

The impact of a new public health approach to end-of-life care: A systematic review

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Abstract

Background: Communities play an increasingly significant role in their own health and social care, and evidence demonstrates the positive impact of this work on a range of health outcomes. Interest is building regarding the application of the principles of the new public health approach to those facing the end of life and their families and communities.

Aim: To review the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

Design: A systematic review employing narrative synthesis. Both meta-ethnography and the use of descriptive statistics supported analysis.

Data sources: Eight databases (AMED, ASSIA, BiblioMap, CINAHL, Cochrane Reviews, EMBASE, MEDLINE and PsycINFO) were searched from the earliest record to March 2015 using set eligibility criteria.

Results: Eight articles were included in the analysis. Three main themes emerged from the meta-ethnography: making a practical difference, individual learning and personal growth and developing community capacity. The quantitative findings mapped to the meta-ethnography and demonstrated that engaging communities can lead to improved outcomes for carers such as decreased fatigue or isolation, increase in size of caring networks and that wider social networks can influence factors such as place of death and involvement of palliative care services.

Conclusion: Evidence exists for the impact of community engagement in end-of-life care. Impact assessment should be an integral part of future initiatives and policy makers should recognise that these approaches can influence complex issues such as carer support, community capacity, wellbeing and social isolation.

Keywords

Palliative care, public health, health promotion, community engagement, impact, outcomes

What is already known about the topic?

- Community engagement is increasingly acknowledged as contributing important outcomes for health and wellbeing.
- Community engagement in end-of-life care is increasingly recognised in policy documents and practice examples exist worldwide.
- Little evidence exists regarding the impact of such approaches.

What this paper adds?

- This review demonstrates positive outcomes resulting from community engagement in end-of-life care, for individuals with life-limiting illnesses, their carers, community members participating in care and the community as a whole.

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Implications for practice, theory or policy

- The qualitative synthesis provides a map of the range and type of impact that can be experienced. Few aspects have been measured, demonstrating the research gaps in the field currently.
- Evidence demonstrating positive impacts of engaging communities in end-of-life care is of relevance to policy makers and funders, particularly when seeking to address complex issues of carer support, community capacity, social isolation and wellbeing.

Introduction

A public health approach to palliative care has been advocated by the World Health Organization since the 1990s, with the aim of improving opiate availability, developing appropriate policies and integrating palliative care services into the mainstream.^{1,2} The World Health Assembly recently recognised palliative care as a component of universal health coverage, recommending integration from the level of civil society to hospital care.³ While these remain important concerns for many delivering palliative care services, the contemporary challenges of social isolation, the professionalisation of dying, inequity of access to services and changing demographic trends have led to new pressures, and have prompted many to return to the principles of a public health approach, re-examining it in the light of these present-day challenges.

Public health encompasses a broad range of approaches, from the traditional techniques of disease control and prevention, to the newer approaches of health promotion, focusing on education and empowerment. The emergence of a health-promoting approach in the 1980s paved the way for 'new public health', placing people as active participants in their own health and recognising the importance of the social determinants of health. The Ottawa Charter⁴ was the central document in developing the new movement. It was based on five pillars or goals which should be addressed in order for a population's health to be improved: build healthy public policy, create supportive environments, strengthen community action, develop personal skills and reorient health services. Over recent years, the evidence base for such approaches has developed. A health promotion approach has been used successfully in fields such as HIV/AIDS and cardiovascular disease for decades, with important improvements in health outcomes⁵⁻⁷ and calls are increasingly being made to incorporate community engagement into healthcare more generally.⁸⁻¹⁰ A recent meta-analysis concluded that there is solid evidence that engaging communities in health projects leads to improvements in health behaviours, health consequences and self-efficacy, across a range of diseases and conditions¹¹ and the evidence base for why such approaches are needed is building, with the effect of social isolation on survival quantified¹² and the impact of strong social networks in preventing admissions to secondary care and in substantial health service cost savings demonstrated.¹³

A health-promoting or new public health approach to end-of-life care was first outlined by Kellehear¹⁴ and now encompasses a large-scale, international effort to incorporate the principles of health promotion into end-of-life care. It can be understood as a series of social efforts by communities, governments, state institutions and social or medical care organisations that aim to improve health and wellbeing in the face of life-limiting illness.¹⁵ Although the juxtaposition of health promotion and end-of-life care has been thought to be contradictory,¹⁶ it is now widely acknowledged that health and wellbeing can be improved in the context of a life-limiting illness, both for the individual and those around them. The morbidity and mortality associated with being a family caregiver, being bereaved or becoming socially isolated are well documented,^{12,17-19} in addition to the impact of suffering with a life-limiting illness. A health-promoting approach to end-of-life care argues that the answers to the above problems do not lie in increased services and more professionals. Rather loneliness, stigma and other social problems are best tackled by friends or community members rather than healthcare professionals. A strong community response augments rather than supplants the professional response.

