

Physical, Psychosocial, Relationship, and Economic Burden of Caring for People With Cancer: A Review

By Afaf Girgis, BSc(Hons), PhD, Sylvie Lambert, PhD, Claire Johnson, RN, CM, PhD, Amy Waller, PhD, and David Currow, BMed, MPH, FRACP

Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, UNSW Medicine, The University of New South Wales, Sydney, New South Wales; University of Western Australia, Crawley, Western Australia; Flinders University, Daw Park, South Australia, Australia; and Tom Baker Cancer Centre, Calgary, Alberta, Canada

Abstract

The aim of this article is to provide an overview of the issues faced by caregivers of people diagnosed with cancer, with a particular emphasis on the physical, psychosocial, and economic impact of caring.

A review of the literature identified cancer as one of the most common health conditions in receipt of informal caregiving, with the majority of caregivers reporting taking on the role of caring because of family responsibility and there

being little choice or no one else to provide the care. For some, caregiving can extend for several years and become equivalent to a full-time job, with significant consequent health, psychosocial, and financial burdens.

Having a better understanding of the critical and broad roles that caregivers play in the oncology setting and the impact of these on their health and well-being may assist health care professionals in supporting caregivers with these tasks and targeting services and interventions toward those most in need.

Introduction

A cancer diagnosis is a major event for the person diagnosed and also to his or her family and caregivers.¹ Some studies report that a cancer diagnosis actually has a greater impact on family members than patients.²⁻⁸ Given outpatient care, longer survival, and patients' wishes to be cared for at home, most cancer care is community based.^{9,10} An aging and growing population is associated with more elderly patients being treated for cancer. These shifts in health services and population demographics result in cancer being one of the most common health conditions in receipt of informal care giving.¹⁰ The majority of caregivers report taking on the role of caring because of the family responsibility, with little choice and no one else to provide care. For some, caregiving can extend for several years¹¹ and be equivalent to a full-time job.^{11,12} The aim of this article is to provide an overview of the issues faced by caregivers of people diagnosed with cancer, with a particular emphasis on the physical, psychosocial, and economic impact of caring. Having a better understanding of the critical and broad roles that caregivers play in the oncology setting and the impact of these on their health and well-being may assist health care professionals in supporting caregivers with these tasks and targeting services and interventions toward those most in need.

Caregiver Roles

Caregiving is a common task, with one in 10 people having provided hands-on care for someone at the end of life (the majority of whom had cancer) in the past 5 years.¹³ The intensity of care defines distinct caregiver groups with differing needs.¹⁴ Some caregivers may have been unaware of the extent of the role when they became caregivers and often experience an

insidious onset to the role; others feel they have little choice. A study by Kim and Schulz¹¹ reported comparable levels of caregiving and burden across cancer and dementia caregivers; however, both of these groups provided more hours of care per week, assisted with a greater number of daily activities, and reported greater levels of physical burden and psychological distress than caregivers of individuals with diabetes or frail elderly.

Caregiving activities are varied and numerous, including personal care, mobility, transportation, communication, housework¹³; management and coordination of medical care, administration of medications and therapies, emotional support, assisting with personal care,¹⁵ organizing appointments, social services, assistance with social activities, managing money¹⁶; ambulating, transferring, incontinence care, shopping, housework, meal preparation, telephone calls and managing finances.^{17,18} Girgis and Lambert¹ reported that among a mixed group of caregivers of cancer survivors, common caregiving tasks included household tasks (daily 68.5%), emotional support (daily 39.9%), and managing money (daily 22.7%).¹ More than half of caregivers in another study reported having more things to do than they could handle, and caregiving did not necessarily cease when the patient was admitted to an inpatient facility; 12% of caregivers reported that they provided care to a person in residential care.¹⁶ Hayman et al¹² reported that individuals diagnosed and treated for cancer received an average of 10 hours of informal caregiving per week, as compared with 6.9 and 6.8 hours for those who have no history of cancer or are diagnosed with cancer but did not receive treatment in the past year, respectively ($P < .05$). Yabroff and Kim²⁰ found that caregivers participating in the American Cancer Society's Study

of Cancer Survivors provided care for 8.3 hours per day for 13.7 months over the first 2 years after diagnosis. Caregivers of patients with lung cancer, ovarian cancer or non-Hodgkin lymphoma spent the most hours per day caregiving (>10 hours), and caregivers of patients with breast and bladder cancer, melanoma of the skin, or uterine cancer spent the fewest hours per day (< 7 hours).

