self-reported diagnoses of the non-communicable diseases. The results for hypertension suggest that this self-report may represent an underestimation of the true situation. On the other hand, the self reported approach to measure smoking and drinking may lack specificity and therefore could tend to overestimate levels of risk. Another limitation is the relatively small number of participants, which limits the potential for exploring the relationship between some of the variables.

The individuals in this study were born during the Apartheid era and were almost certainly disadvantaged in the early years of their lives, with low survival. By age 50, the youngest age for inclusion in this study, those who survive and were included in the study may represent a selectively healthier group. While we are confident that this random sample represents the older population of the Agincourt sub-district, the sub-district itself may not represent the rural population of South Africa. The Ehlanzeni district, where Agincourt is situated, is the poorest district in Mpumalanga Province, as assessed by the proportion of individuals living in households where the income is below the monthly income defined as that needed to sustain a household. In Ehlanzeni district, 54.5% of individuals were living in such households, compared with the national rate of 40.7% (28).

The use of anti-retrovirals is unlikely to have had any effect on the health of the individuals in this study. In 2006, when this study was conducted, very few people knew their HIV status and even fewer were using anti-retroviral treatment (ART). These drugs were only available from late 2005 and only in two hospitals between 25 and 60 km from the Agincourt sub-district.

**Table 4.** Health facility use (outpatient) by socio-demographic variables in the Agincourt sub-district in 2006

	No use	Only once	Two or more	<i>p</i>
	N (%)	N (%)	N (%)	
Gender				
Male	81 (60)	36 (26.7)	18 (13.3)	0.041 <sup>β</sup>
Female	150 (52.0)	69 (24.0)	69 (24.0)	2 d.f.
Age groups				
50–54	44 (52.4)	22 (26.2)	18 (21.4)	0.962 <sup>β</sup>
55–59	44 (60.3)	18 (24.7)	11 (15.1)	12 d.f.
60–64	28 (48.3)	15 (25.9)	15 (25.9)	
65–69	38 (56.7)	14 (20.9)	15 (22.4)	
70–74	26 (59.1)	11 (25.0)	7 (15.9)	
75–79	29 (52.7)	13 (23.6)	13 (23.6)	
80 plus	21 (51.2)	12 (29.3)	8 (19.5)	
PHC clinic in village <sup>®</sup>				
No PHC	100 (53.8)	49 (26.3)	37 (19.9)	0.817 <sup>β</sup>
PHC present	130 (55.1)	56 (23.7)	50 (21.2)	2 d.f.
Union status*				
Currently married	123 (61.8)	38 (19.1)	38 (19.1)	0.012 <sup>β</sup>
Single	108 (48.2)	67 (29.9)	49 (21.9)	2 d.f.
Years of education**				
No education	158 (58.5)	61 (22.6)	51 (18.9)	0.066 <sup>β</sup>
Less than 6 years	45 (50.6)	23 (25.8)	21 (23.6)	4 d.f.
Six years or more	20 (38.5)	20 (38.5)	12 (23.1)	
Employment status <sup>§</sup>				
Employed	40 (58.0)	14 (20.3)	15 (21.7)	0.199 <sup>z</sup>
Unemployed	12 (60.0)	7 (35.0)	1 (5.0)	
Retired/sick/family	106 (48.9)	60 (27.7)	51 (23.5)	
Nationality of origin				
South African	161 (51.0)	79 (25.0)	76 (24.1)	0.005 <sup>β</sup>
Mozambican	70 (65.4)	26 (24.3)	11 (10.3)	2 d.f.
Household asset score (2005) <sup>#</sup>				
Lowest	38 (63.3)	16 (26.7)	6 (10.0)	0.28 <sup>β</sup>
Middle low	37 (51.4)	22 (30.6)	13 (18.1)	8 d.f.
Middle	56 (60.9)	16 (17.4)	20 (21.7)	
Middle high	49 (50.5)	25 (25.8)	23 (23.7)	
Highest	50 (50.5)	26 (26.3)	23 (23.2)	
WHODAS <sup>†</sup>				
Very good/good	106 (60.9)	51 (29.3)	17 (9.8)	<0.001 <sup>β</sup>
Middle	43 (53.8)	16 (20.0)	21 (26.3)	4 d.f.
Bad/very bad	82 (48.5)	38 (22.5)	49 (29.0)	
WHOQOL <sup>††</sup>				
Very good/good	122 (63.5)	51 (26.6)	19 (9.9)	<0.001 <sup>β</sup>
Middle	39 (54.9)	14 (19.7)	18 (25.4)	4 d.f.
Bad/very bad	70 (43.8)	40 (25.0)	50 (31.3)	
Self-reported health conditions <sup>‡</sup>				
Stroke	3 (42.9)	1 (14.3)	3 (42.9)	0.008 <sup>z</sup>

Table 4 (Continued)

	No use	Only once	Two or more	<i>p</i>
	N (%)	N (%)	N (%)	
Musculoskeletal pain	66 (37.5)	49 (27.8)	61 (34.7)	<0.001 <sup>β</sup>
Angina	9 (52.9)	4 (23.5)	4 (23.5)	0.02 <sup>α</sup>
Diabetes	10 (38.5)	5 (19.2)	11 (42.3)	<0.001 <sup>α</sup>
Respiratory disease	8 (38.1)	5 (23.8)	8 (38.1)	<0.001 <sup>α</sup>
Depression	9 (39.1)	9 (39.1)	5 (21.7)	0.001 <sup>α</sup>
Hypertension	43 (32.6)	40 (30.3)	49 (37.1)	<0.001 <sup>β</sup>

<sup>α</sup>Fisher's exact test; <sup>β</sup>Chi square test; <sup>Ⓜ</sup>PHC in village: comparison of villages with a primary health care facility and those without; \*Union status: currently married includes official and traditional unions. Single includes never married, divorced, and separated; \*\*Years of education: completed years of schooling; <sup>δ</sup>Employment status: employment situation for those who worked in the past. Employed are currently working. Unemployed are those not currently working but looking for a job; <sup>#</sup>Household asset score: household weighted measured in quintiles used as a proxy to calculate socio-economic status. Data from 2005; <sup>†</sup>WHODAS II (World Health Organization Disability Assessment Schedule II) is a self-rated measure of functionality presented in quintiles; <sup>††</sup>WHOQOL (World Health Organization quality of life) is self-rated general health and questions on life satisfaction presented in quintiles; <sup>‡</sup>Self reported health conditions: health conditions reported by respondent as being diagnosed in the 12 months previous to the interview. Analysis is on health facility use comparing those who reported a health condition with those not reporting any health condition.

A key finding is the low level of health care use by older people, despite the prevalence of non-communicable diseases and HIV in this population. Previous research has also found low levels of health care use in South Africa (12, 29, 30). Forty-three percent of participants reported that they had not needed care in the last year. In comparison, a study in Botswana found that 42% of the elderly had used health care facilities during the month previous to the interview (31). It is likely that there is considerable unmet and unrecognised need for health care. This is supported by the high proportion of individuals in the study who were unaware they had hypertension. Adherence may also be a problem. A study in Tanzania found that even when older people are referred to a health facility after screening for hypertension, a low percentage of them used Western health care. However, hypertensive treatment was not free, as it is in South Africa (32).

While the figures on use of medication in those reporting diabetes and other major conditions might indicate good adherence to medication, they should be interpreted with considerable caution since they only indicate some medication use within 12 months. We have no information on duration of use or on whether the medication used was prescribed by a health professional. It is routine in clinics in this area to provide no more than one month's supply of medication at a time, and this may be a barrier to long term adherence.

As part of improving treatment for this group of people, a better drug supply in the primary health care facilities would be necessary to allow nurses to provide treatment for more than 1 month, which is still the routine in most clinics in this rural area.

The significantly higher level of respiratory disease reported by men may relate to smoking habits or prolonged stay on the mines and underground, a long standing feature of the South African and regional economy.

When we measured the blood pressure of participants, we found a very high prevalence of hypertension (57%), much higher than self-reported. One earlier national study carried out in 1998 in South Africa reported a combined rural and urban prevalence of 21% in the population aged 15 plus, with 44% in African men aged 45 years and older, and 50% in African women of the same age (12). As in our results, the earlier study found that the high levels of hypertension came with low levels of awareness of the condition (10).

Our study shows high levels of hypertension in a rural South African setting, even higher than those found 8 years ago in urban areas. These findings support earlier predictions that hypertension levels were going to increase in the early 2000s and indicate that the problem of hypertension in older people is not just an urban phenomenon but is universal (3).

We found that women were more likely than men to be aware of their blood pressure status, which may well be explained by their more frequent use of health services. This corroborates findings in other African settings where women had higher levels of awareness, treatment, and control of hypertension (2, 3).

Gender differences related to health and health-seeking behaviour are well characterised in this study. In a previous study (33), women reported higher levels of disability and poorer quality of life. Our study corroborates other reports that women use health facilities

**Table 5.** Risk factors for high blood pressure in people aged 50 years or older in a rural South African setting (Agincourt sub-district, 2006)

	Male			Female		
	OR	<i>p</i>	[95% CI]	OR	<i>p</i>	[95% CI]
<b>Age</b>						
50–54	1			1		
55–59	0.76	0.734	(0.16–3.60)	3.12	0.011	(1.29–7.52)
60–64	0.64	0.592	(0.12–3.29)	2.25	0.074	(0.92–5.48)
65–69	0.95	0.948	(0.21–4.39)	1.87	0.164	(0.77–4.5)
70–74	0.68	0.662	(0.12–3.88)	1.57	0.359	(0.6–4.16)
75–79	0.35	0.231	(0.06–1.94)	5.19	0.001	(1.9–14.14)
80 plus	0.92	0.923	(0.15–5.52)	5.04	0.004	(1.7–14.93)
<b>Waist/hip ratio</b>						
Normal				1		
Substantially increased				2.68	0.004	(1.37–5.26)
<b>Education level</b>						
No education				1		
Less than 6 years				2.31	0.025	(1.11–4.82)
Six years or more				1.07	0.873	(0.46–2.49)
<b>Waist circumference</b>						
Normal	1					
Increased	4.28	0.018	(1.29–14.22)			
Substantially increased	3.71	0.022	(1.21–11.41)			
<b>Alcohol consumption</b>						
Never drink	1					
Past drink	1.39	0.569	(0.45–4.29)			
Currently drink	5.21	0.009	(1.50–18.13)			
<b>Household asset score</b>						
Lowest	1					
Middle low	1.56	0.576	(0.33–7.4)			
Middle	2.22	0.317	(0.47–10.57)			
Middle high	4.13	0.061	(0.94–18.23)			
Highest	1.39	0.657	(0.33–5.92)			

more than men and are more aware of their health situation (10).

Women were very much more likely than men to be obese. A similar gendered pattern of body size has been reported previously in southern Africa (34–36), but no credible explanation has yet been put forward. Despite these findings, there was no difference between men and women either in the prevalence of hypertension or in mean levels of blood pressure. A recent systematic review of hypertension in sub-Saharan Africa found similar findings to those reported here. There were low levels of detection, treatment, and control and only minimal differences between men and women in the prevalence of hypertension (3).

As emphasised by the South Africa Minister of Health, Aaron Motsoaledi, in his talk to the Board of Health Care Funders in 2011, South Africa is running ‘a health care system that is not working’, and, he argued, ‘the solution lies in re-engineering primary health care’ (37). It remains to be seen whether a new system of integrated chronic care will successfully meet the currently unmet needs of a growing population of older people with chronic disease. The Department of Health is piloting an integrated chronic care system in primary health care clinics in Bushbuckridge and the evaluation of this pilot will provide important information to guide the development of the South African primary health care system.

### Ethical clearance

Ethical clearance for the MRC/WITS Rural Public Health and Health Transitions Research Unit's (Agincourt) Health and socio-Demographic Surveillance System was granted by the Committee for Research on Human Subjects (Medical) University of the Witwatersrand, Johannesburg, South Africa (Ref M960720).

Ethical clearance for the Agincourt-INDEPTH Study on Global Ageing and Adult Health was given by the Committee for Research on Human Subjects (Medical) University of the Witwatersrand, Johannesburg, South Africa (Ref R14/49).

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### Conflicts of interest and funding

We declare that we have no conflicts of interest.

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**\*Francesc Xavier Gómez-Olivé**

MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt)  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Email: [xavier@agincourt.co.za](mailto:xavier@agincourt.co.za)



## Exploring the paradox: double burden of malnutrition in rural South Africa

Elizabeth W. Kimani-Murage<sup>1,2\*</sup>

<sup>1</sup>African Population and Health Research Center, Nairobi, Kenya; <sup>2</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

**Background:** This article is a review of the PhD thesis by Elizabeth Kimani-Murage that explores the double burden of malnutrition in rural South Africa. This is in the context of a worryingly rapid increase in obesity and obesity-related diseases in low- and middle-income countries (LMICs) including South Africa, and in the wake of on-going nutrition transition and lifestyle changes in these countries.

**Objective:** To understand the profiles of malnutrition among children and adolescents in a poor, high HIV prevalent, transitional society in a middle-income country.

**Methods:** A cross-sectional growth survey was conducted in 2007 targeting 4,000 children and adolescents aged 1–20 years. In addition, HIV testing was carried out on children aged 1–5 years and Tanner pubertal assessment among adolescents aged 9–20 years.

**Results:** The study shows stunting at an early age and adolescent obesity, particularly among girls, that co-exists in the same socio-geographic population. The study also shows that HIV is an independent modifiable risk factor for poor nutritional outcomes in children and makes a significant contribution to nutritional outcomes at the individual level. Significant predictors of undernutrition at an early age, documented at individual, household, and community levels, include child's HIV status, age and birth weight, maternal age, age of household head, and area of residence. Significant predictors of overweight/obesity and risk for metabolic disease during adolescence, documented at individual and household levels include child's age, sex, and pubertal development, household-level food security, socio-economic status, and household head's highest education level.

**Conclusions:** The combination of early stunting and adolescent obesity raises critical concerns in the wake of the rising public health importance of metabolic diseases in LMICs. This is because, both paediatric obesity and adult short stature are risk factors for metabolic syndrome and metabolic diseases in adulthood. Clearly, policies and interventions to address malnutrition in this and other transitional societies need to be double-pronged and gender-sensitive.

