THE CARER EXPERIENCE IN END-OF-LIFE CANCER CAREGIVING: A DISCUSSION OF THE LITERATURE

Anne M Wilkinson
Chair in Palliative and Supportive Care, Cancer Council Western Australia (WA); WA Centre for Cancer and Palliative Care, Edith Cowan University.
Email: anne.wilkinson@ecu.edu.au

Abstract

Research into the experience of unpaid caregiving has been growing since the 1980s with the introduction of ‘community care’ policies in Australia and in other Western societies. There is now a large body of research that sheds light on various aspects of the experience of cancer end-of-life caregiving. The aim of this article is to explore what is known about the roles, needs, adverse impacts and concerns of family caregivers providing care to advanced cancer patients at the end of life. Reviewed literature, published between 1990 and 2010, focused on end-of-life cancer caring in the home, but includes in-patient palliative care interventions. Where relevant, general end-of-life caregiving literature to supplement the cancer specific research is included. Five major dimensions of the end-of-life cancer carer experience are identified: the end-of-life cancer carer role, impact of end-of-life caregiving; positive aspects of caregiving; carer perceptions of need; and access to palliative care.

In 2004-5 (the latest year for which we have national data), 2% of the Australian population, or about 390,000 people, reported that they currently had cancer and 87% reported that their cancer was malignant.1 Moreover, cancer was the cause of over 40,000 deaths in 2007, or just over 29% of all deaths in Australia.1 The most common cancers in Australia (excluding non-melanoma skin cancer) are prostate, colorectal (large bowel), breast, melanoma and lung cancer.2 Although cancer incidence increases with age, improvement in cancer survival rates has meant that people are living with the disease longer and receiving successful outpatient treatment. Nevertheless, despite advances in the early detection and treatment of cancer, half of all cancer patients either present with, or eventually develop, incurable metastatic disease.3

Carers are essential for ensuring treatment compliance, continuity of care, social support and assisting the healthcare system in achieving the patient’s treatment goals. It has been estimated that the annual replacement value of the vital role carers play in caring for family or friends is over $30.5 billion annually.4 A survey of family carers found that almost 2.6 million people, or 13% of Australians living in households, provided some assistance to those who needed help because of disability or age. About one in five carers, or 474,600, self-identified as the primary carer, that is, someone who provided the majority of informal help to a person with a disability. Just over half (54%) of all carers were women, but women were more likely (71%) to be the primary carer. Most primary carers (78%) cared for a person living in the same household. Twenty-four per cent of primary carers were aged 65 years and over, compared to 13% of the total population.5 Nearly two million of these carers were of workforce age, but many have had to leave the workforce, reduce the hours they work, or work below their skill capacity because of their caring responsibility. In addition, one million, or 39% of carers were simultaneously caring for children, partners and/or ageing parents.2 On average, carers were found to spend around 40 hours a week providing care.6

End-of-life cancer carer role

The increased use of outpatient services for cancer treatment, shortened hospital stays, longer survival and the trend to accommodate patients’ desire to be cared for at home, and when possible, to die at home, has resulted in up to 90% of terminally ill cancer patients spending much of their last year of life in the community cared for by lay carers.7-9 Irrespective of the underlying type of malignancy, most patients with advanced cancer experience a prolonged period of gradual decline before a short phase of accelerated decline and intense need in the last month or two.10 Several of the issues cancer patients and their carers face at the end of life are similar, regardless of their illness or initial type of cancer. Patients are likely to experience physical and emotional symptoms from the treatment as well as from the disease itself, including pain, dyspnea, anorexia, depression, fatigue, nausea and delirium.11,12 Advanced cancer patients have been reported to experience an average of 11-13 symptoms and frequently have other comorbid illness burden.13,14