Examples now exist throughout the world of the application of health-promoting principles to end-of-life care. These incorporate a range of processes, determined by local need and resources and a descriptive literature is building, documenting these interventions. Projects frequently describe the mobilisation of community resources, either through naturally occurring social networks^{20,21} or externally facilitated ones,^{22,23} or through the direct support of trained community volunteers.^{24,25} Other projects describe attempts to influence society's perception of and reaction to death and dying, such as through work with schools,^{26,27} businesses²⁸ or professionals^{29,30} or offer seed grants to communities to develop work themselves.^{31,32} Others still focus on awareness, education and training of community members directly in topics such as writing a will and advance care planning^{33,34} or efforts to explore society's perception of the issues through local or national conversation.³⁵⁻³⁷ Policy examples exist where lobbying from local services and communities has led to policy reform³⁸ and the emergence of dementia-friendly communities is an example of how the environment may be manipulated to improve experiences of those living with life-limiting illnesses.³⁹

Although a range of practice exists under the heading of health-promoting end-of-life care, a dominant interpretation has been through the strengthening community action pillar of the Ottawa Charter, involving community engagement, participation or development and often described using the phrase ‘compassionate communities’.^{40,41} The rise in interest in these approaches has not been matched by a rise in the evidence supporting their use. With the importance of measuring outcomes in end-of-life care recognised,⁴² a need exists to understand and measure the impact of this work. This systematic review aims to determine the impact of a health-promoting or new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.

Method

Search strategy

Eight databases were searched (AMED (1985–2015), ASSIA (1987–2015), BiblioMap (2015), CINAHL (1983–2015), Cochrane Reviews (1996–2015), EMBASE (1980–2015), MEDLINE (1966–2015) and PsycINFO (1806–2015)) using a search strategy based on MEDLINE search terms and adapted for other databases as necessary (Appendix 1). The search was limited to adult participants (>18 years). Reference lists of key papers were searched, key authors’ publications searched, three journals were hand-searched from the first issue to March 2015 (*Journal of Palliative Care*, *Palliative Medicine* and *BMJ Supportive and Palliative Care*), experts within the field were contacted and a specialist librarian supported the search strategy.

Eligibility

Papers were included if they reported on the outcomes of community engagement, mobilisation or social network development in end-of-life care. All potential stakeholders were included as participants. Both naturally occurring examples and those resulting from an external intervention were included. Only original, published studies were included and no papers in languages other than English were identified.

Screening and data extraction

Searches were performed by one author (L.S.) against the eligibility criteria and excluded articles discussed with a second author (H.R.). Figure 1 represents the selection process. The full text papers ($n=8$) were reviewed by one reviewer first (L.S.) and a second reviewer (H.R.) independently reviewed four randomly selected papers. Disagreements were resolved through discussion with the two remaining authors (S.M. and A.K.). Data were extracted into a data extraction table (Table 1).

Quality assessment

All studies were assessed for methodological quality. The heterogeneity of the papers required a broad approach to quality and the checklist proposed by Hawker et al.⁴⁷ allows research from different paradigms to be graded. The score ranges from 1 (poor) to 40 (good). One reviewer (L.S.) graded all the studies and this was verified by a second reviewer (H.R.). Two authors of papers included in the final analysis were contacted for clarification.