**Keywords:** *nutrition transition; double burden of malnutrition; stunting; underweight; wasting; overweight; obesity; metabolic disease risk; HIV; low- and middle-income countries; South Africa*

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Nutrition transition, being experienced in low- and middle-income countries (LMICs) undergoing rapid economic transition and urbanisation, is a major driving force behind the increase in levels of obesity in LMICs, despite persistence of undernutrition (1, 2). Therefore, both undernutrition- and obesity-related diseases contribute substantially to the burden of disease in these societies (3). The problem of obesity is not only experienced among adults but also in children (4). Childhood obesity is the driving force behind paediatric metabolic syndrome risk that has become a growing public health concern in LMICs (5). Childhood obesity is associated with short-term health

problems including heightened risk of psychosocial morbidity, cardiovascular complications and type 1 and type 2 diabetes. It is also associated with long-term problems including obesity and cardio-metabolic diseases and impaired social and economic productivity in adulthood (6).

Due to its historical background, characterised by nearly half a century of Apartheid, high levels of HIV/AIDS over the past few decades (7), and the recent rapid economic and social transition and urbanisation (8, 9), South Africa has undergone a complex health transition (10–13). It is characterised by high levels of persisting undernutrition among the Black population (13),

potentially due to high levels of food insecurity reported at the household level (14). On the other hand, a rapid nutrition transition has been experienced in the country with a marked shift from staple foods towards an energy dense diet occurring alongside urbanisation (15, 16). High levels of physical inactivity and sedentary lifestyles have also been associated with the nutrition transition in several studies in South Africa (16, 17). This has resulted in a high prevalence of overweight and obesity among adults, particularly women; for example, 55% of adult women are either overweight or obese, with a consequent high disease burden of non-communicable diseases (10–13).

Evidence of obesity among children and adolescents is emerging though still limited, and little is known about co-existence of undernutrition with obesity among children in the same geographical setting (18, 19). This co-existence is the focus of this study. This article presents a review of a PhD thesis based on a study whose main objective was to better understand the profiles of malnutrition among children and adolescents in a poor, high HIV prevalent transitional society in a middle-income

country and in so doing, to inform policies and interventions. The results are organised into three thematic areas including: (1) patterns of malnutrition; (2) adolescent obesity and risk for metabolic disease; and (3) child undernutrition in the context of HIV. The different themes are distilled from four studies emanating from the doctoral research (20–23).

### Conceptual framework

Figure 1 presents a conceptual framework illustrating the hierarchical organisation of the different societal levels that influence a child’s nutritional status (2, 24–26). The framework recognises that nutrition transition and lifestyle changes, occurring in transitional societies, influence a child’s nutritional status at different societal levels. Nutrition transition and lifestyle changes influence nutritional status directly at individual level. They also have an indirect influence through changes experienced at household and community levels. In the reviewed thesis, children’s nutritional status in a transitional society is described. Furthermore, distal factors influencing a

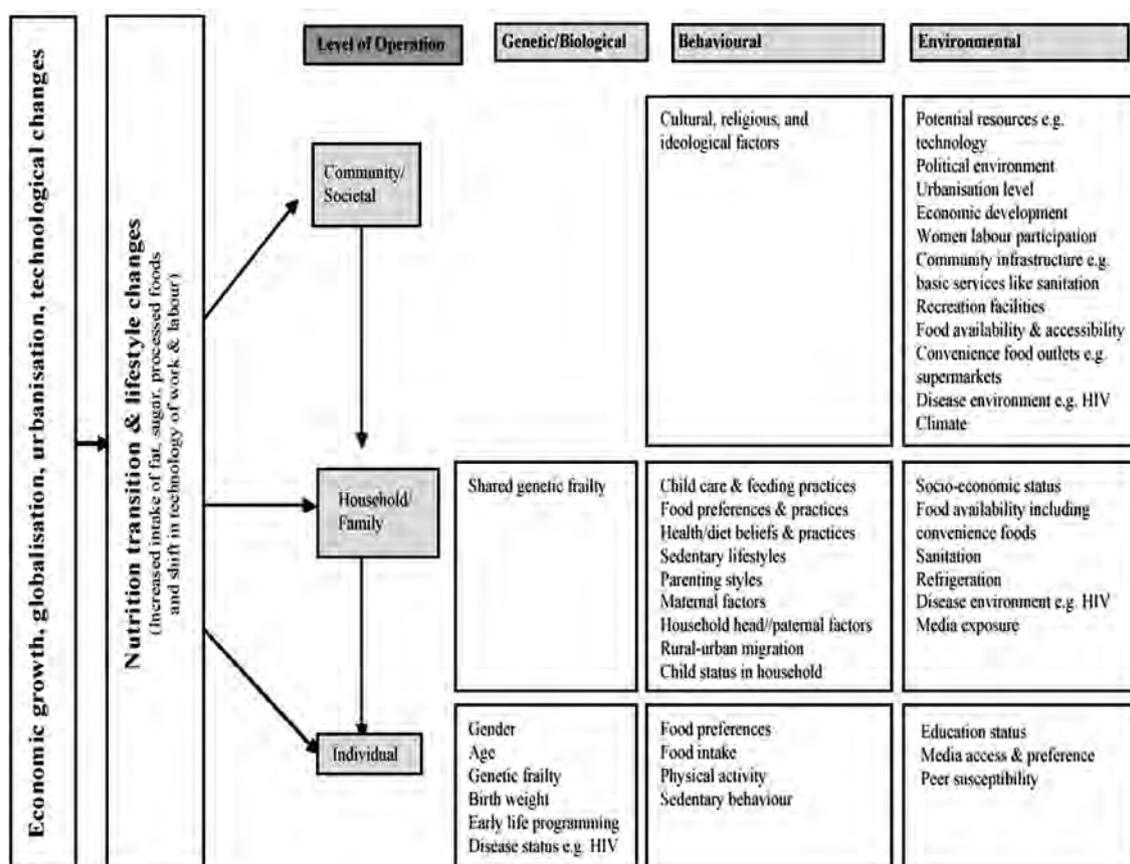


Fig. 1. Conceptual framework on nutrition transition and hierarchical organisation of factors influencing a child’s nutritional status.

Note: The framework is adapted from Popkin’s (2003) model of nutrition transition (2), and Griffiths (2004) framework of interpreting community, family and individual effects on child weight status (24). It is also informed by the Food and Agriculture Organization’s (FAO)’s (2004) model on changes in food systems (25), and Davison’s (2001) ecological model for childhood obesity (26).

child's nutritional status are assessed at the individual, household, and community levels.

## Methods

### Study setting and population

This study was conducted in the Agincourt sub-district, Mpumalanga Province, rural northeast South Africa, alongside South Africa's border with Mozambique. Agincourt is a semi-arid setting, situated in the former Gazankulu homeland. The study was nested within the Agincourt health and socio-demographic surveillance system (HDSS) of the University of the Witwatersrand. The Agincourt HDSS is a multiround prospective community study, which was established in 1992, and covers the entire Agincourt sub-district. Until 2007, when the site was extended, the HDSS followed some 70,000 people living in 11,500 households in 21 villages where about 30% were of Mozambican origin. The area is characterised by high levels of unemployment and poverty (27). Labour migration, mainly circular rural–urban migration, is widespread involving up to 60% of working age men and growing numbers of women (28). Being in a former homeland, the land is subdivided into plots too small to support subsistence farming. Piped water is available at community level, but there are frequent water shortages in most villages. Sanitation is poor, particularly in the former refugee settlements (29). Literacy levels have improved post-apartheid in the younger generation, but high illiteracy levels remain among the older generation, reaching levels of almost 80% for those aged 60 years and above (30). Health care services are limited. The area is characterised by a high prevalence of HIV/AIDS – a third of pregnant women visiting public antenatal health clinics in the province are infected (7). The study area, Agincourt HDSS, and local demographics are described in detail elsewhere (29).

### Data sources

The study used data from three sources: growth survey in 2007, a follow-up study in 2008, and the Agincourt HDSS.

#### Growth survey (2007)

A growth survey nested within the Agincourt HDSS was conducted between April and July 2007 (20, 22, 23). The study sample comprised children and adolescents aged 1–20 years, selected from the entire population, and 4,000 children and adolescents were targeted, comprising 100 males and 100 females for each year of age. We oversampled 10–15 children per age–sex group to counter possible non-participation. Thus, a total of 4,658 children were randomly selected. Only children who had lived in the study area at least 80% of the time since birth, or since 1992 when enrolment in the Agincourt HDSS began were included. The study involved anthropometric

measurements (height, weight, and waist circumference) according to standard procedures (31). Additionally, pubertal assessment of adolescents aged 9–20 years using the Tanner 5-point pubertal self-rating scale (32), and HIV testing of children 1–5 years using two concurrent rapid tests: Uni-Gold™ (Trinity Biotech, Bray, Ireland) and Determine™ (Abbott, Wiesbaden, Germany) in accordance with WHO recommendations for HIV screening in children (33) were carried out.

#### Follow-up study (2008)

A follow-up of a subset of the 2007 growth survey was conducted between May and June 2008 (21). This involved follow-up of HIV-infected children aged 1–5 years identified in the 2007 survey ( $n=35$ ). In-depth interviews with caregivers of HIV-infected children who were aware of the child's status ( $n=22$ ) were conducted. The in-depth interviews explored issues on attitudes, reactions and the impact of knowing a child's HIV status, caregiving and seeking antiretroviral treatment (ART) for the child, and challenges in caregiving.

#### Agincourt HDSS

The Agincourt HDSS is a longitudinal community surveillance that involves systematic annual recording of vital demographic events, including births, deaths, and in- and out-migrations occurring in the entire Agincourt sub-district. Additional data to provide information on particular areas of interest, for example, food security is collected as special census modules nested within the annual update rounds. An asset survey conducted in each household every 2 years gives a measure of household socio-economic status (SES) (29). Data on potential explanatory variables were extracted from the Agincourt HDSS including: individual factors: child's age, sex, birth weight, and relationship to household head; household factors: mother's age, nationality, highest education level, marital/union status, co-residence with child and place of delivery (for index child aged less than 5 years), and household head's age, sex and highest education level, household food security and SES; and area of residence as a proxy for community-level factors.

### Data analysis

#### Outcome measures

This included height-for-age z scores (HAZ), weight-for-age z scores (WAZ), weight-for-height z scores (WHZ), stunting, underweight, wasting, body mass index (BMI), overweight, obesity, waist-to-height ratio, and central obesity. HAZ, WAZ, and WHZ for children up to 60 completed months were generated using the WHO 2006 growth standards while for those aged 5–17 years were determined using the NCHS/WHO reference. Stunting, underweight, and wasting were, respectively, defined as z-scores less than  $-2$  (34). BMI was determined by

dividing weight (in kg) by height squared (in metres). Overweight and obesity in children aged 2–17 years was determined using the absolute age and sex-specific cut-offs for BMI recommended by the International Obesity Task Force (IOTF) (35). For adolescents aged 18–20 years, adult cut-off points of BMI  $\geq 25$  and  $\geq 30$  kg/m<sup>2</sup> for overweight and obesity were used (36). Dividing waist circumference by height generated waist-to-height ratio. Waist-to-height ratio cut-offs of 0.5 for both sexes (37) were used to determine those with central obesity, hence risk of metabolic disease among adolescents.

### Explanatory variables

We included individual-level characteristics (age, sex, birth weight, HIV status [for children aged 1–4 years, although HIV test was done for children 1–5 years], pubertal stage [for adolescents], and relationship to household head); household-level characteristics including maternal characteristics (age, nationality, highest education level, marital status, co-residence with child, and place of delivery), and other household characteristics (household head's age, sex, and highest education level, household food security and SES); and community-level characteristics (area of residence).

### Descriptive analysis

We used described patterns of malnutrition for 1–20 year olds by age and sex; by HIV status for children aged 1–4 years; and by pubertal stage for adolescents aged 9–20 years (20, 22).

### Multiple linear and logistic regression analysis

This was carried out with the outcome and explanatory variables described above to determine predictors of undernutrition in children aged 1–4 years, and predictors of overweight/obesity and risk for metabolic disease for adolescents aged 10–20 years. Only variables significantly associated with nutritional status from the univariate analyses at the 10% level of significance were included in multiple regression analysis. Significant association was determined at the 5% level of significance (95% confidence interval) (22, 23).

### Qualitative data analysis

This was conducted across all transcripts using a constant comparative method, to identify themes and their repetitions and variations (21, 38).

## Results

### Patterns of malnutrition

Analyses involved a total of 3,489 children: 1,724 (49.4%) males and 1,765 (50.6%) females, aged between 1 and 20 years (20).

Stunting was prevalent, particularly in children aged less than 5 years (18%) and highest in children aged 1 year (32%). The prevalence was lowest among children aged 5–9 years (5%), but went up during adolescence particularly in boys between 14 and 15 years of age when the prevalence rose to 14–15%. The prevalence of being underweight was highest among children aged less than 5 years at 10%, and lowest among children aged 5–9 years (6%), and peaked in boys aged 14 years (19%). The prevalence of wasting was 7 and 6% in children aged 1–4 and 5–9 years, respectively. See Fig. 2 (20).

The prevalence of combined overweight and obesity was moderate in early childhood and low in late childhood, and remained so in older boys. The prevalence rose progressively in girls aged 10 years and older. The prevalence was highest amongst adolescents in the age category 15–20 years (12%) and averaged 19% in girls, compared to 4% in boys, reaching 25% at age 18 years in girls. The prevalence was significantly higher in girls than in boys in most of the adolescent years ( $p < 0.05$ , respectively, see Fig. 3) (20). With regard to Tanner staging, combined overweight and obesity was lower in the earlier stages of puberty, but increased markedly during the later stages in girls (from 7% at stage 1 to 35% at stage 5); while in boys the prevalence remained low (<5%) throughout the stages. The prevalence of combined overweight and obesity was significantly different by sex at Tanner stages 3, 4 and 5 ( $p < 0.05$ , respectively). About 10% of adolescents were potentially at risk of metabolic disease, which was significantly higher for girls (15%) than boys (3%) ( $p < 0.001$ ) (20).

### Adolescent obesity and risk for metabolic disease

The analysis for weight status and central obesity involved 1,848 participants aged 10–20 years: 903 (49.6%) boys and 945 (50.5%) girls. Age, sex and pubertal development status (individual level factors) all emerged as significant predictors of a child's weight status and central obesity, which are in turn risk factors for metabolic disease. Older children, girls, and pubertal and post-pubertal adolescents were more likely to be overweight/obese. At household level, among maternal factors included, the mother's age was a significant predictor of overnutrition, with children of mothers aged 50+ years more likely to be over nourished. Other significant predictors at household level included household head's highest education level, food security, and socio-economic status. Little education (less than secondary certificate) was associated with overnutrition. Additionally, food security and SES were both positively associated with overnutrition. Area of residence at community level was not significantly associated (see Table 1) (23).

