

Health and community Care Research Programme

Older People And Community Care In Scotland A Review Of Recent Research

Charlotte MacDonald

This review of research literature focuses on outcomes for service users and informal carers - research relating to older people's perspectives being of particular interest. Current gaps in the research base are identified and some priorities for future research suggested to inform the development of policy and practice on social care services for older people. The review was completed in November 2003.

Main Findings

- The research review indicated that gaps in community care services can often be traced to health and social care agencies not operating as a network of support and not referring people on. A wide range of agencies, and communities themselves, have a role in effective community care.
- Older people's perceptions of their needs relate to their quality of life as a whole – their priorities and expectations in terms of services may not match 'needs' as catered for by health and social care agencies. Making the desired outcomes explicit at the assessment stage helps care managers and providers to focus on improving individual quality of life.
- Minority ethnic groups have poorer access to community care services than others, although their needs are similar. Person-centred mainstream services need to be offered to all on an equal basis to avoid stereotyping minority ethnic groups and excluding groups (such as gypsy travellers and religious communities) with distinctive cultures.
- There is some evidence that the use of smart technology is proving a valuable addition to the range of options available to support people at home.
- Care home residents may be at risk of missing out on health care and specialist services such as physiotherapy and palliative care because nursing staff in care homes may be cut off from information available to primary care. Ageist attitudes may also have an influence.
- It is possible to communicate meaningfully with people with dementia, given the right motivation on the part of staff, appropriate training and sufficient time and space. This opens up the possibility for people with dementia and other forms of cognitive impairment to exercise choice and control in their lives.
- Raising standards depends on the recruitment and retention of staff who can be trained and motivated to provide person-centred care. There is currently very little evidence as to whether this is achievable.
- Action research and other participatory approaches bring service users' perspectives to the heart of the service development process. There is scope for more collaborative work of this kind in Scotland and better dissemination about successful projects.

Introduction

This report presents a review of research literature relating to the range and quality of community care services for older people in Scotland. The review focuses on outcomes for service users and informal carers, research relating to older people's perspectives being of particular interest.

Most of the studies included were conducted in Scotland. Some reference is made to research literature from elsewhere where this has direct relevance to Scottish concerns and fills a gap in the Scottish literature. The highly selective nature of these references was necessitated by the short timescale allowed for the review. Ongoing, or soon to be published, research is referred to where relevant.

Policy in community care has undergone rapid development in the past 5 years. The Joint Future Agenda to promote joint working, the development of National Care Standards and the introduction of free personal care have all had an impact on service provision. In a wider context, 'Health for All', 'Involving People' and Social Justice are new policy themes which have a bearing on the direction of community care policy.

The research agenda has also changed in significant ways. More research has focused on the perspectives of service users and carers, participatory approaches to research have been influential and, in dementia research in particular, new approaches to seeking users' views are having an impact on how service users are perceived. This review identifies current gaps in the research base and suggests some priorities for future research to inform community care services and the Joint Future Agenda.

Assessing need in the community

Recent research has demonstrated that needs in terms of people's own quality of life and expectations may be quite different from needs as catered for by health and social care agencies. Other agencies, and communities themselves, have a role to play. Gaps in community care services can often be traced to agencies not operating as a network of support and not referring people on.

A Scottish Executive funded audit of research on minority ethnic groups reinforces this general point with a wealth of evidence that older people in minority ethnic groups have poorer access to community care services than others. The audit highlights particular ways in which community care services need to adapt to achieve more equal access.

A study comparing urban and rural networks is particularly helpful in uncovering the social and institutional mechanisms which determine the way local networks operate. At a more individual level, a study of carers draws attention to the importance of individual assessment of carers' needs as a way of strengthening community supports.

Research involving service users and local communities illustrates how research can play a part in tackling problems

of service delivery. In one example, research contributed to a local needs assessment which then led to local improvements in services which were in tune with the priorities of local people. In the other example the outcome was a direct contribution to professional practice.

Assessment and care management

Research on assessment practice is scarce. Analysis of how different professions approach assessment is potentially valuable in the development of multi-disciplinary assessment practice.

There is, equally, little published research on models of joint and integrated working in Scotland. Collaborative and multi-agency research has met with some success in England in actually promoting joint working. In one example, an action plan to improve hospital discharge was the outcome. In another, an integrated care system was developed employing a 'whole systems' approach with monitoring and evaluation playing an integral part.

Evidence of unmet need and of inadequate practice continues to emerge from research. Unmet needs for social support in older people with schizophrenia in one NHS Board area were found to be significant and attributable to a failure to provide multi-disciplinary assessment.

A Scotland-wide review has revealed a high degree of variation in the way care management is organised and differing interpretations of what care management means. Social Work Departments also appear to offer very different levels of service. 24-hour cover was available in almost all areas but only as an emergency or short term service. Managers from about half of the authorities did not think there was adequate choice for service users.

User satisfaction and outcomes

The policy agenda has focused attention on user satisfaction research. This has progressed in different directions depending on whether the aim is to measure or to improve performance. In English research, using global measures of satisfaction, assessment by a social worker, as opposed to a home care manager, was found to influence satisfaction in a positive way. However, such measures are of limited use for identifying what aspects of a service people find satisfactory or what needs to be changed.

An alternative approach focuses on outcomes of social care for individuals. Three different kinds of outcomes have been distinguished related to: maintenance of quality of life, change, and the process of service delivery. The researchers involved propose that agreeing outcomes with service users as a stage between assessment and care planning provides care managers with a tool to monitor standards of care.

Support at home

A number of studies demonstrate the centrality of service users' perspectives in achieving good quality services. People's judgements about specific services are directly related to the effect of the service on the quality of their lives as a whole.

Evidence from research and audit indicates that overall in Scotland there has been a reduction in total home care provision at the expense of people with low level support needs.

