Caregiving Burden and Other Psychosocial Considerations

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1 Introduction

Cancer is a significant cause of informal caregiving [1]. In 1930, about 20% of people diagnosed with cancer lived another 5 years [2]. In the United States, the 5-year survival rate for all malignancies has increased from 49% in 1975 to 69% in 2013 [3]. By 2020, it is projected that more than 53 million Americans will serve as informal caregivers, including approximately 3 million caring for a person with cancer [4, 5]. By 2030, 22.1 million Americans are expected to be cancer survivors, most of whom will be 65 years of age or older [6]. As a result, a significant number of families are forced to deal with caregiving and grief due to cancer. The study found that 84% of the elderly received support from family members and other unpaid caregivers before diagnosing cancer. Spouses were the primary informal caregivers, followed by children, friends, siblings, and parents [7]. In addition, cancer survivors who rated their health as poor or fair were more likely to report having an informal caregiver than those who rated their health as good to excellent [7]. In addition, nearly 56% of care recipients had more than one caregiver [8]. In addition, informal caregivers are the backbone of the palliative care workforce and the primary providers of end-of-life care [9]; they are thought to provide 75–90% of home care for people at the end of life [10]. Despite growing evidence that caring for cancer patients severely impacts caregivers' well-being and quality of life, informal caregivers are among the "invisible" or "hidden" workforce providing support and direct care to cancer patients [11].

By 2040, the burden of disease from cancer in Europe is expected to increase by 21%, while the annual number of cancer deaths will increase by 31% [12]. The impact and burden on informal caregivers will increase as the prevalence of cancer

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increases, patient prognoses, and life expectancies improve, and patient reliance on ambulatory care services increases [12]. At this point, it is worth noting that previous research on pre-cancer health-oriented caregiving tasks and the relationship between caregiver activity patterns and caregiver burden has shown that a significant proportion of caregivers are already overloaded with tasks and burdens, which may be exacerbated by the additional responsibilities associated with the patient's new cancer diagnosis and subsequent treatment [6].

2 Cancer Caregivership Burden

Cancer patient caregiving, the process by which family members and friends help a cancer patient, is a unique and special type of stress due to the fear of death associated with a cancer diagnosis and treatment [13]. Informal caregivers of cancer patients are family members, partners, or friends who provide unpaid help in several categories, including social support, help with activities of daily living, and clinical care tasks [14]. Cancer patients' and caregivers' more extensive social networks are indeed becoming more important [15]. More than 40% of American adults are now single [16], and it is essential to consider other forms of supportive partnerships. Informal caregivers, who may or may not be family members, have been characterized as laypersons who play a critical supporting role in the patient's cancer experience, providing essential labor and emotion management [17]. In addition, informal caregivers are critical in the care of older patients and often meet the complicated demands associated with functional dependence, cognitive impairment, and various chronic illnesses [18].

Although the prevalence of psychosocial problems among informal caregivers of older cancer survivors is still unknown, there appear to be a higher prevalence of stress, decreased quality of life, and increased anxiety among informal caregivers of older cancer survivors compared with the general population [19].

The stress experienced by caregivers of cancer patients is greater than that of caregivers of older adults and comparable to that of caregivers of dementia patients [20]. For example, in the 2016 National Alliance for Caregiving study [1], cancer caregivers were significantly more likely than noncancer caregivers to assist with activities such as bed and chair transfers (57% vs. 42%), toileting (46% vs. 26%), dressing (42% vs. 31%), and feeding (39% vs. 22%). Caregiver burden is complex and includes social, physical, economic, and psychological aspects, even when there is no comprehensive description [21, 22].