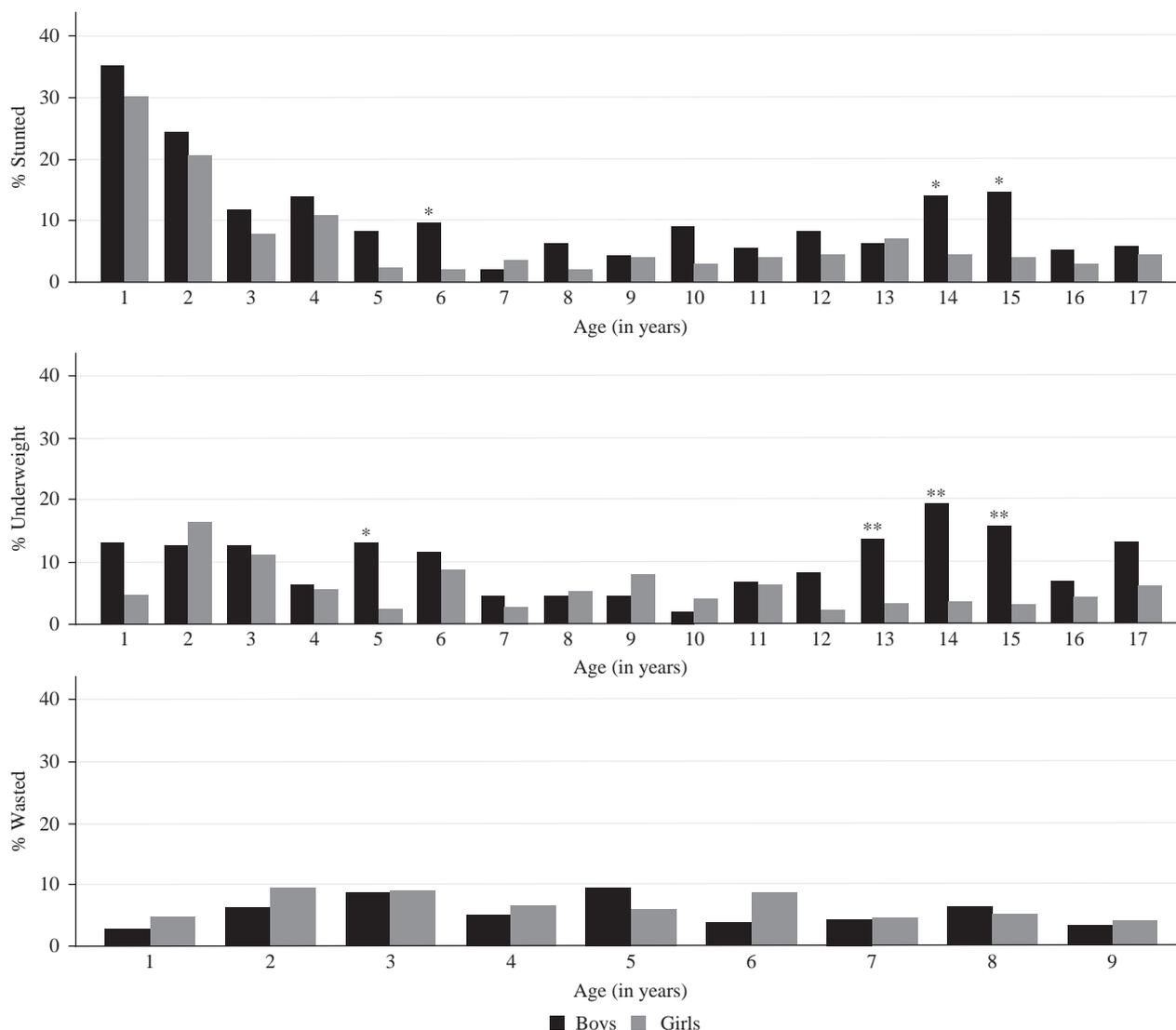


Fig. 2. Prevalence of stunting and underweight for children aged 1–17 years ( $n = 3,070$ ) and wasting for children aged 1–9 years ( $n = 1,641$ ) by sex, Agincourt sub-district, South Africa, 2007. Significant difference by sex: \* $p$ -value  $< 0.05$ , \*\* $p$ -value  $< 0.01$ , \*\*\* $p$ -value  $< 0.001$ . Source: Kimani-Murage et al. 2010 (20).

**Child undernutrition in the context of HIV**

This analysis involved 671 children aged 1–4 years in 2007: 338 (50.4%) boys and 333 (49.6%) girls.

**Patterns of nutritional status by HIV status and predictors of undernutrition**

Consent was given for HIV testing in 640 of the 671 children aged 1–4 years (95%). Six hundred and twelve were not infected with HIV, 28 were HIV infected, while 31 were not tested (no consent for the test) giving a prevalence of 4.4% (95% CI: 2.79–5.97). A negligible number of HIV-infected children were on ART. The mean HAZ, WAZ, and WHZ were all significantly lower in HIV-infected children compared to children not infected with HIV ( $p < 0.05$ , respectively) (22).

In the multiple regression, HIV status was strongly associated with HAZ and WAZ, but its association

with WHZ, stunting, underweight, and wasting was not significant at the 5% level. Other significant predictors of child’s nutritional status included the child’s age, birth weight, maternal age, age of household head, and area of residence. Generally, an increase in child’s age was negatively associated with undernutrition, while low birth-weight (prevalent in about 10% of the children aged 1–4 years) was positively associated with undernutrition. Children of younger mothers and younger household heads were more likely to be under nourished. Additionally, children from villages predominantly inhabited by people of Mozambican origin were more likely to be under nourished (see Tables 2 and 3) (22).

**Caregiving experiences after learning a child’s HIV status**

These findings derive from in-depth interviews with caregivers of HIV-infected children 1 year after disclosure

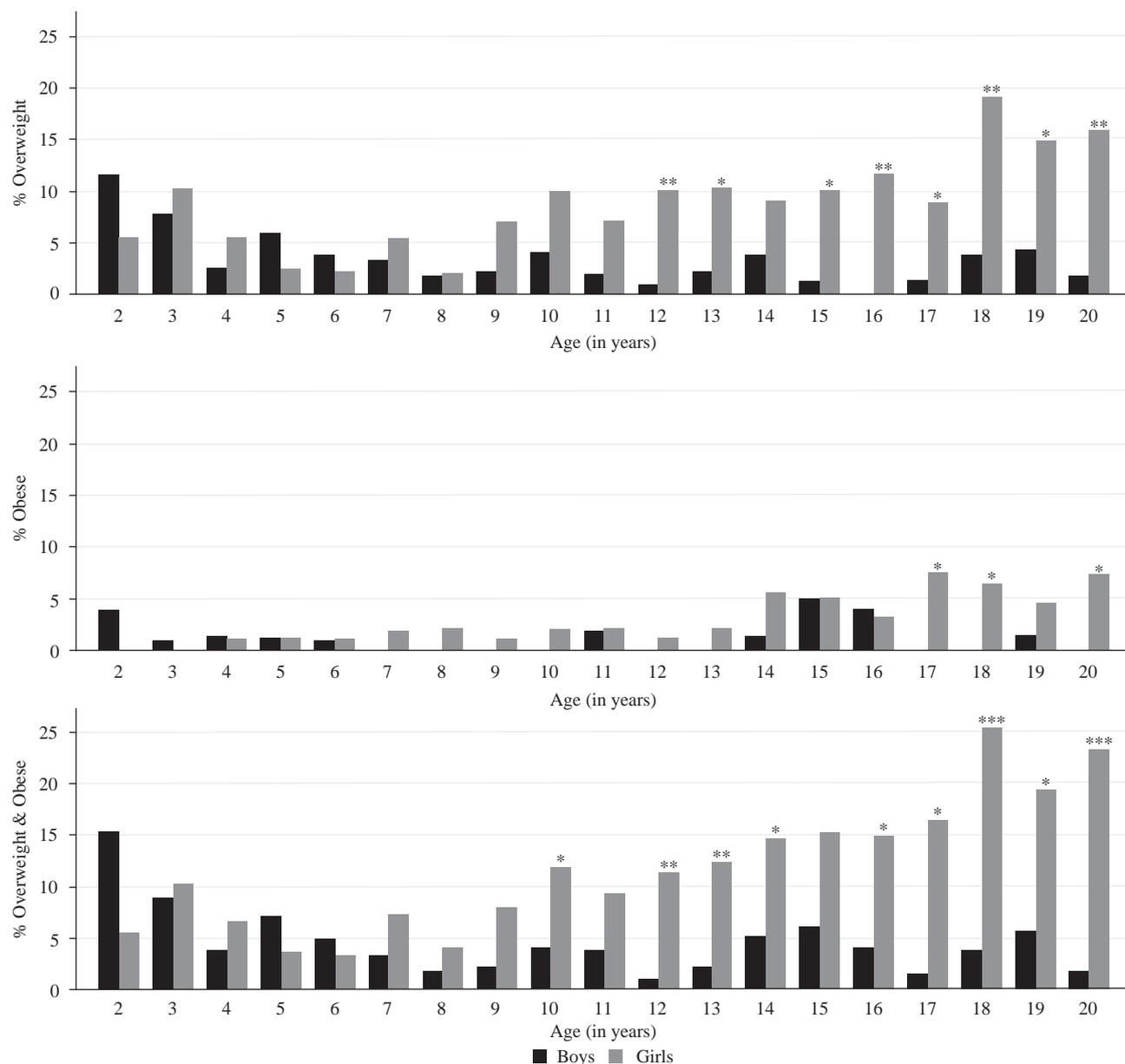


Fig. 3. Prevalence of overweight, obesity & combined overweight and obesity for children aged 2–20 years ( $n=3,358$ ) by age and sex, Agincourt sub-district, South Africa, 2007. Significant difference by sex: \* $p$ -value <0.05, \*\* $p$ -value <0.01, \*\*\* $p$ -value <0.001. Source: Kimani-Murage et al. 2010 (20).

of the child’s HIV status. Knowing the child’s HIV status was perceived as beneficial and as enhancing the caregiver’s competency in caregiving as it led to acquiring helpful advice from health professionals and other people. Reported changes included heightened hygiene, protecting other children from infection, heightened health-seeking behaviour, and improved child-feeding practices. Of importance was seeking ART for the HIV-infected children. Though most children were not on ART, knowing the child’s HIV status stimulated the caregivers to seek ART for the child. Three children were on ART at the time of the follow-up study while eight other women had sought ART but the

children had not been initiated due to medical reasons and other barriers, including financial, access, and social issues (21).

Caregivers of HIV-infected children faced barriers in caring for the children, including financial barriers, poor access to health services, and compromised physical ability to provide care due to their own poor health. Problems with health services included a shortage of drugs, for example, antibiotics for opportunistic infections, limited access to ARVs which were provided by only one health facility in the community distant from many of the villages, lack of confidentiality, and negative attitudes from health professionals, particularly at the

**Table 1.** Predictors of weight status and central obesity among adolescents 10–20 years ( $n = 1,848$ ), Agincourt sub-district, rural South Africa, 2007

Variable <sup>1</sup>	BMI z-scores <sup>2</sup>	Overweight and obesity <sup>3</sup>	WHtR z-scores <sup>2</sup>	Central obesity <sup>3</sup>
	Coeff [95% CI]	OR [95% CI]	Coeff [95% CI]	OR [95% CI]
<b>Child-level factors</b>				
Child age	-0.0 [-0.0, 0.0]	1.0 [0.9, 1.1]	-0.2 [-0.0, 0.0]	1.1 [1.0, 1.2]*
<b>Child sex</b>				
Boys (ref)	0	1	1	1
Girls	0.6 [0.5, 0.7]***	4.2 [2.8, 6.4]***	-0.0 [-0.1, 0.1]	7.2 [3.7, 14.2]***
<b>Pubertal status</b>				
Pre-pubertal	0	1	1	1
Pubertal	0.3 [0.1, 0.5]***	1.4 [0.7, 2.8]	0.1 [-0.1, 0.2]	1
Post-pubertal	1.1 [0.8, 1.4]***	4.4 [1.9, 10.1]***	0.4 [0.2, 0.7]***	2.9 [1.8, 4.6]***
<b>Household-level factors</b>				
<i>Maternal factors</i>				
<b>Mother's age category</b>				
35–49 (ref)		1		1
15–34		1.4 [0.8, 2.3]		1.9 [0.9, 4.0]
50+		1.5 [1.0, 2.2]		1.8 [1.1, 2.8]*
<i>Other household factors</i>				
<b>HHH education</b>				
No education (ref)	0			
<Secondary level	-0.1 [-0.3, -0.0]*	0.6 [0.4, 0.9]*		
Secondary level and higher	0.1 [-0.1, 0.4]	1.1 [0.6, 2.0]		
<b>Food security</b>				
Not enough (ref)	0	1	1	1
Enough	0.2 [-0.0, 0.3]	1.4 [0.8, 2.2]	0.1 [0.0, 0.2]*	1.7 [0.9, 3.2]
<b>Wealth index tertiles</b>				
Lowest (ref)	0	1	0	1
Medium	0.3 [0.1, 0.4]**	1.4 [0.9, 2.2]	0.0 [-0.3, 0.2]	1.3 [0.7, 2.2]
Highest	0.3 [0.1, 0.4]***	2.0 [1.3, 3.1]**	0.1 [0.0, 0.3]*	1.9 [1.1, 3.3]*

<sup>1</sup>Only variables with significant association at 10% level of significance are shown.

<sup>2</sup>Linear regression.

<sup>3</sup>Logistic regression.

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ .

nearly clinics. These barriers were reported to limit caregivers' effective care (21).

