

Caregiving for the terminally ill: at what cost?

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This literature review exposes the nature and extent of physical and psychosocial morbidity and economic disadvantage, home palliative caregivers suffer as a direct result of their caregiving role. Research has demonstrated that caregivers providing support to individuals receiving palliative care report unmet needs for information, communication, service provision and support from health and community services. Three sets of challenges are highlighted in this literature review which help explain why the needs of home palliative caregivers are largely unmet: (i) barriers to seeking help; (ii) a dearth of research-based interventions focused on reducing the negative aspects of caregiving; and (iii) a number of impediments to effective policy and service development for family caregivers. Furthermore, invited submissions from caregivers echoed and confirmed the issues reported in the literature. Recommendations for enhancing caregiver support are outlined. *Palliative Medicine* 2005; **19**: 551–555

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Introduction and objectives

Many individuals are finding themselves becoming the primary care providers for ill and disabled family members. Primary caregivers are defined as people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care.¹ We live longer, but with compromising medical conditions and increased costs of health care. Consequently, families are increasingly replacing skilled health workers in the delivery of unfamiliar complex care. The caregiver role has changed dramatically from promoting convalescence to providing high technology care and psychological support in the home.²

Palliative care is the specialized health care of dying people, which aims to maximize quality of life and assist family and caregivers during and after the death of a loved one.³ Although approximately one-third of all patients receiving palliative care services die at home, studies in Australia and the UK reported that up to 90% of terminally ill patients spend the majority of their last year of life at home.^{4,5} Thus, home palliative care would be impossible for many people without the support of caregivers.⁶

The demand for palliative care services within the home has increased due to the reduced availability of hospital beds, a desire for less institutionalized care and an aging population where the morbidity and mortality associated with illnesses such as cardiovascular disease, cancer and respiratory disease increase with age.⁷ Some 50–70% of terminally ill patients may prefer to die at home in the comfort of familiar surroundings.⁸ The preference for a home death is compatible with government's objective to shift health care away from public institutions and into the community, particularly when there is compelling evidence to indicate that public spending on care is reduced when care is shifted to the community.⁹ Yet there is considerable evidence in the literature that the burden of caregiving is adversely affecting family caregivers who lack adequate resources or who are insufficiently prepared for this new complex role.^{2,10–12}

This literature review was undertaken as a background:

- to inform an Australian National Inquiry into the plight of carers of the latest national and international challenges and unmet needs and
- to consequently help influence policy and practice related to support caregivers.

Thus, this literature review describes the nature and extent of the impact of caregiving on the physical, psychosocial and economic aspects of life of palliative caregivers, highlights their needs and identifies existing challenges in enhancing the knowledge, skills and

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support of caregivers. Further to this, through its National Inquiry into the Social Impact of Caregiving for Terminally Ill People, Palliative Care Australia (PCA) invited public submissions from individual caregivers, support organizations and service providers to complement this review.¹³ The experiences of the caregivers who participated in this public submission process are briefly described towards the end of this article.

The impact of caregiving

Research related to the demands of caregiving was primarily based on studies of caregivers of cancer and palliative care patients. Although this literature review is not exhaustive of all studies addressing the impact of caregiving, the issues covered are representative of those addressed in the national and international literature over the last ten years, in cancer and palliative care, particularly in Australia, Canada, the USA and the UK.

Sources of stress include uncertainty about treatment, lack of knowledge about patient care, role changes within the family, lack of transportation for treatment, strained financial resources, physical restrictions, lack of social support and fears of being alone.^{14–16} Disruptions and emotional strains associated with caregiving are common experiences for families of people with cancer. Feelings of tiredness, difficulty getting enough sleep and feelings of resentment and isolation were the most commonly reported disruptions and emotional strains and among the most difficult coping challenges.^{11,15,17–19} Caregivers suffered from lack of control over everyday life, lack of self-confidence, changes in paid employment, reduction in leisure time, deterioration in their own health, exacerbation of a previous health problem, postponement of their own health care and feelings of distress.^{18,20,21} Providing care to a patient with a terminal illness may require the caregiver to adapt to altered family circumstances such as moving location, reducing or ceasing paid employment or modifying the home, all of which potentially impacts upon the health and well-being of the caregiver.^{22,23}

Ramirez *et al.*,²⁴ reported that, in the year before the death of a cancer patient, the prevalence of anxiety among informal palliative caregivers was as high as 46% and the prevalence of depression as high as 39%. Approximately half of caregivers reported problems sleeping and about one-third reported weight loss during that year. Caregivers' anxiety was rated alongside patients' symptoms as the most severe problem by both patients and families.