Analysis

The papers retrieved were heterogeneous in study design, meaning a technique for synthesising diverse sets of data was needed. The technique of narrative synthesis⁴⁸ was utilised as it offers a robust means of analysing and synthesising quantitative and qualitative data. It aims at producing a synthesis that is useful for and targeted at practitioners in the field. The qualitative findings were combined using the technique of meta-ethnography, and the quantitative findings using descriptive statistics. The systematic review was conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).⁴⁹

The process of meta-ethnography according to Noblit and Hare⁴⁶ was followed. First-order (verbatim quotes from study participants or descriptions from the authors) and second-order constructs (interpretations made by the authors) were extracted. These key concepts were then translated into one another, starting with a comprehensive paper first²³ and matching these with concepts from subsequent papers, in chronological order. Concepts were assessed for congruence, refutation or whether a new concept was being presented. These concepts were then put through a process of reinterpretation, using thematic analysis, to determine higher order themes that made sense of the studies as a whole and offered new insights to the collective data.

Results

Eight papers were included in the final analysis: three qualitative papers,^{23,25,43} three mixed methods papers^{20,33,45} and two quantitative papers.^{44,50} Papers came from a range of countries and settings (see Table 1). Four studies concerned two datasets, analysing different components of the data: Jack et al.²⁵/Jack et al.⁴³ and Horsfall et al.²³/Leonard et al.²⁰ Two studies examined the impact of naturally occurring social networks,^{50,45} two studied a mix of naturally occurring and facilitated networks,^{20,23} one examined a facilitated network approach,⁴⁴ two examined trained community volunteer support^{25,43} and one a community education project.³³

Study quality varied from good to moderate quality, with scores ranging from 27 to 37. The three qualitative

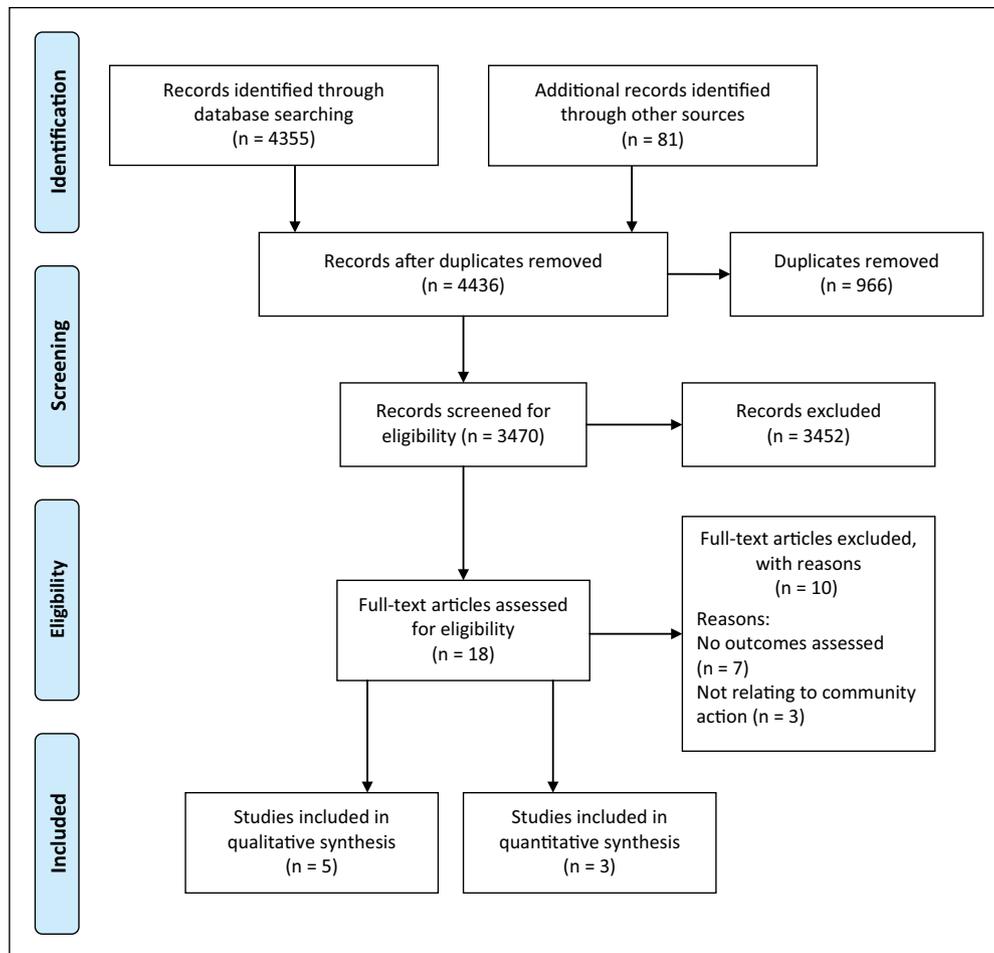


Figure 1. PRISMA flow diagram.