Taking on the caregiver role is a complicated transition that involves patients, families, and health professionals to varying degrees and may not have a definite start point.²¹ Furthermore, patient and caregiver preferences for type of care are not always congruent and require negotiation.²² Health professionals adopt varying degrees of involvement in the decision about the type of care for the patient and who will be involved in the caregiving but commonly initiate the discussion.²¹ Negotiated decisions often result in caregivers who are more prepared and able to cope with their role as they involve open discussion between caregivers and patients.²³

Physical, Psychosocial, and Economic Impact of Caring

Given the potential impact of caring for a person with cancer, the degree of burden experienced has been the focus of a considerable amount of research. Caregiver burden is defined as the extent to which caregivers feel that their emotional or physical health, social life, and financial status have suffered as a result of caring.²⁴ Despite caregiving having a significant impact on caregivers' well-being, their needs are frequently considered secondary to those of the patient or are overlooked.²⁵ Some research has suggested that caregivers of people with cancer may have more unmet care needs than patients.²⁶

Impact on Physical Health and Lifestyle

Some studies have reported increased morbidity and mortality associated with caregiving.²⁷ Frequently, the caregivers themselves are aged (most primary caregivers are age > 65 years and caring for patients in the same age group¹³) and have significant health problems that affect and are affected by the caring role.

A recent review by Stenberg et al²⁸ found that the most prevalent physical problems reported by caregivers included sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss. In an Australian study of caregivers, more than half reported that caregiving had directly affected their overall physical health,¹⁵ including tiredness and exhaustion (54.5%); back, neck, and shoulder problems (33.8%); blood pressure and/or heart problems (12.6%); arthritis (10%); stress-related illnesses (6.6%); being physically unfit and weight problems (5.5%); digestion and bowel problems (4.6%); and leg and foot problems (4.6%).¹⁵ A study of caregivers of people with advanced cancer found that more than two thirds reported fatigue (69% at baseline), which increased as time went on and as the patient deteriorated.³⁰ Fatigue was reported to result in decreased ability to concentrate (in 69% of cancer caregivers), decreased motivation (58%), affected relationships (46%), de-

creased ability to perform usual activities (42%), and effects on mood (35%).²⁹ Grbich et al³⁰ identified a substantial physical impact of the caring role, with caregivers reporting back and leg strain caused by heavy lifting, with further physical strain being reported when the patient was incontinent of urine and feces, due to the increased amount of washing. The impact of the constancy of care for physical needs was exacerbated by continual lack of sleep if patients needed care during the night.³⁰ Up to 82% of female cancer caregivers reporting sleep disturbances, with sleep disturbances significantly associated with depression, anger, and anxiety.³¹

Weitzner et al³² found that caregivers of patients who were receiving palliative care reported greater impairment in physical functioning ($P < .001$), general health ($P < .001$), and vitality (ie, energy/fatigue; $P < .002$), as well as worse overall physical health ($P < .02$) than patients with cancer who were receiving active, curative treatment. In comparison to the general population, caregivers of patients with cancer who were receiving hospice care report poorer overall physical health.³³

A study in the United States identified 36% of caregivers as vulnerable due to being in fair or poor health or having a serious health condition, more likely to have difficulty providing the care, having unmet needs in providing care, and providing high-intensity care. Of concern, vulnerable caregivers were no more likely than nonvulnerable caregivers to have received help from paid support services for their care recipients; overall, up to 82% of caregivers had no formal help in providing care.¹⁷ An Australian study reported that more than 7% of active caregivers, predominately caring for people with cancer at the end of life, would not take on the role again.³⁴

Cancer caregiving also has a negative impact on health-related activities, including skipping exercise. A study by Beesley et al³⁵ found that 42% of caregivers of people diagnosed with ovarian cancer reported decreasing their physical activity since their family member was diagnosed with cancer, and slightly more than one third gained weight to a level that exceeded their healthy body mass index range. Although most caregivers did not report a change in their fruit and vegetable consumption, 12% increased their alcohol intake.

Impact on Anxiety and Depression

Prevalence of anxiety and depression among partners and caregivers ranges from 16% to 56% and 10% to 53%, respectively.^{5,36-38} and, in some studies, exceeds patients' rates.^{5,38} For instance, a study of caregivers who had been caring for a patient with cancer for an average of 2 years reported that 52.9% were at risk of clinical depression (ie, Center for Epidemiological Studies–Depression scale > 15).³⁹ Lambert et al⁴⁰ found that more than one third of caregivers reported borderline or clinical levels of anxiety, and almost 17% reported borderline or clinical depression, with most depressed caregivers also reporting anxiety, at 6 and 12 months after patient diagnosis.⁴¹ Recently, Price et al⁴² reported significantly higher prevalence of borderline or clinical anxiety and de-

pression among caregivers of women with invasive ovarian cancer compared with patients' rates and community norms. In studies looking at post-traumatic stress disorder (PTSD) in caregivers and partners of people with cancer, 4% of caregivers experienced PTSD,⁴³ and one third of partners experienced traumatic symptoms.⁴⁴ Despite the significant psychological impact of caring, caregivers might not seek required treatment, with Vanderwerker et al⁴³ reporting that almost half of cancer caregivers who met diagnostic criteria for a psychiatric condition did not seek treatment for it.

