Chapter 6
The Impact of Cancer and Chronic Conditions on Caregivers and Family Members

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Abstract Caregiving by a family member or a friend is critical in maintaining and improving the health and well-being of individuals living with cancer, and in reducing demands on the health care system. The increased prevalence of cancer and co-morbidities is applying pressure on already stretched cancer care resources and high-quality cancer care now relies on caregivers taking on more and more complex illness management roles (once performed by health care professionals). Caregivers provide about 70–80 % of patients' cancer care, the economic value of which is estimated to be at least in the millions. Although caregiving is a valued societal and financial resource, caregivers remain largely a hidden workforce. Caregivers often take on their roles and responsibilities with little to no formal training, leading to high levels of burden and lower quality of life for both the caregivers and the person they are caring for. Cancer caregivers are a particularly vulnerable sub-group, as they report higher burden than caregivers for individuals with diabetes or frail elders. Although across caregiver studies it might be assumed that many of the patients cared for have co-morbidities, this information is not always explicit and there are no studies specifically examining the burden endured by caregivers of patients with cancer and co-morbidities. Therefore, the purpose of this chapter is to summarize what is known about cancer caregiving and note how these findings might be extrapolated to begin to understand the issues faced by caregivers of patients with cancer and co-morbidities. The chapter provides an overview of caregivers' roles in cancer care and the impact of this involvement on caregivers' health and functioning; their patterns of health care services utilization; a description of the type of support caregivers require more of (unmet needs); and the effectiveness of interventions that can support caregivers throughout the cancer trajectory. A discussion of future directions for research and practice concludes this chapter.

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Key Points

- With the expected growth in the number of caregivers due to the aging of the population and changes in the health care system as well as the substantial burden endured, caregiving is now a public health priority.
- Caregivers fulfill a wide range of roles and responsibilities and often feel unprepared to meet the multiple demands of caregiving.
- An extensive reliance on caregivers adversely impacts on their own physical health, immune function, health behaviors and lifestyle, mental health, social functioning, and financial status, which may limit the extent to which they can sustain their involvement.
- Despite significant challenges, caregiving can also be a positive experience, whereby between 42 and 98 % of caregivers identify at least one positive element in or change arising from their caregiving experience.
- Caregivers report unmet needs in the following domains: comprehensive cancer care, emotional and psychological, partner or caregiver impact and daily activities, relationship, information, and spiritual.
- Although caregivers seem to engage with health care services in regards to cancer screening and primary care visits, there is evidence to suggest that caregivers under-utilize available services, particularly in relation to their mental health needs.
- The ultimate goal of caregiver interventions is to identify the most effective ways of supporting caregivers and meeting their most pressing needs. Significant effects of caregiver interventions are particularly noted for improving knowledge, appraisal, self-efficacy, coping, relationship communication, psychological well-being, sexual functioning and intimacy, and relationship functioning.

6.1 Introduction

Cancer is among the most common conditions worldwide requiring help from informal caregivers, such as a friend, partner, family member, or neighbor. The cost-containment health care context and the increased reliance on outpatient cancer treatment is shifting cancer care from the hospital to the community and is leading to an unprecedented dependence on caregivers' support for high-quality care [1]. Also, with the aging of the population and the concurrent increase in life expectancy, there is a rise in the incidence of cancer, and co-existing chronic diseases, which is leading to an ever increasing cohort of caregivers needing assistance to sustain their role.

Caregivers are patients' primary source of support, with the informal care provided often involving a considerable number of hours per week [2]. Although caregivers' support reduces the demands on the health care system [3], too often caregivers take on their novel roles and responsibilities with little to no formal training [1, 4]. Many caregivers assume their roles and responsibilities without being fully aware of the burden these might cause, and regardless of their readiness to do so. Despite caregivers' best efforts to manage the demands of their role, these might inadvertently exceed their capabilities and result in high levels of physical, emotional, social, and/or financial burden [5–9]. Of concern, caregivers often put aside their own needs to focus on supporting patients [6] and resist using health services to alleviate their burden, which might decrease their ability to sustain their caregiving role and increase caregivers' risk for long-term health complications [10].

With the expected growth in the number of caregivers due to the aging of the population and changes in the health care system, the increased complexity of their role due to the rise in multi-morbidities, and the substantial burden endured, caregiving is now a public health priority. The recognition of caregivers' personal, physical, social, and financial investments in patients' recovery by researchers, clinicians, and policy makers has been coupled with an exponential increase in the research on the psychosocial impact of a cancer diagnosis on caregivers [11]. However, this literature has mainly focused on cancer caregiving in isolation, ignoring the presence of co-morbidities for many patients. This, despite the fair assumption that as the complexity of care increases for patients with multi-morbidities, so does the complexity of informal caregiving. Although it can be supposed that in most cancer caregiver studies the patients had at least one other co-morbidity, these co-morbidities are rarely reported (mainly limited to cancer type, stage, and treatment) and it is therefore difficult to draw conclusions from these studies for this sub-group of caregivers. Given the scarcity of studies examining the issues specifically faced by caregivers of patients with cancer and co-morbidities, this chapter will summarize what is known about cancer caregiving to date and identify directions for future research. This chapter commences with a review of who the caregivers are and what their main roles and responsibilities in cancer care are. Then, the impact of these roles and responsibilities on caregivers' health, functioning, and well-being is presented. This is followed by an overview of caregivers' common supportive care needs and their patterns of health care service utilization. The last section of this chapter provides in-depth evidence about the effectiveness of caregiver interventions. A discussion about the implications of these findings for caregivers of patients with co-morbidities and priorities for future directions for research and practice concludes this chapter.

The definition of caregiver used in this chapter is: family member, partner, friend or neighbor assisting with health care activities for someone with cancer who is unable to independently care for him or herself or needs assistance to manage his/her cancer care or cancer treatment [12].

6.2 The Roles of Caregivers in Cancer Care

6.2.1 How Many Caregivers Provide Care?

Caregivers are a diverse group representing a significant proportion of the population [3, 13, 14]. Whilst the assessment of caregiving responsibilities differs across countries, the proportion of the population defined as caregivers ranges from 10 to 50 %. For example, in a survey conducted by the National Alliance for Caregiving (NAC) in the US, 18.2 % of respondents were caregivers in the previous year, with top conditions requiring caregivers' assistance including "old age," Alzheimer's disease or dementia, surgery or wounds, and cancer [13]. This translates to cancer alone accounting for 7 % of all informal caregivers in the US [13]. In Canada, 28 % of Canadians aged 15 years or older report providing care in the previous 12 months to a family member or friend experiencing a health or age related condition [3]. This rate increases to 46 % when considering whether similar care was provided at some point in their lives [3]. Top conditions requiring assistance from caregivers include: age-related needs, cancer, cardiovascular disease, mental illness, and Alzheimer's disease or dementia [3]. Hence, in Canada, 11 % of caregivers provide care for someone with cancer [3]. In Australia, 12 % of the population were caregivers in 2012 [14], with cancer also representing 1 of the 10 most common health conditions for which people received informal care [14, 15].

6.2.2 Who Provides Care?

Although caregivers across all health conditions are overwhelmingly family members, cancer caregivers are more likely to be the spouses of the care recipient. This is in contrast to those caring for someone with mental health-related needs or age-related needs who are more commonly a parent or adult child, respectively [3, 13]. An estimated 54–60 % of caregivers are women [3, 13, 14], although the number of men taking on caregiving responsibilities has markedly increased [13, 16, 17] and is expected to continue to increase due to the aging population and changing conceptualizations of family and gender roles [18, 19].

Caregivers are predominantly between the ages of 45 and 64 [3, 13]. It is noteworthy that currently nearly one in 10 American caregivers is over the age of

75 [13]. Similarly, Canadian seniors aged 65 years or older represent 12 % of all caregivers. Although a relatively small proportion of the caregiver population, these individuals are the most likely to spend the longest hours providing care [3]. Another particularly vulnerable group are those "sandwiched" between raising children and taking on additional caregiving responsibilities, a growing group because of the overall aging of the population [3].

Information about the race and ethnicity of caregivers is scant, though it is estimated that in US, 62 % of caregivers are White, 17 % are Hispanic, 13 % are African American, and 6 % are Asian American [13].

