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CHALLENGES EXPERIENCED BY INFORMAL CAREGIVERS IN CANCER

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Abstract

Evidence from the literature highlights the significant negative impact of care giving on the physical, mental and financial aspects of caregivers' lives. It also reinforces the importance of reducing the barriers to meeting the unmet needs of caregivers and that research priorities in intervention development need to focus on reducing the negative aspects of care giving. Increased assistance to caregivers needs to 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 in light of the predicted shortfall in the number in caregivers and especially as caregivers are increasingly replacing skilled health workers in the delivery of unfamiliar, complex cancer care at home.

Cancer is a major disorder which affects many people directly and indirectly. In Australia, one in three men and one in four women will be diagnosed with cancer before the age of 75.¹ There has been a significant increase in long-term survival for most cancers and more than half of all newly diagnosed cancer patients will survive for more than five years.² The course of many cancers is now chronic, requiring long-term treatment and a continuing need for care.

The diagnosis of cancer presents a major event not only to the patient, but also to the family and caregivers. The primary setting for the delivery of care to patients with cancer has shifted from the hospital to the home as a result of increased use of outpatient services for cancer treatment, longer survival and patients' wishes to be cared for at home.^{3,4} Care giving is commonly equivalent to a full-time job with 20% of caregivers providing full-time or constant care.⁵ The increased trend for home-based care of advanced cancer in the Australian health system⁶ places a greater emphasis on the care given by the patients' informal caregiver.

However, concerns have been raised about the future availability of informal caregivers in the light of social and demographic changes.^{7,8} The increased proportion of older people in the population, declining fertility rate, increased rates of female labour force participation, increased rates of relationship breakdown and health care reforms that are shifting care from the hospital to home are all pressures that will impact on the availability of an informal family caring workforce.⁷

The study by the National Centre for Social and Economic Modelling has added a new dimension to the debate by contrasting the demand for care to the likely supply of informal care in Australia. As the number of older people needing care increases, there will be a lesser increase in the number of potential caregivers due to population ageing. Older age groups contribute more to the disabled population than they do to caregiver populations, with the ratio of primary caregivers to older

persons needing informal care estimated to drop from 57/100 to 35/100 in the next 30 years.⁸ Thus, there may be an increased demand for institutional care due to an inadequate supply of primary caregivers.

Profile and roles of caregivers

In Australia, caring for people with a disability is a role predominantly assumed by women, with 71% of primary caregivers being female, 13% being female and 65 years or over. Most primary caregivers aged 65 and over are caring for patients in their own age group.⁹ Almost 80% of primary caregivers live with the person receiving the care and 43% of all caregivers are partners, 25% are children and 21% are parents of the person receiving the care. The majority of caregivers report taking on the role of caring because of family responsibility and there being little choice or no one else to provide the care.

Care giving activities undertaken for people who are terminally ill or who have a disability are varied and numerous and include personal care, assistance with mobility, transportation, communication and housework, emotional support, organising appointments, social services, assistance with social activities, shopping, meal preparation, managing finances and management and coordination of medical care (including the complex management associated with patients in pain, administration of medications and therapies and managing infusions).¹⁰⁻¹⁶ More than half of caregivers have reported more things to do than they could handle.¹⁷

Impact of care giving

Although many caregivers derive deep satisfaction and feel positively about caring,¹⁴ feelings of sadness,^{13,18} anger, resentment¹⁹ and a sense of inadequacy²⁰ are other common reactions. Not only are caregivers confronted with the fear of a potentially life threatening illness, the continuous caring can result in feeling exhausted and burnt out.^{15,21} Opportunities for social contact and support

are also reduced, as caring disrupts usual activities and reduces the caregiver's personal time.^{4,22} The emotional and social burden of care giving contributes to significant mental health morbidity, with elevated rates of anxiety, depression and distress^{16,23} and poor quality of life²⁴ being reported in caregivers of patients with cancer.