papers^{23,25,43} scored similarly well, with the analysis process described and extensive use of verbatim quotes. The two papers by Jack et al.^{25,43} include interpretations of a more descriptive nature, whereas the paper by Horsfall et al.²³ presents higher levels of abstraction in their interpretations. No discussion of reflexivity was undertaken in any of the papers. The two quantitative papers were both judged to be of a high quality and both included rigorous analysis of relatively large populations.^{44,50} Greene et al.⁴⁴ did not deliver on their primary outcome measure of anxiety and report only on significant secondary outcomes. The three mixed methods studies included two of the lowest scoring papers,^{33,45} both of which contained limited reporting on methods and analysis, with a limited distinction between findings from the qualitative and quantitative methods, such that only the qualitative data could be used in this review. The remaining mixed method paper, Leonard et al.,²⁰ was predominantly quantitative in nature, with few details on analysis and interpretation for the qualitative data. For this reason, the qualitative findings from Leonard et al.²⁰ were not included in this review. No sources of systematic bias were evident across the papers.

Key themes and findings

Meta ethnography. Three main themes emerged from the meta-ethnography: *Making a practical difference* which describes the impact such work has on the immediate experiences of those facing the end of life and their caregivers; *Individual learning and growth* which describes the journey of personal reflection, development and confidence that those involved embark on; and *Developing community capacity* which refers to the impact of the work beyond the individuals involved, to the wider community where sustainable change can occur. Figure 2 provides an overview of the themes and subthemes.

Theme 1: Making a practical difference. This describes the impact the involvement of communities can have on experiences at the end of life. This was represented in both first-order descriptions of what impact the care and support had on individuals and in a second-order concept regarding the ability of basic care to bring about substantial change – ‘the ordinary becomes the extra ordinary’.²³

Table 1. Data extraction table.

Author(s), year	Aim	Country	Study design	Participants	Study quality (/40)	Main findings
Benkel et al. (2009) ⁴⁵	To explore social support for bereaved friends or relatives in the first year post bereavement	Sweden	Mixed methods: survey and interviews	Bereaved friends and family Survey (n=55) Interviews (n=7)	28	The social network is relied upon to deliver the majority of practical and psychological support. Professional support is sought if the network was dysfunctional or the individual does not want to burden their network
Burns et al. (2011) ⁵⁰	To provide information on the role of friends as caregivers	Southern Australia	Annual face-to-face health survey	2093 bereaved friends	37	Home deaths more frequent ($p=0.014$) and use of palliative care services higher ($p=0.008$) when friends are caregivers as opposed to only family members
Greene et al. (2012) ⁴⁴	To assess if caregivers perceived they were better supported and less anxious in their roles if they accessed a community network facilitator	Southern Australia	Quasi-experimental, single-blind design, pilot study	66 caregivers of palliative care patients	35	Improved within-arm changes for carers in intervention group: reduced fatigue ($p<0.05$), feelings of isolation ($p<0.01$), improved support from others ($p<0.01$), confidence in asking for assistance ($p<0.05$), ability to find resources ($p<0.001$). Manageability of care significantly improved in control arm ($p<0.05$). No between-arm differences
Horsfall et al. (2012) ²³	To understand the quality and effect of caring networks and the impacts for family, friends and the wider community	Eastern Australia	Qualitative study including individual and group interviews	94 participants in 17 caring networks	33	Four main themes: it takes a community, resisting isolation and staying connected, the ordinary becomes the extraordinary and developing death literacy
Jack et al. (2011) ²⁵	To evaluate the impact of the palliative care community volunteer programme	Uganda	Stakeholder evaluation through interviews and focus groups	21 patients, 32 volunteers and 11 hospice staff	32	Three main themes: impact on patients and families, education and support and a bridge to the hospice
Jack et al. (2012) ⁴³	To explore the personal impact of being a community volunteer worker	Uganda	Qualitative methodology using semi-structured interviews	32 volunteers and 11 hospice workers (same dataset as Jack et al. 2011)	33	Two main themes: impetus for becoming a volunteer and personal impact of being a volunteer
Leonard et al. (2013) ²⁰	To describe caring networks, to determine whether community development can be demonstrated through caring and to understand the role of social network analysis in this context	Eastern Australia	Mixed methods: focus groups discussions and participatory network mapping	76 current or bereaved carers and their networks, one patient	34	Quant: size of networks increased from T1 to T2 ($p<0.05$) with a decrease in transitivity ($p<0.01$) Qual: increase in number and quality of relationships and loss of relationships
Seymour et al. (2013) ²⁰	To report on volunteers' perspectives on a peer education initiative, their feelings about becoming peer educators and the community engagement activities they had engaged in	United Kingdom	Participatory action research with mixed methods of data collection	Peer educators 20 in focus groups 25 in interviews 24 survey respondents	27	Three main themes: sharing concerns and anxieties, developing a new understanding and personal and emotional implications. Survey data of poor quality – not extracted