Analyzing the impact of informal caregivers' perceived difficulties in cancer care is critical to discover benefits throughout the caregiving experience [23]. Caregivers who engage in religious coping and feel the availability of social support are more likely to report discovering benefits [13]. In addition, a representative prospective study examining the relationship between the presence of an informal caregiver and all-cause mortality among older adults, as well as the relationship between caregivers' perceptions of burden and benefits and care recipient mortality, found that caregivers of older adults who report only benefits or with caregivers who report only burden have an increased risk of mortality. In contrast, this risk is increased but lower for care recipients with informal caregivers who perceive both burden and benefits [24]. Even after adjusting for health, socioeconomic, and demographic factors associated with mortality, this pattern of informal caregivers remained associated with higher mortality risk among older persons, suggesting that interventions aimed at both reducing caregiver burden and increasing perceived benefits when burden reduction is not possible may support recipient longevity [24]. Therefore, caregiver burden may contribute to death through psychological and physiological systems that need further investigation [24].

2.1 Physical and Sleep Burden

Although informal caregiving has been the primary source of protection for those struggling with health difficulties since prehistoric times, informal caregiving of relatives with cancer has been associated with poor physical health. Subjective caregiver stress was related to physical impairments during the 2 years of cancer caregiving and the later onset of these impairments. For example, caregivers who returned to care over time and widowed were more likely to develop arthritis and heart disease [25]. Cancer caregivers have increased electrodermal and cardiovascular reactivity compared with controls [26, 27]. The extent to which the survivor and their caretaker spouse were comparable in their physical and mental health and relationship satisfaction was examined. The research shows that the survivor's physical and psychological health significantly impacts the spouse's satisfaction with the marriage. Survivor physical and mental health has also been associated with poorer quality of life and increased caregiver distress [28].

While caregivers' health has been shown to deteriorate due to cancer caregiving, the demographic and psychosocial predictors of long-term deterioration in their health are less well understood in terms of the unique contribution of caregivers' depressive symptoms to their physical decline. For example, in observing the physical and mental health of cancer patients and their informal caregivers over a year after diagnosis, it was found that patients' and caregivers' reports of physical health at each time point were unrelated. In contrast, their reports of mental health at each time point were positively associated to a small to moderate degree [29]. Psychosocial variables are known to impact the deterioration of caregivers' physical health significantly, and caregivers are at increased risk for premature illness compared with non-caregivers [30].

Numerous informal caregivers, even those who do not perceive caregiving as a burden, struggle with various issues, including anxiety, depression, practical and financial challenges, and insomnia [31]. Sleep is a critical component of health and health-related quality of life, and sleep disturbances can adversely affect physical and psychological well-being. Between 36% and 95% of caregivers reported that their nightly sleep was interrupted due to poor sleep quality. Depending on disease stage, prevalence rates ranged from 36% to 80% in the early stages of cancer and from 42% to 95% when patients with advanced disease were treated. During active treatment of patients, 37–59% of caregivers reported sleep problems before the start of treatment, while more than 70% of respondents reported sleep problems during patient treatment [32].

Sleep disturbances commonly experienced by caregivers include difficulty falling asleep and staying asleep due to frequent interruptions from patient care and nocturnal hypervigilance due to constant monitoring of the patient or the caregiver's concerns, resulting in a significant reduction in total sleep time [33]. In addition, numerous urgent or ongoing patient demands can disrupt caregiver sleep patterns, while increasing caregiver stress can decrease caregiver ability to provide care and perpetuate patient sleep disturbances due to unresolved symptoms or unmet concerns [34]. Disrupted sleep can be so debilitating that it jeopardizes both the patient's well-being and the caregiver's ability to provide effective care [35]. In addition, less than 20% of caregivers take a prescription or over-the-counter sleep medication [32].

2.2 Psychosocial and Spiritual Burden

Cancer is a traumatic experience for both patients and family caregivers, who assist with self-care and medical activities and offer knowledge, emotional support, and financial assistance. Caregivers of cancer or palliative care patients have been shown to have increased levels of anxiety, depression, and strain, as well as unmet needs for knowledge and psychological and physical support [17]. While information needs are high in the initial phase of cancer, they gradually decrease in the posttreatment phase as caregivers obtain knowledge from medical professionals and the internet [31]. To what extent the demands of caregivers providing ongoing, resuming, or emerging care differ from those providing end-of-life care remains unclear [3]. In conversations with social workers, the most commonly expressed concerns (49%) were psychological, followed by physical (28%), social (22%), and spiritual (2%) [36]. A few studies found a high incidence of cancer-related communication problems and the distress associated with these challenges. These studies focused on cancer patients' difficulties talking about their disease with family members and friends who do not have cancer. The majority of patients and partners who reported communication problems did so an average of 9 months after completing treatment, suggesting that even after completing treatment, either painful memories of cancer-related communication problems persist or communication problems have persisted during past treatment [37].