Sub-groups of caregivers may be at increased risk of psychological morbidity due to personal physical, social and psychological factors and/or factors associated with patients they are caring for. Caregivers are reported to be more likely to have higher levels of psychological distress and strain if they are female, younger,²⁵ or are the spouse, rather than the child of the patient.²⁶

Caregivers with higher levels of anxiety, higher levels of anger, smaller social networks, lower perceived caregiver satisfaction and higher years of care giving are at increased risk of depression, as are caregivers who care for patients with higher perceived levels of stressful behavioural and self-care problems, and with higher levels of pain.^{27,28} Caregiver wives are reported to have higher levels of depression and poorer health than caregiver husbands.²⁸

Conversely, lower levels of depressive symptoms are reported by caregivers if they perceive that doctors listen to them and consider their opinions regarding the patient's illness, needs and medical treatment.²⁹

Physical health risks have also been found to be associated with caring and include high blood pressure, tiredness, stress, burnout, physical injury²¹ and poor overall physical health compared to the general population.^{30,31} In addition, care giving is often performed by people who are themselves elderly or ill.⁹

Research has identified a significant impact of care giving on areas including holidays, time away, travel and having limited time for social life, personal relationships, hobbies and for themselves.^{17,21} These limitations result in social isolation and loneliness, changes in family and other relationships and a sense of grief and loss.^{21,32} Caregivers report trying to participate in social activities, but give up due to concern for the patient whilst they are absent. Younger caregivers and caregivers of patients with cancer who have limited social networks and more restrictions in their daily activities are reported to have the highest caregiver burden.³³ Some caregivers report difficulty expressing their own needs, unless asked specifically away from the hearing of the patient.²⁵

Care giving creates a financial burden for family members, both in outright expenses and in lost income and benefits. An Australian study found that caring for a person with illness and disability amounted to an extra \$119 per week.³⁴ One quarter of bereaved caregivers report that caring for someone with terminal cancer a financial strain, with one third using their savings or inheritance for costs associated with home care and one fifth modifying their usual expenditure on other items.³²

Care giving also appears to reduce a person's chance of being employed.⁹ Many caregivers are unable to work, need to take leave without pay, work fewer hours, are in lower paid jobs or work from home to manage the caregiver demands.^{17,35} In Australia, only 15% of caregivers list paid work as their primary source of

income, with two-thirds on a government pension or benefit as their primary source of income. Financial impacts of care giving include loss of superannuation and savings for retirement.⁴ Caregivers who work report being worried about the patient while absent and being interrupted repeatedly during working hours. While work may be a relief from care giving, it is also a source of conflicting demand.¹⁷ Reduction in paid work also contributes to social isolation.³²

While caregivers report experiencing surprise, shock, disbelief, anger, distress, fear and depression in response to a terminal diagnosis, they also feel that caring for a patient with advanced cancer is an experience that can produce positive emotions. In an Australian study, 60% of caregivers were able to identify positive aspects of their role.³⁶ When patients' symptoms were minor, time together was described as very precious and allowed the exploration of emotions and expression of love. Post-bereavement, caregivers report being proud, pleased and satisfied that they had managed the care giving role.³² Happiness over quality time spent with the patient, the ability to explore and resolve issues and feelings of value and self-worth have all been reported by caregivers.^{14,37} It is suggested that caring for the patient may help caregivers to accept the death and work through their grief.³⁷

Caregivers' information needs

Lack of adequate information is reported as one of the most important concerns of caregivers of patients with advanced cancer.³² Sixty per cent of close relatives of deceased cancer patients have reported that they were not able to find out all they had wanted to know about the patient's medical condition and how it would affect him or her.³⁸ Caregivers identified a need for updates on the course and prognosis of the disease and treatment. Not knowing much about the illness and fear of not knowing what to do or to expect was perceived as very stressful and led to an increase in caregiver anxiety, increasing frustration and uncertainty.³⁹ Understanding details relating to the illness were reported to help caregivers cope.⁴⁰ Once specialist palliative care services (SPCSs) are involved, communication is reportedly more likely to be honest and direct.³²

However, barriers confronting health care professionals regarding provision of support need to be acknowledged in order to more effectively provide relevant interventions to family caregivers. The dynamics of relationships within the family may restrict optimal communication with the health professional. Incongruent patient and caregiver needs also make it difficult for service providers to determine whose needs take priority. This is particularly challenging when the caregiver precludes health professionals and other family/friends from disclosing the prognosis to the patient or the patient does not want the caregiver or other family members to know about the prognosis.⁴¹ Caregivers are often reluctant to disclose their needs to health professionals, for reasons including not wanting to put their needs 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.⁴²

Utilisation of existing services

Australian research suggests that few caregivers report being aware of the extent of services available to them and most of their information comes from friends and family rather than health professionals.^{32,43} Knowledge of community and health services is lower for non-metropolitan caregivers and higher for retired caregivers. Knowledge of allied health professionals and community nursing is high, however federally funded programs such as Home and Community Care and Aged Care Assessment teams are poorly recognised. Patients report greater knowledge of supportive care services than their caregivers.⁴³

Respite services are not well utilised by caregivers and despite the significant financial impact of care giving few Australian caregivers are aware of some of the government benefits available to them and only one third have accessed any payment. Others have difficulty accessing payments, do not meet the criteria, are given incorrect advice and experience delays.³² Some patients and caregivers report not accessing specialist services because of their own or relatives' fear of death or emotional difficulties in discussing such issues.⁴⁴

Addressing some research gaps

It is evident that caregivers of cancer patients are an important target group for further research to better understand how their needs change over the course of the patient's illness and to streamline their access to available services that may assist in addressing identified needs.