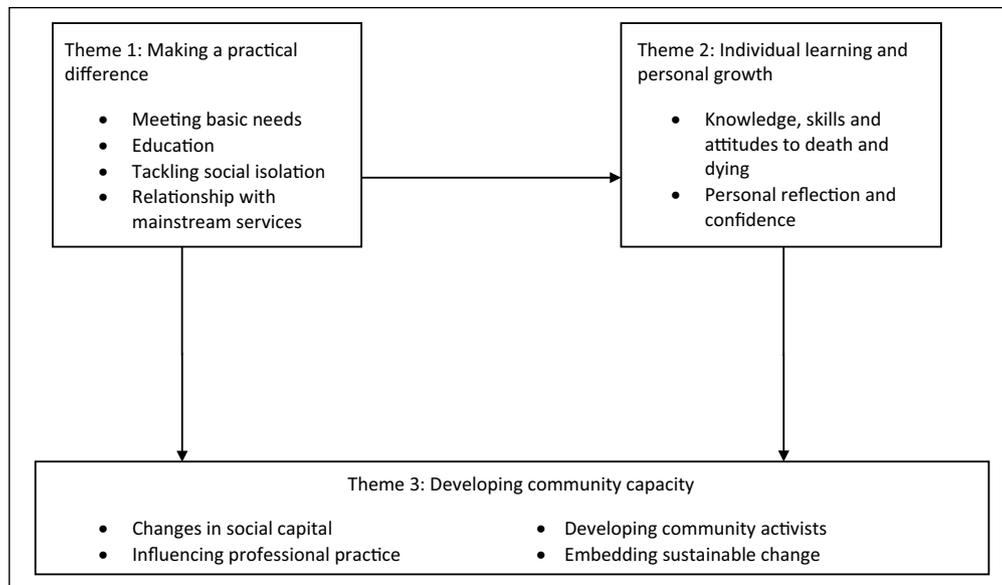


Figure 2. Themes from meta-ethnography regarding community action in end-of-life care.

Four subthemes illustrate this theme. The first, ‘meeting basic needs’, describes the practical tasks that communities are faced with and the impact meeting those needs has on the individuals and their families. Communities may be confronted by a series of urgent needs, relating to basic human requirements for food, water and shelter. Meeting these basic human needs would not be classed as end-of-life care but were recognised as essential support provided by communities. This subtheme was strongly represented in the papers from low resource settings^{25,43} but also featured in more developed contexts²³ and included the perspectives of both those giving and those receiving the support:

I did not have money to buy any food, the volunteer gave me money, even prepared food for me to eat – at the next visit she brought me a skirt and a blouse.²⁵

She didn’t need massage or mediation lessons, she needed firewood.²³

Respondents detailed the basic nursing care that was provided. This included physical care such as wound dressing, and support for the family such as respite:

She made sure the wound does not smell.²⁵

I asked her to give some respite when Mum and Dad are out ...²³

Some impact was achieved by attending to psychological needs. A range existed of the support that was offered, from lay to semi-professional:

... we were lucky to have a very good female priest who we could talk to before the funeral ... so I felt a great deal of support and sense of community.⁴⁵

The Volunteer she encouraged my mother to stop worrying and told her that she did not think I was going to die soon.²⁵

The second subtheme, ‘education’ describes how, through education and awareness-raising, community members helped individuals and family carers to change their experiences of care and illness. For some, this was related to symptom control support:

They counselled me about the drugs because I had already lost hope in life.²⁵

For others, it was the sharing of practical tips and knowledge that made the caring process easier:

You kind of gleaned bits from everyone who came in ...²³

The wider community was also trained and mobilised around individuals and their families, to support the caring process:

... we are training these people who are caring for these patients – so you can change them and they die in a good way.²⁵

‘Tackling social isolation’, the third subtheme, was seen by participants as an important issue, both for individuals with a life-limiting illness and their carers:

I have helped some families, whereby some of the patients have been isolated in their room ...²⁵

In their second-order interpretation ‘resisting isolation and staying connected’, Horsfall et al.²³ recognised the central role the community plays in preventing or alleviating social isolation.