A negative attribution style does appear to exacerbate the association between informal cancer caregiver stress and cortisol levels but does not affect informal caregivers' depressive symptoms [38]. In addition, the literature on cancer survivors has shown that cancer-related stress may even cause patients' fruit and vegetable consumption to decrease and family caregivers' fruit and vegetable consumption to increase after treatment [39].

A loved one's cancer diagnosis causes significant emotional distress for family caregivers. This experience is compounded by the obligation to provide clinical and health care, impacting caregiver's well-being, the safety of care, and care outcomes

[40]. In addition, there is a disproportionately strong association between mothers' psychological distress and their adult caregiver daughters' quality of life, as mothers are likely to share their psychological concerns about cancer diagnosis, treatment, and survival with their adult daughters, as sharing emotional experiences is common in female relationships [41, 42]. Male caregivers view their involvement in cancer care positively, whereas adult daughters view it negatively [43]. In addition, wives, husbands, daughters, and sons tend to approach caregiving differently, affecting caregivers' emotional well-being [44]. For example, male caregivers were more likely to report higher levels of caregiver appreciation than female caregivers, which was associated with lower levels of caregiving stress [45].

Caregivers' cultural views and values affect their assessment of the caregiving situation [46–48]. In a study highlighting the depression and social support of caregivers of elderly cancer patients from Israel, depression was prevalent among both caregivers (76%) and patients (85%); moreover, the majority of caregivers lived with the patient in a shared apartment [18]. All of these findings suggest that when a family is struggling with a life-threatening illness such as cancer, patients' depressive symptoms are critical to their well-being and that of their family caregivers [49].

In addition, a cancer diagnosis can lead to an increase in existential concerns. Because cancer is often a life-threatening illness, family caregivers have existential concerns impacting their spiritual well-being. Spirituality has been highlighted as a psychological resource that can help family caregivers cope with stressful situations [50]. In addition, the spiritual well-being of cancer caregivers has received less attention in studies. A few studies concluded that the harmful effects of caregiving stress on mental health were less pronounced in caregivers with higher levels of spirituality [13]. Spiritual well-being among caregivers is similar to that of cancer patients and is mainly constant over time [51]. Moreover, spiritual well-being, mental health, and physical health are modestly associated between survivors and caregivers, indicating that survivors and caregivers have comparable levels of spiritual well-being and quality of life [52].

Evidence suggests that a strong sense of meaning and purpose in life is associated with improved mental health and physical symptoms [53]. Family support is critical to the spiritual well-being of family caregivers in the months following a cancer diagnosis in a family member. A study examining the extent to which caregiver experiences were associated with changes in spiritual well-being in the months following a family member's cancer diagnosis found that a perceived lack of family support for caregiving was associated with a decrease in caregivers' sense of meaning in life and peace over the 4-month study period. At the 4-month follow-up, a lack of family support in caregiving was significantly associated with lower levels of meaning and peace but not with faith. This conclusion is consistent with the hypothesis that low levels of social support impair meaning-making by limiting people's ability to process stressful experiences [51]. Specific data support the notion that lower social support and higher caregiver burden are products of profoundly rooted personality traits that contribute to the development or exacerbation of depressive symptoms, as both lower social support and higher caregiver burden mediate the relationship between neuroticism, interpersonal self-efficacy, and depression [54]. In addition, caregivers with high levels of neuroticism or low interpersonal self-efficacy see less accessible social support and experience more personal and role pressures, leading to or exacerbating depressive symptoms in the caregiving setting [54]. Kim and Carver (2007) have shown that the attachment theory provides a robust framework for understanding caregiving behaviors and difficulties. They have also shown that individuals who are more likely to be ineffective caregivers of cancer patients can be identified by their attachment orientation, particularly insecure attachment qualities [23]. Therefore, it is essential to emphasize that attachment orientation toward the cancer patient is a critical predictor in the level of distress, in addition to the caregiver-reported level of physical functioning [55].

