

Cost of informal caregiving in cancer care

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Abstract

In 2015, approximately 2.7 million Australians were unpaid caregivers, including partners, family members, friends and neighbours. However, the true population of Australian caregivers may be under-estimated due to lack of carer self-identification, and this may be even more so for Australians of culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islanders. Increasing cancer incidence and survival has resulted in a corresponding increase in the demand for unpaid caregivers, prompting in-depth exploration of the economic, psychosocial and physical impact of caring. Caregivers' physical health is significantly impacted and is sometimes reported to be lower than the patients they care for, perhaps as a consequence of prioritising the patient's needs and health over their own. Caregivers are also at increased risk of poorer psychological outcomes than the general population, reporting high levels of depression and anxiety. The financial impact is significant, with informal caregiving representing 18-33% of the total financial cost of cancer. The burden of this financial responsibility can adversely impact caregivers' quality of life, limiting their capacity to fulfil other caregiving roles and also having a direct adverse impact on the patients' quality of life. This paper reviews the costs of caregiving, from a financial, physical and psychosocial perspective.

It was estimated in 2015 that 2.7 million Australians were unpaid caregivers, including partners, family members, friends and neighbours, providing short-term or ongoing assistance to someone with a chronic disease or disability.¹ While the majority of caregivers are female, a statistic which is consistent across Australia, the US and Canada, the past few decades have seen an increased proportion of male caregivers.²⁻⁶ Cancer is one of the top 10 health conditions requiring a carer. Across all caregivers, family members constitute the majority, with cancer caregivers more likely to be spouses of the care recipient.⁷ The increase in cancer incidence and survival has resulted in a corresponding increase in the demand for unpaid caregivers,⁸ prompting in-depth exploration of the economic, psychosocial and physical impact of caring.

Caregivers undertake a very wide range of tasks, including providing practical care, emotional support, household tasks, financial management and advocacy/decision-making. For many caregivers (42-98%), the experience of providing care is associated with positive aspects, including a feeling of accomplishment, improved quality of their relationship with the care recipient and the broader family, and deriving meaning from caregiving.⁹ However, many caregivers feel unprepared for their role and the caregiving experience is by no means positive for all who take on that responsibility. The broader financial and health impacts of caregiving are numerous and significant, with accumulating evidence painting a compelling picture of negative impacts of caregiving on the financial standing of caregivers, as well as on their mental, physical and social functioning.⁷

Financial impacts of caregiving

Health system restructuring has led to a greater focus on home-based cancer care as an alternative to in-patient care, which consequently changes the distribution of costs families incur.¹⁰ This shift is an important consideration, as financial status is a significant factor associated with caregiver burden.¹¹⁻¹⁴ Informal caregiving represents 18-33% of the total financial cost of cancer.¹⁵⁻¹⁹ The burden of this

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financial responsibility can adversely impact caregivers' quality of life, limiting their capacity to fulfil other caregiving roles and also having a direct adverse impact on the patients' quality of life.^{20,21} In a study by Tsigaropoulos et al,²² increased economic burden was the third most common problem reported by 51% of caregivers of patients with advanced cancer, only exceeded by anxiety regarding the patient's future (62%) and troublesome symptoms such as pain (54%). Despite this prevalence, less attention has been given to economic burden than other aspects of caregiver burden, such as emotional burden.

Direct and indirect expenses

The financial cost of caregiving includes direct out-of-pocket as well as indirect expenses, including: taking time off work to care for the patient; paying for treatments and medications; travelling to cancer appointments; paying for accommodation to stay near treatment centres; reorganising daily and home life, such as help with housework; and coping with the disease, including long distance calls to other family members.²³⁻²⁷ One of the only Australian studies in this area found that half of the caregivers of haematological cancer survivors reported personal expenses related to their role, with the three most common expenses including parking while at hospital (36%), travel to cancer appointments (33%), and drugs or treatments (25%).²⁷ More than half (52%) of caregivers in this study reported a financial impact because of their role, including taking time off (40%), having less income (29%) and using up savings (19%), and some reported difficulties paying bills (14%) or meeting day-to-day expenses (9%). These caregivers identified free parking (43%), free medication (32%) and being able to access treatment in their region (25%) as strategies to reduce the financial impact.

