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Family Caregivers' Unmet Needs in Long-term Cancer Survivorship

Youngmee Kim, PhD, **Charles S. Carver, PhD**, **Amanda Ting, BS**
University of Miami, Coral Gables, FL

Abstract

Objectives: To review the family caregivers' unmet needs in the long-term phase of survivorship to identify unique challenges faced by family caregivers.

Data Sources: Research-based articles and published reports.

Conclusion: Family caregivers diverge into three distinct groups in the long-term survivorship phase: those remaining in care, those whose patients have survived and where care is no longer needed, and those whose patients have died. Their primary unmet needs vary by the different caregivership trajectories.

Implications for Nursing Practice: Comprehensive understanding of family caregivers' unmet needs is required to develop family caregiver care plans in long-term survivorship.

Keywords

unmet needs; caregivers; long-term survivorship; long-term cancer care; bereavement

Improved 5-year survival during the past four decades and accumulating evidence on long-term mental and physical sequelae of cancer treatment have informed survivorship care plans for cancer survivors for years after completion of cancer treatment.[1-3] Studies have also found psychological distress and poor quality of life among family caregivers,[4-7] but these studies focus mainly on the time of initial treatment and end-of-life phases and most are cross-sectional. To date, efforts to address these problems are lagging. An important initial step is to identify the extent to which family caregivers' poor quality of life is attributable to their needs not being fulfilled during their patients' long-term survivorship.

Given the reduction in cancer recurrence during the first 5 years following diagnosis,[8] approximately two thirds of cancer patients are alive 5 years after the initial diagnosis, some are in remission, others are in cancer care; one-third have passed away.[2,3,9] Family members experience the same passages. By 5 years after their relative's cancer diagnosis, family caregivers who were once actively involved in cancer care diverge to different paths: some

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Address correspondence to: Youngmee Kim, PhD, Department of Psychology, University of Miami, 5665 Ponce de Leon Blvd., Coral Gables, FL 33146. ykim@miami.edu (Y. Kim).

become former caregivers whose patients no longer need their care (former caregivers–remission), others continue or resume cancer care to the patient (current caregivers), and others become bereaved (bereaved caregivers).[10,11] Family caregivers' needs presumably vary at 5 years after the survivors' initial diagnosis, depending on their patients' prognostic status. Unmet needs of these three distinct groups of caregivers may be critical determinants of their quality of life. Table 1 is a summary of the unmet needs of these distinct groups of caregivers.

Former Caregivers - Remission

The majority of family members are no longer involved in cancer care for the relative with cancer by 5 years after the initial diagnosis. Although these former caregivers' cancer-related needs decrease by 2- and 5-year marks, some unmet needs remain highly endorsed. Those are needs for managing emotional distress and concerns about cancer coming back, reducing the patients' stress that is associated with the cancer experience in daily life, managing interpersonal relationships, and balancing various other needs with health care needs.[12-16] Psychosocial unmet needs remained the most prevalent during the first 5 years.[14]

During the first 2 years, younger caregivers reported greater unmet needs in psychosocial, medical, financial, and daily activity domains. Caregivers with higher income reported greater unmet needs in financial and daily activity domains. Caregivers' ethnicity was not significantly associated with their unmet needs.[14] At the 5-year mark, however, younger caregivers reported greater unmet needs only in the daily activity domain. Caregivers with higher income reported less financial unmet needs and greater daily activity unmet needs. White caregivers reported less unmet needs in psychosocial, medical, and financial domains.[14] In another study, greater number of unmet needs among younger caregivers was also reported. However, those associations did not differ by the time since diagnosis.[17]

Former caregivers' psychosocial unmet needs were associated with poorer mental health, beyond the contribution of demographic factors, which was the case throughout the first 5 years since the diagnosis.[14] At 2- and 5-year marks, only financial unmet needs were associated with their poorer mental health.[14] Unmet needs that remained highly prevalent during the first 5 years since the diagnosis were related to concurrent heightened anxiety but not to depression.[16] On the other hand, caregivers' unmet needs were not significantly associated with their physical health.[14]

Current Caregivers

Although cancer is increasingly considered as a chronic disease, family caregivers' current caregivers caregiving status during the long-term survivorship phase is rarely assessed. Thus, we speculate that the patterns of unmet needs and their associations with quality of life observed for former caregivers whose patients no longer need their cancer care at the 5-year mark may be similar to some degree among family caregivers who are actively providing care to the index patients at the 5-year mark. In addition, caregiving challenges during the time of initial diagnosis and treatment may repeat when the patients continue to need, or resume needing, cancer care during the long-term survivorship phase, including the needs to meet patients' complex care demands, communicate with various medical health care professionals and family and friends, manage daily activities, etc [18-23]

On the other hand, palliative or end-of-life care studies may be informative in providing insights on current caregivers' unmet needs years after the initial diagnosis, although the time since diagnosis is often not examined in such studies. For example, some new needs pertaining to the end-of-life care period can arise for long-term caregivers, such as the need to maintain intimacy with the patient and the need to reconstruct the relationship with the patient to face impending death.[24] Managing emotions about prognosis, fear of cancer spread, balancing one's own and the patient's needs, impact of caring on work, and making decisions in the context of uncertainty were highest unmet needs of the caregivers in the last 6 months of the ovarian cancer patient's life (who were diagnosed on average 31 months prior to study participation) during the 2-year follow-up period.[25] Other needs for materials and information,[26] and financial burden that were highly prevalent at the early survivorship phase and that had once decreased could become prevalent again as patients require extended treatment.