Cancer caregivers and cancer patients often view the realities of treatment efforts as a release from the cognitive burden imposed by the existential threat of cancer. Patients and informal caregivers often use the metaphor of "treatment as hope" and may be reluctant to discontinue treatment despite potentially fatal side effects [56]. Similarly, related research on caregiver motivation has found that autonomous reasons do not predict spirituality or mental health [57].

2.3 Financial Burden and Caregiver Guilt

Financial toxicity is a term that refers to the psychological distress, negative coping behaviors, and material circumstances experienced by cancer patients due to high treatment costs, increased cost-sharing, and reduced household income as a result of cancer and its treatment. Family caregivers may suffer the adverse consequences of the high co-payments and reduced work hours associated with cancer treatment [58]. For example, caregivers reported spending a significant amount of time providing medical, emotional, instrumental, and other material support to cancer patients in the 2 years following diagnosis, with average time costs ranging from $38,334 for breast cancer caregivers to $72,702 for lung cancer caregivers. These figures were comparable to direct medical expenditures associated with cancer care in the United States [59]. In Europe, informal caregivers contribute an estimated one-third of total cancer treatment expenditures [60]. These long treatment times are reflected in the high costs reported for informal cancer care [61]. For cancer caregivers, time is structured differently, and they cannot anticipate future life goals or decisions. This temporal anomie requires caregivers to live in the present moment, which offers several benefits and comes with a fair amount of discomfort and obligation [62]. According to one study, caregivers miss approximately 50% of their potential workdays each month to assist with patient care [63]. Caregiving that disrupted daily caregiver routines was associated with lower self-reported mental health and dysregulated cortisol patterns in older caregivers but better-regulated cortisol patterns in younger caregivers [64]. Working younger adult caregivers who had to balance the demands of work and family were shown to be more prone to feelings of guilt [65, 66]. A more significant impact on the caregiver's schedule was strongly associated with greater feelings of caregiver guilt [66]. Guilt as a significant emotional phenomenon in cancer caregiving has not been adequately explored. However, data suggest that higher levels of psychological distress and impaired mental, social, and physical functioning are significantly associated with caregiver guilt, above and beyond the variance explained by covariates [66].

Nonetheless, family caregiving's financial costs and consequences are increasingly well understood. For example, the Comprehensive Score for Financial Toxicity study found a modest association between patient and caregiver financial burden and identified characteristics associated with caregiver financial burden. For example, older adult caregivers may have particular financial difficulties [67]. In addition, financial toxicity was associated with higher patient nonadherence to treatment, increased lifestyle-altering behaviors, and poorer quality of life in both patients and caregivers [21].

There is a dearth of research using standardized approaches to determine the economic value of psychological support [10, 68, 69]. The financial cost of care should be considered alongside other well-documented inequities in palliative care and a significant social determinant of the end-of-life experience [10]. Informal caregivers appear to make a substantial financial contribution to the broader health care system. Some research suggests that informal care accounts for up to 70% of total health care expenditures [10, 70]. However, those from lower socioeconomic backgrounds continually face the most significant financial burden. This relates to education per se. Across Europe, there is a significant correlation between education and wealth; those with high levels of education earn up to 70% more than those with low levels of education [71].

Cost figures are one approach to quantifying the value of caregivers; however, patients' and caregivers' narratives about the impact of cancer on their lives are much more meaningful [5]. The lived experience of being an informal caregiver can be understood when compared to the idea of co-dependency [12]. A consensus study found that the financial burden of caregiving deserves a more substantial research focus, with regular examinations of critical outcomes reported by caregivers and clinician education. Priorities will vary depending on the caregiver at risk [72].