Studies examining end-of-life caregiving have tended to focus on research exploring the adverse effects and needs for assistance associated with end-of-life caring, patients’ and carers’ views of communication with their physician and obstacles to care, the perceptions of surrogate decision makers about end-of-life care, or retrospective studies of the end-of-life experience of families.15,17 As patients move through the cancer trajectory, and as disease progresses, the needs of patients and their carers increase exponentially. The role of the cancer carer has been transformed from the simple provision of custodial care into a multifaceted role with responsibilities that can be complex and burdensome. Caregiving now
includes a variety of direct, hands-on care activities, including carrying out nursing and medical procedures, as well as indirect care activities ie. activities carried out on behalf of the patient. Indirect care include activities such as transportation to health care appointments, accessing needed services or resources, supervising unpaid care workers, coordinating care among healthcare professionals and facilitating care transitions (eg. hospital to home or to hospice or residential aged care), making medical decisions when the patient cannot, and throughout the course of illness, serving as the patient’s advocate in response to a rapidly changing array of healthcare professionals, settings and medical circumstances to ensure that the patient’s needs are adequately met. One of the most important roles of the family carer is to assist the cancer patient with symptom management. Carers are expected to assess and monitor patients for changes in hallmark symptoms, to identify side-effects from therapy as well as any new symptoms, to administer and supervise the cancer patient’s medications (eg. which medication, when to dispense it, at what dosage, when to refill), and to handle symptom exacerbation emergencies. Furthermore, technological advances in pain management require caregivers to engage in more complex care tasks, including managing patient controlled analgesia pumps, epidural catheters and home infusions.12,18-21 However, family carers may be ill prepared to assume these tasks. As Burridge et al report,22 family carers regularly report feeling unprepared for the role of carer and ‘overwhelmed’ by their responsibilities, particularly when providing end-of-life care. For many, caregiving must be balanced against already established roles and role responsibilities. Carers may feel anything from highly committed to not at all interested in caregiving, yet powerful social norms pressure them to accept the role. Indeed, carer reluctance may be hidden in order to avoid censure. However, this ‘inner conflict’ may be an intrinsic element of caring due to the inherent conflict between the needs of the patient and the carer’s own needs and/or those of other family members. Choice appears to be the major factor in carer reluctance, however reluctance may not remain static over the caregiving trajectory.22 For the most part, those who assume the carer role are motivated by love and concern. Indeed, most carers appear to view caregiving as an extension of the family relationship, where increasing caregiving responsibilities evolve over time and are seen as a normal part of family life.23 Impact of end-of-life cancer caregiving Extensive international and Australian research has confirmed that caregiving places far reaching demands on the carer, physically, emotionally, financially, in existential and social domains, and can negatively impact the carer’s health, well-being, immune system, risk for disease (eg. heart disease and metabolic syndromes) and life expectancy when compared to non-carers.15,17,24-32 The physical and psychological wellbeing of the patient and carer have been found to be interrelated and patient psychological and physical suffering, particularly at the end of life, affect the carer’s psychological adjustment and morbidity during caregiving and in bereavement. Between 32% to 70% of advanced cancer patient carers have been found to experience a high level of distress or depressive symptoms at a level suggesting clinical depression.33-35 Schultz and Beach (1999) found a 63% higher mortality risk in bereaved elderly carers experiencing distress, compared to those who provided care but did not feel stressed.36 Caregiver burden and depression are also associated with family dissatisfaction with end-of-life health care services, including hospice and palliative care.37 Carer characteristics associated with negative caregiving impacts include carer age (eg. younger carers report more depressive symptoms), ethnicity (eg. non-white populations report more negative effects although the evidence is mixed), gender (female carers report more negative effects), socioeconomic status (lower income), and carer health and functional status. Other factors include the duration and intensity of caring demands, carer mood and physical health, a recurrence of the illness, the caregivers’ subjective burden (or, feeling overwhelmed) and entrapment. Cancer patient characteristics include the patient’s age and gender (older, female), patient functional impairment and need for assistance. Patients who display more symptom distress or depressed mood all appear more likely to have caregivers who report greater depressive symptoms and negative perceptions of health.38-40 Positive aspects of end-of-life caregiving Despite the challenges of caring for a terminally ill patient, the majority of family caregivers are able to identify positive aspects of the role. Positive elements of end-of-life caring include: the discovery of emotional strength, physical abilities and personal growth through adversity; acceptance of uncontrolled situations, in managing care, and out of necessity; the deepening of the relationship with the person for whom they care; altered relationships with others; and altered perspectives on living.41 While many carers give accounts of positive benefits from caregiving, the extent to which the positive aspects of caring buffer the negative aspects of the role is unclear. The long-term impact of the caregiver role on those who are unable to recognise positive elements warrants further exploration.42 Carer perceptions of need The ability of families to assume caregiving responsibilities is contingent on the material, informational and educational, social and professional guidance and support they receive from their healthcare professionals. Inadequate or inappropriate support to the terminally ill and their carers can result in the misuse of resources and added burden to the family. Studies consistently identify carer unmet needs in information, education, skills training and communication with healthcare professionals regarding care for the dying patient. Specifically, end-of-life carers require information about: the patient’s prognosis and disease progression; practical and nursing patient care education; understanding of the goals of medical treatment and awareness of approaching death; better access to social support services; and more information about what to expect at the patient’s death.16,43-47 However, health
professionals appear to consistently underestimate the level of carer need, as well as the availability of services when compared to their patient and carer reports.\textsuperscript{9,48-50} 