## Discussion

### *Patterns of malnutrition*

We found a co-existence of substantial levels of undernutrition, particularly stunting at an early age, with marked levels of overweight/obesity and an elevated risk for metabolic disease in adolescent girls. The levels of early undernutrition in this rural community correspond with earlier findings in South Africa (18, 39, 40). This indicates persistence of the problem despite post-apartheid development. The higher prevalence of under-

nutrition amongst adolescent boys compared to girls is in line with findings in other South African studies (41). This differential prevalence of undernutrition by sex among adolescents is most likely due to a delay in the pubertal growth spurt in boys compared to the reference group, which occurs where undernutrition is prevalent (42). However, other factors may also contribute to these differences and may need further investigation. The finding of a higher prevalence of overweight/obesity and risk for metabolic disease among adolescent girls, and almost non-existent levels in adolescent boys, has been documented in other South African studies (19, 41), and in other LMICs (43). The prevalence of overweight/obesity in South African girls compares to that found in several

**Table 2.** Linear regression analysis for predictors of height-for-age, weight-for-age, and weight-for-height z-scores among children aged 12–59 months ( $n = 671$ ), Agincourt, South Africa (2007)

Variable <sup>1</sup>	HAZ	WAZ	WHZ
	Coeff [95% CI]	Coeff [95% CI]	Coeff [95% CI]
<b>Child-level factors</b>			
<b>HIV status</b>			
Negative (ref)	0	0	0
Positive	−0.8 [−1.2, −0.3]**	−0.7 [−1.2, −0.3]**	−0.5 [−1.0, 0.1]
Unknown status	0.2 [−0.2, 0.6]	0.2 [−0.2, 0.6]	0.2 [−0.3, 0.7]
Child age	0.2 [0.1, 0.3]***		−0.2 [−0.3, −0.1]**
<b>Birth weight</b>			
≥2.5 kg (ref)	0	0	0
<2.5 kg	−0.6 [−0.9, −0.3]***	−0.7 [−1.1, −0.4]***	−0.7 [−1.0, −0.3]***
<b>Household-level factors</b>			
<i>Maternal Factors</i>			
<b>Mother's age</b>			
25–34 (ref)	0	0	
15–24	−0.3 [−0.5, −0.1]**	−0.3 [−0.5, −0.1]*	
35+	−0.1 [−0.3, 0.2]	−0.1 [−0.3, 0.2]	
<b>Mother's education</b>			
None (ref)		0	0
<Secondary		0.2 [−0.1, 0.5]	0.2 [−0.2, 0.5]
Secondary and tertiary		0.3 [−0.0, 0.6]	0.2 [−0.2, 0.6]
<b>Mother co-residence</b>			
Co-residing (ref)	0		
Not co-residing	0.6 [−0.1, 1.2]		
<i>Other household factors</i>			
<b>Household head age</b>			
35–49 (ref)		0	0
15–34		−0.3 [−0.6, −0.0]*	−0.3 [−0.7, −0.0]
50+ years		−0.1 [−0.3, 0.7]	−0.2 [−0.4, −0.0]
<b>Community-level factors</b>			
<b>Area of residence</b>			
Predominantly South African (ref)	0	0	
Predominantly Mozambican	−0.3 [−0.7, −0.0]	−0.3 [−0.7, 0.0]	

<sup>1</sup>Only variables with significant association at 10% level of significance are shown.

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ .

upper-middle- and higher-income countries, whilst that of boys is generally lower (41).

### Factors associated with the double burden of malnutrition

As demonstrated in the conceptual framework (Fig. 1), the patterns of nutritional status observed may be influenced by nutrition transition and lifestyle changes, driven by changes such as economic growth, social change, and urbanisation occurring in South Africa (15, 16). These may work through other factors at individual,

household, and community levels, some of which we have identified in this study (22, 23).

### Individual level factors

Undernutrition was associated with low birth-weight, HIV status, and child age. Low birth-weight, prevalent in the study population, may be a key reason why younger children were more likely to be stunted or underweight. While low birth-weight is an individual factor, it could also be interpreted as operating at household or community level as the health and nutritional status of the mother, which may be influenced by factors such as food

**Table 3.** Logistic regression analysis for predictors of stunting, underweight, and wasting among children aged 12–59 months ( $n = 671$ ), Agincourt, South Africa (2007) Variable<sup>1</sup>

	Stunting	Underweight	Wasted
	OR [95% CI]	OR [95% CI]	OR [95% CI]
<b>Child-level factors</b>			
<b>HIV status</b>			
Negative (ref)	1	1	1
Positive	2.3 [0.9, 5.6]	1.5 [0.5, 4.4]	1.9 [0.5, 6.5]
Unknown status	0.4 [0.1, 1.6]	0.3 [0.0, 2.2]	0.5 [0.07, 4.1]
Child age	0.6 [0.5, 0.7]***		
<b>Birth weight</b>			
≥2.5 kg (ref)	1	1	
<2.5 kg	1.9 [0.9, 3.8]	3.1 [1.5, 6.4]**	
<b>Household-level factors</b>			
<i>Maternal factors</i>			
<b>Mother's age</b>			
25–34 (ref)	1		
15–24	1.6 [1.0, 2.6]		
35+	1.1 [0.6, 1.9]		
<b>Delivery place</b>			
Health facility (ref)			1
Home			2.0 [1.0, 4.1]
<b>Community-level factors</b>			
<b>Area of residence</b>			
Predominantly South African (ref)	1	1	1
Predominantly Mozambican	2.2 [1.1, 4.3]*	2.0 [0.9, 4.4]	2.3 [0.9, 5.5]

<sup>1</sup>Only variables with significant association at 10% level of significance are shown.

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ .

security at the household or community level, plays a major role in determining birth-weight. HIV increases vulnerability to undernutrition directly for the infected child (44), or indirectly particularly due to decreased food security associated with lowered productivity or death of the bread winner (45). Consistent with other studies, obesity and risk for metabolic disease in the study participants were higher among girls, increased with increasing age and were positively associated with pubertal development (46). This may reflect the effect of factors such as increased sedentary behaviour and decreased physical activity with age and pubertal onset related to subsequent physical, social and emotional changes, particularly among girls (47). Several factors may explain the sex difference, including biological, behavioural, and social (48, 49). Biologically, energy needs differ for boys and girls and also in relation to rate of growth, and the timing of maturation differs by sex (48).

A link between early undernutrition and later obesity at the individual level in the study community may be explained by the developmental programming theory (50). Most of the adolescents, particularly those aged

15–20 years in our study setting, were born during or shortly after the apartheid era when nutritional deprivation due to political restrictions of the South African black population were apparent. Programming among children in deprived households may have occurred, while socio-economic changes and rapid urbanisation since 1994 may have increased access to food, particularly high dense foods, leading to obesity in later life. The difference in the prevalence of obesity between boys and girls needs further research.

#### Household-level factors

At the household level, maternal age and age of household head were associated with young child undernutrition, while maternal age, household head's education level, food security, and SES were all associated with overweight/obesity and risk for metabolic disease among adolescents. While children of younger mothers and household heads were more likely to be undernourished, children of older mothers were more likely to be overnourished. We do not have enough data to explain these findings. However, we have a few postulations that need

further research to guide interventions. Increased risk of undernutrition for children born of young mothers may relate to inexperience and inadequate childcare, or to biological characteristics (51). Age of the household head may be related to undernutrition through income and food security of the household, with younger household heads being potentially disadvantaged, due to having fewer resources. The higher risk of overnutrition among children of older mothers may be due to illiteracy (30), hence less knowledge of diet and the adverse health effects of obesity in the older age group, and possible stronger adherence to the cultural value ascribed to larger body size in women. Additionally, older mothers may monitor their child's behaviour less, which may affect the child's diet and physical activity patterns (26).

Education may affect nutritional status through knowledge of a proper diet and the harmful effects of overnutrition. Education level may also affect income levels, hence diet and sedentary lifestyle. In this study, a small amount of education was protective against overnutrition. On the other hand, the education level that would substantially affect SES in the study community (completed secondary and tertiary education) was not significantly associated, though it tended towards a positive association with obesity. The effect of education is mixed.

While we found a positive association between food security and overnutrition, available but limited literature on the association between food security and child/adolescent obesity is generally conflicting, and is often dependent on the level of development (52). Given a low food production base in the study area, food security may relate strongly to the ability to purchase food – in a society undergoing nutrition transition, this may generally mean energy-dense cheap processed foods. Likewise, the relationship between socio-economic status and childhood obesity varies across different populations depending on economic development (53). The positive relationship that we found is in keeping with some studies in LMICs, but conflicts with findings in many higher income countries (53). In this study setting, with high levels of poverty, SES may be related to affordability of purchased food items, including processed foods, while the poorer may generally rely on their limited farm products and wild foods. SES may also be related to overnutrition through sedentary behaviours related to, for example owning a car, hence walking less. Household members in higher SES households are likely to be involved in (circular) labour migration, commonly reported in the study area (28), which facilitates the transfer and introduction of urban practices to rural settings with consequent changes in diet (16).

### **Community-level factors**

The area of residence being a proxy for various factors, including environmental risks, availability of services,

and shared cultures, emerged as a significant predictor of undernutrition. While the nationality of the mother per se was not associated with nutritional status, children living in villages mainly inhabited by people of Mozambican origin had poorer nutritional outcomes. These villages served as refugee settlements during and after the civil war in Mozambique from the early to mid-1980s. The villages have poor dwellings and infrastructure and are worse-off than predominantly South African villages with respect to basic services, including water, sanitation, electricity, and health facilities (54). Boys in the study community are generally more physically active compared to girls (data not shown) as indicated through a focus group discussion with community leaders (Group Discussion, Community Advisory Group, June 2008). This was also found in a national survey in South Africa in 2002 (19). As in many African countries, studies in South Africa have indicated that heavier bodies among females are preferred even during adolescence, particularly in rural settings (49), which may result in obesity among adolescent girls.

### **Study limitations**

We examined distal factors influencing a child's nutritional status at childhood, household, and community levels. We did not directly examine the proximal factors, including dietary intake, child's health status (apart from HIV status), physical activity patterns, and sedentary behaviour, which are also important in determining nutritional status, and need further investigation in future studies. The food security measurement tool was primarily designed as a simple tool to measure trends in household food security in the study area over time rather than to detail multiple dimensions of food security.

### **Conclusion**

This study has confirmed links between factors at different societal levels affecting nutritional status among children as portrayed in the conceptual framework presented (Fig. 1). The level of undernutrition that we have documented, particularly stunting at an early age in a country that has transitioned economically into a middle-income country, is worrying and may suggest the inadequacy or ineffectiveness of interventions that were put in place in the post-Apartheid era as a priority to address food insecurity and malnutrition. The substantial levels of overweight/obesity, particularly among adolescent girls, indicate that child growth and nutrition in rural South Africa is clearly shifting along the rural–urban continuum and is tending towards an urban-like profile. It is likely that this profile relates to changes in nutrition and dietary patterns in South Africa (15), as in other LMICs (1, 2). However, variation in other factors such as patterns of physical activity and social influences need to be investigated.

These findings have implications for public health policy and practice. The combination of early stunting and adolescent obesity may be an explosive combination associated with higher risk for obesity and cardio-metabolic diseases in adulthood (6). Childhood obesity and risk factors for metabolic diseases have been tracked into adulthood (6). The overweight/obesity prevalence in adolescents, particularly girls, may partly be contributing to the high levels of overweight/obesity reported in South African adults, particularly women (13). The substantial risk for metabolic disease in adolescent girls is of great public health importance as chronic diseases associated with obesity are already contributing markedly to the burden of disease in this community and other parts of South Africa among adults (10–12, 17).

These findings call for evidence-based interventions to alleviate the dual burden of malnutrition. With regard to obesity and metabolic disease risk, the study has identified predictors that may help in pointing out target groups for obesity prevention programs. Given the gender disparity in vulnerability to obesity (41), gender-sensitive programs targeted particularly to adolescent girls are needed. Although further research is required to clearly establish the proximate causes in this particular community, findings in other settings in South Africa (19, 46) suggest interventions should address physical inactivity, sedentary behaviour, and dietary patterns, particularly among adolescent girls. To address undernutrition, effective maternal interventions such as nutrition education and food programmes, are recommended. Interventions to improve nutritional outcomes of children infected or exposed to HIV may include targeted paediatric HIV screening and support to infected children. This study has demonstrated a high response rate and perceived usefulness of paediatric HIV testing with disclosure and counselling of caregivers on caregiving. However, several barriers highlighted in the results, including financial and health care access barriers, need to be addressed to reap the best from such an undertaking (21).

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## Conflict of interest and funding

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**\*Elizabeth W. Kimani-Murage**

APHRC Campus  
Kirawa Road  
Off Peponi Road  
PO Box 10787, 00100, Nairobi, Kenya  
Tel: +254 (20) 4001000, +254722322193  
Email: ekimani@aphrc.org; lizmurage@gmail.com

# The non-fatal disease burden caused by type 2 diabetes in South Africa, 2009

Melanie Y. Bertram<sup>1\*</sup>, Aneil V.S. Jaswal<sup>1,2</sup>,  
Victoria Pillay Van Wyk<sup>3</sup>, Naomi S. Levitt<sup>4,5</sup> and  
Karen J. Hofman<sup>1</sup>

<sup>1</sup>MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt), School of Public Health, Faculty of Health Sciences, University of Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Department of Public Health, University of Oxford, Oxford, UK; <sup>3</sup>Burden of Disease Research Unit, Medical Research Council of South Africa, Tygerberg, Western Cape, South Africa; <sup>4</sup>Department of Medicine Health Sciences Faculty, Division of Endocrinology and Diabetes, University of Cape Town; <sup>5</sup>Chronic Diseases Initiative in Africa, Cape Town, South Africa

**Background:** Increasing urbanisation and rising unhealthy lifestyle risk factors are contributing to a growing diabetes epidemic in South Africa. In 2000, a study estimated diabetes prevalence to be 5.5% in those aged over 30. Accurate, up-to-date information on the epidemiology and burden of disease due to diabetes and its sequelae is essential in the planning of health services for diabetes management.

**Objective:** To calculate the non-fatal burden of disease in Years Lost due to Disability (YLD) due to diabetes and selected sequelae in South Africa in 2009. YLD measures the equivalent loss of life due to ill-health.

**Methods:** A series of systematic literature reviews identified data on the epidemiology of diabetes and its sequelae in South Africa. The data identified were then applied to Global Burden of Disease (GBD) methodology to calculate the burden attributable to diabetes.

**Results:** Prevalence of type 2 diabetes in South Africa in 2009 is estimated at 9.0% in people aged 30 and older, representing approximately 2 million cases of diabetes. We modelled 8,000 new cases of blindness and 2,000 new amputations annually caused by diabetes. There are 78,900 YLD attributed to diabetes, with 64% coming from diabetes alone, 24% from retinopathy, 6% from amputations, 9% from attributable stroke disability, and 7% from attributable ischemic heart disease disability.

**Conclusions:** We estimate that the prevalence of diabetes is increasing in South Africa. Significant disability associated with diabetes is demonstrated. Some of the attributed burden can be prevented through early detection and treatment.

Keywords: *burden of disease; diabetes; South Africa; developing country; epidemiology*

Appendices available online under Reading Tools.

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South Africa is a country which is undergoing rapid epidemiological transition (1). Burden of disease data from 2000 indicate that chronic conditions were already responsible for 30% of the total disease burden (2). Ongoing rapid urbanisation is leading to escalating lifestyle risk factors, such as unhealthy diet and lack of physical activity, which in turn contribute to increasing chronic disease rates (3, 4). Understanding the main contributors to disease burden is essential in the

planning of health care facilities and programmes aimed at addressing this growing problem (2).