In two international studies, one from Europe and one from the US, that reported on the total costs of caregiving, one consistent finding was that 85-90% of the total cost was attributed to indirect time cost,^{25,28} which included: visiting and waiting during diagnostic tests and/or surgery; travel time; time spent on housework, such as preparing food and drinks; and assisting the patient with activities of daily living. The American study by Van Houtven et al,²⁸ reported that 89% of time costs was attributed to caregivers' direct care efforts, with the remaining time cost due to cost of sick hours, vacation hours, unpaid hours, work hours lost per week and leisure lost per week. Although representing a lower proportion of the total caregiving cost, direct expenditures were also an important cost, with some of the largest direct expenditures in informal caregiving relating to medication, doctors' visits, household expenses and travel.^{25,28} Either as an indirect time cost or a direct expenditure, travelling to the hospital and for appointments was identified across all three aforementioned studies, with Stephens et al highlighting that the time cost involved in travelling is higher than the direct transport cost.²⁹

Impact on work

In addition to travel, a proportion of the cost of caregiving is attributed to the impact on the person's work, with reports that 32 to 45% of caregivers needed to work fewer hours to fulfil their caregiving roles and responsibilities.³⁰⁻³³ However, caregiving also impacted on work more broadly, including having to take some time off work or using holidays or special leave as required, having interrupting phone calls during a work day, changing employment, retiring or quitting altogether.^{32,34} A European study found that caregivers were more likely to report absenteeism, impairments while at work, and impairments during daily activities, and a higher mean number of hospitalisations, emergency department visits, and visits to healthcare professionals than non-caregivers.³⁵ In a month-long American study by Passik & Kirsch,³³ 28% of spousal caregivers reported handling fewer responsibilities at work, 32% had reduced their work hours and 32% felt that they were less effective overall at work. Caregivers missed an average of 2.7 days (SD = 2.95) and took an additional 1.29 (SD = 2.97) sick days and 1.76 (SD = 2.63) vacation days during that time. In one Canadian study, caregivers reported on average seven days lost from work in the previous 30 days.³¹ Dubas-Jakobczyk et al found that caregiving for patients with cervical cancer resulted in approximately 873 working days lost in 2012, with significant production lost due to this absenteeism.³⁶ One review of the financial stress and strain associated with terminal cancer found 10 to 40% of families reported that someone had quit work to provide care.²⁶

The impact of caregiving on work has been less studied in the Australian context. Work productivity data, previously unpublished, were collected as part of the Partners and Caregivers Well-Being Study, a five-year longitudinal study of 547 Australian caregivers of patients with the top 10 incident cancers

in Australia.³⁷⁻³⁹ Twenty per cent (112/547) of all caregivers surveyed reported having to take sick leave, 6% (31/547) had to stop work and 9% (48/547) had to reduce hours to care for the person with cancer. Furthermore, of the half (n = 262) of the caregivers who were working at the time of the initial survey, that is six months following the patient's diagnosis, 13% reported that their caregiving role adversely impacted their work productivity, and 18% reported that their productivity at work in the last week was lower compared to their productivity in the last six months. These changes in caregivers' work might result in loss of income, as well as lead to concerns about job loss or employability, lack of promotion, and inadequate pension build-up.^{23,27,32}