**Access to palliative care services**

Although patients, caregivers and healthcare professionals have clear and highly convergent ideas about the care needed at the end of life and how it should be delivered,\textsuperscript{51-54} specific elements of this care are often different at any one time and may shift throughout the course of the patient’s terminal illness, especially as patients move from curative to supportive or comfort care. A majority of patients report that they want to ‘die at home’, however access to palliative care and a home death is highly dependent on the availability of a willing and able carer and a variety of patient, healthcare professional and health system factors (eg. availability of home based hospice, hospital bed capacity, physician referral practice patterns, patient diagnosis).\textsuperscript{55-57} 

The primary intervention for advanced cancer patients and their carers has been in-patient and community based palliative care services. Evidence regarding the positive impact of palliative care services is strongest in cancer care, reflecting the degree to which palliative care has been integrated into oncology practice.\textsuperscript{16} Studies demonstrate strong associations between patient and carer satisfaction with: accessibility to and care coordination by the healthcare team; competence in symptom management and comfort with dying; the manner and extent of communication with family and practical education concerning patient care; emotional support for both the patient and carer; personalisation of care; and support of patients’ decision making.\textsuperscript{16,58} However, accumulating evidence suggests that a sizeable portion of cancer patients are not referred or are referred to specialist palliative care and/or community based palliative care late in the course of their illness.\textsuperscript{59-62} Schockett et al found almost 15% of patients were referred too late to receive services, while Adams et al found fully one third of patients or families in community palliative care reported that they wished they had been referred ‘earlier’.\textsuperscript{63,64} 

Johnson et al investigated cancer specialists referral practices to specialised palliative care and found specialists mainly referred people with advanced cancer for symptom related reasons, but that patient or carer psychosocial, emotional, cultural and spiritual issues rarely triggered referral.\textsuperscript{59} Sekelja et al examined bereaved cancer carers’ palliative care experiences and views on optimal timing of referral, finding that carers were grateful for the support, practical help and the respect shown to them and their loved one, however they also acknowledged the limits of hospice.\textsuperscript{65} Carers generally would like palliative care to be introduced when patients or carers first need help at home, or when symptoms become difficult to control, rather than when patients are told that their cancer is incurable.

**Conclusion**

Most of the research on cancer end-of-life caring has been qualitative, cross-sectional and conducted on small, fairly homogeneous samples, limiting our understanding of the precursors of and changes in carer needs over time, setting or populations. It has tended to focus on the identification of people at risk for adverse outcomes potentially needing therapeutic intervention, rather than on the appropriate type or timing of specific interventions for specific groups of carers, or on how to support carers so as to prevent or limit adverse effects in the first place. Support services for carers are greatly influenced by the available resources and carer needs are often neglected or under-appreciated, by most, including palliative care health professionals. More attention needs to be paid to exploring preventative interventions that address: avoidable symptom exacerbations and hospitalisations; end-of-life carer burden, stress, anxiety and burnout; and complicated bereavement; and that proactively assist the cancer carer and patient to live life as fully as possible in the time they have left. Questions that still need to be addressed include: what are the differences and similarities in cancer end-of-life caregiving with other forms of caregiving; when and for which populations of caregivers to intervene; ethnic differences in end-of-life caregiving; the economic burden and consequences of various forms of end of life caregiving; and finally, how to better organise the delivery of good palliative and supportive cancer care. There is an urgent unmet need for innovative solutions to the challenges involved with providing high quality, compassionate care to the terminally ill and their carers.

**References**