Diabetes is a growing cause of premature mortality and morbidity worldwide. In 1998, the World Health Organization (WHO) estimated that there were 135 million people with diabetes (5). By 2008, the estimated global prevalence had more than doubled to 347 million (6). This figure is expected to continue to increase. Despite previously being considered a disease of high-income

countries, middle-income countries undergoing rapid epidemiological transition are now considered the epicentre of the future diabetes epidemic (7), largely due to an ageing population and the lifestyle changes associated with urbanisation (8). The age pattern of diabetes prevalence is expected to differ between Africa and higher income regions. The majority of diabetes in Africa is prevalent in working-age people, aged between 40 and 60 years, rather than those older than 60 years (9).

Globally, diabetes was estimated to cause 3.96 million excess deaths and 6.8% of all deaths in 2010 (10). Complications associated with diabetes, such as retinopathy and blindness, kidney disease, neuropathy, vascular diseases, and amputation, lead to significant morbidity (7). In 2004, the WHO estimated that diabetes accounted for 19.7 million disability-adjusted life years (DALYs) (11). One DALY represents the loss of the equivalent of 1 year of full health.

Burden of disease data is an important input in evidence-informed policy making (12). In South Africa, this is especially important in the presence of a 'quadruple burden of disease', including HIV&AIDS, maternal and child health, chronic disease, and injuries. Though specific costing data are not available for South Africa, across the six richest African countries, the direct and indirect cost of diabetes is estimated to be as much as INT\$11431.6 per diabetes case per year (13).

In South Africa, the only previous study on the overall burden of disease attributable to diabetes estimated the burden for 2000 (14). The estimated prevalence of diabetes was 5.5% for South Africans aged over 30, accounting for 4.3% of deaths and a total of 258,000 DALYs.

The aforementioned national burden of disease study for South Africa (SA NBD) was generally unable to prospectively evaluate the non-fatal burden. For a few diseases local data could be used, but for most diseases a ratio was taken between the fatal and the non-fatal component of the DALY for the WHO Africa estimates, and this same ratio applied to mortality in South Africa (15). The current analysis uses a prospective methodology, in line with global estimates, which will increase comparability and increase the data available from the results. Because this methodology is far more data intensive, it presents difficulties in a middle-income setting such as South Africa, where such data are not always available. This study models incidence, prevalence and mortality due to diabetes as well as its sequelae, and provides a summary of diabetes epidemiological data available in South Africa.

## Methods

The methods were largely based on the established Global Burden of Disease (GBD) methodology (16) and use the Years Lost due to Disability (YLD) as the outcome

measure (16). This allows for comparability with the previous SA NBD data and GBD data for the sub-Saharan African region. We calculate the YLD attributable to type 2 diabetes and a limited set of sequelae, including blindness due to retinopathy, leg and foot amputations, and the attributable burden to diabetes from cardiovascular diseases.

## Data collection

### *Diabetes cases*

A systematic review of the literature was performed to identify published prevalence and mortality studies for diabetes in South Africa, from 1990 to present. The search was undertaken in PubMed in June/July 2011. Experts were also contacted for any unpublished work (full details, Appendix 1). Ideally, only data from 2005 onwards would be included in the analysis; however, because we could not be certain that sufficient recent data would be available, we expanded the search dates.

Prevalence studies were included if they were community-based studies, and diagnosis of diabetes was based on the revised WHO criteria for diagnosis of diabetes for a 75 g Oral Glucose Tolerance Test (OGTT), that is, fasting plasma glucose (FPG)  $\geq 7.0$  mmol/l and/or 2-h plasma glucose  $\geq 11.1$  mmol/l (17). Mortality studies were included if they reported community-based deaths in patients with diabetes. Studies which reported Statistics South Africa vital registration data were not included because we had access to the source data.

### *Diabetic sequelae*

A systematic review of the literature was performed to identify published prevalence and incidence studies for diabetic retinopathy, amputations, diabetic foot, neuropathy, and kidney failure in South Africa, from 1990 to present. PubMed searches were undertaken in June/July 2011 (full details, Appendix 1). The year 1990 was used as a cut-off for data to ensure we covered as many sequelae as possible. Inclusion criteria were a population- or clinic-based screening study in patients with diabetes. For retinopathy, the time since onset of disease was an inclusion criteria.

### *Attributable burden of stroke and ischaemic heart disease*

There is well-documented evidence that diabetes mellitus increases the risk of morbidity and mortality due to cardiovascular diseases, namely stroke and ischaemic heart disease (IHD). We attribute some morbidity due to stroke and IHD to diabetes using a population attributable fraction (PAF), which calculates the proportional reduction in disease morbidity or mortality that would occur should risk factor exposure be removed.

The PAF equation is as follows:

$$\text{PAF} = \frac{p(\text{RR} - 1)}{p(\text{RR} - 1) + 1}$$

Where  $p$  = prevalence of diabetes and  $\text{RR}$  = relative risk of stroke in people with diabetes.

Currently, in South Africa, no local information is available on the relationship among diabetes, stroke, and IHD. In the Asia Pacific Cohort Studies Collaboration, the relative risk of stroke was 2.04 in diabetic males and 2.0 in females (18). These relative risks are used in the GBD study and have been used in a number of national level burden of disease analyses where no local data exist (19). Applying the PAF to the YLD previously calculated for stroke (20) provides an estimate of the burden of disease attributable to diabetes. IHD burden has not been updated for South Africa for 2009. In place of direct information on disease burden, we applied a ratio to the YLD attributable to stroke, based on WHO estimates of disease burden (21). This enabled an estimation of the attributable YLD from IHD.

## Calculating the burden of disease

### *Derivation of incidence and duration using computer-based modelling*

The epidemiological parameters required to calculate YLD, incidence, and duration are not always available. DisMod II is a specialised software tool which creates an internally consistent set of epidemiological parameters for a condition given three parameters as inputs (22). In DisMod, remission is defined as 'cure', hence no remission is possible when modelling people with diabetes. Accordingly, the data gathered from the literature for prevalence and relative risk of mortality and a remission rate of zero were used as inputs for DisMod, yielding estimates of incidence and duration as outputs.

### *Disability weights*

Disability weights are a comparative measure of the impact of the complications of illness. No disability weights specific to South Africa were available. For this study, GBD disability weights and, where these were not available, Dutch disability weights were used (23). We did this for consistency with previous GBD estimates and to enable comparisons between the results of the current study and previous studies. For uncomplicated diabetes, a GBD weight of 0.012 for untreated diabetes and 0.033 for treated diabetes were used; for retinopathy, Dutch weight of 0.17 for moderate diabetes and GBD weight of 0.522 for severe diabetes were used (assuming 66% of cases as severe and 33% as moderate, based on data from the Australian burden of disease study, as no data were available for South Africa (24)), and for amputations,

GBD weights of 0.102 for toe and 0.300 for foot/leg amputation were used.

## Results

### *Literature search results*

A total of 117 articles published between 1990 and July 2011 were identified through the search for diabetes prevalence in South Africa. After title and abstract screening, the full text of 16 articles was read. Full details of the literature search results are given in Appendix 2. At this stage, we restricted the years of inclusion to 2005 onwards. Three studies were deemed to contain sufficient information for inclusion (25–27). Raw data were provided by the authors of all studies. One unpublished study, since published, was identified and included in the analysis (28). Overall, we had data from two rural populations, one urban township, and one metro urban population. Data were combined by weighting for the population it represented. The sources of data are shown in Table 1.

Twenty-one studies reporting retinopathy were identified, with four giving information on time since diagnosis, which is required to model incidence (29–32). One of these contained two mutually exclusive populations, giving five data points (32). Incidence of proliferative diabetic retinopathy is derived from data on the progression to retinopathy by duration of diabetes (male and female progression is assumed to be the same; insufficient data were available to separate by sex). Using linear regression, an annual incidence of retinopathy was calculated which was then applied to survivors of diabetes by age. The annual incidence calculated was 126 per 100,000 across all ages.

Thirteen articles that discussed diabetic foot disease in South Africa were identified, with only one presenting sufficient information to use in our analysis. Levitt et al. reported 1.4% of patients with diabetes in attending primary care clinics had an amputation of either foot or toe (29). Insufficient information was available to include either diabetic foot or neuropathy. Although information is increasing, data in this area is lacking for South Africa (33).

Of the 15 articles identified through the search for kidney failure, one presented sufficient information on renal failure mortality (34). Our search revealed no information on incidence or prevalence of kidney failure for South Africa, so it was not possible to include it as a sequela in this analysis. Left untreated, renal failure is largely fatal; it contributes minimally to the non-fatal burden due to diabetes.

### *Burden of disease results*

The overall prevalence of type 2 diabetes in those over age 30 was estimated at 9.0% (7.4% in men and 10.4% in

**Table 1.** Data used in the epidemiological modelling

Author	Year	No.	Method	Location	Reference
<b>Diabetes prevalence</b>					
Motala et al.	2008	1,025	Cross-sectional survey	Rural KwaZulu Natal, South Africa	(26)
Stewart et al.	2011	1,311	Screening in consecutive primary care patients	Soweto, South Africa	(27)
Groenewald et al.	2009	552	Cross-sectional survey	Rural southern Free State, South Africa	(25)
Levitt et al.	2012		Cross-sectional survey	Cape Town, South Africa	(28)
<b>Retinopathy prevalence</b>					
Rotchford	2002	253	Consecutive patients attending diabetes clinic	Rural KwaZulu Natal, South Africa	(31)
Motala	2001	219	Retrospective analysis of clinical records	Durban, South Africa	(30)
Levitt	1997	300	Random sample of patients attending diabetes clinic	Cape Town, South Africa	(29)
Conradie	1998	311	Retrospective analysis of clinical records	Cape Town, South Africa	(32)
<b>Amputation prevalence</b>					
Levitt	1997	300	Random sample of patients attending diabetes clinic	Cape Town, South Africa	(29)

women), a significant increase over the 5.5% prevalence reported for 2000 (14). This gives a total of 1.97 million cases of type 2 diabetes in South Africa. A secondary finding from the literature search was that 55% of cases are undiagnosed – for South Africa this means that about 1 million people with type 2 diabetes do not know they have it. Modelled age-specific diabetes prevalence is shown in Fig. 1.

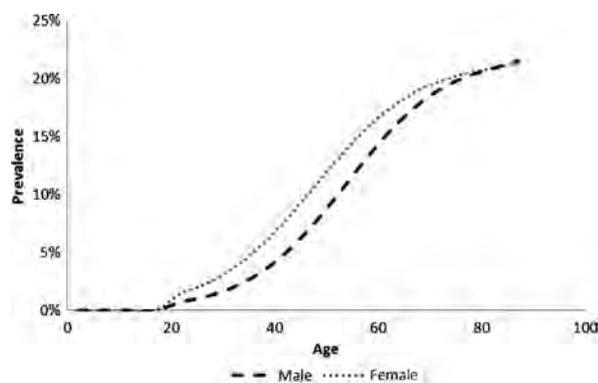
As well as 1.97 million people with type 2 diabetes, the model also shows that 115,000 new cases develop each year, along with 7,800 cases of vision impairment due to retinopathy and 2,100 toe or foot amputations due to diabetes (Table 2).

The number of people categorised as urban or rural was last analysed for 2001, when it was estimated that 57.5% of people lived in urban areas and 42.5% lived in rural areas (35). According to our analysis, 35% of people

with diabetes live in rural areas and 65% in urban areas, indicating an unequal distribution. In urban areas, among the aged, prevalence is higher in females, whereas in rural areas, prevalence is higher in females than males at all ages (Fig. 2).

A total of 42,919 YLD were estimated as attributable to type 2 diabetes alone, with a further 13,458 arising from retinopathy, 4,527 from amputations, 7,233 from stroke, and 5,577 from IHD, totalling to 73,714 YLD.

A sensitivity analysis was undertaken to look at the impact of the highest and the lowest prevalence measures on the outcomes. By excluding the highest prevalence study (28) overall diabetes prevalence drops to 5.2% in line with a decade previously and results in a halving of the attributable YLD, to 23,000. Excluding the lowest prevalence study for both urban and rural areas (25, 27) had the opposite impact, causing prevalence to increase to 12.1% overall, resulting in 53,000 attributable YLDs.



**Fig. 1.** Modelled type 2 diabetes prevalence in South Africa, 2009.

## Discussion

Our estimates indicate that the burden of disease due to diabetes may have grown significantly since the previous South African burden of disease study in 2000 (14). Prevalence of diabetes in people over age 30 has potentially increased from 5.5 to 9.0% since the previous estimates. This may partly be a reflection of the prevalence data used in 2000, which was largely from the early 1990s, so the increase seen may have occurred over almost two decades. The assumption made in the previous study that diabetes prevalence in rural areas was half that in urban areas was likely too conservative and contributes to the differences between the previous study

**Table 2.** Modelled incidence of diabetes and sequelae in South Africa, 2008

Age group	Diabetes		Retinopathy		Amputation (foot or toe)	
	Male	Female	Male	Female	Male	Female
25–34	7,106	11,853	18	38	0	0
35–44	12,644	17,594	143	213	166	246
45–54	15,419	16,768	493	551	316	386
55–64	10,373	9,238	956	838	246	214
65–74	4,722	4,518	1,260	985	158	140
75+	2,191	3,009	1,182	1,134	94	114
Subtotal all ages	52,455	62,980	4,050	3,760	980	1,100
Total both sex		115,435		7,810		2,080

and the current study results. Due to ethnic variations in diabetes prevalence in South Africa, there may be continuing issues around data representativeness. In particular, there are no recent studies in either Indian or Coloured populations. Comparison between the YLD from the SA NBD study in 2000 (14, 15) to the current study was not considered due to the different methodologies used.

Global estimates of diabetes prevalence and burden of disease, such as the International Diabetes Federation prevalence projections and the WHO's GBD study rely on publicly available data and projection modelling. For our analysis, we had access to primary data from various strata of the South African population. Global modelled estimates have generally assumed that risk factors such as obesity will remain constant (5, 8). Given that obesity is increasing globally, this assumption is too conservative to accurately predict diabetes prevalence (36, 37). In South Africa, the estimated prevalence of overweight and obesity in 1998 was 29% in men and 56% in women, and that number is thought to have increased significantly since then (38).