The fourth subtheme was ‘relationship with mainstream services’. In undertaking these caring and supportive roles, community members were forced to consider their position relative to mainstream healthcare services. This subtheme contained some diversity and represented a refutational theme. Some community members felt that their responsibility was to work in partnership with existing services, to support and enhance their work:

We are working hand in hand with them – we cover the ground.²⁵

Others felt that mainstream services were failing them and that their job was to work outside that system:

... she was dying and not fast enough for the hospital system and they kept sending her home ... it was very distressing and without any knowledge I decided that we could do better and brought her home ...²³

Within this subtheme, two second-order themes emerged from two papers, illustrating the differing views presented by respondents – ‘a bridge to the hospice’²⁵ and ‘resisting the system’.²³ The two studies were conducted in different contexts, but it illustrates the positioning that community members must consider when embarking on this work and that the relationships between communities and professional services must be negotiated.

Theme 2: Individual learning and personal growth. The second theme explores the personal impact of being involved in this work. It includes impacts on the carers and family members, the person with a life-limiting illness and individuals in the wider community. It comprises two subthemes. The first ‘knowledge, skills and attitudes to death and dying’ captures the effect of direct experience or education on individuals’ understanding of and thoughts about death and dying. Of particular note was the change in attitudes to dying at home, with respondents describing how the experience of caring for someone at home made them realise it was possible:

Even Mum did not think she was allowed to die at home ...²³

The second subtheme, ‘personal reflection and growth’, relates to the impact participants’ experiences had on them personally, either in reflecting on past bereavements, their thoughts regarding their own deaths, or feelings of satisfaction, pride or improved self confidence that the caring or training experience generated:

... on a personal note, I too have taken notice of what I’ve learned from here, and I’ve made all my arrangements ...³³

There’s a selfish act in caring ... you’re learning more about what it is to live.²³

Theme 3: Developing community capacity. This theme describes the impact that is evident beyond the individuals involved in a specific case of caring, or an educational initiative. These changes act to embed this work in the wider community and make use of the skills and capacity that have developed in relation to specific situations. This is an integral component of a new public health approach; the ripple effect moves the work beyond improving experiences for individuals to influencing community change. This theme had four subthemes. ‘Changes in social capital’ described the often positive but occasionally negative impact on the nature, strength and number of relationships that being part of a caring network had led to. Examples of stronger relationships were given, beyond immediate contacts, and of wider trust within the community being built:

The community has more trust and confidence in those volunteers ...⁴³

The second subtheme, ‘influencing professional practice’, describes the further impact this work can have on professionals, through working together, feeding back or influencing them directly:

... it [has] made it seem like something more natural to talk about, not to feel so awkward about discussing end of life matters and decisions ...³³

A further subtheme, ‘developing community activists’, described how some felt their experiences prompted them to look for wider outlets for their acquired skills or capacities. Participants described how the personal impact of being involved in such work gave them the confidence to take the learning out into the community. Some remained within the end-of-life care field but others took on more general, civic roles:

I’m very proud to see her as an advocate for other people and using her experience to be an enabling thing in community for others.²³

... some of them [community volunteers] have even had the chance to join politics as a result of their voluntary work.⁴³

The final subtheme, ‘embedding sustainable change’, describes how participants attempted to change or tackle the structures in their community that were limiting good care for those at the end of life. Examples include lobbying local government, hosting community education days or taking part in research studies:

We literally pressed our PCT to get an [end-of-life care] strategy together ... we said okay we’re going to hold an information day and we will invite them to come and talk.³³

A second-order interpretation from Seymour et al.³³ was that this type of sustainable action was only possible when the community members were embedded in a

strong social network and could draw on social capital and resources.

Line of argument synthesis. A meta-ethnography can produce a ‘line of argument’ which draws together the themes that emerged from the papers and represents a new way of conceptualising the collective data. The line of argument for this meta-ethnography is as follows.