Bereaved Caregivers

Although the 5-year survival rate has improved for a all cancers combined, from 49% in 1975 to 69% in 2013,[27,28] cancer remains the second leading cause of death in the US and more than 609,000 die from cancer each year in the US.[28] This results in a substantial number of families experiencing bereavement because of cancer. Although some bereaved family members have displayed relatively stable levels of psychological distress, levels that are comparable to those of non-bereaved counterparts,[29] the majority of bereaved family members have shown clinical levels of psychological distress, not only some months but years after the death.[30-35] While elevated distress shortly after the loss is considered normative, professional intervention is recommended when it is prolonged for years, as prolonged distress compromises not only daily functioning but also long-term health.[36-39] Thus, it is a substantial concern, particularly when the bereaved caregivers' psychological distress remains elevated for years after the loss.

Needs for balancing between full grieving about the loss and adjusting to life without the deceased are primary challenges bereaved caregivers face.[15,40,41] During the first 6 months after the death, younger age and female gender, premorbid mental health conditions, and lack of preparedness for the death were found to relate to poorer bereavement outcomes.[30] Unrelieved pain and anxiety of the patient before the death, and caregivers being unprepared for the impending death were related to several psychological and physical morbidities of the surviving caregivers.[30]

The majority of studies describe bereavement outcomes cross-sectional and caregiving experiences retrospectively after the patients' death, limiting adequate evaluation of the impact of bereavement that occurred in the long-term phase of survivorship.[41,42] However, one study reported that a substantial number of caregivers (15% to 30%) showed pathological levels of anticipatory grief symptoms during the end-of-life care period, whereas none of the caregivers showed complicated grief using the same measure after the care recipients passed away.[43] Another study[40] revealed that caregivers' demographic and earlier caregiving characteristics are strongly related to the caregivers' unmet needs pertaining to the loss years later. Namely, younger adults (mean age was 56) reported greater unmet needs for reintegrating their daily lives and managing the loss. In addition, the stress of the caregiving that occurred 3 to 6 years earlier was significantly related to bereaved caregivers' unmet needs. An important point here is that the caregiving stress in question was the caregivers' subjective evaluation that providing care to the index patient was overwhelming, not an objective evaluation of how severe was the cancer the index patient had. Ethnicity was also a significant predictor of bereaved caregivers' unmet needs for reintegration at the 8-year mark. Non-white caregivers, compared with non-Hispanic whites, reported greater unmet needs for reintegrating their lives after the loss.

Unmet needs regarding the loss were in turn related to the caregivers' adjustment to bereavement during the long-term survivorship phase.[40] Specifically, unmet needs for managing the loss were a strong predictor of intense emotional reaction to the loss, prolonged complicated grief, and post-traumatic stress disorder-like symptoms that are related to the loss, which were present years, not months, after the loss. Such associations were significant beyond what a host of demographic and earlier caregiving characteristics could account for. The findings call for more studies bridging cancer survivorship with bereavement research, which are currently scarce.

Conclusion

Cancer caregivers' needs are complex, as is cancer care itself. Cancer caregivers' needs in the period of long-term survivorship add more complexity because their needs diverge as their patients' survivorship trajectory does so. Around the 5-year mark, when the probability of cancer recurrence plateaues, studies have found that family caregivers who are no longer involved in cancer care to the index patient reported that many of their needs were unmet. Their primary unmet needs were managing the concerns that the cancer may return and readjusting to the "new normal" because this large group of family caregivers, particularly for the patients who do not need cancer care anymore, remain "lost in transition" in the health care system.

Another critical group of family caregivers, who are often unrecognized, is those who are actively involved in cancer care many years after the relative's initial diagnosis. The reasons they are involved in cancer care in the long-term survivorship phase could depend upon the patients' continued or the resumption of their care needs, following treatment for recurrence or newly emerged care needs arising from end-of-life care. Studies reviewed here in the current caregivers section focused mainly on the end-of-life care phase, which could occur anywhere from weeks to decades after the initial diagnosis. Despite their limited applicability to the longterm survivorship phase, these findings suggest that actively engaging in cancer care for years, or resuming such caregiver role years after the initial diagnosis, is highly likely to be associated with greater needs in all aspects of caregiving. Unknown is the degree to which such current caregiving in the long-term survivorship phase differs from that in the early survivorship phase. Also unknown is the extent to which needs of caregivers providing continued, resumed, or newly emergent care, differ from those engaged in end-of-life care. Identifying the unique needs that are unfulfilled among current caregivers in the long-term survivorship phase is crucial for optimal patient care plans.