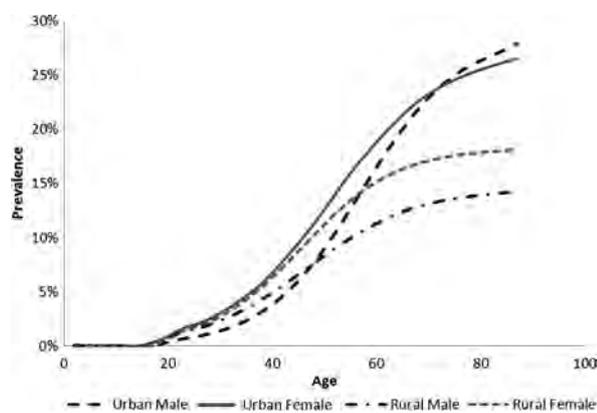
Sensitivity analyses indicate the uncertainty within the estimation of diabetes prevalence and burden in

South Africa. Given the diversity of the South African population, the use of a single estimate from a non-representative population sub-group to model prevalence is unlikely to provide reliable estimates. Our use of multiple data points to represent urban, peri-urban and rural populations provides the most accurate overview of the national situation in South Africa, given the current data availability in the country. However, given strong ethnic variations in diabetes prevalence indicated in prior literature, the collection of more representative data would provide stronger estimates of disease burden.

The major weakness of the analysis relates to data unavailability. For this reason, we did not incorporate all the sequelae the GBD studies generally recommend. Missing in this study are estimates of cataract, glaucoma, diabetic foot, neuropathy, renal failure, and peripheral vascular disease. Although cataract and glaucoma generally contribute only a small amount to the disease burden, other complications such as diabetic foot, neuropathy, and peripheral vascular disease can each be responsible for up to 5% of the attributable burden to diabetes (19). Furthermore, the sequelae data that exist are less recent than information on diabetes prevalence. Given the rapid increase in diabetes prevalence from 2000 to 2009, it is likely that the epidemiology of the sequelae has also changed during this time.

Data on case fatality rate or relative risk of mortality in people with diabetes in South Africa does not exist. Information from the vital registration system regarding diabetes mortality is not accurate as multiple underlying causes of death are reported with diabetes, for example, cardiovascular diseases, hypertensive heart disease, IHD, and stroke (39, 40). This could result in deaths from diabetes being coded to one of the underlying causes.

The methodological developments which are currently underway within the GBD update, due out in 2013, may have implications for our results. First, methodology will be available to fill gaps using data from elsewhere. This would improve our ability to include sequelae, yet still would not use data specific to South Africa. Second,

**Fig. 2.** Modelled prevalence of type 2 diabetes in urban and rural South Africa, 2008.

an update to the disability weights used in the GBD study is anticipated. We do not know how new disability weights will compare to those used in this study. These factors need to be considered when interpreting these findings or comparing with previous and future studies.

In an era of growing obesity, rapid urbanisation, and an ageing HIV positive population in South Africa, this work has highlighted the need for more accurate and complete data with respect to diabetes. The first priority is a diabetes registry. This would be a challenging proposition in the current climate of inadequate informatics programmes even in the most organised provincial health departments. Since half of people with diabetes remain undiagnosed and untreated, a national registry would likely capture only those with known diabetes, but at least this would inform the rollout of South Africa's National Health Insurance Scheme. The second imperative is a nationally representative cross-sectional survey to properly establish the prevalence of diabetes.

This work sets the stage for future analysis on the cost-effectiveness of diabetes prevention and treatment campaigns for South Africa. Whilst it is essential to know the main causes of disease burden, and to be able to quantify the epidemiology, information on the costs and avoided disease burden associated with interventions is also crucial. With the burden of disease information now available, more studies can more thoroughly explore these hypotheses. There is a need to systematise data collection around diabetes and primary health care delivery to facilitate these analyses.

### Conflict of interest and funding

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**\*Melanie Y. Bertram**

MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt)  
School of Public Health  
Faculty of Health Sciences  
University of Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Tel: +27 11 717 2623  
Email: Mel.Bertram@wits.ac.za

# A rapid assessment of a community health worker pilot programme to improve the management of hypertension and diabetes in Emfuleni sub-district of Gauteng Province, South Africa

Tshipfuralo Ndou<sup>1</sup>, Greer van Zyl<sup>1</sup>, Salamina Hlahane<sup>2</sup> and Jane Goudge<sup>1\*</sup>

<sup>1</sup>Centre for Health Policy, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Department of Health and Social Development, Sedibeng District Health Service, Vereeniging, Gauteng Province, South Africa

**Background:** Non-communicable diseases (NCD) and infectious chronic illnesses are recognised as significant contributing factors to the burden of disease globally, specifically in South Africa, yet clinical management is often poor. The involvement of community health workers (CHWs) in TB and HIV care in South Africa, and other low- and middle-income settings, suggests that they could make an important contribution in the management of NCDs.

**Objectives:** Using a rapid assessment, this study examines the outcomes of a pilot CHW programme to improve the management of hypertension and diabetes in Gauteng province, South Africa.

**Methods:** A record review compared outcomes of patients receiving home visits (n56) with a control group (n168) attending the clinic, matched, as far as possible, on age, gender, and condition. Focus group discussions and semi-structured interviews with CHWs, patients, district, clinic, and NGO staff were used to obtain descriptions of the functioning of the programme and patient experiences.

**Results:** Despite the greater age and co-morbidity among those in the pilot programme, the findings suggest that control of hypertension was improved by CHW home visits in comparison to usual clinic care. However, too few doctor visits, insufficient monitoring of patient outcomes by clinic staff, and a poor procurement process for supplies required by the CHWs hampered the programme's activities.

**Conclusion:** The role of CHWs in the management of hypertension should be given greater consideration, with larger studies being conducted to provide more robust evidence. Adequate training, supervision, and operational support will be required to ensure success of any CHW programme.

Keywords: *community health worker; chronic care; home visits; South Africa; hypertension; diabetes*

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Management of chronic illnesses in low- and middle-income countries is often poor with health systems struggling with an outward flow of human resources and insufficient funds (1–3). There has been a re-emergence of community health worker (CHW) programmes in such settings to strengthen outreach activities and increase the number of health workers, in order to improve access to care (4). However, the focus

of these programmes has predominately been on improving maternal and child-related health outcomes. Efforts to strengthen chronic disease management have focused primarily on HIV and TB treatment. In South Africa, CHWs have played a crucial role in the provision of effective HIV and TB care (from pre- and post-test counselling, administering treatment, adherence, to tracing defaulters) (5). The contribution of CHWs to infectious

chronic disease care in South Africa suggests they could play an important role in non-communicable diseases (NCD) care.

This study provides a rapid assessment of a CHW pilot programme in Emfuleni sub-district of Gauteng, South Africa, that aimed to improve the management of hypertension and diabetes. A description of the programme and the research objectives in the next section are followed by the research methods, findings, and a conclusion discussing the relevance of the findings for national and international policy.

### *The Kgatelopele community health worker programme*

The Gauteng Provincial Department of Health South Africa in 2008 initiated the 'Kgatelopele' programme at one clinic in Emfuleni sub-district, in collaboration with Hands of Hope, a non-governmental organisation. The programme seeks to improve the management of hypertension and diabetes among patients by home delivery of medication and assessment of basic clinical indicators. Home visits by CHWs are intended to improve the accessibility, acceptability and affordability of health care, and strengthen the referral system between the community and health facilities. The CHWs provide social support and counselling to improve patient literacy and adherence, and to encourage appropriate visits to the PHC clinic. The clinic serves a population of 27,199, of whom 23,677 are un-insured, and hence use the public health sector. At the time of the study, patients enrolled on the Kgatelopele programme were visited once a month by one member of a team of six CHWs. A pharmacist packed a month's supply of medication for delivery to named patients. Patients are required to visit the clinic every 6 months for a physical examination by a doctor, who provides a renewed prescription. CHWs have attended a 14-week training course that focuses primarily on home-based care, other than providing skills in adherence counselling and health promotion, with a particular focus on chronic illnesses, including hypertension and diabetes. Other anticipated benefits of the programme included a reduction in clinic visits for elderly patients for whom there are physical challenges in attending the clinic, a reduction in transport cost for patients, and opportunities for CHWs to identify and refer other family members in need of health care. Hypertensive and diabetic patients not in the pilot programme attend the clinic on a monthly basis.

The objectives of the study are to, first, provide a comparison of treatment outcomes to give some insights into how extension of care into the community may be developing; second, to describe the operational challenges of the programme; and finally, to draw lessons relevant to CHW programmes providing NCD care in other settings,

both within South Africa and other low- and middle-income countries.

### **Methods**

We were asked by the Sedibeng district manager to conduct a rapid evaluation of the pilot CHW programme. The evaluation used a retrospective case study approach, employing both qualitative and quantitative methods. The study population consisted of individuals registered in the Kgatelopele programme (56 patients) in Emfuleni sub-district, Gauteng, as well as patients receiving usual clinic care at the same clinic. Interviews were conducted with 20 Kgatelopele patients on their experience of the programme. Seven key informants (clinic, NGO, and district staff) were interviewed to obtain information on the training of CHW, supervision, procurement, and referral processes in addition to other elements of the programme operation and its challenges. Two focus group discussions were held with two groups of six CHWs to obtain a description of practical day-to-day functioning of the pilot and its challenges.

A record review was undertaken, using a pre-designed record review form, of patients on the Kgatelopele programme and a control group comprising three clinic patients matched for condition, age, and gender for every Kgatelopele patient. The Kgatelopele programme enrolled stable patients, and a clinic patient was deemed a suitable match if, where possible, the person was within 5 years of age the Kgatelopele patient. With 56 patients in the intervention group and three-fold more controls, we would be able to detect a difference between groups if hypertension was controlled in 40% of intervention group and in 20% of controls, with 80% power (control defined as having a normal blood pressure (BP) for at least >40% of clinic visits). There is little gain in power with having more than three-fold the number of participants in the control arm.

The record review collected data for the year prior to the study on a number of variables, including age, sex, number of home visits, monthly measures of BP and blood glucose, doctor reviews, and clinic attendance. For this study, we took 110/60–130/85 mmHg as an acceptable range for controlled hypertension. We used 3.6–5.8 mmol/l as an acceptable range for controlled diabetes. The record review data were analysed by comparing the BP levels and glucose level (Hgt) (using a random sample) of patients on programme and comparison group.

Thematic analysis was conducted on interview and focus group discussion transcripts, identifying data on *a priori* and emergent themes. Respondent views that were divergent from common perspectives were explored further to ensure opposing views were retained within the analysis. Ethical approval was granted by the University of the Witwatersrand Committee for

Research on Human Subjects. Informed consent was given by all respondents.

## Results

The sample consisted of 56 patients on the outreach programme and 168 clinic patients, with slightly more female patients than males in both groups (Table 1). Despite attempts to match patients on the programme with those at the clinic, there were important differences between the two groups.

The mean age of those on the programme was 75 years (range 54–96), and 69 years (range 51–92) in the clinic group. Nearly 40% of the programme patients had both hypertension and diabetes, in comparison to 25% in the clinic group. The mean number of months on treatment was nine (range 1–20) compared to 6 months (range 2–13) for clinic patients, and the mean number of months since enrolment on the programme was eight (range 2–18).

### Comparison of outcomes

For patients with hypertension, the condition was controlled for a higher proportion of patients on the Kgatelopele programme in comparison with those attending the clinic (Table 2). 21.4% of Kgatelopele patients (12/56) were controlled at >40% of health checks in comparison to 13.1% of clinic patients (22/168). In contrast, diabetes was better controlled among clinic patients, with 26.1% (11/42) controlled for >40% of health checks compared to only 9.1% (2/22) of the Kgatelopele patients.

If we consider only those *with both conditions*, hypertension was controlled amongst a considerably higher proportion of Kgatelopele patients (27.3%; 6/22) >40% of health checks in comparison with 4.8% of clinic patients (2/42).<sup>1</sup>

**Table 1.** Description of the sample and the comparison group

	Kgatelopele patients	Clinic patients
Number of patients	56	168
Female (n)	69.6 (39)	69.9 (117)
Mean age (range)	75 (54–96)	69 (51–92)
Patients with co-morbidities (n)	39.3 (22)	25.0 (42)
Months on treatment recorded in file (range)*	9 (1–20)	6 (2–13)
Months on Kgatelopele programme	8 (2–18)	N/A

\*When treatment was interrupted or the patient's record could not be found, a new record was started. Hence, the relatively short period on treatment is unlikely to be accurate.

<sup>1</sup>All diabetic patients also had hypertension.

### Demand-side issues

Study participants stated that the Kgatelopele programme had a positive impact on access to care: “Kgatelopele is helping many people and is saving many people's lives. So people in this area are getting help from it and they are happy with the program” (KII). In particular, the programme assisted elderly patients who had difficulties travelling to the clinic:

With the problem of taxis and being old, this programme is helping by delivering my medication at home. (Patient)

Patients were also satisfied with the CHW counselling and health information:

The care giver who comes here always gives me advice on how to avoid high BP and sugar level. She told me that if I don't follow the advice it might cause me stroke. (Patient)

A variety of explanations were given for the overall poor levels of control of both conditions. Some patients explained they discontinued their medication because of side effects: staff confirmed this.

Patients are defaulting. They are not taking medication as they are directed. Medications are packed with written instructions but then the patient will not take some medication; they will choose (which pills to take). (KII – Clinic nurse)

The elderly respondents reported difficulty in attending the 6 monthly review (by a doctor) at the clinic due to the inability to walk to the public transport, or funds to pay for public transport. One key informant also reported: “Patients do not want to go see a nurse. When we tell the patients they must come to the clinic they say ‘You said I must come to see a doctor; so where is the doctor, not a nurse again’”. As a result, the patients' prescriptions are not renewed and treatment is missed.

### Supply-side issues

An important benefit of the programme was the reduction in the patient load at the clinic:

It is good programme because our clinics are flooded with patients. Some of the patients really don't need to be at the clinic. (KII)

There were different views as to the criteria for enrolling patients on the programme, with some respondents stating that the programme should be for all chronic disease patients. Other respondents were of the view that younger, more mobile patients should come to the clinic, as they are often not at home when the CHW make visits.

I don't think she (the doctor) understands what is happening really, even people who are very well who can come to the clinic, but I took them on the side and said no you are not going to be on the program,

**Table 2.** Percentage of patients with controlled hypertension and diabetes at health checks in the past year in the programme and control groups (*n*)

Percentage of health checks in the previous year at which the condition was controlled	Hypertension patients			Diabetes patients			BP control for patients with both conditions		
	Kgatelopele	Clinic	<i>P</i>	Kgatelopele	Clinic	<i>P</i>	Kgatelopele	Clinic	<i>P</i>
0–40	78.6 (44)	86.9 (146)	0.13	90.9 (20)	73.8 (31)	0.11	72.7 (16)	95.2 (40)	0.01
41–100	21.4 (12)	13.1 (22)		9.1 (2)	26.2 (11)		27.3 (6)	4.8 (2)	
Total	100% (56)	100% (168)		100% (22)	100% (42)		100 (22)	100 (42)	

Health checks may have occurred either on a home visit or a 6-monthly clinic review.

we are taking care of people who cannot come to the clinic, those who must hire the transport to the clinic because they are very sick. (KII)

However, an insufficient number of visits to the clinic by the rotating doctor increased the number of visits required to renew a prescription. The doctor was not available for the patient review as scheduled in 14% of cases.

