Supporting lay carers in end of life care: current gaps and future priorities
G Grande, K Stajduhar, S Aoun, C Toye, L Funk, J Addington-Hall, S Payne and C Todd
Palliat Med 2009 23: 339 originally published online 20 March 2009
DOI: 10.1177/0269216309104875

The online version of this article can be found at:
http://pmj.sagepub.com/content/23/4/339

Published by:
PALLIATIVE MEDICINE
http://www.sagepublications.com

Additional services and information for Palliative Medicine can be found at:

Email Alerts: http://pmj.sagepub.com/cgi/alerts

Subscriptions: http://pmj.sagepub.com/subscriptions

Reprints: http://www.sagepub.com/journalsReprints.nav

Permissions: http://www.sagepub.com/journalsPermissions.nav

Citations: http://pmj.sagepub.com/content/23/4/339.refs.html
Supporting lay carers in end of life care: current gaps and future priorities

G Grande School of Nursing, Midwifery & Social Work, University of Manchester, Manchester, K Stajduhar School of Nursing and Centre on Aging, University of Victoria, Centre on Aging, Victoria, British Columbia, S Aoun Western Australian Centre for Cancer and Palliative Care, Curtin University of Technology, Faculty of Health Sciences, Perth, Western Australia, C Toye School of Nursing and Midwifery, Curtin University of Technology, Bentley, Western Australia, L Funk Centre on Aging, University of Victoria, Victoria, British Columbia, J Addington-Hall School of Nursing & Midwifery, University of Southampton, Southampton, S Payne International Observatory on End of Life Care, University of Lancaster, Lancaster; Institute for Health Research, Lancaster University, Lancaster and C Todd School of Nursing, Midwifery & Social Work, University of Manchester, Manchester

Informal carers are central to the achievement of end of life care and death at home and to policy aims of enabling patient choice towards end of life. They provide a substantial, yet hidden contribution to our economy. This entails considerable personal cost to carers, and it is recognised that their needs should be assessed and addressed. However, we lack good research evidence on how best to do this. The present position paper gives an overview of the current state of carer research, its gaps and weaknesses, and outlines future priorities. It draws on a comprehensive review of the carer literature and a consensus meeting by experts in the field. Carers’ needs and adverse effects of caregiving have been extensively researched. In contrast, we lack both empirical longitudinal research and conceptual models to establish how adverse effects may be prevented through appropriate support. A reactive, “repair” approach predominates. Evaluations of existing interventions provide limited information, due to limited rigour in design and the wide variety in types of intervention evaluated. Further research is required into the particular challenges that the dual role of carers as both clients and providers pose for intervention design, suggesting a need for future emphasis on positive aspects of caregiving and empowerment. We require more longitudinal research and user involvement to aid development of interventions and more experimental and quasi-experimental research to evaluate them, with better utilisation of the natural experiments afforded by intra- and international differences in service provision. Palliative Medicine (2009); 23: 339–344

Key words: family carers; review; research methods; palliative care

Introduction

Carers are defined as ‘lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management’.1 Their contribution is crucial to both patients and society. The achievement of end of life care (EOLC) and death at home heavily depends on their ability and willingness to provide care,2,3 and policy aims to enable patient choice towards end of life4 become unrealistic without their input. It is furthermore estimated that in the United Kingdom, the overall value of their care is greater than the cost of the National Health Service and four times that of social care services, and if even a small proportion were to give up caregiving through ill health, the economic impact would be substantial.5 Similar contributions to the economy are reported elsewhere in the developed world.6,7 The relative value of carers’ contribution becomes even higher towards the end of life7,8 with an estimated 500,000 people providing such care in the United Kingdom.9 However, caregiving entails considerable cost for primary carers and the wider family, including emotional, social, financial and physical cost, and even increased mortality.10,11 This burden is likely to increase as in the future there will be fewer carers and more dying people with complex care needs.12 Although caregiving at end of life is often rewarding and willingly undertaken,13,14 we do need to recognise both its burdens to carers and its value to society and support carers in this...
important task. Accordingly, it is increasingly recognised that carers’ needs must be assessed and addressed.\textsuperscript{1,4} However, although we know a lot about carers’ needs, we lack good evidence on how these should best be addressed.\textsuperscript{15}