Caregivers at increased risk of anxiety or depression:

- Are predominantly younger^{25,45-49} and female.^{8,25,45,47,49,50}
- Report lower socioeconomic status^{6,46,51} or education.^{11,51}
- Live with the patient^{6,45,50,52}; are the spouses, rather than the children, of the patient⁵³; or report poor relationship quality with the patient.^{6,47,51}
- Are unmarried³⁷ or in shorter-term marriages.⁵¹
- Report high levels of unmet needs for supportive care.^{14,45}
- Report comorbidities⁴⁸ or more unhealthy behavior.⁴⁵
- Use avoidant coping.^{54,55}
- Feel less prepared for caregiving⁴⁷ or confident in their abilities.⁴⁸
- Are caring for patients that are older,⁴⁶ are at a later disease stage,^{48,56} have symptoms,^{31,48} and report poorer physical functioning.^{57,58}
- Have high caregiving demand⁴⁷ and report higher intensity of care.^{6,45}
- Report lower levels of social support.^{42,50,59-62}

Impact on Social Activities and Relationships

Several studies have reported that caregiving disrupts social connectedness and activities as caregivers' energy and time are focused on the patient and their recovery.²⁸ A study of Australian caregivers revealed that more than half (58%) reported a major or a dramatic effect of caregiving on their lives and choices. Caregiving was reported to negatively affect holidays and time away (45.4%), travel (30.2%), available time for hobbies (25.6%) and available time for socializing (15.6%). These impacts resulted in social isolation and loneliness (32%), changes in family and other relationships (25%), a sense of grief and loss (24%), and limited time for personal relationships (11.1%).¹⁵ In another study, almost half of caregivers reported having no time for themselves.¹⁶ The main concern here is that caregivers of people with cancer who have limited social networks and more restrictions in their daily activities are more likely to report caregiver burden.⁶³ A recent study by Price et al⁴² found that lower social support was a predictor of both anxiety and depression for caregivers of women with ovarian cancer.

Caregivers often report trying to participate in social activities but giving up as a result of concern for the patient while they are absent. In a study by Payne et al,⁶⁴ younger caregivers particularly felt that caring impinged on their own life,²⁵ and they found it difficult to express their own needs, unless asked specifically away from the hearing of the patient.²⁵

The significant toll that a cancer diagnosis takes on a relationship is more and more understood.⁶⁵ Even high-functioning couples may struggle to manage the stress and challenges of cancer, as well as changes in their relationships brought on by the cancer diagnosis.⁶⁵ Such stress might lead to tension and conflict within the couple. A qualitative study by Fergus and Gray⁶⁵ among couples facing cancer found that patient reactions that impede couple adjustment included self-absorption, exaggerated dependency, being overly independent, and being overly controlling. Similarly, spouse reactions found to contribute to tension or discord included not knowing how to support the patient, unexpressed anger, withdrawing from the situation, and not prioritizing the patient. Although it has been suggested that cancer might lead to higher rates of divorce, a review by Dorval et al⁶⁶ among couples facing breast cancer does not support this claim.

Caregiver abuse and the risk of abuse in families of patients receiving palliative care has been examined to a small degree.⁶⁷ An Australian study reported that 5% to 13% of elderly people experience psychological, physical, or financial abuse perpetrated mostly by people in a caregiving relationship.^{68,69} A US study found that 26% of care recipients living in the community were exposed to potentially harmful caregiver behavior.⁷⁰ As established patterns of family interaction are carried into a caregiving relationship when a family member becomes ill, abuse of patients may be occurring but not be evident as a result of the stigma of reporting abuse and the secluded lives of patients.⁶⁷ Risk factors for caregiver abuse include greater levels of patients' needs in activities of daily living, being a spousal caregiver, greater caregiver cognitive impairment, physical symptoms, and depression symptoms.⁷⁰ Research suggests that early intervention and support may prevent abuse from occurring or reoccurring.⁷¹ Community palliative care nurses in particular may be well placed to identify where abuse is occurring or likely to occur.