The first challenge is the availability of the doctor and this is the serious one. When I say the availability of the doctor I mean like now the last time she came here was 12th of August till today (19 October). So the patients who were supposed to be reviewed are not getting medication. (KII – District staff)

In addition, the insufficient number of doctor visits limited clinical supervision available for nurses.

The interview data provided a limited explanation as to the differential effects on control of hypertension and diabetes. CHWs and NGO staff complained of shortages of glucose strips, which are likely to have hindered monthly monitoring of blood sugar levels, and efforts at self-management by patients. Lack of materials, a key to barrier effective functioning of the programme, was caused by a lack of dedicated funding and unclear procurement processes and responsibilities:

The [provincial Department of Health] gave us the bags and there's BP machine, sugar strips and everything but when those things are finished we (NGO) have to find the money (for materials such as glucose strips). (KII – NGO staff)

No regular meetings among the NGO, clinic staff, and district staff were held to discuss issues such as shortages of CHW equipment, or funding constraints to purchase new supplies.

CHW records provided descriptive data on activities, such as the number of patients seen, patients' health complaints and dates for next visit. The information collected by the CHW was reported to supervisors at the NGO, who did not see it as their responsibility to

intervene should a patient have poor clinical outcomes. Clinic nurses did not regularly examine the CHW records. As a result, they did not identify, or take action to assist patients that required intervention or referral.

I don't get time to communicate or sit with the NGO manager and discuss the work of CHWs or which patients were added. They could at least give me copy of papers where CHWs record test results for patients. (KII)

## Discussion

Systematic reviews have provided evidence of the efficacy of CHW programmes with respect to certain health service outcomes (such as immunisation, uptake of breast feeding, TB treatment compliance), in a range of different low- and middle-income settings (6). However, there is little evidence on the effectiveness of their role in management of hypertension and diabetes. The comparison of the outcomes of this pilot programme with usual care is limited by the differences in age and co-morbidity between the two groups of patients. Further limitations include that BP was measured by CHW rather than nurses (electronic devices were used), the range for controlled hypertension was lower than the internationally accepted range, and that random glucose estimation was used for assessing control of diabetes rather than a fasting or HbA1C test. However, despite these limitations, the findings suggest that hypertension is better controlled amongst patients in the pilot programme.

Despite concerns of adherence and problems with doctor availability, these findings suggest home delivery of medication and monitoring by CHWs (rather than nurses) did not worsen control of hypertension; instead the benefit of not having to travel to the clinic, as well as perhaps the care provided in the home setting, led to better control. The findings of this study suggest that the role of CHW in the management of hypertension should be given greater consideration, with larger studies being conducted to provide more robust evidence.

However, the same was not true for diabetes, where the condition was better managed among clinic patients.

Diabetes was controlled for 26% of patients at the clinic in comparison to 9% of the Kgatelopele patients. The explanation for this was unclear from the interviews. It may be due to insufficient training of CHW on assisting patients to manage diabetes (mentioned in the description of the programme), a condition that requires more active self-management by patients (7), or the irregular supply of glucose strips, preventing the CHWs from monitoring glucose levels.

Although the level of control for either condition was far from ideal, the findings were not dissimilar to other South African studies. (The level at which BP is deemed controlled varies across research studies, reducing ability to draw comparisons. The level used in this study (130/85 mmHg) is lower than the international and South African standard (140/90 mmHg). Edwards et al. (8) assessed hypertension control levels of about 12,000 South African hypertensive private patients with medical aid insurance of whom 34.7% had BP <140/90 mmHg. A study of 9,133 patients attending 680 private practices throughout the country found 53% of patients with controlled hypertension (<140/90 mmHg) (9). Both studies suggest better management of hypertension in comparison to the Kgatelopele programme, possibly due to provision of care by private general practitioners, and a higher cut-off of 140/90 mmHg rather than 130/80 mmHg used in this study. However, a population survey at the rural health and demographic surveillance site in Mpumalanga of pre-dominantly public health service users, found only a small proportion (~9%) of people with hypertension had their BP successfully controlled with medication (Xavier Gomez-Olive – personal communication). In a study at Hlabisa district hospital, Kwa Zulu Natal, of 164 patients with both diabetes and hypertension, only 20% achieved a target BP of <130/85 mmHg (10), and acceptable glycaemic control (HbA1c <2% above normal population range) was found in only 15.7% of subjects (95% confidence interval).

International evidence has shown that CHW programmes often do not yield the expected outcomes because of insufficient training and skills, and inadequate support from the health system (both in terms of clinic staff and referrals to high levels) (11). The findings from this study suggest similar conclusions. Higher quality and more relevant training for CHW (which previously focused on TB and HIV) are needed as such training has shown to be successful in other low- and middle-income settings (12).

Lack of support from the health system was evident in that the CHWs did not report their monthly clinical assessments of patients to the nurses. As a result, the information that was collected did not trigger an intervention for patients whose condition was not controlled. Moreover, too few doctor visits to the clinic prevented renewal of patient prescriptions and hence limited clinical

oversight. Furthermore, poor procurement processes for required materials hampered programme activities. In addition, poverty and the associated social determinants of health, often result in barriers to care that CHW are unable to resolve without intervention from other sectors such as social welfare (13). Again this is reflected in this study with patients experiencing considerable difficulty in attending the clinic for the doctor's review.

South Africa's antiretroviral treatment programme, the largest worldwide with recent notable increases in coverage, has generated substantial knowledge on how to improve adherence, tracing defaulters, and enabling patient participation through treatment literacy and patient support groups (5). It is important that this knowledge and experience is translated into the management of other chronic conditions, such as hypertension and diabetes, in this and similar outreach programmes. Other low- and middle-income countries have begun to integrate HIV care with hypertension and diabetes (14), or provide an integrated chronic care service (15). The findings of this rapid assessment of a pilot programme suggest that CHW can make a useful contribution to the management of chronic conditions. However, to ensure greater success, more effort is required to ensure there are effective procurement processes, communication between clinic and outreach staff, as well as better clinical supervision than was demonstrated in this pilot.

## Conclusion

Outcomes of this pilot programme suggest that home visits and delivery of medication by CHWs can lead to improved control of hypertension in comparison to patients attending the public clinics on a monthly basis. However, this programme did not meet CHW training and supervision needs, or ensure effective procurement processes. Further efforts are required in this regard for CHW programmes to contribute successfully to improved management of NCD.

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### \*Jane Goudge

Centre for Health Policy  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Email: Jane.goudge@gmail.com

# Outreach services to improve access to health care in South Africa: lessons from three community health worker programmes

Nonhlanhla Nxumalo<sup>1\*</sup>, Jane Goudge<sup>1</sup> and Liz Thomas<sup>1,2</sup>

<sup>1</sup>Centre for Health Policy, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa; <sup>2</sup>Medical Research Council - Health Policy Research Group, Pretoria, South Africa

**Introduction:** In South Africa, there are renewed efforts to strengthen primary health care and community health worker (CHW) programmes. This article examines three South African CHW programmes, a small local non-governmental organisation (NGO), a local satellite of a national NGO, and a government-initiated service, that provide a range of services from home-based care, childcare, and health promotion to assist clients in overcoming poverty-related barriers to health care.

**Methods:** The comparative case studies, located in Eastern Cape and Gauteng, were investigated using qualitative methods. Thematic analysis was used to identify factors that constrain and enable outreach services to improve access to care.

**Results:** The local satellite (of a national NGO), successful in addressing multi-dimensional barriers to care, provided CHWs with continuous training focused on the social determinants of ill-health, regular context-related supervision, and resources such as travel and cell-phone allowances. These workers engaged with, and linked their clients to, agencies in a wide range of sectors. Relationships with participatory structures at community level stimulated coordinated responses from service providers. In contrast, an absence of these elements curtailed the ability of CHWs in the small NGO and government-initiated service to provide effective outreach services or to improve access to care.

**Conclusion:** Significant investment in resources, training, and support can enable CHWs to address barriers to care by negotiating with poorly functioning government services and community participation structures.

Keywords: *primary health care; access to care; community health workers; social determinants of health; accountability; South Africa*

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Many low- and middle-income countries face growing health inequities and have made insufficient progress towards the millennium development goals (MDGs). This has been attributed to the poor performance of the health system as well as barriers to care experienced by poor and vulnerable communities. The lack of access to transport, clean water, sanitation, and nutrition limit health improvements. International calls for greater focus on the social determinants of health have highlighted the importance of services capable of responding to the complex intertwined social causes of ill health experienced by marginalised communities (1, 2).

Community health worker (CHW) programmes aim to improve access to care by providing outreach services. Operating at the interface between health systems and communities, CHWs have a crucial role in assisting households to overcome barriers to care. Although there is growing evidence of the effectiveness of CHWs to facilitate improvements in certain health outcomes (3), programmes often fail because of insufficient skills or support (4). Information about successful outreach programmes is needed to guide policy and implementation. This article examines the factors that facilitate success (and failure) of three South African CHW programmes with differing institutional contexts: a small

local non-governmental organisation (NGO), a local satellite of a national NGO, and a government-initiated service.

This article provides a brief description of the current challenges faced by the South African government in addressing increasing health inequities as well as current efforts to strengthen primary health care (PHC) through CHW outreach teams. The subsequent sections describe the methods of the study, present and discuss the key findings, and conclude with lessons for CHW programmes.

## Background

South Africa's transition to democracy in 1994 was accompanied by the development of progressive policies in all sectors to address the past structural inequities inherent in the apartheid system and entrench the far-reaching rights in the Constitution (i.e. 'the progressive realisation of the right to healthcare, housing and education') (5). Since 1994, South Africa has made considerable investment in PHC through increased infrastructure, rapid expansion of TB, HIV, and maternal-health-related programmatic interventions. This has been coupled with an increase in utilisation of services and the re-emergence of CHWs (6). However, these efforts and investments have not resulted in the expected improvements in the MDGs and other health outcomes due to the complex and growing burden of disease, and the failure to develop and implement an efficient district health system (DHS), responsive to local needs (6). The increasing numbers of service delivery protests by local communities around the country, after 18 years of democracy, demonstrate the frustration of many who have yet to benefit from the provision of basic services.

CHW programmes were initiated in the 1970s by non-governmental organisations (NGOs) in response to the inadequate and intentionally inequitable PHC services under the apartheid government (7–10). Although these programmes have gone through a range of changes, many of the programmes still remain active. In contrast to CHW programmes in countries such as Iran and Brazil, where there are more formalised and structured programmes, those in South Africa remain diverse, and for the most part, fragmented, unstructured, and unregulated (10, 11). These CHW programmes are primarily run through NGO intermediaries. This sector is largely funded by the government. Many of the international and national NGOs and community-based organisations developed in response to HIV/AIDS-focused funding. The NGOs described in this article form part of this diverse sector.

Current health sector reform in South Africa is focused on strengthening the district and sub-district level, including the formalisation and integration of community-based services. In the draft 2011 policy document on strengthening PHC (12), community outreach teams of

CHWs led by a nurse will be responsible at the local level for preventative and promotive care, adherence and psychosocial support, with an overall focus on maternal and child health, HIV and TB, and chronic non-communicable disease (6).

## Methods

We used a case study approach to compare the functioning and context of three CHW programmes that provide services in two provinces, namely the Eastern Cape and Gauteng, in South Africa. This allowed us to carry out an in-depth examination of the organisational and contextual factors associated with outreach services.

### *Selection of case studies*

The database of registered CHW organisations held by the Gauteng Department of Health was examined to identify NGOs in a sub-region of the province that met the selection criteria (currently providing a wide range of services and with more than 15 CHWs). NGOs that met the criteria were interviewed, and final selection was on the basis of willingness to participate in the study. To better understand the reasons for success (and failure), we selected an organisation with a reputation of being well functioning (Eden programme in the Eastern Cape) to compare with the Gauteng programmes. This NGO was chosen as relationships of trust had been built previously with key players.

### *Data collection, ethical consideration, and analysis*

Key informant interviews (KIIs) with government officials, NGO managers, and key stakeholders collected data on the role of CHWs, the institutional characteristics of NGOs, and management and support mechanisms for CHWs. Daily activities, and experiences of CHWs, including the types of services provided, the strategies employed to negotiate with formal service providers, and the factors that enabled and/or constrained outreach services were recorded in field notes written after participant observations. Three focus group discussions (FGDs) explored CHWs' perspectives on the management and support they received and their experiences of working with other sectors. A total of 23 interviews and 74 participant observations were conducted with households. Data collection took place during 2010.

Ethical approval was obtained from the Gauteng Department of Health & Social Development and the Committee for Research on Human Subjects at the University of the Witwatersrand. Prior to data collection, informed consent was obtained from all participants. Formal introductory meetings and information sheets were used. All participants were given the opportunity to refuse to be interviewed or observed without prejudice. Names of the programmes and geographical place

names described in the article have been replaced with pseudonyms.

Transcripts and field notes were analysed to ascertain the factors that facilitated (un)successful outreach services. Atlas.ti software was used to assist with the identification of *a priori* and emergent themes. The data were compared within, and between, cases, and we returned to the data to confirm emerging themes. Care was taken to identify evidence that diverged from the dominant perspectives. As the Eden programme was considered to be a ‘good example’, efforts were made to ensure that any perspectives critical of the programme were retained within the analysis.

## Results

### Description of the three CHW programmes

#### Case study 1

The Khanya programme was an independent NGO,<sup>1</sup> initiated by a local community member that relied on funding primarily from the Gauteng Department of Health & Social Development. The organisation aimed to improve general health outcomes, primarily through home-based care (HBC), tracing patients on chronic treatment, and facilitation of support groups. The CHWs were residents of the community they served. CHWs attended the 69-day training workshop provided by the National Department of Health. The curriculum included HBC, TB DOTS, disabilities, child and family health, pregnancy, and preparedness for disease outbreaks (13). Having completed the course, qualified CHWs were paid a monthly stipend. Very limited ongoing CHW training was available, with no opportunity for internal career progression. In addition to the CHWs, the sole staff member was the manager (who initiated the programme) who was responsible for fundraising, operational management, supervision, and mentorship of the CHWs. A government-employed health promoter offered occasional support to the CHWs during their home visits.