In the US, The American Cancer Society's (ACS) *Quality of Life Survey* for Caregivers (N = 739 caregivers) is the most complete source of information on cancer caregivers [20, 21]. Overall, the findings of this survey have been consistent with those of studies examining caregivers as a whole: cancer caregivers are predominantly Caucasian, middle-aged women who were the spouses of the care recipient [22, 23]. One notable difference is that nearly 90 % of the participants are Caucasian. This might be related to particular patient populations being more likely to participate in research and subsequently nominating their caregivers [20]. In Australia, a 5-year longitudinal *Partners and Caregivers Well-Being Study* (N = 547) reported similar demographics [5, 8, 9].

6.2.3 How Much Care Is Provided?

Most patients with cancer identify an informal caregiver, who fulfills essential roles and responsibilities that contributes to their illness adjustment [24]. In the US, Kim and Schulz [2] found that cancer caregivers provided on average 31 h of informal caregiving per week, with the burden of cancer caregiving among the highest compared to other caregivers. A report by Statistics Canada found that cancer caregivers were among the top three caregiver sub-groups providing more than 10 h of care per week [3]. In another study, Yabroff and Kim [24] found that on average cancer caregivers dedicated 8.3 h per day (in a range from 4.2 to 12.0 h) to providing care over approximately 13.7 months (in a range from 11.4 to 16.7 months). Medical characteristics, such as the type of cancer and the stage at diagnosis, further increased caregiving intensity, with ovarian and lung cancers requiring the greatest time commitment (>10 h), compared to kidney and bladder cancers (<7 h), which required the least time input. Also, caregivers' socioeconomic status was inversely related to the number of hours per day spent providing care. Finally, Hayman et al. [25] reported that individuals treated for cancer received on average 10 h of informal caregiving per week, compared to about seven hours for those who were diagnosed with cancer, but did not receive treatment in the last year ($p < 0.05$).

6.2.4 What Kind of Care Is Provided?

The transition to the caregiving role is life changing [26], with many caregivers perceiving their responsibilities as unknown and demanding [27]. Caregiver roles and responsibilities typically include: practical care, emotional support, household tasks, financial management, and advocacy/decision-making. In Australia's *Partners and Caregivers Well-Being Study,* caregivers reported being mostly involved in: household tasks (daily 68.5 %), emotional support (daily 39.9 %), and managing money (daily 22.7 %) [6]. Interestingly, providing emotional support, liaising with doctors, making appointments and assessing needs for and managing medication were more associated with caregiver anxiety than other tasks [6].

6.2.4.1 Practical Care

Practical care involves the home-based provision of specialized medical care, planning and coordinating care, monitoring the patient's health status and anticipating health needs, and meeting the day-to-day needs (e.g., activities of daily living, personal care) of the person with cancer [28–30]. Ussher et al. [30] reported that medical tasks typically assumed by caregivers include administering injections, dispensing medications, maintaining a colostomy bag, and wound care. In a study by Kim and Schulz [2], activities of daily living most often performed by cancer caregivers included helping patients transfer into and out of a bed, chair, or toilet; providing assistance with bathing; showering and dressing; and feeding the care recipient. Transportation of the patient to and from medical appointments can also constitute a significant task for caregivers, particularly for those who rely on public transport [31].

6.2.4.2 Emotional Support

Emotional support involves providing accompaniment, encouragement, and distraction throughout the cancer experience [32]. It involves tasks such as talking, engaging in pleasurable activities together, being present during medical consultations, encouraging questions during appointments with healthcare providers, and openly discussing worries [24]. Many caregivers experience least confidence and greatest uncertainty in performing these emotional tasks [29, 33], and acting as an emotional buffer and dealing with the psychological responses to cancer are among the most difficult tasks for caregivers [29]. Nonetheless, caregivers recognize the benefits of providing emotional accompaniment for both themselves and the patient [27].

6.2.4.3 Household Tasks

Many caregivers are challenged by the additional responsibilities in the household tasks previously performed by the ill person [30], such as shopping, housework, meal preparation, garden maintenance, and being the family designated driver [8, 30]. Men and women caregivers report assuming different household tasks, primarily those previously performed by their spouse of the opposite gender; this is especially prevalent in the older adult age group [30]. Additionally, those with children have the added pressure of maintaining daily routines and providing childcare [27, 28]. The assumption of these household tasks is especially cumbersome during times in which the patient is perceived to be in poorer health [28].

6.2.4.4 Financial Management

Managing money is another daily task that has long-term implications for caregivers, including mitigating the loss of savings for retirement, altered educational plans for family members, and loss and/or change of housing [2, 8, 15]. Financial management includes distribution of family income to cover illness-related costs, paying household bills, and supporting lifestyle activities [34]. In support of this, Parker et al. [35] identified three main financial concerns among caregivers of patients with terminal cancer: (a) expenses directly related to patient care, (b) costs associated with caregiver lifestyles (e.g., mortgage); and (c) managing financial assistance from insurance companies and government aid.

6.2.4.5 Advocacy/Decision Making

Caregivers often adopt the role of decision-maker [30]. Although patients are encouraged to make their own care decisions, cognitive changes or communication difficulties may result in the caregiver confronting the decisions about treatment and care provision [28, 30], end-of-life care, and household matters [26]. Caregivers also often advocate for the patient by obtaining the necessary support, information, and resources [27]. McIlfatrick et al. [36] found that caregivers assumed the role of advocate through first identifying the knowledge gaps of the patient, and then helping him/her acquire the necessary information to make informed decisions. Likewise, Bowman et al. [37] found that caregivers played a key role in health maintenance advocacy, which mainly encompassed encouraging health-promoting activities (e.g., exercise, healthy eating) among patients.

6.2.5 What Kind of Skills Do Caregivers Need?

To engage effectively in caregiving processes, caregivers must first have knowledge of the illness, the possible treatment, the patient's care plan, and the short- and long-term implications of the illness [38]. Once this foundational knowledge is in place, caregiver skills can be developed, i.e. the "ability to engage effectively and smoothly" in various care-related processes [39]. Given et al. [38] identified three categories of caregiver skills: psychomotor, cognitive, and psychological skills. Psychomotor skills involve the coordinated activity required to perform medical tasks. Cognitive skills involve higher-order thinking related to illness management such as symptom monitoring, decision-making, and problem-solving. Finally, psychological skills allow the caregiver to provide emotional support and manage the emotional burden associated with caregiving. Schumacher et al. [39] identified nine key caregiver skills: monitoring, interpreting, decision-making, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system.

Research suggests that cancer caregivers score relatively low on measures of self-efficacy or their confidence in their ability to provide the required care [40]. However caregivers' self-efficacy varies greatly across studies [38], and some factors contribute to enhanced self-efficacy. For example, the following factors positively influenced self-efficacy in caring for lung cancer patients: (a) being older, (b) caring for a patient who has never undergone chemotherapy or radiation, and (c) reduced symptoms and distress among patients [40]. Improved self-efficacy has positive implications for both the patient and the caregiver [40, 41]. Among caregivers, higher self-efficacy has been associated with a reduced risk of mood disturbances and role strain [41] and improved energy levels, reduced time in bed, and improved symptoms among patients [41].

6.3 The Impact of Cancer Caregiving

For many, caregiving can become an enduring and exhausting experience. The following section summarizes the impact of cancer caregiving on their physical health, immune function, health behaviors, mental health, social activities, and finance. An overview of the positive impact of caregiving is also provided.

6.3.1 Physical Health

As many caregivers are elderly themselves, they are not only managing patients' illness(es), but they are also coping with their own chronic illness(es), which affects and is affected by the caring role [42]. Caregivers often prioritize patients' health needs over their own, and they might consequently lose control of the management of their illness(es) [12]. Common physical chronic illnesses among caregivers include hypertension, high cholesterol, chronic back pain, heart disease, and arthritis, with the majority of caregivers reporting more than one chronic illness [42]. Although Shaffer [43] found that cancer caregivers had comparable cardiovascular health to the general population, Ji et al. [44] found that spouses of patients with cancer had greater risk for coronary heart disease and stroke after their spouse was diagnosed compared to those without a spouse with cancer. Possible reasons explaining these different findings include: timing of measurements, caregivers' age, type of caregivers included, and methods used to determine disease status [43].

A recent review reported that caregivers' main physical health problems included sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss [7]. Dhruva et al. [45] found that approximately 40–60 % of caregivers experience sleep disturbances, with a similar proportion reporting moderate levels of fatigue. A study of caregivers of individuals with advanced cancer found that 69 % reported fatigue at baseline, which increased as the patients' disease progressed over time [46]. Other factors that contribute to caregiver fatigue and sleep disturbance include emotional distress [47, 48], financial problems [47, 48], an inadequate support system [47, 48], and high level of patient fatigue [47]. Caregivers' physical health problems can extend for years. For example, a study by Asgeirsdóttir et al. [49] examined the impact of spousal loss among widowers on chronic pain 4–5 years later and suggested that low-preparedness prior to a wife's death may contribute to an increased risk of chronic pain among younger widowers and comorbid anxiety, depression, and sleep disorder.