In a review of cancer care literature specific to caregiver interventions, Pasacreta and McCorkle reported limited research on evidence-based interventions aimed at caregivers. Considering the lack of positive findings in some of the studies reviewed, the authors concluded that an important direction for research was identifying caregivers who were at risk of having problems in specific areas and tailoring interventions to their special needs.⁴⁵

Harding and Higginson also lamented the lack of outcome evaluations in the care giving 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 randomised clinical trials of caregiver interventions in cancer and palliative care, other experimental designs might be more feasible and should be considered.⁴⁶

Landmark Australian studies are currently underway that will improve our understanding of the psychosocial needs of partners and caregivers of cancer survivors over the course of the illness. The Centre for Health Research & Psycho-oncology (CHeRP), of The Cancer Council NSW and University of Newcastle, is undertaking a large longitudinal study of the partners and caregivers of recently diagnosed cancer survivors from NSW and Victoria who are recruited to the Cancer Survival Study. The Partners and Caregivers Study, which has recently commenced recruitment, will: a) describe changes in the levels of anxiety, depression, quality of life and unmet needs reported by partners/caregivers of cancer survivors over the first five

years since the cancer diagnosis; b) identify the partner/caregiver factors associated with these outcomes including social support, coping style and demographic and financial characteristics; c) describe the relationships between cancer survivors' and partners'/caregivers' psychosocial and other health outcomes; d) assess the costs associated with living with or caring for a person with cancer; and e) identify the partner/caregiver predictors of poor bereavement following the death of the cancer survivor-pair.

Researchers from the Medical Psychology Research Unit, University of Sydney and the Queensland Institute of Medical Research are undertaking the Australian Ovarian Cancer Study (AOCS) Quality of Life Study, collecting information on quality of life, psychological distress, social support, coping style and unmet needs for women with ovarian cancer and their partners/carers, with access to medical and demographic information from the main AOCS. This study will: a) track variations in quality of life and psychological distress over two years; b) examine the role of psychological distress, social support and coping style in predicting outcomes, in terms of quality of life, recurrence, and survival; and c) determine whether services are currently meeting the needs of women and their carers.

Palliative care services have been demonstrated to benefit not only the patients but also the families and the bereaved.⁴⁷⁻⁴⁹ A South Australian population study has found that caregivers who reach out for support, especially for day-to-day care, have fewer unmet needs and are much more likely to move on with their life in the first 6-12 months after their loss than caregivers who do not reach out to services.⁵⁰ While health professionals are ideally placed to provide information and proactively assess the need for referral to SPCSs, Australian research has shown that referral to SPCSs is often late or does not occur at all. Furthermore, some sub-groups consistently under-utilise SPCSs, including those of lower socio-economic status, the elderly and people of Aboriginal and Torres Strait Islander backgrounds.⁵¹⁻⁵⁴ There is also a focus on physical symptoms and prognosis as the main triggers for referral to SPCSs, at the exclusion of psychosocial and caregiver needs. To improve needs-based access to palliative care, the Australian Government Department of Health and Ageing has funded a national team headed by CHeRP to undertake research into palliative care referral. Part of that work is to develop SPCS Referral Guidelines and a Palliative Care Needs Assessment Tool (PC-NAT), initially for people with cancer. The systematic use of the guidelines and PC-NAT could reduce the identified gap between knowledge and practice, thus reducing the incidence of late and crisis referral and improving referral where psychological, spiritual, social and physical problems are evident. The PC-NAT will provide a rapid strategy for efficiently and systematically identifying patients and families who need specialist palliative care initially, as well as any change in status over the course of their advancing disease.

Conclusion

Care giving is associated with a significant negative impact on the physical, mental and financial aspects of caregivers' lives. Increased assistance to caregivers must 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 in light of the predicted shortfall in the number in caregivers and especially as caregivers are increasingly replacing skilled health workers in the delivery of unfamiliar complex cancer care at home. Needs based access to existing services, including SPCSs, also needs to be encouraged and facilitated to help caregivers in their important role. □

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