There is wide variation in satisfaction with services both from service users and home care workers but also a lack of evidence about what contributes to this variation. One source of service user and carer dissatisfaction identified is the limited use of care management to monitor and review needs once services have been allocated. The effect of factors such as management practices, service models, labour supply and training on quality as perceived by service users could usefully be explored.

There is a need for more research to examine joint services and the lessons to be learned from different models of integration. A national survey of waiting times for adaptations and equipment identified an association between the extent of joint arrangements and lower waiting times.

Studies of community-based palliative care focus on the input of nurses and medical staff and tell us that a high proportion of palliative patients in one NHS area are older people with diagnoses other than cancer.

Innovation in housing and support through the use of telecare has created a new area of interest for researchers. Ongoing evaluation of telecare projects is identifying a generally positive response from staff and service users.

A recurring theme is the problem of poor or inconsistent management information. This compounds the inevitable difficulties for researchers caused by local authorities employing different service configurations and different interpretations of national policy and guidance in their areas.

Long-term care

A substantial amount of research on care homes focuses on quality of life for residents, research which has helped to formulate the principles and standards embodied in the National Care Standards. The role of care staff and the relationship between job satisfaction and quality of care remains a neglected area which has obvious relevance for management, training and implementing the required standards of care.

More research is also needed to examine access to health care for care home residents as an issue of social justice. Studies of physiotherapy and palliative care address some important aspects of health care for frail older people. These studies draw attention to the risks of nursing staff in care homes being isolated from information current in primary care teams, and of ageist attitudes influencing access to specialist services for care home residents.

Offering more intensive support in a range of settings is one alternative to the care home model of service. Experience in Denmark and the Netherlands shows the potential for moving towards a person-centred approach to residential care by separating the care plan from the accommodation.

A study of an advocacy service for care home residents found that demand for and understanding of the service could not be taken for granted and that public promotion was essential to ensure take-up. The evaluation also found that longer term involvement by advocates with their partners was needed than had originally been envisaged by the project.

UK wide research on people admitted to care homes on a self-funding basis revealed that they had received relatively less in the way of support services prior to admission than publicly funded people. The findings suggest that there is unmet need for support at home offering social contact and interest as opposed to intensive personal care.

Dementia care

There now exists in Scotland an active network of researchers applying and extending new research methods which focus on 'hearing the voice' of the person with dementia. This network is part of a wider international network of researchers whose work is closely linked to innovation in practice. The enthusiasm and commitment of research in this field is distinctive and has generated methods and approaches applicable beyond the field of dementia care.

Dementia research has demonstrated that, given motivation and appropriate training, researchers and others can communicate meaningfully with people and include them in research. One study found that by encouraging non-verbal interaction between carers and people with dementia, more people with dementia were included socially in a group.

There are cultural differences in how dementia is perceived and therefore person-centred approaches and services are the key to understanding and meeting the needs of people with dementia from different ethnic groups.

The main benefit of day care as perceived by unpaid carers is respite for themselves. However by including the perspectives of the service users themselves, research has been able to reveal the therapeutic value of the service for people with dementia.

Research on the potential for people with learning disabilities and dementia to exercise choice and control emphasises the importance of staff attitudes and the need to allow time and space for people to make their choices.

A research agenda

Research could contribute more to a Scotland-wide view of provision for older people if better use were made of existing data sources, including national surveys and information collected by the Scottish Executive for monitoring purposes.

Action research and other participatory approaches bring service users' perspectives to the heart of the service development process. There is scope for more collaborative work of this kind in Scotland and better dissemination about successful projects.

Active collaboration between researchers and practitioners has produced a wealth of new methods and insights which allow people with dementia to be included in discussions about their care, something which was unheard of ten years ago. Health and social service research has a great deal to learn from dementia research about how to 'hear the voice' of service users and carers.

We know more now than five years ago about the experience which older people from minority ethnic groups have of community care. More research is needed involving people from a wide range of ethnic groups and parts of Scotland to

help to overcome the ignorance and prejudice which stand in the way of more equitable service provision.

Social justice requires all older people to have similar access to basic health and social care whether they live at home or in a care home. There is some evidence that care home residents may be isolated from particular health and other services. More research is needed, based on large representative samples, to establish the extent of inequity and to inform solutions.

The characteristics of the workforce who provide basic care is a neglected area in community care research. Raising standards depends on the recruitment and retention of staff who can be trained and motivated to provide person-centred care. There is currently very little evidence as to whether this is achievable.

If you wish further copies of this Research Findings or have any enquiries about social research, please contact us at:

Scottish Executive Social Research
4th Floor West Rear
St Andrew's House
Regent Road
EDINBURGH
EH1 3DG
Tel: 0131 244-2256
Fax: 0131 244-5393
Email: socialresearch@scotland.gsi.gov.uk
Website: www.scotland.gov.uk/socialresearch

If you wish a copy of "Older People and Community Care in Scotland A Review of Recent Research" the research report which is summarised in this research finding, please send a cheque for £5.00 made payable to:

The Stationery Office Bookshop
71 Lothian Road
EDINBURGH
EH3 9AZ
Tel: 0870 606 5566
Fax: 0870 606 5588
<http://www.tso.co.uk/bookshop>

This document (and other Research Findings and Reports) and information about social research in the Scottish Executive may be viewed on the Internet at: <http://www.scotland.gov.uk/socialresearch>

The site carries up-to-date information about social and policy research commissioned and published on behalf of the Scottish Executive. Subjects covered include transport, housing, social inclusion, rural affairs, children and young people, education, social work, community care, local government, civil justice, crime and criminal justice, regeneration, planning and women's issues. The site also allows access to information about the Scottish Household Survey.

ISBN 0-7559-3711-2