Although a number of quality of life studies have found that caregivers' physical health is comparable to population norm (commonly determined by the SF-12 or SF-36 health surveys) [12, 22, 42, 50–52], others have emphasized the strain of caregivers' roles on their physical health [52–55]. The longitudinal study by Lambert et al. [54] found that caregivers' physical health was comparable to the population norm at 6 months following the diagnosis of cancer in the patient. However, a steady decrease in physical health over time meant that by 2 years post-diagnosis, their physical health fell below population norm. This decline was noted until the last data collection time point of 5 years post-diagnosis. Caregivers' physical health has also been found to be lower than what patients report [56, 57]. Key risk factors associated with low caregiver physical functioning include: being a women [52, 56] or older [22, 50, 51, 53, 56]; reporting lower education [22, 52, 53], unemployment [22, 52, 53], or lower socioeconomic status [50, 52]; not having all the support needed [51]; experiencing symptoms [53]; reporting high psychological distress [56], caregiver stress [53], or depression [54, 55]; caring for someone who also report high distress [56] or lower physical functioning [22, 52]; and caregiving for other family members [22].

6.3.2 Immune Function

Recently studies have documented that caring for a patient with cancer has an adverse impact on caregivers' immune function [58, 59], providing evidence of biological mechanisms that might underpin caregivers' poorer health in comparison to non-caregivers. For instance, Wells-Di Gregario et al. [60] examined the impact of breast cancer recurrence and cancer-specific stress on spousal health and immune function. The results indicated that only the cancer-specific stress was associated with increased physical symptoms and lower T-cell blastogenesis in caregivers, whilst patient recurrence status did not significantly predict caregivers' physical health or immune function. Mortimer et al. [61] added that living for a longer time with an ill spouse, reporting depression symptoms, and having more intrusive thoughts were associated with suppressed cell-mediated immunity. Of note, Rohleder et al. [59] found that the C-reactive protein level of caregivers of patients with brain cancer in the year following the diagnosis was in the range associated with a higher risk of coronary heart disease.

6.3.3 Health Behaviors

Caregivers report multiple unhealthy behaviors, including low fruit and vegetable intake, increased use of tobacco and alcohol, low physical activity, and being overweight [62–67]. Beesley et al. [62] found that after three years, 54 % of caregivers of women with ovarian cancer did not meet the Australian guidelines for physical activity, 71 % were overweight/obese, 40 % ate less than two servings of fruits per day, 80 % ate less than five servings of vegetables per day, 37 % consumed more than two alcoholic beverages per occasion, and 10 % were smokers. In this study, slightly more than half of caregivers reported more than one negative health behavior change since they took on their role. However, some positive changes were also noted, including 14 % of caregivers increased their physical activity, 7 % increased their fruit, and 13 % their vegetable intake, 20 % purposefully lost weight, and 3 out of 13 quit smoking. Of concern, Kershaw et al. [67] found that caregivers tended to use alcohol and drugs as a coping strategy more so than patients (although this strategy was the least used avoidant coping strategy for both patients and caregivers).

Few studies have examined risk factors for caregivers' unhealthy behaviors, but those that have, draw attention to: being a woman [64]; low caregiver health [64, 66], social support [64], and education [62]; and high interference in daily activities due to caregiving [62, 68] and distress [62]. Humpel et al. [69] found that family and friends of cancer survivors who perceive a greater risk of developing cancer were more likely to increase their physical activity and sun-prevention behavior than those family members who did not perceive a greater risk. Stage along the cancer trajectory, and associated variations in caregiver burden, also seem to have an impact, with active caregivers more likely to report higher levels of unhealthy behaviors than those in the survivorship phase [65]. Despite caregivers being prone to unhealthy behaviors, some studies underscore caregivers' motivation and perceived benefits to improve their health behaviors [63, 64]. Cooley et al. [63] found that family members of patients with lung cancer had high rates of unhealthy behaviors; however, between 42 and 56 % expressed readiness to change one unhealthy behavior in the next 30 days. In this study, most (92 %) were interested to participate in a health promotion program.

6.3.4 Mental Health

The most common mental health issues experienced by cancer caregivers are psychological distress, anxiety, and/or depression [70–72]. A quarter (26 %) of caregivers report depression (range = 18.4–35.0 %), and 40.1 % report anxiety (range = 25.4–55.9 %) [73]. The prevalence of caregivers' psychological distress, anxiety, and depression is often reported as being greater than that of the general population [9, 72, 74–76], and in some cases, rates exceed those reported by the patients' [70–72]. For instance, among a mixed group of caregivers of cancer survivors, Lambert et al. [9] noted that 35.8 % of caregivers reported clinically significant levels of anxiety 6 months post patient diagnosis. This prevalence exceeded the anxiety rate reported by the patients themselves [77] and population norm [9]. However, at 12 months, 30.5 % of caregivers reported anxiety, a rate comparable to population norm. The proportion of caregivers reporting clinically significant depression exceeded population norm at both 6 and 12 months post patient diagnosis (15.1 and 15.9 % respectively) [9]. Although caregivers' anxiety and depression tend to decrease over time [78–81], Lambert et al. [5] further reported that caregivers reporting clinically significant anxiety or depression at 6 months continued to do so throughout the first 2 years post-diagnosis.

Predictors for increased risk of psychological distress, anxiety, and/or depression in caregivers include:

- *Gender*: Females experience in general poorer mental health than their male counterparts, regardless of their role in the illness (i.e., caregiver versus patient) [70, 82–87].
- *Marital status*: Spouses experience more anxiety than other caregivers (i.e., relatives, friends) [84, 86, 88, 89], and caregivers living with the patient tend to be more depressed [89].
- *Age*: Young to middle-aged caregivers tend to be more anxious than older caregivers [74, 85].
- *Physical/mental functioning*: Caregivers who are in poor health and are unable to function normally are more likely to experience depression [86].

- *Role in family*: Caregivers who are adult children of patients with cancer and/or those who have children at home tend to experience high anxiety and depression [85, 88, 90].
- *Employment status*: Caregivers who are employed report higher levels of depression [90].
- *Quality of life*: Caregivers with lower quality of life are more anxious and depressed [74, 75, 87].
- *Social support*: Caregivers with lower social support tend to be more anxious and depressed [5, 9, 72, 91–95].
- *Care burden*: Burden appears to be a key predictor of depression in caregivers [86].
- *Unmet needs*: Higher unmet needs tend to be associated with greater levels of anxiety [9, 87].
- *Coping*: Avoidant coping is a recurrent predictor of high caregiver anxiety or depression [9, 91]. Also, higher use of problem-focused coping by patients has been associated with higher fatigue among caregivers [82].
- *Interference with regular activities*: Interference with caregivers' schedule is associated with anxiety and depression [9].
- *Phase along the illness trajectory*: Caregivers tend to report the most anxiety or depression around the time of diagnosis [96, 97].
- *Type of cancer*: Caregivers of patients diagnosed with lung, hematological or head and neck cancers have been found to experience high anxiety and depression [9].
- *Type of treatment*: Caregivers of patients who have surgery and chemotherapy or surgery and radiation therapy tend to be more anxious and depressed than caregivers of patients who undergo surgery alone [97, 98]. Increases in patients' symptoms and severity have also been linked to more distress, anxiety, and/or depression in caregivers [99].

In addition to these variables, a meta-analysis by Hagedoorn [100] has found a moderate, positive association between patients' and caregivers' levels of distress ($r = 0.29$, $p < 0.001$); which implies mutuality in response. That is, if one member of the dyad is distressed, the other is also more likely to be distressed, suggesting that patients and their caregivers react to the cancer diagnosis as an interdependent, emotional system. Of note, increases in caregivers' levels of distress tend to be higher at time of diagnosis and treatment, whereas patients' distress tend to be higher once treatment is completed; however, these differences disappear over time where both patients and caregivers experience similar levels of distress [96].

