

ResearchSummary

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Care provided by generalists at the end of life: scoping exercise on research priorities

The care that most people receive at the end of their lives is provided by generalists such as GPs, district nurses, hospital consultants and staff, nursing home staff and other health and social care professionals. Only around half of those people with cancer, and a minority of those with diseases other than cancer, receive care from specialists in palliative care. But we know much less about the end of life care provided by generalists than we do about specialist care.

To improve our understanding of generalist care, we first need to establish what is known already and where there are gaps in our knowledge. This research summary presents an overview of the findings from a scoping exercise (a literature review and a consultation exercise) to identify the current evidence base and priorities for further research. The project was commissioned by the National Institute for Health Research Service Delivery and Organisation Programme and led by Professor Irene Higginson at King's College London.

These findings are of relevance to all those with an interest in care at the end of life, including care professionals, managers in health and social care, researchers, patients, carers and the public.

Key findings

- Generalist end of life care is care provided by many different practitioners who are not specialists in palliative care.
 - The scope of generalist and specialist care is a matter for debate and variations in practice are evident. Definitions of 'end of life' care also vary, sometimes incorporating palliative care and sometimes referring just to the last few days of life.
 - The limited research in this area has tended to describe existing services or needs, rather than to evaluate models of care or to examine health economic effects.
 - Stakeholders are keen to see more research on models of care and place of care.
- Recommended priority areas for future research are:
 - defining and evaluating models of collaborative working in primary and secondary care
 - defining and evaluating models of out-of-hours provision
 - reviewing place of care and place of death for people dying from non-malignant disease
 - defining and evaluating models of care provided in different hospital settings.
 - Research in each of these priority areas should include, in all settings, information on the:
 - patient and carer experience
 - resource and health economic effects and implications.

Background

Most care at the end of life is provided by generalist health and social services, such as GPs, district nurses, hospital doctors and social care staff. In comparison to the knowledge base on hospices and specialist palliative care services, there are more unanswered questions and gaps in our knowledge about how generalist services are defined, how they work best and how they operate alongside specialist services. This knowledge gap is recognised by practitioners, who are eager for more research into this important area. This study (Gysels, 2007; Higginson, 2007; Shipman, 2007) takes the first step towards filling these gaps, by scoping out the priorities for future research for generalist services for adults at the end of life.

The policy and practice context

Until recently, policy on end of life care has tended to focus on specialist palliative care, for example as set out in the NHS Cancer Plan (Department of Health, 2000). The focus began to shift towards generalist settings with the introduction of the Patient Choice initiative (Department of Health, 2003) and was reinforced by the White Paper *Our health, our care, our say* (Department of Health, 2006), which envisaged more health care in the community and support for patients to die in their place of choice. It discussed end of life care networks, rapid response teams (hospice at home services) and the dissemination of tools to support generalists in their work with the dying. This policy was supported by the introduction of an End of Life Care Programme in 2004. Also in 2004, the National Institute for Clinical Excellence published guidance on supportive and palliative care for patients with cancer in England and Wales. This formed a major part of the development of the supportive and palliative care strategy announced in the NHS Cancer Plan. In Scotland, currently, there is no one single strategy for end of life care. However a working group has recommended a cohesive national approach to the Scottish Executive (Scottish Partnership for Palliative Care, 2007).

The practical application of these policies is variable as all programmes are locally-driven. Three tools have been recommended by the Government to improve the quality of end of life care in generalist settings and these are currently being adopted in many areas:

- the Gold Standards Framework to improve palliative care provided by primary care teams
- the Liverpool Care Pathway to improve care at the very end of life
- the Preferred Place of Care Plan (now known as the Preferred Priorities of Care plan), an advanced care plan.

The inclusion of a small number of additional QOF (quality and outcomes framework) palliative care points in the new GP contract reflects the rising priority the NHS is giving to palliative care in a generalist setting.

Practical findings



What is generalist end of life care?

Generalist end of life care is a broad and diffuse concept. It gained in importance as a result of the establishment of the End of Life Care Programme, but there is not a common understanding of what the term stands for. It is often defined in terms of what it is not, as the type of palliative care not provided by specialist teams, which opens up a very wide field of enquiry.