Meeting out-of-pocket expenses

The financial burden of cancer can lead caregivers to use their and other family members' savings, sell assets, take out loans or seek additional work to cover the additional costs and burden of caregiving.²⁶ A review of the financial strain incurred in the terminal phase of the illness identified that 17 to 38% of patients or their families used most or all their savings.²⁶ A Korean study found as a consequence of the financial burden endured, caregivers reported losing family savings (68%), altering educational plans for another family member (29%), moving to a less expensive home (20%), and delaying medical care for another family member (14%).⁴⁰ In this study, caregivers were more likely to lose their family savings if they had a monthly household income of less than \$US833, had fair or poor health status, were married, provided care for more than 12 months after diagnosis, cared for patients with poor performance status or paid high medical expenses. Of note, loss of savings was the variable most strongly associated with caregivers' quality of life, along with requiring caregiving assistance, major life change, inability to function normally, loss of income and altered educational plans.⁴⁰ In our Australian longitudinal Partners and Caregivers Well-Being Study, out-of-pocket expenses among caregivers were examined; 75% had out-of-pocket costs and 84% of caregivers said they were meeting out-of-pocket expenses using their income, savings (47%) and loans to cover the additional expenses (3%). The most common expenses for caregivers because of the cancer diagnosis were health care professionals (42%), prescription medicines (40%), travel (32%) and over the counter medicines (32%). Further consequences for some caregivers include house repossession, bankruptcy, loss of independence and relationship breakdown.²³

Variables associated with financial burden

To date, the literature on the financial cost of caregiving has identified vulnerable sub-groups of caregivers, mostly based on the care recipient's phase along the illness trajectory and cancer stage and/or type.^{19,24,25,27,28} Caring for someone in the advanced stage of the disease has been found to be particularly costly for caregivers, especially as it extends for several years, in comparison to other stages along the illness trajectory such as primary treatment and rehabilitation.^{15,41} An American study by van Houtven et al estimated that the accumulated economic burden for caregivers in the terminal phase was \$US14,234, in comparison to \$7028 and \$19,701 for those evaluated during the patient's initial phase and continuing phase of disease, respectively.²⁸ Of note, for caregivers evaluated in the continuing phase, costs had been accrued over 17 months versus seven to eight months for those in the initial and terminal phases. This study further documented that the economic burden was higher for caregivers caring for a woman versus a man, with lung cancer versus colorectal cancer, diagnosed at stage 4 versus stage 1, with lower quality of life, and for caregivers who were working and the patients' spouses, as opposed to other relatives or friends.²⁸ Yabroff et al also corroborated that the time cost for caregivers varied by cancer type, whereby caregivers of patients with lung cancer incurred costs almost twice as high as those noted for caregivers of patients with breast cancer.⁴² Similarly, a difference of almost \$US31,000 was noted between the cost of caregiving between the localised stage at diagnosis versus distant stage.⁴²

The aforementioned Australian study found that caregivers of patients with a haematological cancer in the active treatment phase reported experiencing more personal expenses than caregivers in the pre-treatment, maintenance, follow-up or remission phases.²⁷ In this study, male caregivers reported more personal expenses, but less financial impacts than their female counterparts. One study has documented the impact of locality on costs, reporting that rural caregivers face more costs than urban caregivers related to prescription medication, out-of-pocket costs and transportation. However, urban caregivers face more costs related to formal home care.¹⁸ Other factors contributing to caregivers' financial burden include the presence of children at home, being a younger caregiver, caring for a

patient with symptoms or one who needs assistance with activities of daily living, and lower educational attainment by caregivers.^{31,43}

Broader costs of caregiving

Unlike the financial costs of cancer, there have been many reviews on the psychosocial impact of cancer on caregivers,⁷ and this section only highlights key findings. Since cancer largely remains a disease of the ageing population, caregivers tend to be older themselves and are therefore providing care for someone with a chronic condition while trying to manage their own health and chronic conditions.⁴⁴⁻⁴⁶ They suffer loss of physical strength, loss of appetite, weight loss, fatigue, pain and sleep disturbance and spouses have been reported to be at greater risk of coronary heart disease and stroke following their partner's cancer diagnosis compared to spouses whose partner does not have cancer.^{47,48} Of concern is that caregivers' physical health has been reported to be lower than the patients they care for, perhaps as a consequence of them prioritising the patient's needs and health over their own.⁴⁹⁻⁵¹