6.3.5 Social Activities and Relationships

Social changes associated with caregiving include disrupted household routines, reductions in time for family or social activities, and changes in family functioning and relationship quality with family, friends, and the patient [52, 101]. Although caregivers may want to participate in various social activities to help them cope with the stress of their role, they often worry or feel guilty if time is spent away from the person they are caring for [8]. Litzelman et al. [101] found that, among caregivers of patients with lung or colorectal cancer, social stressors (e.g., others making too many demands on them, being critical of them) were more often reported than disruptions in family functioning and relationship quality. In this study, older caregivers, with higher education, who were the patients' primary caregiver and involved in more caregiving tasks, were at risk of experiencing more social stress. Similarly, Mosher et al. [52] found that social changes most frequently reported by caregivers of patients with lung cancer were reductions in time for social activities with friends (57 %) and for family activities (47 %), whereby relationships with the patient and family were least negatively affected. This is consistent with reports that 42 % of patients and spouse caregivers find cancer brought them closer [102]. Although many couples identify remaining strong during the turmoil of cancer, those experiencing troubles pre-diagnosis often find their relationship further deteriorates with the added stress of cancer [103]. Relationship vulnerabilities for couples include interruptions in intimate relationships [104, 105], incorporating the prospect of death and separation [105], managing differential preferences for communicating about cancer [105], negotiating what is helpful or not to the other person [105], accommodating changes (e.g., change in personality, goals for the future, behaviors) in the other person [105], and coping with each other's emotional reactions [104, 105]. Despite these challenges, the claim that cancer leads to higher rates of divorce in comparison to the general population is not supported [106, 107].

In some instances, caregivers report lower social support and higher loneliness than both the patients and matched controls [108]. Although lower social support can adversely impact on their mental health [5, 9, 72, 91–95], it is important to note that not all types of support equally buffer caregivers' burden [5, 109]. For example, Lambert et al. [5] examined the impact of four different types of support—emotional/informational, practical, positive social interaction, and tangible support—on caregivers' anxiety and depression, and found that only low emotional/informational support was significantly associated with high anxiety and depression. In addition, the stress buffering effect of social support seems to depend on the extent to which patients and caregivers are willing to provide or engage in a particular type of support. Incongruence in the type of support patients and caregivers prefer to receive or engage in might actually lead to poorer outcomes (even if that support is considered inherently positive) [95]. Regan et al. [94] further documented that among wives of men with prostate cancer, wives' support behaviors had no impact on their own anxiety and depression, but an increase in men's supportive behaviors predicted an increase (not a decrease) in wives' anxiety and depression. This might reflect wives' discomfort in eliciting support from their partner whom she recognizes is also under significant stress, or it is possible that engaging in open discussions with a partner about serious and sensitive issues might initially increase their salience, resulting in greater distress [94]. In this study, wives' perceptions of men's negative support behaviors were also associated with an increase in their anxiety and depression, which further highlights that the perception of whether the support behavior is positive or negative might be as important (if not more) than the actual behavior itself in determining effects [94].

6.3.6 Finance and Work

As patients and caregivers are preoccupied with the diagnosis, treatment, and recovery, they are often unaware of the impact of cancer on their finances [34]. However, both the direct out-of-pocket and indirect expenses incurred by patients and their caregivers can be substantial and contribute to financial strain [34, 110–112]. Sources of costs include travel to and accommodation during treatments, treatments and medication, taking time off work, reorganization of daily and home life (e.g., help with housework), and coping with the disease (e.g., long distance calls to other family members) [34, 110–113]. Hanly et al. [110] estimated that the cost of the first year of informal care was €29,842 per caregiver, with time lost from other activities accounting for 85 % of the total economic burden, out-of-pocket costs 13 % (e.g., medicine, household expenses), and travel costs 2 %. Others have corroborated that time costs for caregivers contributed the most to the economic burden endured, with caregivers' direct care effort accounting for the majority of the total time costs followed by time lost related to work and leisure [114]. In a study by Carey et al. [113], half of the caregivers reported personal expenses related to their role, with common expenses including parking (36 %), travel to cancer appointments (33 %), and drugs or treatments (25 %). Longo et al. [115] found that 35.6 % of patients required others to take time from work, with these caregivers loosing a mean of 7 work days in the previous 30 days. In addition to missing work, other effects of caregiving on work include: leaving work for appointments, receiving interrupting phone calls, using holidays or special leave, and decreasing work hours [116]. This not only results in loss of income, but could lead to concerns about job loss, employability, lack of promotion, and inadequate pension build-up [34, 113]. To manage financial burden, caregivers might have to sell their assets, use their and other family members' savings, take out loans, or take on an extra job [112]. Further consequences might include house repossession, bankruptcy, loss of independence, and relationship breakdown [34]. Two sub-groups of caregivers appear to be at high-risk for financial strain: those caring for someone in active treatment [110, 111, 113] and caregivers of patients diagnosed with a later stage cancer [24].

6.3.7 Positive Impact of Caregiving

Despite the challenges faced by cancer caregivers, caregiving can also be a positive experience; with between 42 and 98 % of caregivers identifying at least one positive element in or change arising from their cancer caregiving experience [102, 117–119]. A recent review by Li and Loke [120] concluded that positive aspects of caregiving included: (a) improvement in the quality of the relationship between caregiver, care recipient, and the broader family unit; (b) feeling of accomplishment incorporating awareness of their knowledge and capabilities to help the patient and receiving a sense of respect and appreciation from the patient; and (c) meaning derived from caregiving, including elements of reprioritization, altered values, and efforts to maintain normality for the patient and the family unit.

Recognition of the potential benefits that can be derived from the caregiving experience has led to increased research into the concepts of post-traumatic growth and benefit finding, both of which are possible in both spouses [119, 121, 122], adult children and other family caregivers [121–124], in the short- [122, 125] and long-term [122–124] and throughout the cancer trajectory [125, 126]. Weiss [119] found that 88 % of husbands with a wife with breast cancer reported post-traumatic growth in the areas of connection with partner, life priorities, personal strength, and spirituality. Kim et al. [121] found six domains of benefit finding: acceptance, empathy, appreciation, family, positive self-view and reprioritization. Similar results were found in the qualitative study by Levesque and Maybery [124], whereby adult children of patients with cancer reported benefit finding in their relationship with their sick parent, increased emphasis on family, altered life priorities, and personal development. Levesque and Maybery [123] also reported that the level of benefit finding is likely to be higher in caregivers who also report high levels of caregiver satisfaction, suggesting that the two concepts are related and reflect the caregivers' cognitive efforts to positively appraise stressful situations, potentially as a coping mechanism.

The link between post-traumatic growth or benefit finding and the psychological outcomes of cancer caregiving is not yet definitively known. Although the review by Li and Loke [120] concluded that benefit finding contributed to overall caregiver well-being, other research suggests the situation is equivocal. Kim et al. [121] found that different domains of benefit finding had different patterns of association with psychological adjustment. Specifically, higher levels of acceptance and appreciation and lower levels of reprioritization were positively associated with positive adjustment, whereas high levels of empathy and reprioritization and low levels of acceptance and positive self-view were predictive of higher levels of depression. In a study examining the psychological outcomes of the adult children of cancer patients, Levesque [118] found that benefit finding was unrelated to anxiety and well-being, but was a protective factor for depression, whereas Teixeira and Pereira [125] found that positive growth moderated the association between distress and the presence of post-traumatic stress disorder symptoms. Another beneficial outcome is that for some caregivers, the caregiving experience provides an avenue for emotional expression, eliminating feelings of guilt [127], saying goodbye, spiritual development, and gaining a sense of closure [128], which in turn has been shown to assist with grief and adjustment post-bereavement.

Although not denying the negative impact of caregiving, it is equally important to acknowledge the positive aspects of this experience. If attention is not paid to benefit finding and post-traumatic growth, the perception of caregiving will be biased, limiting the extent to which comprehensive theories of caregiver adjustment can be generated [129, 130]. Cohen et al. [117] proposed that screening caregivers for positive elements of the experience may be a way to identify caregivers at heightened risk of poor outcomes. Whilst some have proposed that interventions designed to assist caregivers in acknowledging positive changes brought about by their caregiving role can be beneficial [121, 122], others have expressed concern about the suitability of such interventions, primarily due to disagreement and ambiguity regarding the origins of post-traumatic growth or benefit finding, its measurement, and its relations to psychological health [131–133].

6.4 Common Unmet Supportive Care Needs

Supportive care needs assessment can facilitate the appropriation of services and support for caregivers by optimizing intervention development and allocation of limited economic resources for addressing those needs that remain unmet [71, 134]. A need is labelled as ‘unmet’ when the services required to deal with a particular issue are not received [135]. Caregivers’ most prominent supportive care needs often remain unmet [136], compromising their quality of life [137–140] and adversely impacting on patients’ distress [139]. Hence, both patients’ and caregivers’ illness adjustment may be optimized if caregivers’ unmet needs are addressed [140].