2.4 Long-Term and Quality-of-Life-Related Burden

Five years after diagnosis, 40% of current caregivers and 50% of survivor caregivers had a significant prevalence of depressive symptoms severe enough to be considered clinically significant. However, the incidence was much lower among patients in remission (20%) [73]. In addition, physical morbidity among cancer caregivers was related to their long-term caregiving role and, more specifically, to chronic or developing depressive symptoms 5 years after the initial cancer diagnosis [30]. In addition, the stress of caregiving 3–6 years earlier was significantly related to the unmet needs of bereaved caregivers [3].

While previous research suggests that the quality of life of cancer patient caregivers varies over time due to coping with the stressor [74], caregiver burden over time is significantly associated with anxiety and depression [75]. In addition, the early physical health of cancer caregivers deteriorates compared to demographically comparable non-caregivers due to long-term caregiving responsibilities and depressive symptoms [76]. A study examining changes in caregivers' physical health 2–8 years after cancer diagnosis in their family members and prospective predictors of these changes found that caregivers play a critical role in cancer patients' treatment outcomes. However, caregiving experience increases the risk of long-term deterioration in caregivers' health [30].

The long-term impact of cancer caregiving on family caregivers' quality of life is now well established [25, 77]. One study showed that caregiver age and prior caregiving stress were significant predictors of quality of life in all groups of caregivers, underscoring the substantial impact of caregiving status on quality of life at the 5-year time point [78]. At the 5-year evaluation, caregivers who would become active caregivers or bereaved were more likely to be older and female and less likely to be educated and employed than at baseline. As a result, the bereaved were less likely than other caregivers to be wealthy or the deceased's husband but more likely to be the dead's mother or child [73]. At the eight-year follow-up, most caregivers had stopped actively caring for the relative with cancer because the relative was either in remission (66.2%) or had died (21.2%). However, because cancer survivors face increased morbidity and mortality as they age, the quality of life of their family members after 8 years still depends to some extent on the survivor's prognosis at that time [25, 78].

Just as cancer survivors face increased morbidity and mortality as they age, the quality of life of their caregiving family members at the 8-year mark depends to some extent on the prognosis of survivors at that point. Findings suggest that programs focused primarily on reducing family members' psychological distress can lead to improvements in their overall quality of life 8 years after the family's first cancer diagnosis [25]. Increased uncertainty and concern about disease recurrence remained a significant source of anxiety for caregiving family members, even though patients recovered physically and were free of cancer-related symptoms [74]. In a recent study, family caregivers expressed, on average, a moderate level of anxiety about cancer recurrence in their survivors take [79]. However, the most significant unmet needs of family caregivers were coping with fears of cancer recurrence and transitioning to the "new normal," as this influential group of family caregivers of patients who no longer require cancer treatment remain "lost" in the health care system [3]. These data suggest that years of active involvement in cancer care or resumption of such a caregiver role after initial diagnosis are most likely associated with overall more significant caregiving needs [3]. However, recent findings show that 11% of respondents returned to actively caring for patients several years after being recruited [80]. At this point, we must emphasize that there is compelling evidence that psychosocial support should be prioritized throughout the long-term survival trajectory for family caregivers of patients with recurrent or chronic illness, as well as for higher caregiver depression symptoms [30]. In addition, they are pertinent indicators of vulnerability variables associated with caring for cancer patients.

2.5 Bereavement Burden

Recent evidence suggests that the death of the care recipient places additional stress on cancer caregivers who are already psychologically and socially exhausted by performing the role of the family caregiver. This supports the attrition model of caregiving [25], in contrast to the stress reduction model of grief, which assumes that the care recipient's death alleviates caregiving stress [81, 82]. Due to stress and lack of social support for caregiving spouses, they are less likely to benefit from bereavement [83]. With this in mind, early identification of those at risk for poor grief outcomes and programs to help caregivers make sense of their loss would help engage or retain these caregivers and protect them as they go through care transitions [83–85].