In addition to their physical ill-health, caregivers are also at increased risk of poorer psychological outcomes than the general population, with approximately a quarter reporting depression and 40% reporting anxiety.⁵²⁻⁵⁶ In some contexts, the levels of distress, anxiety and depression have been reported to exceed those of the patients for whom they care.^{53,57,58} While anxiety and depression tend to decrease over time for the majority of caregivers, of concern is a subgroup of caregivers who experience clinical levels of anxiety or depression at six months following their care recipient's cancer diagnosis and continue to experience such clinical levels throughout the first two years post-diagnosis.^{52,59} These findings underscore the importance of screening for caregiver distress early to identify those most in need of support, to help ameliorate potential negative impacts of their caregiving experience.

While understanding and addressing the negative impacts of caring on caregivers' health and wellbeing is important in and of itself, it is also important because of the mutuality in response between caregivers and the patients for whom they provide care. A meta-analysis reported a significant moderate, positive association ($r=0.29$, $p<0.001$) between patient and caregiver distress, suggesting an interdependent reaction to the cancer diagnosis and, therefore, that addressing the caregiver's distress may also have a positive impact on the patient's distress.⁶⁰

Unknown cost for some caregiver sub-groups

The true population of Australian caregivers may be under-estimated due to lack of carer self-identification, and this may be even more so for Australians of culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islanders. The physical, psychosocial and financial costs experienced by these sub-groups may be even more pronounced, if the caregivers are themselves of CALD or Indigenous backgrounds, as well as the patients they are caring for. Although there is increased recognition of these groups' vulnerability, there has been little research documenting the extent of the costs experienced by these sub-groups.

Australia is one of the most CALD countries in the world, with approximately 28% of Australians born overseas.⁶¹ The influence of cultural and linguistic diversity on the caregiving experience and outcomes is potentially quite complex. It is estimated that 25 to 30% of caregivers in Australia are from CALD backgrounds,^{1,62} however the size of the population of non-CALD caregivers who are providing care for CALD patients is unknown. Australian research has reported CALD patients as having significantly lower quality of life, higher incidence of clinical depression, greater side-effects and being less satisfied with their cancer care than their English-speaking counterparts, with unmet needs relating to emotional support, information and coordination of care.^{60,64} These variables are likely to impact on their caregivers' coping and well-being. For example, in the Australian Partners and Caregivers Well-Being Study, 63% of CALD caregivers reported high anxiety at six months post-diagnosis, compared to 36% of Australian-born caregivers ($p<0.05$). The difference was maintained over two years of follow-up. CALD caregivers also reported poorer physical health than the Australian-born caregivers,⁶⁵ a finding partially explained by the high reliance on family for caregiving across many cultures.

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Australian statistics suggest that 12% of the Aboriginal and Torres Strait Islander population are caregivers, compared to 10% of non-Indigenous Australians, Indigenous Australian carers are on average 12 years younger (average age 37) than non-Indigenous Australian carers,⁶⁶ with a large proportion living in rural and remote areas. While across the caregiver population, many caregivers are trying to manage their own health and chronic conditions at the same time as providing care for someone with a chronic condition, this is even more acute for Indigenous Australian caregivers, who are between 1.5 and three times as likely as non-Indigenous caregivers to need assistance with self-care, mobility and/or communication.^{46,66} The financial burdens of caregiving are also more pronounced in this population, with Indigenous caregivers earning lower income and less likely to be in employment compared to non-Indigenous Australian caregivers.

Conclusion

The cost of providing informal care to cancer patients is significant, not only from a financial standpoint, but also in terms of the physical, psychological and social impacts of caregiving. For some Australians, particularly those of CALD background and Indigenous Australians, the costs are amplified. Future research is needed to document the direct and indirect costs of caregiving and determine the costs, particularly among vulnerable groups.

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