People have different understandings both of the term 'generalist' and of the term 'end of life'. Some identified generalists as working in primary care. Others defined them as any practitioner (in primary, secondary, tertiary or social care) working with the dying who is not a specialist in palliative care. Some people see end of life care as akin to terminal care, provided within the last few days or weeks of life. Others described it as the care provided when it is clear that a patient is going to die, interchangeable with palliative care, though this may be a much longer period than the last few days or weeks of life.

In this study, generalist end of life care is defined as:

'Care provided within the last year(s) of life to anyone with advanced progressive disease likely to end in death, by practitioners not exclusively concerned with specialist palliative care.'

Limitations of existing research

A scoping exercise of the literature found a vast and complex area of research covering a disparate range of topics, reflecting the broad and diffuse concept of generalist end of life care. Studies tended to describe what was happening in existing services and practice, rather than identifying how things could be done better, or testing new approaches to find out which is most effective.

The largest group of studies looked at the role of the various health professionals involved in generalist end of life care. The data collected were mainly about service delivery and organisational issues. Where studies focused on people's views and experiences, the data were mainly gathered from health professionals, with a smaller number from patients and very few from carers. Many of the studies focused on cancer patients and there was a distinct lack of evidence on issues such as mental health at the end of life, or end of life care for people from ethnic minorities, people with dementia or the prison population. There is currently little evidence on aspects of service delivery that underpin Government policy – for example end of life care in nursing and residential homes. The economics of end of life care – for example costs, resources and funding priorities – are also under-explored.

The research mainly included quantitative studies concentrated at the lower end of the hierarchy of evidence. They tended to be based on small scale survey methods to deliver exploratory and pilot work rather than the more thorough or novel research designs which are needed either to provide empirically grounded and ethically sound work or to evaluate interventions and their translation into practice.

Defining 'effective' end of life care

There are difficulties in measuring effectiveness in end of life care. Prognostic indicators that can suggest when supportive and palliative care should start are problematic to identify. Setting outcome measures is similarly challenging, since the natural trajectory in palliative care is for patient symptoms and quality of life to worsen as death approaches. Appropriate outcomes might focus on symptom control and the necessary interventions to achieve them.

There are concerns that end of life care cannot be improved without an increase in expenditure. Little is known about cost effectiveness and more work needs to be done to look at the relative costs of end of life care provided by generalists and specialists, including how to define appropriate and inappropriate admissions. Cost considerations may be in tension with considerations about the most appropriate way to provide care. There are concerns among some stakeholders that current funding developments such as practice-based commissioning and payment by results threaten end of life care. For example, would generalists be deterred from seeking advice from specialist palliative care teams if additional charges have to be made for these services?

Defining 'appropriate access' to end of life care

Identifying and defining the end of life can be particularly difficult in cases of non-malignant disease, for example heart failure, dementia and COPD (chronic bronchitis or emphysema). However even if an end of life 'phase' could be clearly defined for such conditions, there is little funding available for such patients in comparison to those with cancer. For example, they have difficulty in accessing grants to fund night sitting services and other forms of support at home.

There are a number of access issues facing people from ethnic minority groups. For those without English as their first language, access to support at the right time and in the right place can be difficult to secure, even where interpreting services are available. Some ethnic minority groups hold different cultural attitudes to death and dying and it may be difficult for people to talk about the situation and discuss potential sources of support. Not all generalists (or specialists) are aware of such cultural issues and how to deal with them.

Access to end of life care services also appears to be harder for frail older people – particularly those who want to remain at home – and for those in remote geographical locations. There are examples in the Scottish islands of services being adapted to accommodate these local requirements, e.g. GPs still providing 24-hour cover, end of life 'care boxes' being held locally, and video conferencing facilities being available to compensate for lack of face-to-face contact.

Recommendations for future research

Stakeholders proposed research into a wide range of areas, reflecting a sense that much needs to be done to establish effective models for providing generalist end of life care.

