The role and supportive care needs of the partners and carers of women with breast cancer

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Abstract

More than 15,000 women are expected to be diagnosed with breast cancer in Australia in 2016. The shift towards delivering cancer care through ambulatory treatment centres means that partners, relatives, children, siblings and friends of women diagnosed with breast cancer are commonly required to provide much-needed care and support for these women post-treatment. The role of ‘carer’ can take many different forms and for some, it can be equivalent to a full-time job, with many carers reporting having more things to do than they can handle. Being a carer can be a positive experience, for example some husbands of breast cancer patients undergoing active treatment reported both interpersonal and intrapersonal benefits of caring, such as feeling closer to their partner and growing as a person. However, there is ample evidence that taking on the role of carer has significant impacts on carers’ physical and mental health and many carers feel ill-prepared for that role, especially if the care requires them to address complex medical needs while also supporting their loved one with the psychological challenges experienced following a cancer diagnosis. The inter-relationship between patients’ and carers’ wellbeing is well-documented, with evidence suggesting that carers’ physical and mental wellbeing may influence patient status. Hence, offering informal carers interventions that are structured, goal-oriented and time-limited is recommended to support them in their roles, and many argue that family carers should be considered a ‘co-user’, or ‘co-client’ of cancer services.

It is projected that over 15,000 women will be diagnosed with breast cancer in Australia in 2016.1 Over the past 20 years, there has been a shift towards providing cancer care through ambulatory treatment centres. This has resulted in a considerable expansion of both family carer numbers and the variety and complexity of tasks they perform.2 Caring for a loved one with cancer has the potential to impact on both the physical and mental health of carers, and many feel ill-prepared for being a carer.3 This paper provides an overview of the roles undertaken by carers, including of women with breast cancer, the impact of being a carer, carers’ supportive care needs and interventions which may support carers in that important role.

Carers of women with breast cancer include their partners, relatives, children, siblings, or friends. In 2015, one in eight (2.8 million) Australians reported being an unpaid carer, 770,000 (29%) of whom identified as a primary carer. In Australia, females represent the majority of primary carers (70%) and carers generally (56%),4 and are likely to be a close relative (e.g. parent, partner or child). Cancer is one of the top 10 health conditions requiring a carer, and the demand for carers will continue to increase as cancer incidence and survival continue to rise.5

Carer roles and responsibilities

Often, carers are a patient’s decision maker, communicator and advocate. The support carers provide to women with breast cancer varies widely and includes instrumental support, such as driving patients to medical appointments, coordinating their healthcare, financial management, assistance with housework,4,6 information support, such as helping patients find information about their cancer and treatment; assistance with decision making,6,7 and emotional support.8,9
Many primary carers are balancing paid work and caring for their loved one. In an Australian study approximately half of carers reported having more things to do than they could handle, and for many, their caring continued even when the patient was admitted to a residential care facility.\textsuperscript{9} Many carers report becoming the primary carer due to a sense of family responsibility and emotional obligation, with little choice and nobody else available to undertake the role.\textsuperscript{4} Stepping into a carer role can be a difficult transition, involving negotiations with the patient, their families and healthcare team. However, often carers assume their novel roles and responsibilities without being fully aware of the burden these might cause, regardless of their readiness to do so and with little to no formal training.\textsuperscript{10}

The caring needs of people with cancer vary. Carers are estimated to provide about 70–80% of patients’ cancer care,\textsuperscript{11} and for some carers the role can extend over several years and be akin to a full-time job.\textsuperscript{12} Yabroff and Kim reported that informal carers of breast cancer patients provided 6.4 hours of care per day for 13.6 months in the two years post-diagnosis, which translated to an average of $38,334 per patient in carer time costs.\textsuperscript{13} In Australia, it is estimated that informal carers save the Federal budget $60.3 billion annually (equivalent to 60% of the health and social work industry), highlighting the economic value of their roles.\textsuperscript{14}

Worryingly, with the increasing shift from inpatient to outpatient healthcare provision and changes in population demographics, forecasts show that the demand for informal caring will outstrip supply within the next 10 years.\textsuperscript{14} This widening healthcare gap presents significant challenges in cancer care that will lead to poorer patient outcomes and greater pressure on informal carers if left unmet.

**The impact of caring for someone with cancer**

Providing care for a partner with cancer has the potential to affect the physical and mental health of carers, who often feel ill-prepared to take on such a role, especially if they are required to address complex medical needs while simultaneously supporting their loved one with the psychological challenges associated with cancer.