The psycho-oncology literature on the grief phase, which for some caregivers begins with the death of the care recipient, found that 13% of caregivers of advanced cancer patients met the criteria for a psychiatric disorder; 24% and 18% of caregivers met criteria for complicated and persistent grief, respectively; and 37% and 44% met criteria for a clinical level of depressive symptoms, approximately 3 and 5 years [17, 74, 82]. In addition, 19–24% of bereaved family members reported experiencing grief-specific stress, such as difficulty accepting the death, avoiding reminders of the loss, or having an increased physiological response when reminded of the loss, and 11–50% of bereaved family members reported experiencing increased levels of general stress, such as depression, sadness, loss of interest, fatigue, anxiety, and the inability to relax [86–89]. In a longitudinal study, pre-loss spirituality predicts post-loss distress in bereaved cancer caregivers [50].

Recently, the first prospective study to examine a cohort of primary caregivers of cancer patients in the last stage of life, collecting pre-loss mental health data and systematically following up the cohort for up to 3 years after the loss, found that 20% of caregivers exhibited symptoms of persistent grief disorder for 37 months after the loss [90]. In addition, studies have shown that family caregivers who are no longer involved in the cancer patient's care reported that many of their needs remained unmet. In addition, unmet needs for coping with loss were a significant predictor of acute emotional response to loss, persistent complex grief, and post-traumatic stress disorder-like symptoms related to loss that occurred years, not months, after death [3].

Caregiving stress, which was shown to be strongly associated with unmet needs during grief, was not the objective assessment of the severity of the index patient's cancer but the subjective assessment of caregivers who found caring for the index patient stressful [91]. Resuming daily and social activities benefits caregivers by alleviating the anxiety associated with grief years after the loss [17]. By improving their ability to care for themselves, informal caregivers can optimize care for their loved ones, reducing the likelihood of hospital readmissions and the associated costs to the medical services providing care [38, 92, 93].

All of these findings suggest that cancer caregiver programs should include information on how to manage caregiver-related stress in the early survivorship phase and how best to identify and recruit effective social programs to improve caregivers' personal and social resources in early survivorship, as depression is a long-term problem for this population [78]. In addition, the different characteristics of cancer care and the psychological factors of individuals participating in cancer care at various stages of survivorship are critical to improving the effectiveness of care and maximizing the quality of life of survivors and caregivers [94].

3 Interventions for the Management of Caregivers' Burden

Family caregivers report high levels of discomfort, highlighting the need to screen caregivers and identify individuals who might benefit from psychological interventions and support [95]. In addition, the literature states that given a choice between a social support system intervention and a reduction in caregiver burden, the latter may be better suited to reduce the intensity of depressive symptoms in spousal caregivers of cancer patients [54]. These insecure caregivers would benefit from educational programs that would improve their caregiving skills and encourage them to seek help from other family members or community members [23].

3.1 Good Examples

The reality is that stress management, family-based interventions, and programs for family members are needed throughout the disease course [74, 91]. Findings imply that cancer survivorship programs should engage family members and provide regular psychological treatment beyond the initial survivorship phase. In addition, persistent psychological distress and difficulties with role adjustment have been documented in spousal caregivers approximately 1 year after the completion of cancer treatment, with scores significantly higher than healthy controls [74].

Patients' spouses, siblings, children, parents, and friends are considered family caregivers. Family caregivers bear a significant burden in providing informal and supportive care to cancer patients throughout cancer treatment, as they must cope with suffering at a considerable physical distance from their support networks, give up their jobs to be within reach of services, or struggle to incorporate religious and cultural requirements into caregiving [40]. The psychological adjustment of cancer caregivers who perform multiple roles, particularly those employed and care for children, depends on the availability of community-based services. Intervention programs targeting informal cancer caregivers who fulfill multiple social functions should be developed to help them adjust to their new caregiving roles and improve their quality of life [96]. In addition, couples may benefit from interventions that will enhance their ability to cope with psychological distress, especially their spouse. This may support both couples' mental and physical health coping with cancer [97]. Research shows that cancer survivors and their caregivers are inextricably linked. Therefore, caregiver quality of life initiatives should focus on caregivers and caregiver-survivor couples [98]. While our knowledge of the caregiving process is improving, there is an urgent need to pay more attention to the barriers families experience during the disease process [44]. Identifying the unmet needs of family caregivers should be the first step in developing initiatives to improve caregivers' quality of life [99].