#### Case study 2

The Zola programme was established and coordinated by the Gauteng Department of Health & Social Development’s HIV/AIDS Directorate and was administered by the local government. It was funded as part of a national government employment generation scheme. The CHWs, recruited from the local community, attended a required 5-day training course on HIV/AIDS, TB and cancer as well as learning about strategies to support the community’s access to other services. The CHWs, paid a monthly stipend, conducted door-to-door dissemination of HIV/AIDS-related information, providing advice on how

households could access the range of government sectors such as housing, social welfare, water and sanitation. One manager was responsible for supervision and day-to-day running of the programme. Similar to the Khanya case study, the organisation did not offer any internal career progression opportunities for CHWs.

#### Case study 3

The Eden programme, located in the Eastern Cape, was a satellite organisation of a ‘parent’ national child and youth care NGO. Its core objective was to improve child health outcomes in households infected and affected by HIV/AIDS. CHWs, paid a stipend, linked neglected or abused children with health and legal services, and provided day-to-day care for child-headed households. After a community-aligned recruitment process,<sup>2</sup> the selected CHWs were required to complete 14 training modules, as well as ongoing assessments, over the 2 years. Content of the modules included the basics of child and youth care work, children’s rights, behaviour management, and life-span development. CHWs received extensive supervision and mentorship; mentors focused on their technical skills and well-being, and various managers were responsible for coordinating different aspects of the programme. Internal career progression was encouraged which led to the retention of skilled staff. The case studies are summarised in Table 1.

### The communities served by the three programmes

The Khanya and Zola programmes served communities located in a predominately urban province. The high level of poverty in both communities was exacerbated by unemployment coupled with high levels of chronic and infectious disease. Households often had insufficient food. With poor transport networks, health and social welfare services located at some distance were not easily accessible:

There’s only one kombi (bus) that passes through the community; if you miss that kombi, you have to walk to the clinic ... (KII–Khanya).

In other examples, lack of food prevented clients with TB from taking their medication and the lack of water for washing deterred clients from attending the clinic. The failure of local government to provide basic services limited the use of the available health care. Nationally provided welfare services, such as social grants and food parcels, contributed to meeting the basic needs of all three communities. However, the clients of CHWs often did not have identity documents and birth certificates required to obtain these social benefits. The struggles of a typical household are described in Box 1.

<sup>1</sup>Not associated with a larger umbrella organisation.

<sup>2</sup>The CHWs, recruited by community members, were required to have prior experience of relevant community service.

*Table 1.* Characteristics of the three community health worker programmes

Characteristic	Khanya Programme	Zola Programme	Eden Programme
Location	Periphery of metropolitan area of Johannesburg, Gauteng Province	Periphery of metropolitan area of Johannesburg, Gauteng Province	Rural re-settlement area, Eastern Cape Province
Community served	Predominately migrants from other South African provinces and neighbouring countries	Predominately migrants from other South African provinces and neighbouring countries	Long-standing community; Most households dependent on remittances from household members working elsewhere
Institutional setting	Independent NGO; run by project manager/ fund-raiser and project coordinator; under-resourced, with no legitimate office space	Local government-managed programme; under-resourced and using a community house as an office facility; no organisational structure; hands-off management process	Part of a national NGO; the organisational structure has comprehensive managerial activities to support CHW activities at this and other sites. Office based in temporary rooms
Objective of organisation	General health outcomes	HIV/AIDS health outcomes	Child-focused health outcomes
Activities	Home-based care, tracing of defaulters, support group facilitation, identifying other needs – grants, food, birth certificates, identity documents, and water and sanitation	HIV/AIDS-related information dissemination, specific health campaigns; referral to other government services such as Social Development (grants and food parcels), Home Affairs (birth certificates, identity documents)	Address broader issues of children, ranging from health to social problems (including families); referral to other government services; link and accompany them to legal services, social services to access grants and identity documents; social workers for food parcels, grants, foster services, and safe houses of orphans and abused children, provide and supervise daily after school care for children in Safe Park
Funding source	Gauteng DOH	Gauteng DOH (via the Joburg Metro's HIV Directorate)	International funding (PEPFAR)

**Box 1.** A typical household

During a participant observation, a CHW visited an elderly couple who had been farm employees. Laid off with no formal employment benefits, the couple lived in a makeshift building without water and sanitation. They rely on scraps of food from neighbours, who are equally poor. The elderly woman was too sickly to walk to the nearest clinic. The old man mentioned that at times he walks up to the road to stop a taxi so that it can drive inland to collect the old woman. The CHW inquires if they buy food because there was no sign of food in the house. The elderly man comments that he sometimes does not have the strength to cook because he has to set up a fire outside. (*Field notes: Khanya*).

The community served by the Eden programme was located within one of the poorest provinces in South Africa. The dense rural settlements were established by the apartheid government's separate development policy. Government services are still sparse, inefficient, and inadequately financed. Many of the families, resident in the area for at least two generations, depend on remittances from migrants working in other provinces. As in the Gauteng case studies, poverty is pervasive. Although many of the homes were formal structures (constructed of brick), overcrowding was common: "The hygiene in one household where I worked for two years was very bad, because the house was small and there were 14 or 15 people in the house" (FDG – Eden).

**Conceptualising the role of CHWs in each of the programmes**

Understanding social determinants as a cause of poor health is key to shaping the role and services of CHWs. The Khanya programme was conceptualised within the health sector and CHW activities were confined to health issues. The Zola programme aimed to provide health information and refer clients to a range of social services. The Eden programme aimed to meet the needs of children affected by the HIV epidemic, which often included responding to broader household needs: "... if there is alcohol abuse in the family, it leads to the possibility of being infected with HIV/AIDS so we do early intervention for those families" (FGD – Eden). The Eden programme actively recruited community members who understood the need to respond to the broader range of determinants of poor health. Moreover, the CHWs "received training with other service providers ... not only health [police, social development], to help them to address the multifaceted aspects of their work" (KII – Eden).

**Outreach services are resource intensive**

The success of the Eden programme was, in part, due to the resources invested in ongoing training, supervision, and mentoring to assist CHWs, particularly in problem-solving skills. The programme provided funds for CHWs to accompany clients to access services, such as health care or to register for a social grant. Mobile phone vouchers enabled the CHWs to keep in contact with supervisors. The clients, often disempowered, required the presence of a CHW at a clinic or government department. If negotiations with government authorities proved to be difficult, the CHWs were able to contact a supervisor by cell phone to intervene.

This support encouraged the CHWs to negotiate with service providers on behalf of their clients:

The parents of a physically abused child were not here in Selby, so we persuaded the doctor to admit the child to hospital for some few days so that we can contact the parents. We could not take the child back to the abusive grandmother. (FDG – Eden)

Investment in training and support for the CHWs increased their own commitment. One CHW described the benefit of a 'care-for-the-caregiver' programme:

We spent a week on a retreat away from work, during which we did some grief management work. We are attracted to the work that we do because of our own experiences. The psychologist helped us a lot. We were all together and we were sharing and it opened us up so much. (FGD – Eden)

In contrast, the CHWs in the Khanya & Zola programmes were expected to navigate a complex context with limited support. Both programmes had limited capacity to provide subsequent ongoing training and supervision. CHWs had limited prospects of growing within the organisation or furthering their skills at a tertiary level. The CHWs experienced the same struggles and barriers as the households and were unable to adequately guide or accompany their clients to the referral services:

If there was at least someone who is a bit above us, who has the power or the influence to go to those offices for us, so that we can help people. It would make a difference but we are really standing on our own feet ... we are on our own. (FGD – Zola)

**Reporting mechanisms – Monitoring and Evaluation indicators**

In the Eden programme, the CHWs reported on the activities and progress of each household on a case-by-case basis. This mechanism ensured that CHWs took a holistic approach to meeting a child's needs. In contrast, the reporting requirements in the Khanya & Zola programmes were limited to numbers of cases and households visited. Given their monthly quotas, the

CHWs were not encouraged or able to invest the time necessary to address the multiple needs of their clients.

### *Coping with poor cross sectoral coordination*

The fragmentation and resultant lack of coordination within and between government departments at all levels was a common and significant constraint to improving access in all three communities. “You can go to National and you see that sectors [housing, water, social development, health] still function as silos, the same for the Province” (KII – Gauteng District Department of Health representative). Most respondents commented on how the lack of coordinated efforts at the higher levels of government made it difficult for CHWs to provide outreach services to communities:

Coordination can only be achieved if the higher levels are coordinated. If those people that design the key performance targets for the specific departments spoke to one another, it would be so much easier to coordinate at the bottom, because the coordination would already have been established and developed. (KII – Regional Department of Human Development representative – Gauteng)

The CHWs in the Gauteng programmes (Khanya & Zola) found it difficult to navigate this fragmentation with the nominal support provided: “Right now we don’t know where to send these clients to ... we need social worker services” (KII Zola programme). Many of the patients in these two programmes often gave up going to the various government departments. In contrast, the Eden CHWs were able to link clients up with different government departments, despite the limited coordination within and between departments: “The team has formed really good relationships with the police, the school principals, with some of the key people in the hospital and the clinics. These relationships facilitate many referrals” (KII–Eden). It was noted that the programme had limited interaction with the health sector – an exercise which could have enabled the CHWs to respond better to the health needs of their clients rather than solely relying on other health-related NGOs.

### *Accountability of service providers and community leaders*

The lack of political accountability across all case studies had a detrimental effect on CHWs’ services. Local politicians (called “ward councilors”) are chosen by their political party, rather than the number of votes from local communities, with negative consequences for accountability and development: “the community constantly complains that things don’t get done unless you know ‘X’ [person], or you are related to the ward councilor. That is the deep reality which we have in Selby” (KII–Eden).

Despite these limitations, the ward councilor and other stakeholders were found to have played an active role in setting up and supporting the Eden programme:

... we use the ward committee to communicate with the community. For instance when the NGO coordinators wanted to open a Safe Park for children in these locations (townships), they worked hand-in-hand with the ward committees<sup>3</sup> and with the councilor (FGD–Eden).

This relationship, initiated with the assistance of national office of the NGO, was sustained and the programme continued to benefit from support of the ward councilor and other stakeholders.

In contrast, staff at the Khanya and Zola programmes struggled to involve the ward councilor without success: “Politically, our ward councilor is a (name of political party) councilor, so it’s difficult to get him on board. He can’t relate to the issues” (KII–Khanya).

Moreover, the CHWs were exposed to the continuous turnover of officials so it was difficult to hold specific individuals, or departments, accountable for poor service delivery. The manager in one of the programmes in Gauteng commented:

I requested [the health promoter] to go to social services to see the person in charge. The person in charge was not known. So we ended up not getting any name and unable to contact anyone. If we struggle in this way, it is even more difficult for clients. (KII–Khanya)

Furthermore, the geographical area served by local government offices varied spatially from one service to another. Due to the lack of alignment of areas of jurisdiction, clients were often told that the office, where they were seeking help, was not responsible for the area that a client resided in. Clients were sent from one area to another, often never obtaining any service at all: “Our referral system here is just not working well ... We don’t know where to refer. One minute, you refer patients to the South Clinic [12 km] they say to them: ‘No, you have to go to Hamilton’ [18 kms]” (KII–Khanya).

## **Discussion**

CHWs in the Eden programme made a difference in the lives of individuals and other family members. The ongoing training equipped them with the skills to respond to children’s and their families’ needs as well as to negotiate with service providers. The progress of each client was carefully assessed and regularly monitored. The CHWs in the Gauteng case studies lacked the resources to implement such a model. The manager of the Khanya programme was unable to provide training,

<sup>3</sup>The ‘ward’ is the smallest geographical unit in South Africa; the committee consists of community members and is chaired by the ward councillor.

mentorship, and support to CHW as well as the overall management. Similarly, in the Zola Programme, although closely associated with local government, training and supervision were neglected.

Internationally, strong evidence shows that well-established supervision and training mechanisms are central to the success of CHWs' programmes (3, 14, 15). The Brazilian and Iranian successes have been attributed mainly to the quality of the initial and ongoing supervision and training (16, 17). Although the Iranian and Brazilian programmes are both predominantly health focused, they rely on CHWs to provide a wide range of services, including addressing the broad social causes of ill-health (16, 17).

Slow global progress to address the social determinants of health is indicative of the poor governance particularly at a local level (18). In South Africa, the lack of accountability has compromised the envisaged role of ward councilors in addressing the needs of the community. The councilors in Zola and Khanya did little to hold civil servants accountable to provide basic services or to support the programmes in more specific ways. This in turn curtailed the ability of the CHWs to provide effective outreach services. In contrast, Brazil's municipal councils are elected by the community and decision-making processes are shared with non-governmental groups (16).

The success of the Eden programme was due to a range of factors. It received sufficient funding to be able to establish an effective local organisational structure (with mentors, coordinators, and an overall manager). The local office was able to use resources to support the CHW in ways relevant to the local context. The programme managers understood the need to view clients holistically, that the social determinants of ill-health are intertwined, and therefore facilitating access to a social grant (to enable access to transport and food) may be the only way to ensure sustained access to care.

The study highlights the importance of a locally based organisation with capacity and resources to provide an enabling and supportive environment for CHWs. District and sub-district health structures in South Africa struggle to provide adequate facility-based care (19). Under the new policies, without sufficient investment in capacity and sufficient resources to support the outreach teams, the current reforms are unlikely to achieve their objectives. It is also questionable whether the current NGO sector should be seen as an appropriate mechanism to provide support to the outreach teams. South African NGOs in this CHW sector are generally small, with poor management systems. Fragmentation results in the duplication of services which, in some cases, are poorly aligned to national priorities (20). However, the Eden programme provides important relief to a particular community. It is a valuable case study with lessons for both government and NGO-run programmes.

### Limitations of study

The study examined the functioning of the CHW programmes and observed CHW/client interactions. However, users' perspectives were not ascertained. The use of only one successful case study may have limited our understanding of the factors that facilitated success. The inclusion of additional successful case studies would have provided a more comprehensive understanding.

### Conclusion

To facilitate access to care, and reduce the poverty-related barriers to care, the role of CHW needs to be conceptualised with an understanding of the social determinants of ill-health. The success and sustainability of CHW programmes requires the ongoing commitment of resources, including investment in quality training, supervision, mentoring, and organisational support. In addition, resources are needed to support CHWs to navigate uncoordinated and fragmented government services. Ultimately, strengthening health districts and sub-districts is crucial for effective government-led CHW programmes. The national programme of PHC outreach teams in South Africa is unlikely to achieve its expected outcomes unless there is sufficient capacity to support CHWs to operate effectively at the interface between community and the health system.

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**\*Nonhlanhla Nxumalo**

Centre for Health Policy  
School of Public Health  
Faculty of Health Sciences  
University of the Witwatersrand, Johannesburg  
7 York Road, Parktown 2193  
South Africa  
Email: nonhlanhla.nxumalo@wits.ac.za