Communities can come to take responsibility for end-of-life care issues in a variety of ways – through providing support, direct experience or through education. Those supporting others are presented with a range of needs that, once met, lead to the improved experiences of those being supported and the acquisition of new skills and knowledge by those helping. However, when community members enter the work, the experiences of being involved lead to personal reflections, learning and growth, transforming the individual as a result. Furthermore, changes can be detected beyond the immediate caring networks or individuals involved. Both the direct experiences of supporting those at the end of life and undergoing training around such issues ripple out into the wider community, producing structural and communal changes that embed the work in the fabric of the community.

Quantitative results

The three papers containing quantitative findings^{20,44,50} looked at the impact of engaging communities in end-of-life care from different perspectives, meaning a synthesis of the data from the individual studies is not possible. Leonard et al.²⁰ looked at changes in the social networks surrounding family carers and found that the size of networks increased during the caring experience ($p < 0.05$) but also found that the transitivity, or balance and reciprocity in the relationship between three people, decreased in the sample ($p < 0.01$). They suggest that this was due to the large number of new members joining the group who were only connected to the main carer, rather than having the time to establish stronger and more reciprocal relationships with other network members.

Greene et al.⁴⁴ focused on the impact of a specific intervention aimed at supporting family carers. They conducted a single-blind controlled study, where the intervention involved matching carers in the intervention group with a network facilitator. They demonstrated that carers in the intervention arm showed significant within-arm improvements in fatigue ($p < 0.05$), feelings of isolation ($p < 0.01$), sufficient support from others ($p < 0.01$), confidence in asking for assistance ($p < 0.05$) and ability to find resources ($p < 0.01$). There were no between-arm differences. In the control arm, manageability of care improved ($p < 0.05$) while it worsened in the intervention arm ($p < 0.01$). One explanation postulated for the lack of a between-arm difference was that the action of undertaking assessments and

surveys can constitute an intervention in itself and, as such, may have contributed to an effect in the control group. One reason the authors gave for the improvement in the manageability of care in the control arm, with a worsening in the intervention arm, may be that the process of organising and managing a network of friends and community members actually involved more work and contributed a degree of stress.

The paper by Burns et al.⁵⁰ examined the role of friends as caregivers for people with a terminal illness. In a large sample, they found that home deaths were significantly more likely when friends were caregivers ($p = 0.014$), as opposed to only family members and the rate of palliative care use was higher when friends/others were the caregivers ($p = 0.008$). Age, gender and illness were controlled for. The authors described how this data may suggest that people may be turning to wider social networks, beyond the family, and that this change may be influencing experiences and practices at the end of life.

Synthesis of findings

The three quantitative papers take different angles of community involvement in supporting those at the end of life and as such stand separately. However, when these findings are mapped onto the themes from the meta-ethnography, greater insight is afforded and a broader understanding of the contribution of the differing findings can be appreciated. For example, the findings from Greene et al.,⁴⁴ that having a facilitated network improves the experiences of carers, reflect the qualitative findings described in theme 1, *Making a practical difference*, with networks practically changing the experiences of carers. The improvements in confidence and ability to find resources described by carers in Greene et al.⁴⁴ are congruent with the personal developments in knowledge and attitudes described in theme 2, *Individual learning and personal growth*. The demonstration of increased numbers of home deaths and increased use of palliative care services when friends form part of a supportive network⁵⁰ again resonates with theme 1, as networks can work with the mainstream system to support more joined up care. We cannot tell whether the increased numbers of home deaths were through participation with mainstream healthcare or despite it. We can infer that the increased use of palliative care services in this cohort points to this being a cooperative rather than a resistive effort on the part of the community.

The increase in network size from Leonard et al.²⁰ supports the change in social capital from theme 3, *Developing community capacity*, although the decrease in transitivity, or reciprocity between people, suggests a more complex relationship. This was highlighted in the subtheme *changes in social capital*, where although stories existed of relationships being built and strengthened through the process, there were also examples of relationships that had been

damaged. The finding from Greene et al.,⁴⁴ of the decrease in manageability of care when a network was involved, may also shed light on this, as it suggests that being part of or managing a network caring for someone at the end of life can place a strain on participants, particularly the family members.