6.4.1 Prevalence of Unmet Needs Reported by Caregivers

A recent systematic review identified that caregivers report between 1.3 and 16 unmet needs on average (in a range from 17 to 67), suggesting that 5–47 % of caregivers’ needs remain unmet [136]. In some studies, caregivers’ needs often exceed the levels reported by patients [136, 141]. Caregivers of individuals in the acute post-diagnosis phase [140], or advanced or palliative care phase [142, 143] and those diagnosed with a brain tumor [138] report considerably high unmet needs. To date, as there has been no attempt to quantify the clinical significance of a given unmet need, it is difficult to determine the significance of experiencing one unmet need [144]. However, many of the top ranking unmet needs reviewed below pertain to key aspects of the caregiving process and it is foreseeable that experiencing any one (even only one) of these would adversely impact clinical outcomes.

6.4.2 Types of Unmet Needs Reported by Caregivers

Caregivers report unmet needs in the following six domains: comprehensive cancer care (prevalence = 1.1–96 %), emotional and psychological (prevalence = 2–93 %), caregiver impact and daily activities (prevalence = 3–79 %), relationship (prevalence = 3.7 and 58 %), information (prevalence = 2.2–86 %), and spiritual (prevalence = 6.7–43 %) [136]. Below are examples of prominent unmet needs across each domain.

6.4.2.1 Comprehensive Cancer Care Unmet Needs

Prevalent unmet needs within this domain include: to be told about the help health care professionals can offer, have a supportive relationship with health care professionals, access to health services, and have possibilities to participate or help in patients' care [136]. Eriksson and Lauri [145] reported that although 63 % of caregivers felt accepted by health care professionals, 96 % felt that health care professionals rarely asked them whether they wanted to talk about their experiences and 86 % were not provided sufficient information about ways they can partake in the patient's care. Overall, fewer caregivers of patients with head and neck cancer [146] or cancer survivors [147] identified needing help with this domain, but higher caregiver unmet needs in this domain were found in studies where the care recipients were hospitalized patients [145], in the acute diagnostic and treatment phases [148, 149], or in the palliative care phase [87, 142, 150, 151].

6.4.2.2 Emotional and Psychological Unmet Needs

Top emotional and psychological unmet needs include: help dealing with own emotional distress, get emotional support for self/have someone to talk to, know how to provide emotional support to patient or others, and manage fears about the situation getting worse [136]. Overall, lower prevalence of emotional unmet needs was reported by caregivers of cancer survivors [139, 147, 152]. Conversely, Buscemi et al. [142] reported that 86 and 83.1 % of caregivers of patients diagnosed with terminal cancer identified needing more help to deal with feeling of loss and getting emotional support for self, respectively; and two studies of wives of men with prostate cancer reported a high prevalence of unmet needs for help to emotionally support the patients (53–59 %) [148, 149].

6.4.2.3 Caregiver Impact and Daily Activities Unmet Needs

Finding out about financial support, knowing how to maintain sense of control, dealing with uncertainty and life after cancer, and curtailing impact on lifestyle and schedule are common unmet needs in this domain [136]. Similar to the previous domains, a lower prevalence of unmet needs was reported in survivorship studies [139, 140, 147, 152]; with a higher prevalence in caregivers of patients in the palliative care phase [142, 151]. For instance, in a study by Eriksson et al. [151] examining the support caregivers received from health care professionals before and after the patient's death, 79 % did not receive much information regarding financial support available. Caregivers of patients diagnosed with terminal cancer who participated in the Buscemi et al. [142] study identified the following impact and daily activities unmet needs: know how to maintain self-control (66.1 %), have more time for myself (59.3 %), and deal with uncertainty and life after cancer (44.1 %).

6.4.2.4 Relationship Unmet Needs

Two unmet needs are particularly prominent in this domain: help communicating with patient about illness and his/her concerns and have an intimate relationship with the patient and consideration for sexual needs [136]. Overall, the pattern of prevalence is consistent with the other domains: studies of caregivers of cancer survivors reported lower unmet needs [139, 147, 152, 153] than caregivers either in the early phases of the illness [149] or in the palliative care phase [142].

6.4.2.5 Information Unmet Needs

Overall patterns of unmet needs previously noted according to illness trajectory were further corroborated for this domain, with the most common information unmet needs including: knowing what to expect, the illness and treatment, death and dying, and providing care to the patient [136].

6.4.2.6 Spirituality Unmet Needs

Spirituality needs are less often documented than the other domains, but a common unmet need in this domain related to feeling there is hope for the future [136].

6.4.3 Comparison Between Patients' and Caregivers' Unmet Needs

Although patients and caregivers share a number of common unmet needs, some needs are unique to the challenges faced by caregivers. Soothill et al. [154] noted the following overlapping unmet needs among patients diagnosed with breast, colorectal, lymphoma, or lung cancer and their caregivers: help with financial matters, help in filling out forms, help with anger, opportunities for meeting others who are in a similar situation, and advice about food and diet. The following top three unmet needs were unique to caregivers: help in considering sexual needs, help with feeling of guilt, and help in dealing with tiredness. Hodgkinson et al. [139] found that patients' and their caregivers' highest unmet needs domains were different, with caregivers needing help in the areas of relationships and partner impact and patients' highest needs pertained to the existential survivorship and comprehensive cancer domains. However, when comparing individual unmet needs items, patients and caregivers identified the same top three unmet needs: managing concerns about the cancer coming back, more accessible hospital parking, and reducing stress in survivors' life. Similarly, a survivorship study by Turner et al. [155] noted that within-dyad agreement was the highest ($\geq$50 %) for help for managing fears of recurrence, coordinated care, and having complaints dealt with properly.

6.4.4 Change in Caregivers' Unmet Needs Over Time

A longitudinal by Girgis et al. [147] found that 50 % of caregivers reported at least one unmet need at 6 months post-diagnosis, with a significant decrease to 35.9 % at 12 months and 30.7 % at 24 months, with the average number of unmet needs also decreasing across these time points (from 4.6 at 6 months to 2.1 at 24 months). Interestingly, ranking of unmet needs revealed some core unmet needs across time, including managing concerns about cancer coming back, reducing stress in the person with cancer's life, understanding the experience of the person with cancer, and more accessible hospital parking. However, at 12 and 24 months, a shift in unmet needs was apparent, with needs related to caregivers' well-being and relationships (e.g., impact that cancer has had on your relationship with the person with cancer, looking after own health) taking priority over patient-focused needs. This might reflect a change in focus for caregivers from prioritizing the patient's recovery within the first year post-diagnosis to processing and managing the impact cancer has had on themselves in survivorship. Conversely, Butow et al. [143] identified increasing unmet needs among caregivers of women with ovarian cancer in the last year of life, with 58 % of caregivers reported at least one unmet need 10–12 months before the patient's death, 70 % 7–9 months, 83 % 4–6 months, and 88 % 0–3 months. Butow et al. [143] also noted that reducing the patient's stress was the only unmet need consistently prevalent across time. A shift in top unmet needs was also noted, with the initial focus on obtaining support for the wider family, discussing cancer in social situations, and issues around sexuality being replaced with needing help with disappointment and fear and making decision within the context of uncertainty.

6.4.5 Variables Associated with Caregivers' Unmet Needs

6.4.5.1 Caregiver Demographics

Several studies have not supported a relationship between demographics and level of unmet needs [136]. However, those that have, note that caregivers who are not the patient's spouse (or partner) experienced higher unmet needs [31, 87, 145, 150, 151].

6.4.5.2 Psychosocial Variables

Generally, studies have found that partner or caregiver distress [71, 139], anxiety [71, 134, 138, 142, 147, 152, 153, 155], and/or depression [138, 142, 147, 152, 153] are associated with higher unmet needs. Some studies have also noted that patients reporting higher distress [134, 139] and higher unmet needs [71, 134, 139] have caregivers reporting higher unmet needs of their own. Low social support [31, 147], low relationship satisfaction [139], and having caring responsibilities [31, 142, 147] have all been associated with higher unmet needs.

6.4.5.3 Health/Illness Variables

Although trends have been noted whereby caregivers of individuals with advanced cancer reported higher unmet need, a number of studies do not support a significant relationship between caregiver or patient health/illness variables and unmet needs [31, 134, 138, 139, 152, 153, 155].

6.4.5.4 Health Care Context and Care Variables

Some studies have suggested a relationship between some cancer care variables and unmet needs [137, 150, 156]. For example, Nikoletti et al. [156] found that caregivers who received information from the breast nurse counselor and medical staff had fewer unmet needs than those receiving their information from any other source.