The six most popular categories were analysed in more depth and from this a list of research priorities arising from the stakeholder consultation events was generated:

1. Research into models of care: defining, evaluating and testing different forms of organisation of service provision for out of hours care; different generalist models; services for non-cancer patients and older people; and access to care and inequalities in provision.
2. Research that includes the patient and carer experience.
3. Research to understand more about factors affecting place of care and death, about the experience of dying, resource, support and care needs within the home; hospital; and care homes.
4. Research that includes the resource and health economic implications.

Ethical and methodological challenges

Carrying out research on appropriate care for the dying presents a number of ethical challenges. A key concern among stakeholders is the difficulty of engaging with users at such a vulnerable time, and identifying an appropriate time to speak to patients and relatives, particularly as not everyone wants to talk about death. Researchers also have to consider the patient's capacity to make decisions and be involved in research activity when very ill. Patient confidentiality presents challenges, as does participation in double blind trials.

There are also a range of methodological challenges. For example, 'gate keeping' by professional staff is understandable but can make it difficult to gather the views of patients and carers. Defining appropriate outcomes for achieving 'a good death' is also problematic. It is important to establish appropriate research methodologies in such a complex area. To test different models of intervention, a mixed methods approach appears to be the most valuable, since qualitative designs can provide rich information about processes and contextual issues, complementing quantitative evaluations of outcomes.



Conclusions

The main aim of the scoping exercise was to understand the existing knowledge base and the priorities of stakeholders with regard to generalist end of life care, in order to recommend key areas for future research. There was considerable enthusiasm from all participants in the consultation exercise and a recognition that this is a vital area of health and social care. Future research and development in priority areas will help to ensure the development of more effective care in this important field.

By comparing the top four themes identified in the consultation exercise with the results of the literature review and other ongoing research, the authors were able to conclude that the following areas are priorities for future research.

1. Defining and evaluating models of collaborative working in and between primary and secondary care. This would employ a systems approach to investigate different organisational forms (for example GPs and district nurses working collaboratively in the community) in the context of collaboration with specialist palliative care and social services. It should identify current forms of organisation, establish how well they work, identify best practice and the models which lead to optimum outcomes for patients from all disease groups, families and services, as well as factors leading to gaps in provision. In addition it should investigate and test the different service models from the perspective of patients and carers as well as health professionals and ideally consider costs to patients, carers and health and social care.

2. Defining and evaluating models of generalist out of hours care. This would employ a systems approach to assess how service configurations with a range of providers work in different geographical areas, identifying factors that lead to improved patient care including information transfer, appropriateness of response, availability of drugs, channels of communication between providers, role remits and collaborative working, as well as factors that prevent optimum care. It should test models of good practice and ensure that the experiences and preferences of patients and carers form a major component of the impact assessment and consider the costs of different models.

3. Delivering end of life care for those with non-malignant conditions. This would involve a systematic literature review on the place of care and place of death of people dying from non-malignant disease. It would identify factors affecting transitions of care as well as place of death.

4. Defining and evaluating models of care in different hospital settings. This would assess the impact of different forms of care, taking account of the additional impact of palliative care tools such as the Liverpool Care Pathway. It would be important to undertake this research from both patient/carer and professional perspectives and focus particularly on the experience of patients dying from non-malignant disease. It would also be important to undertake additional research on how preferences are formed and develop over time.

5. Cross cutting themes

There are two important themes which feature in all four of the above topics and the authors recommended that these should be explored further as cross-cutting themes.