Despite the physical, social, and emotional burden of care, respite services are not well utilized by caregivers.³⁰ Some patients and caregivers do not access specialist services because of the emotional difficulties in discussing death and dying.⁷²

Impact on Financial and Work Status

Caregiving creates a financial burden for family members, both in outright expenses and in lost income and benefits.^{30,73} Some studies have documented the economic burden of informal caregiving in the United States. For instance, Hayman et al¹⁹ found that cancer treatment was associated with an incremental increase of 3.1 hours per week of informal caregiving, which translates into an additional average yearly cost of \$1,200 per patient and just over \$1 billion nationally. Yabroff and Kim²⁰ found that within the 2 years after diagnosis, the value of informal caregiver time varied by cancer site, with the highest time cost for patients with lung cancer (\$72,702; 95% CI, \$56,814 to \$88,590), ovarian cancer (\$66,210; 95% CI, \$40,750 to \$91,670), and non-Hodgkin lymphoma (\$59,613; 95% CI, \$43,423 to \$75,803), and lowest for patients with breast cancer (\$38,334; 95% CI, \$31,442 to \$45,226). The value of care-

giver time also varied by cancer stage at diagnosis from \$40,973 (95% CI, \$35,326 to \$46,620) for localized disease to \$71,278 (95% CI, \$56,303 to \$86,253) for distant disease at diagnosis. Despite this, many caregivers do not avail themselves of available financial help.⁷³

Caregiving also appears to reduce a person's chance of being employed,¹³ and many caregivers are unable to work, need to take leave without pay, have fewer work hours, are in lower paid jobs, or work from home to manage the caregiver demands.^{16,56} Reduction in paid work also contributed to social isolation.³⁰ Long-term financial impacts of caregiving include loss of savings for retirement.¹⁰

Positive Impact of Care Giving

While caregivers report experiencing surprise, shock, disbelief, anger, distress, fear, and depression in response to a cancer diagnosis, they also felt that caring for a person with cancer is an experience that can produce positive emotions. In one Australian study, 60% of caregivers were able to identify positive aspects of their role.⁷⁴ When patients' symptoms were minor, the time together was described very emotively as "precious time," which allowed the exploration of emotions and expression of love for the patient. Postbereavement caregivers in an another Australian study reported being proud, pleased, and satisfied that they had managed the caregiving role.³⁰ 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.^{75,76} In addition, it has been suggested that caring for the patient may help caregivers to accept the death of the patient and work through their grief.⁶⁶

Helping the Caregivers: Supportive Care Interventions

Caregivers are often patients' primary source of support, and although they confront a range of challenges as outlined above, they often receive little or no preparation. Although supportive care interventions have been shown to improve quality of life among patients diagnosed with cancer, few studies have examined psychosocial interventions to optimize adjustment outcomes among caregivers. A recent meta-analysis by Northouse et al⁷⁷ found that three types of interventions are typically offered to caregivers: psychoeducational, skills training (coping, communication, and problem-solving skills), and therapeutic counseling. Although these interventions were found to have small to medium effects, they significantly reduced caregiver burden, enhanced coping behavior, increased self-efficacy (ie, perceived confidence, preparation, and/or mastery to provide care), and improved aspects of quality of life.

Although these interventions are promising in enhancing caregivers' illness adjustment, most are delivered by highly trained health professionals, limiting their accessibility due to high costs; limited availability of qualified professionals, especially in nonmetropolitan areas; transportation costs⁷⁸ and accessibility, particularly for people in rural areas. Self-directed interventions have been proposed to overcome these limita-

tions, with evidence of acceptability to patients and partners.^{78,79} Self-help supportive care interventions have several potential advantages for caregivers, including enabling caregivers to select what, how, and when they want to learn.

Few studies have examined the potential of self-directed interventions to enhance patient adjustment. Beatty et al⁷⁸ examined the efficacy of a self-directed, coping skills workbook for women recently diagnosed with cancer and found support for the efficacy of the workbook in improving PTSD symptoms, cognitive avoidance, and feelings of helplessness or hopelessness. Lambert et al⁸⁰ have begun testing the feasibility of a self-directed intervention for patients and their partner and found that many people prefer a self-directed format. Evidence is urgently needed to support the efficacy of self-directed interventions in enhancing caregivers' illness adjustments.

Conclusion

Many caregivers report deep levels of satisfaction from their caring role. However, many more experience significant burden, particularly with respect to their physical and psychological well-being, economic circumstances, and social and personal relationships. Caregivers play a critical role in the overall care of people with cancer; for some, caring is equivalent to a full-time job. However, there is currently little support available specifically to assist caregivers in undertaking this important task. Health care professionals are well placed to identify caregivers who may be at risk of significant burden and to support them through direct care or by referral to appropriate services to help meet their needs.

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Provision of study materials or patients: Afaf Girgis

Collection and assembly of data: All authors

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Afaf Girgis, BSc(Hons), PhD, Executive Director, Translational Cancer Research Unit, Ingham Institute, South Western Sydney Clinical School, UNSW Medicine, The University of New South Wales, PO Box 7103 (Westfield), Liverpool BC 2170 Australia; e-mail: Afaf.girgis@unsw.edu.au.

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