6.4.6 Implications for Service Delivery

A review of caregivers' unmet needs provides a strong evidence-base to guide the design and implementation of supportive care services, especially as many caregivers' unmet needs are amenable to change. In addition, caregivers' range of unmet needs highlight that a multidisciplinary approach to supportive care is most appropriate. Although a multidisciplinary approach is the preferred model of care for patient, it is unknown whether this approach has reached caregivers in the same way [31]. However, as caregivers often do not access services, even when these are available [10], this suggests that health care professionals might first need to reassure caregivers that by taking time to meet their own needs they are not only contributing to their own well-being, but to patients' quality of life.

6.5 Health Care Service Utilization by Caregivers

Overall, very little is known about the way that caregivers engage with the health care system to meet their supportive care needs. There is evidence to suggest that caregivers under-utilize available services, particularly in relation to their mental health needs [10, 157–159]. Specifically, in a study of caregivers providing care to patients with advanced cancer, Vanderwerker et al. [10] found that despite 13 % of their sample meeting the diagnostic criteria for a psychiatric disorder; only 46 % of this group accessed mental health services. Studies of bereaved caregivers with a diagnosed mental disorder have also found low numbers of mental health service utilization, ranging from 27 to 47 % [158, 159]. Negative perceptions of mental health professionals, guilt about accessing services for their own needs rather than patient needs, and wanting to self-manage emotional concerns are core barriers to obtaining professional help [160].

However, caregivers do engage with other types of health care services, especially cancer screening and primary care visits. For example, Son et al. [161] found that spousal caregivers undertook screening behaviors for gastric, colorectal, cervical and breast cancer at a significantly higher rate, often more than double the rate, than matched controls. Reeves et al. [162] found that there was no overall difference in screening behaviors between caregivers and non-caregivers; however, they did find that caregivers were more likely to have had a pap test and clinical breast exam within the past 12 months. Finally, a longitudinal study of Australian female caregivers found that caregivers reported a higher number of GP visits compared to women who had never undertaken the caregiving role or who had stopped caregiving [163]. This study futher documented that caregivers were more likely to be taking medication for sleep, nervous conditions, or depression [163].

Caregivers also access some supportive care and psychosocial services. For example, Mosher et al. [164] found that lung cancer caregivers who were currently not receiving services expressed an interest in complementary and alternative medicine (40 %), mental health services (29 %) and practical support (29 %), with a smaller proportion considering couples or family counselling (15 and 19 % respectively). Applebaum et al. [165] found that 92 % of caregivers currently not receiving support were interested in counselling services; however, 48 % of these caregivers identified barriers to accessing this care, including time, guilt at leaving patient, finances and scheduling conflicts. In both of these studies caregivers expressed a preference for phone interventions, potentially as they are more flexible, less costly, and would allow caregivers to receive support in their home without having to be away from their care recipient [164, 165].

6.6 Caregiver Interventions

Without the help of informal caregivers, the costs of cancer to the formal healthcare system would be considerably higher. However, caregivers' own supportive care needs must be addressed to enable them to confront the complexities of their caregiver roles in a way that leads to the best possible patient outcomes [4, 166]. Therefore, over the past decade there has been a rapid increase in the number of interventions developed to: (a) improve caregivers' ability to provide care; (b) reduce the adverse impacts of caregiving on caregivers' health and functioning; (c) enhance patients' reported outcomes; and (d) reduce the cost to society and the health care of caring for patients with cancer. None of these interventions have explicitly targeted caregivers of patients with multi-morbidities. A challenge particular to cancer caregivers (in comparison to, for instance, caregivers of individuals with dementia or the elderly) is that they are given a short timeline to learn all that is required and apply these new skills to the situation to have an impact on clinical outcomes [166]. This section will provide an overview of the caregiver interventions published to date and of their effectiveness.

6.6.1 Types

Caregiver interventions typically employ cognitive, physical, emotional, and/or social mechanisms of action or strategies to have an impact on caregivers' outcomes, and can be categorized in five major types:

1. *Psycho-educational*: Educate caregivers regarding the patient's disease process and other aspects of care, and provide information on available services. Attention is also given to meeting the supportive care needs of patients, caregivers, and/or marital or family relationships [4].
2. *Skills training*: Develop coping and self-management skills (e.g., coping, communication, and problem-solving skills), including increase caregivers' motivation and confidence to apply these to their situation [4, 167].
3. *Counseling*: Opportunity to address problems, concerns, and/or feelings related to caregiving with health care professionals [4].

4. *Palliative care/hospice interventions*: Relieve suffering and improve the quality of life of those living with or dying from advanced illness as well as their caregivers [166].
5. *Respite*: Designed to give the caregiver time off [166].

Most caregiver interventions are psycho-educational or include a combination of psycho-education and skills training [4, 167–169]. The literature reviewed below pertains mainly to these types of interventions.

6.6.2 Format

Caregiver interventions are commonly delivered jointly to the patient and his/her caregiver (also referred to as dyadic interventions) [168–171], by a nurse or a combination of health professionals, and face-to-face, either in the clinical or home setting [4, 168, 172–174]. However, the health care professional delivering the intervention varies according to the type of intervention, with couple-based interventions more often delivered by psychologists, therapists, or counselors [167, 169, 173, 174]. Another popular option is to use the telephone [4, 167, 168, 172, 173], which matches previous reports of caregivers' preferences for supportive cancer care [164, 165]. Although group interventions are less often used [4, 167, 171], this format appears most used for caregivers of patients in the palliative phase [166]. Groups have the advantage of providing opportunities for individuals in a similar situation to interact; however, it might be too difficult for caregivers to attend these [175]. When a combination of formats is used, typically this includes face-to-face sessions with telephone-based follow-ups [167, 172, 173]. Although dose and duration vary widely, caregiver interventions appear to include on average 6–7 sessions [4, 167, 170]. This is in contrast with the literature that longer psychosocial interventions (8–12 sessions) are more efficacious than shorter interventions [176].

6.6.3 Focus

Caregiver interventions can be grouped as: caregiver self-care, marital/family care, and/or patient caregiving [4]. Intervention foci are not mutually exclusive, and many interventions will include some content to address all three [4, 167]. The intervention by Carter [177], which included self-assessment of maladaptive habits affecting caregivers' sleep quality, stimulus control, relaxation techniques, cognitive therapy, and sleep hygiene to maximize caregivers' ability to improve their sleep quality is an example of a caregives self-care intervention. One example of a marital/family care intervention is the counselling intervention by Kuijer et al. [178], which is focused on patient and caregiver mutual support to reduce feelings of inequity and enhance relationship quality. The psycho-educational and skills training intervention developed by Northouse et al. [179] is an example of patient caregiving intervention. This intervention included home visits and telephone follow-ups to provide caregivers with the information, skills, and support needed to manage patient's care and assist patients with managing uncertainty and maintaining an optimistic attitude. This intervention also had a marital/family care component (e.g., improving family functioning) and caregiver self-care content.

Similarly, a review by Badr et al. [172] emphasized that interventions delivered jointly to patients and caregivers involve caregivers in one of two ways. In the first approach, the focus is on promoting individual change in the patient and the role of the caregiver is mainly to facilitate learning and coping skills in the patient [180]. In the second one, the focus is on both patients' and caregivers' needs, both member of the dyad are treated together [172].

6.6.4 Efficacy

Overall, meta-analyses [4, 170] and reviews [167, 173, 174, 181] have supported the efficacy of caregiver interventions on a range of caregiver-reported outcomes. To contextualize the effect sizes presented below, those for psychological and behavioral intervention typically range from 0.35 to 0.50 [182], and the effect sizes for psychosocial interventions for patients with cancer are generally small to moderate: range = 0.17–0.42 [176, 183, 184] (although some types of interventions have been found to result in large effect sizes on selected outcomes [176, 184]).

6.6.4.1 Proximal Outcomes

Proximal outcomes are conceptualized to be more directly affected by an intervention and can be clearly identified from the content and goals of the intervention. The psycho-education and skills training focus of most caregiver interventions means that key proximal outcomes include monitoring caregivers' acquisition of the required knowledge, coping skills, and self-efficacy. Most often the selection of proximal outcomes is based on Lazarus and Folkman's [185] Stress and Coping Framework. Despite the focus of interventions on changing proximal outcomes, these typically receive less attention than more distal outcomes (e.g., anxiety, depression, quality of life).