Carers report high levels of anxiety and depression,\textsuperscript{15} burden and unmet needs,\textsuperscript{16,17} and declining physical wellbeing,\textsuperscript{18} and some carers do not ‘bounce back’ after a period of initial adjustment, creating an at-risk group of carers.\textsuperscript{15,17} Across the first year post-diagnosis, psychosocial adjustment levels in breast cancer patients’ husbands were reported to be worse than husbands of women with benign breast disease and no different to that of the breast cancer patients themselves.\textsuperscript{19} Psychosocial adjustment difficulties are reflected in poorer carer quality of life (QOL) in domains including general health, vitality, role-emotional, and mental health.\textsuperscript{20} Importantly, the strongest predictor of husbands’ psychosocial adjustment one year post-diagnosis was adjustment levels immediately post-diagnosis,\textsuperscript{21} indicating that initial difficulties persist over time, and also highlighting the importance of early intervention to support carers.

The physical and psychosocial impact of caring can vary significantly depending on the patient’s functional status. For example, carers of breast cancer patients with more comorbidities report significantly higher levels of fear of cancer recurrence.\textsuperscript{22} Caring for women with advanced breast cancer can exact a particularly high toll. Grov et al found that male primary carers of advanced breast cancer patients experienced greater anxiety and lower mental QOL compared with age-adjusted norms.\textsuperscript{23} Further, Grunfeld et al reported that significantly more carers of women with advanced breast cancer were depressed (30% vs 9%) and perceived a greater burden at the start of the terminal period (i.e. closer to death) versus the start of the palliative period; and that burden was the strongest predictor of anxiety/depression.\textsuperscript{24}

Sleep quality has been explored in breast cancer patients and their carers, given its established correlation with psychological mood and interpersonal relationship quality.\textsuperscript{25} The prevalence of sleep problems in carers of women with breast cancer is high (up to 88-95%).\textsuperscript{26} Importantly, in one study, sleep problems predicted 63% of variance in carer depression.\textsuperscript{26} While non-pharmacological interventions have been shown to improve patients’ sleep quality and immune function,\textsuperscript{27} reduce sleep medication use and mood disturbance,\textsuperscript{28} and reduce fatigue and enhance daily activities,\textsuperscript{29}
there is a dearth of interventions targeting carer sleep quality. This is clearly an area that requires attention.

The impact of the relationship between the carer and patient on carer outcomes has been explored in several studies. In a qualitative study of bereaved carers of women with advanced breast cancer, Coristine et al found that spousal and non-spousal carers perceived their roles quite differently, with spousal carers considering themselves decision makers and non-spousal carers seeing themselves more as patient advocates.\(^{30}\) Non-spousal carers also perceived they had more roles to juggle, as they managed separate residences, jobs and/or their own family. Many studies of breast cancer carers have included only heterosexual male partners. While gender may influence carer outcomes - for instance Lopez et al found adherence to masculine norms of stoicism meant male carers were less supported\(^{31}\) - carer sexual orientation does not appear to be significant, although more research is needed in this area.\(^{32}\)

Carers’ affective states and personality traits may colour their perceptions of the impact of caring. Kurtz et al found that carers (25% of sample was caring for breast cancer patients) with higher optimism levels reported a lesser impact on their schedule and health and lower levels of depression.\(^{32}\) Male spouses of breast cancer patients who felt more hopeful, less guilty, and had greater self-efficacy reported better QOL.\(^{33}\) This research highlights the need to explore a wide range of variables to better understand carers’ preparedness to cope with the known stresses of a carer role, particularly as impairments in carers’ wellbeing can limit their ability to provide care.

Despite cancer carers facing many challenges they also experience positive outcomes. In one Australian study, 42-98% of carers identified at least one positive element in their cancer caring experience.\(^{34}\) Another study found husbands of breast cancer patients reported both interpersonal and intrapersonal benefits of caring, such as feeling closer to their partner and growing as a person.\(^{35}\) More research is needed to understand the complex interrelationships between caring benefits and burdens, with mixed associations found to date.\(^{35,36}\)

**Carers’ unmet needs**

Carers report significant unmet needs, particularly relating to comprehensive cancer care, information, emotional and psychological, daily activities, social and relationship, and spiritual issues. A recent systematic review identified that carers of cancer patients report an average of 1.3-16 unmet needs (range 17-67), suggesting that 5-47% of carers’ needs remain unmet.\(^{37}\) Studies have also reported carers’ needs exceeding those of patients,\(^{37}\) including within the breast cancer context,\(^{38,39}\) and persisting well beyond the cancer diagnosis.\(^{17}\) Predictors of unmet needs include: being female, distress, anxiety, interpersonal conflict, having lower social support, caring for someone other than a partner/spouse, and having other caring responsibilities (e.g. for children).\(^{37,40}\)