We have established a solid foundation for establishing successful programs over the past two decades as various research efforts have identified the needs of cancer patient caregivers [44]. Despite the decreasing stigma associated with seeking psychological support in the modern era, some research indicates that informal caregivers of patients with terminal cancer are rarely offered psychosocial support [100]. Studies examining the effectiveness of psychosocial interventions to reduce psychological distress in cancer caregivers found that psychosocial interventions successfully reduced depression and anxiety in cancer caregivers compared with usual care [101]. Psychological interventions may help reduce the burden on informal caregivers of cancer patients. However, more careful, multicenter randomized controlled trials and examining the long-term effects of psychosocial interventions on caregivers are needed [102]. Caregivers' needs may vary at different stages of the care pathway, and support should be tailored to meet those needs accordingly. There is still considerable range and inconsistency in the content and quality of research examining the function of psychological support for caregivers. Psychoeducational programs to support family caregivers are widely used [21], but cognitive-behavioral interventions for informal caregivers of cancer patients and survivors have had a modest overall impact [75]. Although cognitive-behavioral therapy components such as coping skills training, problem-solving, cognitive restructuring, structured homework, and relaxation were found to be marginally more effective for younger, female caregivers, the effect of cognitive-behavioral interventions was not statistically significant compared to a control group in randomized designs [75]. Caregiver stress can be managed with emotion regulation therapy and life review therapy, which may also have a protective effect on informal caregivers' self-esteem [84, 103, 104].

In addition, findings suggest that both survivors and caregivers may benefit from interventions that increase their capacity for meaning and peace in the cancer experience, which may be associated with improved mental and physical health for themselves and their partners as they engage with cancer beyond the early stages of the disease process [52]. In addition, informal caregivers may benefit from interventions that strengthen their ability to accept their circumstances and find meaning in their caregiving experience, resulting in overall satisfaction with life and decreasing depressive symptoms [105].

The needs of informal caregivers in cancer are primarily unmet, as studies have shown that informal caregiving for a relative or friend who has cancer or advanced terminal illness can lead to a variety of problems, including insomnia, deterioration in overall health, exhaustion, and anxiety/depression [106]. Here, there is a particular need to identify the unmet needs of family caregivers during the long-term survivorship phase and establish programs to assist them in psychosocial and spiritual adjustment to cancer in the family [78]. In the long-term survivorship phase, interventions for caregivers must take into account caregivers' fear of recurrence of their patient's cancer [3]. In addition, cancer survivors and their family caregivers may benefit from interventions that improve their ability to control the fear of recurrence, improving their mental and physical health later in life, such as during the long-term survival phase [107].

As the number of older cancer patients continues to increase, the growing number of caregivers of older cancer patients has expanded the caregiving work to include the unique issues associated with the needs of oncology, palliative, and end-of-life care [18, 108]. Although caregivers are essential partners in promoting the health and well-being of older cancer patients, they are often excluded from patient education initiatives before discharge [53]. A recent review examining the impact of various support programs focusing on psychoeducational needs through face-to-face sessions, and counseling indicates that support programs aimed at addressing disparities must be effective and sustainable if they are to go beyond addressing a specific health disparity and help affected groups empower themselves through systemic change [109].

3.2 eHealth Options

Information and communication technology has become increasingly important in recent decades in facilitating information delivery and data sharing, overcoming physical barriers, and addressing human needs. eHealth refers to disseminating information about diseases or health care and supporting patients and informal caregivers through computers or related technologies. eHealth interventions are increasingly used in cancer care, for example, to help patients and informal caregivers manage everyday symptoms and problems [110].