- *Information needs and knowledge* (*positive findings*): Only the meta-analysis by Northouse et al. [4] has reported on the overall significant effect of interventions on this outcome (effect size = 1.36).
- *Caregiving benefit* (*mixed findings*): Post-intervention findings tend to be non-significant (effect size = 0.17); however, significant findings have been found at follow-ups (effect size = 0.31) [4]. A review by Brandão et al. [174]

noted that significant benefits of couple-based interventions among women with breast cancer and their spouse included reporting more post-traumatic growth.

- *Caregiving burden* (*mixed findings*): Small but significant effect sizes noted post-intervention (effect size = 0.22 [4]). However, effects do not seem to be sustained [4].
- *Self-efficacy* (*positive findings*): The hypothesis that the main underlying mechanism by which caregiver interventions are expected to have an impact is through increased self-efficacy has been confirmed [4].
- *Coping* (*positive findings*): Intervention studies have also reported significant improvements in caregivers' ability to cope (i.e., promoting active coping, and reducing ineffective coping) [173], with a moderate effect size (effect size = 0.47) and enduring effects noted [4]. In recent years, a growing literature is going beyond individual caregiver coping to consider how patients and caregivers engage in the coping process together (termed dyadic coping) [94, 95, 186]. Few studies have reported on the effect of caregiver interventions on dyadic coping. However, those that do have found that caregivers participating in an intervention report higher dyadic coping in comparison to those who do not [186, 187].
- *Communication* (*positive findings*): The few interventions that measure changes in communication have generally noted improvements [167, 173]. For instance, Kayser's [186] Partners in Coping Program for women with breast cancer and their partners resulted in partners being more willing to communicate their stress to patients as well as more positive individual and dyadic coping.

6.6.4.2 Distal Outcomes

Whereas proximal outcomes are directly affected by the content of an intervention, distal outcomes depend on factors that are not directly influenced by the intervention [188]. The challenge of focusing on such distal outcomes, is that change might not be a reasonable expectation given the short periods of time [181].

- *Quality of life* (*positive findings*): Weak to moderate effect sizes (effect sizes = 0.05–0.54) have been noted, not only immediately after the intervention, but also at follow-ups [167, 168, 173].
- *Psychological outcomes* (*mixed findings*): The Badr and Krebs [170] meta-analysis of couple-based interventions reported a small, but significant effect on psychological outcomes (effect size = 0.18). The Northouse et al. [4] meta-analysis reported encouraging effect sizes for distress and anxiety, both post-intervention and at follow-up. However, caregiver interventions have not been found to be as effective in reducing depression [4, 173]. This finding might be partially explained by low levels of baseline caregiver depression and the high rate of attrition of depressed caregivers [4, 181].

- *Physical functioning* (*non-significant findings*): Caregiver interventions do not seem efficacious post-intervention on this outcome (effect size = 0.11 [4]); however, they might be at follow-up (effect size = 0.22–0.26 [4]).
- *Social functioning* (*mixed findings*): Mixed results have been noted regarding improving caregivers' ability to maintain family, vocational, and social roles [173], with minimal effect noted post-intervention (effect size = 0.11 [4]). However, a positive effect has been noted at follow-up (effect size = 0.39 [4]).
- *Sexual functioning* (*positive findings*): Few studies have focused on sexual functioning and intimacy of the caregiver, but those that have, have shown some positive impact [169].
- *Relationship functioning and satisfaction* (*mixed findings*): Marital satisfaction and relationship functioning have generally been found to improve following caregiver interventions [4, 167, 170, 173]. However, improvements in relationship functioning obtained following a caregiver intervention do not seem to be sustained over time [4], which might emphasize the need for booster sessions to improve long-term outcomes.

6.6.4.3 Impact on Patient-Reported Outcomes

There is increasing evidence that when interventions engage both the caregiver and patient as a dyad, important synergies are achieved that significantly enhances each person's outcomes [170, 171, 173]. The meta-analysis by Badr and Krebs [170] emphasized that interventions jointly delivered to patients and caregivers had a significant impact on the patients' psychological (effect size = 0.18), physical (effect size = 0.31) and relationship (effect size = 0.25) functioning. The Regan et al. [173] review of couple-based interventions documented that the benefits of these interventions for patients paralleled those noted for their spouse caregivers, including improved psychological and physical distress, sexuality and relationship functioning, communication, and coping. These findings were echoed by the Brandão et al. [174] review of couple-based interventions for women with breast cancer and their spouse, whereby many of the benefits for the spouse were noted for the patient as well.

There is also evidence that dyadic interventions are potentially more efficacious than patient-only interventions in enhancing patients' well-being outcomes [189, 190]. For instance, Nezu et al. [190] examined the efficacy of a problem-solving therapy (PST) among a mixed sample of patients diagnosed with cancer and included two treatment groups: one in which patients attended the PST alone and a second one where PST was attended with a significant other. Post-PST positive effects on quality of life and distress were similar in the two treatment groups. However, at 6- and 12-month follow-ups, patients participating in PST with their significant other reported lower distress than patients who attended the PST alone. The support and shared learning that occurs in dyadic interventions might increase the likelihood of improvements [173].

6.6.5 Moderators of Intervention Effects

Northouse et al. [4] examined the potential impact of four study characteristics on intervention effects: (a) participants (caregiver alone vs. caregiver-patient dyad), (b) mode of delivery (face-to-face vs. phone vs. group vs. mixed), (c) type of intervention, and (d) duration and dose. For many outcomes, none of these characteristics had a significant effect. Inconsistent findings were noted for intervention length, whereby caregivers receiving longer interventions reported significantly more burden and depression and lower relationship functioning than those in shorter interventions. However, the opposite was noted for coping. Coping was also more favorable for interventions delivered face-to-face or using a group format than those using mixed modes of delivery. Caregiver-only interventions reported more positive outcomes in terms of appraisal of caregiving benefit than dyadic interventions. This might be because these interventions focused more on caregivers' own needs. Overall these findings emphasize that decisions about intervention design need to take into consideration the desired outcomes.

A systematic review by Regan et al. [173] also did not note any differences in efficacy based on mode of delivery. However, interventions targeting early-stage cancer were suggested to result in greater improvement in comparison to interventions targeting late-stage or advanced cancers. Also, interventions with patient-caregiver dyads or couples in less supportive relationships or in a shorter relationship were found to be more efficacious. This suggests that tailoring interventions to key risk factors might increase the likelihood of positive outcomes.

A review by Baik and Adams [171] concluded that couple-based interventions focused on improving communication, reciprocal understanding, and intimacy in the couple appeared to be most promising in reducing illness-related distress for caregivers and improving dyadic adjustment. Similarly, Waldron et al. [168] also emphasized that interventions targeting communications pose to make the greatest impact on caregivers, as well if these integrate problem-solving skills training.

Of note, the review by Wootten et al. [169] found that cognitive behavioral-based interventions appeared to be more effective than psycho-educational interventions in improving sexual intimacy and satisfaction for partners of men with prostate cancer. However, psycho-educational interventions were as effective as cognitive behavioral based interventions in reducing distress. This might indicate that the lack of information is a significant contributor to psychological distress for caregivers. This review also emphasized that face-to-face interventions produced more beneficial outcomes than those delivered solely over the telephone.

6.6.6 Attrition and Retention

Caregiver interventions are typically acceptable to caregivers, with high satisfaction reported [181, 191], but uptake rates across studies vary widely. In a review by

Regan et al. [192] of interventions targeting both the patients and their spouse caregivers, uptake rates varied from 13.6 to 94.2 % (overall rate = 48.8 %). Specifically for caregivers, uptake rates for dyadic interventions (46.3 %) was slightly lower than for individual-based interventions (48 %), and both were lower than coaching interventions (59.2 %), possibly reflecting logistical issues if patients and caregivers are unable to participate in an intervention simultaneously or feel they need different levels of support [192, 193]. Caregivers' uptake rates were higher for psycho-educational or coping skills training interventions (51, 51.8 %) than for those focusing on communication (43.1 %). Finally, face-to-face intervention had a higher uptake (49.8 %) than telephone interventions (45 %).

Regan et al. [192] also found that caregivers' attrition rates post-intervention ranged from 0 to 38.7 % (overall rate = 17.6 %). Attrition rates for dyadic interventions (22.5 %) were higher than for individual-based (18.5 %) and coaching (attrition rate = 15.8 %) interventions. Attrition rates were higher for psycho-educational and coping skills interventions (22.4, 22.7 %) than communication-focused interventions (13.8 %), suggesting that although communication interventions might not initially be attractive to patients and caregivers, their benefits might become more apparent as they engage with the intervention [193]. This, in turn, raise a critical issue regarding marketing the benefits of these interventions to participants. In addition to a higher uptake rate, face-to-face interventions had a lower attrition rate (16.7 %) than telephone interventions (19.9 %).