Discussion

This systematic review describes and demonstrates the impacts that can follow from supporting community action at the end of life, an important component of a health-promoting approach to end-of-life care. This is significant as it is a field with few outcomes demonstrated thus far, but with a rapidly developing interest in what the approach might achieve. This result is congruent with the broader literature, which suggests that engaging communities in health matters leads to improvements in health and wellbeing, capacity and longer term community change.^{10,11,13} Health promotion initiatives are acknowledged as exerting influences on a range of stakeholders, and this review permits an overview of the impacts that can occur with this work. This overview is important for practitioners in the field, as interventions and evaluations can be focused on specific outcomes.

This review demonstrates the contribution mixed methods can make to the evaluation of a field such as health promotion. The value of using mixed methods has been acknowledged in health promotion in general.^{51,52} The qualitative findings provide a depth of meaning and contextual richness to the work, while the quantitative findings allow an understanding of the causation of specific outcomes and the strength of specific relationships in the field.

The first theme, *Making a practical difference*, describes the actions that communities undertake when faced with supporting people at the end of life. Much of this work would not be considered to be end-of-life care, and would constitute more general forms of community aid. Communities respond to the varied needs they are presented with and their input is not limited by professional boundaries. This has implications for training and risk management of community volunteer programmes. Attempting to limit the care communities provide to end-of-life care only could be problematic when communities are in control of the support they provide. This can and has led to a broadening of the understanding of the term palliative care or end-of-life care. In Kerala, India, the community provides a large component of palliative care services and, as the volunteers are answerable to the community, services respond to new needs presented. In some cases, communities have moved into community psychiatry or chronic renal disease, as these were the most pressing issues communities were faced with. In the words of one community volunteer, 'we are trained to diagnose

suffering, not diseases'.⁵³ Similarly, many of the broader problems facing communities with regard to the end of life are not remedied by supporting one family at a time. This work may act as a catalyst for individuals and community organisations to begin campaigning on other social platforms for social change. It is not possible to view end-of-life care issues as separate from other social issues facing communities, such as poverty, education and inequity.

Limitations

This review is based on the published literature relating to community action in end-of-life care. Clearly there are other health promotion outcomes and applications described in the *Ottawa Charter*,⁴ that might be assessed as part of public health approaches to end-of-life care – education, policy developments, re-orientation of service designs or development of personal skills. This review benchmarks the published literature available at this point on strengthening community action but recognises that assessing the other dimensions of health promotion will become possible as the field matures and expands. Furthermore, outcomes in health promotion interventions are known to impact on a wide range of anticipated and unanticipated stakeholders and over variable time periods. The articles in this study looked at pre-selected participants and over short time frames. There may be impacts felt beyond these participants and beyond these time periods that have not been collected. The inability to capture these potential impacts is acknowledged in this review, as is the prospect that future research will take this into account. The quality grading tool was selected to be applicable to the diverse methodologies represented in the selected papers, but may have limited generalisability by not using criteria specific to particular methodologies. Additionally, quality grading exercises are acknowledged to be exercises in grading the quality of reporting rather than the quality of the actual study carried out.

This review focused on impacts relating to community action in end-of-life care but the results spanned beyond this, into other pillars of the *Ottawa Charter*, such as the development of personal skills, building healthy public policy and reorient health services. It is therefore conceivable that impacts relating to community action may be found following interventions under the other pillars and these have been missed by the specific focus of this review.

Conclusion

Issues of social isolation, carer support, personal and community capacity and wellbeing increasingly feature in policy documents for end-of-life care. This review shows that work that engages communities can meet these goals, and that the positive impact can be demonstrated, even at

this early stage of development. This has important implications for policy makers, practitioners and researchers, first that such initiatives can deliver on these complex goals and second that it is possible to measure and capture the impact. This should comprise an integral component of this work going forward.

Declaration of conflicting interests

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Appendix I*MEDLINE search strategy (1966–March 2015)*

(Public Health exp. OR Health Promotion exp. OR Social Change exp. OR Social Support exp. OR new public health.mp. OR community development.mp. OR community participation.mp. OR community engagement.mp. OR compassionate communit\$.mp. OR social network.mp.)

AND

(Palliative Care exp. OR Terminal Care exp. OR Hospices exp. OR end-of-life care.mp. OR incurable.mp.)

AND

(impact.mp. OR measure\$.m_title OR outcome\$.m_title OR evaluat\$.m_title)