The aim of this article is to identify what is required to improve the evidence and aid the development of effective interventions to support carers in EOLC. It considers current evidence on carer needs, adverse effects of caregiving and interventions to address these; the gaps and weaknesses in the evidence; and how to improve the evidence base and interventions in the future. It draws on a comprehensive review of the carer literature performed for an international, three-day meeting between the authors to assess the current state of carer research. The participants’ combined expertise encompasses family care, aging, and palliative care research. During the meeting, research gaps and future priorities were debated and agreed on the basis of the review and the authors’ combined experience of the field. An outline of the contents of this article has previously been presented by the first author to a Department of Health workshop to inform the End of Life Care Strategy for England.\textsuperscript{4} This article outlines what is already known, existing gaps and problems, and the steps required to develop appropriate and effective support for carers.

**Needs and adverse effects from caregiving**

There has already been considerable research identifying carers’ needs in EOLC. These include psychological support, information, help with personal, nursing and medical care of the patient, out of hours and night support, respite, domestic and financial help.\textsuperscript{9,10,16–21} There is also a large body of research into adverse effects of caregiving, such as anxiety, depression, stress, strain, fatigue and mortality.\textsuperscript{22–24}

Given this strong evidence base, any further investigation into the prevalence of needs and adverse effects should mainly focus on under-researched groups to ensure that future interventions are sensitive to their specific concerns. This includes carers of patients with conditions other than cancer, including neurodegenerative disorders,\textsuperscript{25} respiratory\textsuperscript{26} and cardiovascular diseases,\textsuperscript{27} to help us understand how differences in disease trajectories, awareness of the terminal nature of the disease and available support\textsuperscript{28} translate into different carer experiences. Although carers of patients with dementia have been extensively researched, little is known about their needs during patients’ final phase of life.\textsuperscript{9}

More research is also required into the concerns and context of carers from ethnic minorities,\textsuperscript{23,29} including specific communication needs and differences in social dynamics, traditional values\textsuperscript{18} and expression of grief in bereavement.\textsuperscript{24}

Furthermore, the needs of an increasing population of older carers need to be better understood. While younger carers (<60 years) report more distress and burden,\textsuperscript{22,23,30,31} older carers provide higher levels and longer hours of care,\textsuperscript{32,33} have fewer social,\textsuperscript{34} economic\textsuperscript{35} and specialist palliative care resources to cope\textsuperscript{36}; and suffer more serious health conditions\textsuperscript{32–34} and worse long-term bereavement outcomes.\textsuperscript{37–39} Investigation is required to disentangle the effects of age per se versus generational or relationship effects (e.g., being a spouse versus adult child).

Finally, we need to understand the needs of male carers better. Men are less likely than women to express psychosocial concerns,\textsuperscript{40} but may suffer undisclosed strain\textsuperscript{41} and more problems in bereavement.\textsuperscript{24,38}

**Addressing needs and preventing adverse effects**

Research into carer needs and adverse effects to date gives service providers few pointers for how best to address needs and prevent adverse effects. Main problems include the method and focus of existing research.

Studies have mainly been cross sectional, failing to uncover process and development over time. There is a lack of longitudinal studies\textsuperscript{5,40} to aid understanding of changes in needs over time, the precursors of increased need, appropriate timing of interventions and the consequences of a failure to meet needs. Similarly, the psychological literature on adverse outcomes\textsuperscript{22,23} and bereavement\textsuperscript{24} contains little prospective, longitudinal research to investigate how early factors that may be amenable to intervention predict outcome. Further longitudinal research is therefore needed.