Information needs are frequently cited by carers of breast cancer patients. A study of information needs of informal carers of women treated for breast cancer found that information regarding prognosis and treatment options were priority areas for carers.\(^{41}\) Furthermore, carers wanted honest information so they knew what to expect in the future. Similarly, Schmid-Buchi et al reported that unmet information needs, particularly regarding medication, side effects, treatment plans and knowing what to expect, were the primary unmet need for relatives of breast cancer patients.\(^{38}\) Additionally, family carers needed greater access to, and opportunity to communicate with, medical staff. Obtaining information from medical professionals is important, with Nikoletti et al finding that family carers of post-surgery breast cancer patients who received information from a breast care nurse and medical staff reported significantly fewer unmet needs compared with carers who used other information sources.\(^{42}\) Spouses of women with breast cancer have expressed a preference for information from physicians and nurses rather than family, friends, books and the internet.\(^{43}\) Carers are more likely to be distressed, anxious or depressed if they are not adequately informed,\(^{40}\) highlighting the importance of addressing carers’ information needs.
Within the context of breast cancer, informal carers report unmet needs in other domains, including emotional/psychological, navigating the health care system, social and practical support, and sexuality. For example, Hilton et al found that spouses of breast cancer patients report difficulties navigating the health care system and a sense of marginalisation through health care professionals' failure to adequately acknowledge their role. Regarding sexuality, male carers frequently indicate negative changes to sexual relationships, although few seek assistance. The inter-relationship between patients' and carers' wellbeing is now well-documented, with evidence suggesting that carers' physical and mental wellbeing may influence patient status. For example, a meta-analysis by Hodges et al found a positive correlation between patient and carer psychological distress. Importantly, there is also the potential for carer outcomes to positively impact on patients, with Keeffe et al finding that high self-efficacy for pain management tasks in carers was linked to increased patient energy and time out of bed, and reduced patients' sense of feeling ill. Other studies have shown beneficial outcomes for patients where their carers have received support, with improvements in patient depression and hopelessness, enhanced symptom management and reduced symptom severity/intensity. Therefore, by supporting carers and improving their wellbeing and self-efficacy, there is the potential to enhance cancer patients' QOL.

**Interventions to address carer needs**

While support groups can assist some carers, there is a paucity of groups specifically for male carers of women with breast cancer and carers may not attend due to time constraints. Research has consistently found that cancer carers have insufficient knowledge and skills regarding caring tasks (e.g. symptom management) and experience communication barriers and inadequate emotional support. Most carers report needing some level of support, and identify psycho-educational programs as an avenue to address their needs. A meta-analysis of cancer carer training interventions showed carer training significantly improves carer burden, QOL and self-efficacy; has the potential to improve anxiety and depression; and improves carer preparedness and competence. A review by Applebaum and Breitbart concluded that interventions for informal carers that are structured, goal-oriented and time-limited are most effective and feasible.

There is a developing literature examining the effectiveness of interventions specifically developed to address the needs of carers for women with breast cancer. A review by Lally and Brooks found six interventions designed for supporters of women with early breast cancer, and while results were mixed, all studies found positive change in at least one outcome. Similarly, a review of couple-based interventions in breast cancer found that both women and their partners reported improvements in QOL and relationship functioning, with reductions in distress and physical symptoms. Results from several pilot studies suggest that supportive care interventions targeting carers or patient-carer dyads dealing with breast cancer can positively impact cancer-related stress and mental health, carer burden, sexual dysfunction, partner anxiety, depression, caring skills, self-confidence and self-care.

Larger randomised controlled trials are also beginning to emerge examining the efficacy of interventions for patient-carer dyads in both early-stage and advanced-stage breast cancer. Manne et al compared a couple-based support group to an eight-week structured skills group intervention for couples dealing with early-stage breast cancer (n=302), finding improvements in anxiety, depression, distress and positive wellbeing over time in both groups. A moderating effect was observed for baseline distress, with supportive group therapy most effective for highly distressed patients and structured skills-based therapy most beneficial for less distressed patients. Another trial conducted by Northouse et al with a mixed sample of advanced cancer patients and supporters (n=157; 32% breast cancer patients and carers) compared a three or six-week information and support intervention to a usual care control group. Overall, findings suggested that both intervention groups benefitted, with short-term improvements in coping, self-efficacy and QOL (social and emotional). Both interventions reduced avoidant coping and maintained social QOL, the three-week intervention was particularly effective in improving patient and carer health behaviours, while the six-

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week intervention had a greater effect on self-efficacy. While intervention effects were not sustained over time, this is understandable given the advanced disease facing couples in this trial.

In light of the evidence presented in this paper, some argue that family carers should be considered a ‘co-user’, or ‘co-client’ of cancer services. However, in reality, most carers are not the recipient of care in relation to their caring role and are often considered by health care providers as being outside their scope of responsibility, despite growing recognition of their unmet needs. New models of care are needed to both acknowledge carers’ inclusion in the broader care team and also to support them in the critical role they play in caring for women with breast cancer.

References