Schulz and Beach,²⁵ identified that older spousal caregivers who experience stress from caregiving were 63% more likely to experience early mortality than non-caregivers. The relationship between caregiving and

mortality was tested in the Caregiver Health Effects Study using approximately 400 spousal caregivers and 400 matched controls aged 66–96 years. A combination of loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems leading to increased mortality. Christakis and Iwashyna,²⁶ conducted a matched retrospective cohort study involving a population-based sample of elderly couples in the USA. A total of 30 838 couples where the decedent used hospice care were matched to the same number of couples where the decedent did not use hospice care. They found that if the decedent was the recipient of hospice terminal care, their surviving spouse was less likely to fall ill and die during bereavement.

Research findings from the US indicate that many caregivers of terminally-ill patients with moderate or high care needs reported spending 10% of their household income on health care costs, that they or their families had to sell assets, take out a loan or mortgage or obtain an additional job to meet health care costs.²⁷ The economic impact of day-to-day family involvement in living with cancer can be profound, especially due to the unavailability of support services in many geographic areas.² Findings from the few cost-estimate studies indicate that families find themselves responsible for purchasing medications and home care supplies, for renting equipment and for paying for transportation and respite services.²⁸

Unmet needs

Although the negative impact of caregiving for a relative/friend with a life threatening illness has been well documented, research has demonstrated that caregivers providing support to individuals receiving palliative care report unmet needs for information, communication, service provision and support from health and community services.

Four types of family care needs are consistently reported in the palliative care literature: patient comfort, information needs, practical care needs and emotional support.¹² Caregivers desire information on how to provide practical care for a patient, how to ease a patient's discomfort, what to expect in terms of both the patient's and the caregiver's emotional responses to the terminal illness, where and how to acquire practical aids like walking frames, wheelchairs, hospital beds and so on. The provision of information is therefore recognized as a central form of support for a caregiver.²⁹

Another consistent theme in the family-needs literature is the importance of effective communication between health professionals and families.¹² Family members need

to feel confident that the patient's comfort, needs and perceptions of symptoms are attended to, requiring liberal amounts of information about the disease and treatment, provided in a way that they can process and at a pace that is comfortable to them. Caregivers also benefit from information about diagnosis, prognosis, treatment options and expected course of recovery to help lessen their fears and increase their sense of predictability.

The current provision of services for informal caregivers has been described as 'crisis intervention', as it is only in crisis situations of imminent or apparent breakdown that services respond.³⁰ Those caregivers who appear to be coping in their role and do not request services are assumed to have minimal unmet support needs.

In a randomized controlled trial to assess the efficacy of a psycho-educational intervention for primary caregivers of cancer patients dying at home, some primary caregivers reported that the most challenging aspects of their role related to inadequate health professional support.³¹ Approximately one-quarter of caregivers were disturbed by poor continuity, inadequate information, limited respite, lack of symptom management education and health professional role related issues. This research also identified that most caregivers, if given the opportunity, were willing to talk about issues specific to their needs and concerns, thus emphasizing the importance of more structured approaches to family care. Caregivers are often reluctant to disclose their needs to health professionals. Reasons for non-disclosure include not wanting to put their needs for care before those of the patient, not wanting to be judged inadequate as a caregiver, and believing that concerns and distress are inevitable and cannot be improved.²⁴

Payne and Ehrlich,³³ investigated three types of barriers that lead to caregiver reluctance in seeking help: information-, service- and value-based. Lack of information about the availability of services, including respite services, is the most common reason for non-use of needed services. Service-based barriers include lack of flexibility in service delivery. Value-based barriers involve caregiver guilt and commonly held beliefs and misconceptions – caregivers may be reluctant to relinquish the caregiving role to others and may experience a level of guilt in leaving their care recipients to seek support for their own needs. In palliative care, Hudson *et al.*,³² identified three types of barriers to seeking support that present challenges to health professionals: communication process barriers, health system barriers and family-related challenges. Therefore, it is important to identify barriers that may confront health care professionals providing supportive family care.

Gaps in research and policy

A substantial number of studies have identified the caregivers unmet needs and prevalence of psychological morbidity amongst caregivers, but the development and evaluation of research-based interventions focused on reducing the negative aspects of caregiving has been neglected.^{2,11,30,34} One reason for this lack of intervention research may be related to the fact that palliative care research is fraught with a number of methodological difficulties, such as recruiting patients, high attrition rates, rapidly changing clinical situations making stability of research conditions difficult, ethical dilemmas associated with research participation and gate-keeping behaviours exercised by professionals (i.e., reluctance to contribute patients for research studies).^{30,35,36} Despite these challenges, the scoping study in palliative care research,³⁵ has called for researchers to develop methodological approaches that capture the complexities of patient and family needs in palliative care and determine the best means of meeting these needs.