To assist in this, development of consistent and validated tools for eliciting, assessing and monitoring carers’ ongoing needs is required. Although carer assessment, including local authority assessment, is built into the EOLC Strategy,\textsuperscript{4} there is demand for comprehensive, well-validated needs measures that can be used in ongoing, routine practice to monitor needs over time and service ability to meet those needs. Current carer assessment conducted as part of EOLC pathways and hospice practice relies largely on non-validated tools with little commonality in content and format (cf. review by Carers Assessment Working Group at Help the Hospices, UK). Conversely, the research literature offers evidence-based and validated measurement tools, but their content and length often render them unsuitable for routine practice assessment. We therefore require assessment tools that bridge this gap.
The primary focus of research into adverse effects has been the identification of people at risk who potentially need therapeutic intervention rather than how to support carers to limit adverse effects in the first place. That is, the focus has been on ‘repair’ rather than prevention. Identified predictors of adverse psychological and physical effects\(^{22,23}\) and poor bereavement\(^{24}\) reflect this; in that care demand, demographic, social or personality variables have primarily been investigated and identified as important (e.g., relationship with the deceased for bereavement). The preventive role of support provision has had little investigation. Although remedial action remains important, prevention would be the preferable option.

In parallel with the lack of empirical evidence, there has been a lack of theoretical and conceptual models for when and how support provision in EOLC should improve carer outcomes. To guide further research, palliative care may here benefit from drawing on models within other fields,\(^4\) such as gerontology,\(^42\) sociology\(^29\) or psychology.\(^43\)

### Evaluations of interventions

Evaluations of interventions should provide strong evidence for appropriate ways of supporting carers. However, lack of a firm empirical and conceptual base, combined with general challenges of palliative care research and inadequate rigour in design, has largely prevented us from designing effective interventions or demonstrating their impact.

The quality of evaluations has been limited\(^17\) with a lack of randomised controlled trials (RCTs) and a predominance of small sample sizes.\(^17\) Many evaluated interventions have not had a carer focus, carer specific outcomes and/or outcomes appropriate for the intervention; therefore, their likelihood of showing an impact on carers has been further reduced.\(^17,44\)

Correspondingly, there is only weak evidence so far that EOLC interventions lead to carer benefits, although there is moderate evidence that they increase carer satisfaction.\(^44\) While there is moderate evidence that interventions for carers of dementia patients improve carer outcome, these are often dementia specific (e.g., tackling behaviour problems and personality change).\(^44\) Although individual or group therapy interventions in bereavement have been found to yield some benefits,\(^24\) these interventions again represent a ‘repair’ rather than a preventive approach.

The evidence that does exist for preventive interventions relates to such a wide variety of interventions that comparison and pooling of results is difficult. Evaluated interventions encompass regular palliative care delivery (e.g., hospice at home), enhanced palliative care (e.g., improved coordination), consultations, facilitation, group-based support (e.g., stress management) or individual sessions (e.g., counselling, skill development).\(^17,44\) Lorenz, et al.\(^{44}\) suggest that common denominators for the more successful interventions may be that they are individual rather than group-based and are multi-component. However, as these trials normally lack consideration of the ‘active’ components of the intervention and its context,\(^45,46\) it is generally difficult to identify transferable principles and understand reasons behind successes or failures of given interventions.

### Challenges for research and interventions with carers

The general challenges of EOLC research are well known and documented.\(^47\) While for patients data collection and design of meaningful outcome measures are particularly difficult due to their inevitable deterioration and death, these challenges are somewhat reduced for carers, although both data collection and outcome measures still require sensitive design. However, challenges in defining the study sample are greater. We not only have the problem of defining the EOLC patient population but also of identifying their main carer(s). Each patient may have a network of carers, made more complex by changing family structures (including stepfamilies)\(^9\) and geographical dispersal.\(^12\) Also, people we may label as ‘carers’ may not define themselves as such. Therefore, more work on how we define, identify and recruit carers is required.