In addition, eHealth systems can enable collaboration among numerous hospital settings to improve health services, patient engagement, monitoring, and management and provide rapid access to expert advice and patient information regardless of where patients are located or where data are collected. For example, interventions that use phone calls or eHealth technologies aim to improve caregivers' physical and emotional well-being to meet various user needs [14]. Although studies indicated substantial benefits in some of the caregiver categories studied, they often had tiny effect sizes [69]. While systematic research found an impact of eHealth on cancer patients' knowledge, information literacy, and perceptions of the help they received, very few systematic reviews examined eHealth for informal caregivers of cancer patients [110]. Caregivers will benefit from tailored programs based on their early survivorship demographic characteristics (younger caregivers, e.g., reported high levels of unmet needs), which will ensure their long-term quality of life after diagnosis, as gender was significantly associated with unmet psychosocial needs at 2 years [98]. From the perspective of the post-cancer, survivorship period, caregivers' baseline demographic characteristics, and perceived caregiver stress must be examined earlier. This will help identify subgroups of caregivers whose different needs are less likely to be met after their patients die [77]. Caregivers' ethnicity, income, and marital status should be considered when developing programs to help subgroups of caregivers meet their needs related to cancer care [98].

Future studies are essential to examine whether video-based instructional interventions are feasible and helpful as a support tool for caregivers, mainly when YouTube is used for pain management [111]. To this point, evaluations have suggested that nurses and helping professionals could more effectively support home-based caregivers by providing the knowledge and feedback needed to perform practical caregiving tasks. By meeting the suitable needs of informal caregivers, health professionals working at the interface of home and palliative care may assist informal caregivers more effectively [112].

3.3 Policy Action Needed

Family caregivers of cancer patients may benefit from social, health, and service policies that uniquely address their emotional and physical distress [113]. Because informal caregivers make a significant contribution to cancer care, cancer policy increasingly focuses on and recognizes the importance of providing effective and appropriate support to informal caregivers in managing the impact of their caregiving responsibilities in addition to their regular job or other caregiving responsibilities [21]. For example, employers may provide early support and assistance to employees caring for cancer patients, such as 45 sick leave days per year [114]. The importance of this issue may reflect a widespread recognition of the tasks caregivers undertake and the associated expenses [72].

Because of the complexity of the caregiving experience, known characteristics that contribute to caregiver burdens, such as physical health, mental health issues, socioeconomic status, social isolation, and family or social support, will persist and often be exacerbated by new cancer therapies. However, given the essential role informal caregivers play in complementing formal care, creative solutions are needed to address these new issues and needs on care throughout the cancer trajectory [115]. This requires the development of appropriate care plans for family caregivers of cancer survivors as long-term survival progresses [77]. While key family caregiver organizations are fighting for "caregiver-friendly" legislation and programs at the national level, advocating for the unique needs of family caregivers of cancer patients may be most successful at the state and local level, where legislators are most accessible [44]. Given the significant burden and distress associated with cancer caregiving, greater emphasis should be placed on improving social service policies and practices [113].

4 Conclusion and Outlook

Most of us will be affected by cancer at some point in our lives. Given the increasing investment in psychosocial cancer care research [72] and the fact that cancer caregivers face the simultaneous stress of significant role transitions and additional responsibility for patient needs, often resulting in caregiver burden, there is acknowledgment that informal caregivers of chronically ill patients also require care and support [75]. However, despite the rapid increase in cancer caregivers, there remain significant gaps in knowledge regarding the variables that lead to individual differences in the cancer care experience [23].

The COVID-19 pandemic directly impacted informal caregiving and increased the burden of family caregivers [116]. The need to maintain a social distance and take extra measures to avoid COVID-19 viral transmission almost certainly significantly impacted the experience of formal and informal cancer care [117]. Family caregivers of community-dwelling elders have faced significant caregiving challenges due to the breakdown of institutional and informal support networks during the COVID-19 epidemic [118]. Nonverbal information cannot always be sent or received, making it difficult to offer and receive care in delicate situations [119]. Increased stress, pain, depression, sleep problems, and irritability are frequently reported health outcomes [116]. Informal caregivers, in particular, may need treatments to promote sleep duration and quality during COVID-19 [120]. Therefore, immediate action is required to alleviate the increasing burden of cancer caregiving and continue supporting caregivers.

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