One of the most common barriers to intervention uptake and completion includes distance to the intervention being too great [170, 173, 192]. Although delivering interventions via other means is increasingly popular to overcome this barrier, caregivers usually desire some level of face-to-face [173]. Other frequent barriers include timing or scheduling issues (e.g., too busy) [168, 170, 173, 192, 194], high patient symptom severity [173], compromised caregiver health [168, 194], high caregiver burden and strain [168, 169] and perception that interventions do not meet caregivers' needs [171, 173]. Consumer involvement in the process of developing the interventions through participatory research strategies might address this last limitation [175].

6.6.7 Under-Researched, but Potentially Promising Caregiver Interventions

6.6.7.1 Orientation Programs

A Cochrane review [195] of information interventions to orient patients and their caregivers to a cancer care facility and the services available within a centre supported their efficacy in reducing distress but not anxiety.

6.6.7.2 Physical Activity Interventions for Caregivers

The health benefits of physical activity (PA) for the general population are well-recognized [196], with evidence that these benefits extend to individuals diagnosed with cancer [197]. A recent systematic review of the impact of PA Interventions on caregivers by Lambert et al. [198] found one among cancer caregivers, with benefits of decreasing distress and increasing aspects of quality of life noted. The remaining 13 trials were mostly conducted among caregivers of individuals with dementia or Alzheimer's, with benefits including increased PA, reduced burden, increased physical outcomes, and improved sleep quality.

6.6.7.3 Self-directed Intervention

Most caregiver interventions raise access barriers related to travel and sustainability due to their high cost and reliance on health care professionals' availability. An increased interest in a self-directed (or self-administered) format is evident as an alternate approach to provide ongoing instruction and support to caregivers in a cost-effective manner. A self-directed format offers caregivers the flexibility to choose when and where to engage in the program and requires less direct input from clinicians. As caregivers are often less likely than patients to access conventional services, self-directed interventions might play a particularly prominent role in supporting them in their coping efforts [10]. Lambert et al. [57, 193] developed *Coping-Together*, a manual-based, self-directed coping skills intervention for couples facing cancer, with initial feasibility testing highly endorsing its dyadic focus and self-directed format.

6.6.7.4 Online Interventions

Web-based interventions are increasingly recognized as a convenient, cost-effective, and efficacious approach for delivering support to large numbers of individuals [199]. The few interventions developed to date show promise in enhancing caregivers' health and well-being [200]. Given the popularity of the internet for delivering psychosocial interventions and the potential effectiveness of this mode of delivery, it is an encouraging platform to deliver caregiver interventions and overcome barriers of conventional caregiver interventions.

6.6.7.5 GP Supported Interventions

In recognition that general practice (GP) consultations provide an opportunity to address caregivers needs, Mitchell et al. [201, 202] have examined the efficacy of a GP-based intervention incorporating a caregiver-reported needs checklist (The Needs Assessment Tool—Carers [203]) and a supporting GP compendium of resources to address caregivers' identified needs. In a randomized controlled trial with caregivers of people with advanced cancer, this novel approach improved mental well-being among caregivers who were clinically anxious at baseline. For caregivers whose baseline anxiety was within the normal range, the intervention led to a significant improvement in their physical functioning. Although the intervention did not reduce the number of unmet needs, drawing caregivers' attention to their needs may prompt them and/or the GP to put in place extra resources to address these. Additional studies are needed to further examine the potential benefits of systematically using a needs assessment tool to improve caregivers' outcomes.

6.6.8 Potential Implications for Caregivers of Patients with Multi-morbidities

As patients with multi-morbidities often have greater self-care needs, an increased reliance on informal caregivers to meet these needs might lead to these caregivers spending more time providing care per week, being involved in more tasks, with potentially lower self-efficacy than caregivers of patients without co-morbidities. These caregivers may also engage in a greater frequency of tasks and more care co-ordination and communicating with health care teams. Since greater caregiving intensity or higher interference in caregivers' daily activities due to their caring role are recurrent risk factors for a number of adverse health and well-being outcomes, caregivers of patients with multi-morbidities may report worse outcomes than those caring for someone with cancer alone. The impact of caregiving for someone with multi-morbidities might be comparable to those caring for someone in the palliative phase. However, more intense caregiving might also mean that these caregivers report higher levels of benefit finding, with Levesque and Maybery [124] noting that adult children who reported greater impact of caring and higher emotional reactions to their parents' illness also noted a higher number of positive outcomes.

As reviewed in this chapter, caregiver education and skill building are key to supporting caregivers. However, caregiver interventions are often disease-specific, and do not take into consideration the multiple demands that might arise across illnesses. Although this approach reflects the disease-specific model used to provide health services [204], it may actually further isolate caregivers of patients with cancer and co-morbidities. The staggering increase in prevalence of multi-morbidities can no longer be ignored and further urges the identification of caregiver interventions and approaches that are effective across illnesses. An integrated approach to caregiver interventions is also justified by findings that caregiver burden is comparable across illnesses [204–206], and is mainly predicted by caregivers' similar needs and approach to coping (not patients' diagnosis) [205, 206]. However, one challenge in the planning and implementation of interventions for caregivers of patients with multi-morbidities is that although they might benefit more from the interventions due to the additional burden and needs, attrition rates might be even higher in this sub-group as key barriers might be enhanced (e.g., too busy, higher patient symptom severity).

6.7 Conclusion and Future Directions

6.7.1 Conclusion

For many, the caregiving role is equivalent to a full-time job, resulting in significant burden in their health, economic and social outcomes. Caregivers also report unmet needs in relation to comprehensive cancer care, emotional and psychological support, partner or caregiver impact and daily activities, relationship, information, and spiritual issues. However, many caregivers also report deep levels of satisfaction from their caregiving role.

Patients and their caregiver react to cancer (and potentially other diagnoses) as a unit, and as a result, both have legitimate needs for help from health professionals; hence, comprehensive care plans should ideally focus on the patient-caregiver dyad [4]. It is imperative that health care professionals identify caregivers who are at most risk and support them through direct care or by referrals to community resources to help meet the needs of this vulnerable population. Utilizing tools such as screening checklists can provide a more systematic approach to needs assessment to ensure the highest priority needs are addressed. Despite the promise of caregiver interventions to achieve clinically significant outcomes, few interventions (if any) have been translated for or implemented in clinical practice [4]. Hence, health care professionals can also become aware of caregiver interventions, detailed in this chapter, which are most effective for supporting caregivers and meeting their most pressing needs and consider some alternate approaches and format that might favor translational in routine cancer care.

6.7.2 Future Directions

Our understanding of the impact of caregiving is limited to the populations and outcomes that have been studied to date. It is difficult to draw inferences to other caregiver populations, including those caring for patients with multi-morbidities, with a high degree of confidence. Hence, extending the research to include under-studies caregiver populations is of high priority. As previously mentioned, the chronic disease profile that comes with the aging of the population is creating an urgency to increase our understanding of the experiences of caregiving of patients with cancer and co-existing chronic diseases. In addition, most studies to date have focused on the patients' spouse or partner as their primary caregiver [168], and more studies are needed to examine the impact of caregiving potentially on other caregiver sub-group, who have been found to be more at risk of adverse outcomes (e.g., daughters higher burden than spouse) [85, 88, 90]; and on same-sex couples [173]. Our understanding of the impact of caregiving on people of different racial, cultural, and socio-economic backgrounds is also limited by the lack of research in these populations. Northouse et al. [4] noted that less than 16 % of participants across 29 intervention studies reviewed were self-identified as members of a minority; and only two studies were identified which tailored interventions for a particular cultural or racial group [207, 208]. Most caregiver intervention studies have focused on breast or prostate cancer populations [167, 170], with only a handful of studies focusing on caregivers sub-group actually at highest risk of anxiety and depression (e.g., caregiver of patients with hematological, head and neck, or lung cancer [9]). Further research into more "accessible" interventions such as using e-Health technology is required, as well as assessing the cost-effectiveness of different intervention approaches [4, 170].

Finally, with significant challenges encountered by many studies in low recruitment and high attrition rates, the challenge to achieve required sample sizes to reach statistical significance calls for more research to clarify the definition of clinically meaningful changes in the outcomes examined, as even small effect sizes can still be clinically significant and important [170].

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