Furthermore, ensuring appropriate support for carers presents unique challenges due to their dual position as both support provider and recipient and the tension between these roles as seen by providers, family (including the patient) and carers themselves.\(^48\) Current policy advocates treating carers as ‘co-workers’.\(^4\) Although largely positive, this approach may inhibit carers from adopting the role of care recipients. Carers are also often strongly influenced by norms and expectations to provide care without due recognition of their own need.\(^13,40\) These norms are embedded in the social and cultural context, often reinforced further in interactions with the wider family and the patient and internalised by carers themselves. Such tensions highlight the importance of assessing carers’ needs separately from those of patients. However, we must also recognise how a wish to protect positive aspects of caregiving\(^14\) (e.g., as part of expression of love, coming to terms with impending loss, and gaining a sense of mastery) and to preserve a sense of normality in the face of disconcerting change\(^1\) may present complex barriers to accepting outside help and require sensitive
solutions for support. Further qualitative investigation is required to understand the potential tensions inherent in expression of needs and acceptance of help to aid the design of interventions appropriate to carers.

Summary
Improving future interventions
To design better interventions, we need to understand the needs of our specific target group and the processes of EOLC, including how needs and adverse effects evolve over time and how and when support will help, using longitudinal design and combining qualitative and quantitative approaches. We require conceptual models of how support may affect outcome to guide research and intervention development (see Figure 1).

We also need to understand the external and internal tensions inherent in the carer role to guide the design and introduction of interventions. Carers’ needs must be assessed separately from the patient, and help with intra-family negotiation and working with the whole system may be required. Support may be more acceptable to carers if it is designed to improve their ability to care and does not appear to divert attention away from patients.40,48 We may therefore need greater emphasis on proactive and preventive approaches that facilitate positive aspects of caregiving14 and focus on strengths, resources and skill building.9,21,40 This contrasts with a more reactive approach of crisis identification and subsequent intervention in the form of service takeover or therapy. Both approaches need to be available, but both need to be sensitive to carers’ specific concerns to improve uptake and effectiveness of interventions. This highlights the importance of user involvement in intervention development to ensure that we are indeed addressing what is important to carers in a manner acceptable to them.

Improving future research
In addition to existing, more comprehensive research tools, we need to develop reliable, valid and consistent measures suitable for use in routine practice to measure carer needs and outcomes. This should enable easier accrual of large quantitative data sets to complement in-depth qualitative research.

We must improve our ability to recruit carers into research, including improved definition and identification of the main carer(s) and understanding of the key roles played within the carer network. There is a small window of opportunity to recruit carers when they move into a caregiving role but are not overwhelmed by it.

Carer interventions are by nature complex, and we need to become more adept at applying the principles of the MRC Framework for evaluation of such interventions.45 That is, we need a better understanding of the intervention and its ‘active’ components, its context and client group to help us understand the main principles for successful carer interventions and their transferability. We need to optimise our evaluations of interventions through better design so that they give us the information required to truly assess the intervention’s value.

The reality of support provision means we must learn to capitalise more on the ‘natural experiments’ afforded to improve support for carers in end of life care.

Figure 1 Components required to improve support for carers in end of life care.
by area differences in service implementation and provision to enable systematic comparison and assessment. We often have neither time nor opportunity to design new interventions to be tested through traditional RCTs in line with the original MRC Framework.\(^{46}\) However, this does not prevent us from conducting evaluations in accord with its principles (see Campbell, et al.\(^{45}\) for recent update). This includes gaining an understanding of the context in which interventions operate; clear definition and understanding of the problem, that is, what precisely is the intervention supposed to address; understanding of the intervention, its components and potential barriers to their effectiveness; and optimisation of the evaluation, for example, selecting outcomes appropriate to the intervention. We also need to use opportunities offered by international collaboration to gain further insights from comparison of carer experience within different policy contexts between comparable nations.

**Acknowledgement**

The international meeting at which this article was developed was funded by the British Academy.

**References**