Harding and Higginson,³⁰ lamented the lack of outcome evaluations in the caregiving population and lack of evidence to ensure cost-effective allocation of resources. The authors argued that, in light of the methodological and ethical issues of randomized clinical trials (RCTs) of caregiver interventions in cancer and palliative care, other designs should be considered. Although RCTs have their place when possible,³⁷ quasi-experimental evaluation methods may offer more feasible research protocols that can be successfully implemented. The authors recommended that caregivers' interventions be feasible, acceptable (in a useful and appropriate format for caregivers) and accessible to caregivers.³⁰

A wide array of policies have ignored the needs of caregivers, including the taxation and social security income benefit structure, as well as employment and labour market policy relating to women and care.^{38,39} This has occurred due to the perception of caregivers by public service agencies as free resources available to care for people with disabilities, the ill and frail elderly. Policy developments have resulted in the marginalisation of caregivers in the social welfare system.³⁸

Part of the problem is that caregivers are still in an ambiguous position both conceptually and practically in relation to social policy and service provision.⁴⁰ They can be seen as holding a unique position of both providing and needing support, and it has been suggested that it is sometimes unclear who is the 'patient'.³⁰ On the one hand, caregivers are regarded as providers within the network of care, on the other, when practical assistance is needed to protect their health and wellbeing, they are regarded as service users and are dependent on means-tested, rationed services.⁴¹

There is a need for more flexible employment arrangements to reduce work conflict and give caregivers, particularly women, more options in combining paid employment and caregiving. The Caregivers Association of Australia,⁴² has recommended developing education programs for employers and employees and amending awards and conditions where necessary to make work places more caregiver-friendly. Similar results have already been achieved in the USA,² and Canada.⁴³ At a general community level, education is needed to promote the social value of caregiving and an awareness of the demands and impact of the caregiving role.^{39,42}

The experience of caregivers

This account is based on submissions received from 20 individual caregivers, six volunteers in palliative care and 23 service providers, describing caregivers' experiences and unmet needs. The majority of caregivers who responded were female, either wives or daughters, caregiving for husbands or parents with mainly cancer (lung, prostate, renal, leukaemia, brain tumour) or dementia. Two males were caregiving for their wives who had Motor Neuron Disease (MND). Service providers came from a wide cross-section of services and support organizations such as cancer councils, caregivers associations, palliative care services, hospices, government departments, nursing and medical professional bodies.

The submissions echoed and confirmed the issues reported in the literature. Caregivers who were fortunate to have received comprehensive and co-ordinated health professional support felt positive about their caregiving experience as exemplified by the following caregiver:

it was a beautiful experience, and one that I will value and cherish always.

A number of caregivers went on to train as volunteers for palliative care 'to repay some of the commitment shown to them'. Those less fortunate carried their caregiving tasks at the expense of their physical, emotional and financial wellbeing and as one caregiver put it:

it is an experience I wouldn't wish on my worst enemy.

Therefore, the availability, quality, responsiveness and cost of support from health and community services have implications on caregivers' health and wellbeing.

Discussion and conclusion

Studies have reported that caregivers have significant unmet needs related to their caregiving role despite the significant, yet often invisible, contribution that caregivers make to society and the economy. Caregivers, in general, contribute more than \$20 billion to the

Australian economy, and the unpaid workforce is estimated to be about five times the paid workforce, in terms of full-time equivalents.⁴⁴ Similarly, in the UK, the current value of the support given by caregivers has been estimated to be around the same level as the total UK spending on health, about £57 billion in 2001–2002. The number of caregivers with heavy caring commitments is over one million, a figure similar to the number of those employed by the National Health Service in England and Wales.⁴⁵ Therefore, more work is required to ensure that caregivers' needs are fully identified and met and gaps in assistance and support are addressed.

Evidence from the literature reinforced the importance of reducing the barriers to meeting the unmet needs of caregivers. Also the evidence that emerged from the submissions gave extra weight and 'voice' to the literature review. Research priorities in intervention development need to focus on reducing the negative aspects of caregiving and provide the evidence for cost-effective allocation of resources. There is a need for improved government policies and programs encouraging employers to allow some flexibility around balancing caregiving responsibilities with the need to earn an income. Thus, increased assistance to caregivers would ensure that they have the knowledge, skills, income security, job protection and other supports to provide care while maintaining their own health and well-being throughout the dying and grieving process. This is particularly important, as caregivers are increasingly replacing skilled health workers in the delivery of unfamiliar complex care for terminally ill people.

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