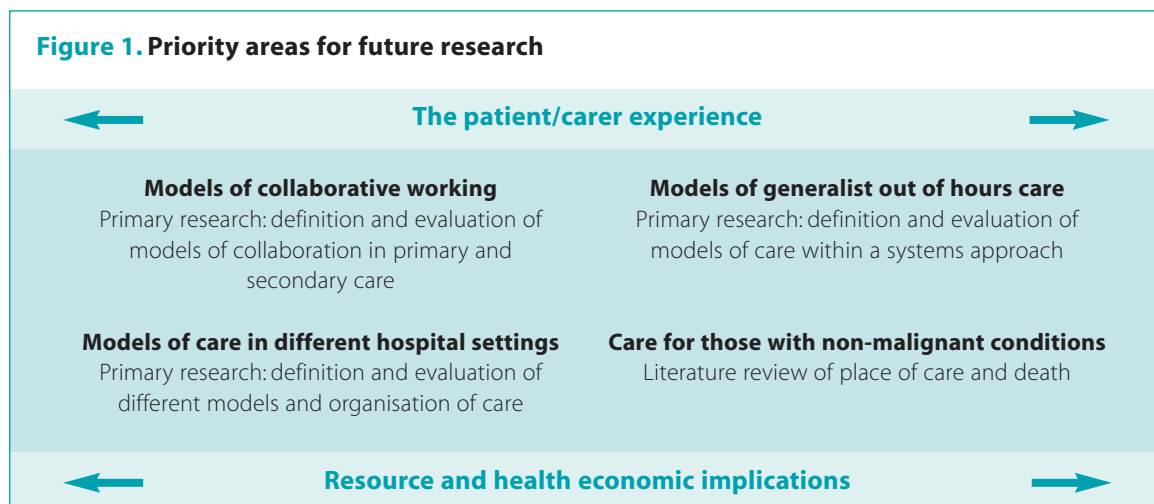
i) Patient and carer experience: This would become a prominent cross-cutting theme across models of service provision and place of care. Further research into interventions to support caregivers more effectively would also be helpful.

ii) Resource and health economic implications: This is an under-researched area and was an important priority for participants in the consultation. It would therefore be helpful to include it as a second cross-cutting theme, linked to service provision and models of care. However there are huge unanswered questions that might suggest this should comprise a further, separate recommendation, for example identifying the real resource and financial costs of care at home, in hospital and in care homes (to patients as well as professionals) as well as the effect of current economic policy on patient care (for example practice-based commissioning and payment by results).

The literature review highlighted that generalist end of life care is a complex area for research which benefits from a mixed method approach. The Medical Research Council's framework for the design and evaluation of complex interventions is particularly suitable for research into generalist end of life care. It spans a number of phases from initial modelling, through to preliminary evaluation and then testing the intervention in a randomised control trial. Sometimes such trials may be inappropriate in end of life research because of practical or ethical obstacles. In these instances, well designed observational methods would be valuable alternatives.



Figure 1 summarises these research recommendations.



About the study

The study aimed to map what is known from existing studies and consult with relevant practitioners to identify the priorities for future research for generalist services for adults at the end of life. The specific research questions were:

- What is meant and understood by generalist services for people at the end of life and what is current policy?
- What is the existing knowledge base and policy context?
- What are the methodological and ethical issues involved?
- What are the views of national and local stakeholders (including statutory and voluntary organisations and users) about current policy and the most pressing research questions concerning the delivery and organisation of generalist services for end of life care?
- What are the gaps and future priorities for research, taking into account existing knowledge, current and planned research, and the priority areas raised by stakeholders?

The study comprised two elements:

1. A literature review of recent publications and reviews. This included an assessment of the number and type of studies and a consideration of the key themes.
2. A consultation exercise with stakeholders from London, Cambridgeshire, Warwickshire and Scotland and from key English national organisations. A modified form of the nominal group technique was used to identify the range of views and develop a broad consensus on key priorities for future research.

The priority research themes from the consultation were compared with the results of the literature review and four broad research themes were developed.

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Further information

The full report, this research summary and details of current SDO research in the field can be downloaded at: www.sdo.lshtm.ac.uk

For further information about anything included in the report, please contact lead researcher Irene Higginson in the Department of Palliative Care, Policy & Rehabilitation at Kings College London (irene.higginson@kcl.ac.uk).

Feedback

The SDO Programme welcomes your feedback on this research summary. To tell us your views, please complete our online survey, available at: www.sdo.lshtm.ac.uk/researchsummaries.html

About the SDO Programme

The Service Delivery and Organisation Programme (SDO) is part of the National Institute for Health Research (NIHR). The NIHR SDO Programme is funded by the Department of Health.

The NIHR SDO Programme improves health outcomes for people by:

- commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care; and
- building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

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