Finally, although cancer is the second leading cause of death, disproportionate attention has been paid to bereavement because of cancer. Existing studies mainly document substantial degree of psychosocial adjustment difficulties that bereaved caregivers face, implying the majority of caregivers' psychological needs to adjust to their lives after the loss not being fulfilled. Similar to current caregiver studies, bereavement studies often do not consider earlier survivorship phases, hindering proper evaluation of the findings in the long-term survivorship phase. Nonetheless, bereaved caregivers' needs are broadly grouped in two categories: managing the loss and reintegrating one's life, supporting general adaptation theory to bereavement.[44]

Future Research Considerations

Identifying demographic correlates of unmet needs among the three distinct groups of family caregivers in the long-term survivorship phase will provide useful information about how to best target sub-groups of caregivers who may be most in need of assistance. Furthermore, information about which unmet needs are more likely to relate to poor quality-of life-indicators will also be useful in guiding researchers and clinicians as to how to best design and develop programs to reduce caregivers' unmet needs, which will in turn improve their quality of life.[15]

The nuanced contributions of caregivers' unmet needs to their specific aspects of quality of life should also be investigated. For example, although spiritual challenges have been fairly consistently mentioned among both caregivers in the end-of-life period and bereaved caregivers, comparable information among other types of long-term cancer caregivers and former caregivers-remission has not been systematically documented.[40] Identifying not only the levels of spiritual needs but also the predictors and consequences of unmet spiritual needs of family caregivers may be warranted, providing important information for mitigating caregivers' burdens and improving their quality of life. Another area that needs further investigation is the long-term impact of unmet needs on various aspects of caregivers' broader quality of life, as the majority of existing studies focus on psychological aspects. For example, owing to the worldwide trend of aging populations, investigating how unmet needs and burdens of cancer caregiving may contribute to physical health in particular, such as higher rates of morbidity and mortality,[45,46] particularly among older caregivers, will be essential.

The majority of studies have small sample sizes and their findings are mainly cross-sectional. Prospective information that begins from the cancer diagnosis of the care recipient and follows through for years is valuable in precisely documenting the cancer trajectory, not only from the care recipients' perspective during the survivorship phases, but also more importantly bridging the survivorship with bereavement phases from caregivers' perspective. The importance of considering the caregivers' place in their life course should also be underscored because the severity of unmet needs and distress varied by the caregivers' age and familial relationship to the patient.[30] Furthermore, larger comparative studies[47] with longitudinal design are needed for systematic investigations of the trajectories of cancer-specific and general caregivers' unmet needs and how their identification influences caregivers' health outcomes. Cost-effective programs and tools that are readily accessible are also needed to measure the multiple, complex concerns of a large number of caregivers.[48,49]

These are substantial concerns that must be incorporated in future studies as the first step to develop evidence-based guidance for programs and policies aimed at reducing family caregivers' unmet needs and improving their quality of life at key transition points across diverse illness trajectories that may span many years. Addressing each of these concerns in future studies will help not only in advancing the science but also in bettering public health by improving family caregivers' health by improving family caregivers' health.

Implications for Nursing Practice

Findings thus far, despite their limitations, support the premise that family caregivers' unmet needs diverge in the long-term survivorship phase by their patients' prognostic status. Psychosocial unmet needs in particular are a critical concern because they link to poorer mental functioning across different trajectories of family caregivership. Findings suggest that nurse-led stress management interventions for cancer caregivers[50,51] should be cognizant of the complex dynamic of family caregivers' needs being associated with their quality of life, which vary by their patients' prognostic status. In long-term survivorship, caregiver interventions must address the needs for managing caregivers' fear that their patient's cancer may return for caregivers who no longer are involved in cancer care; the needs for managing the patients' symptoms for an extended period or for providing end-of-life care for caregivers who are actively involved in cancer care; and finally, the needs for managing the loss of a loved one while attempting to reintegrate their lives for bereaved caregivers.

Nurses can support family caregivers by identifying at-risk subgroups of caregivers based on their demographic characteristics, such as age, household income, spousal status to the patient, as well as the assessment of their stress evaluation of the new cancer caregiver role and appraisal of the patients' cancer severity earlier in the cancer survivorship phases. Also, nurses must be involved in survivorship care plans that include plans for family caregivers, and be equipped to deliver support to family caregivers who are at different places in the cancer journey many years after their patients' initial cancer diagnosis, because needs differ at different places on that journey.

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Table 1.

Caregivers unmet needs.

Group of Caregivers	Unmet Needs
Former caregivers - remission	Managing emotional distress
	Concerns about cancer coming back
	Managing interpersonal relationships
	Reducing patient stress associated with cancer
	Psychosocial
	Medical
	Financial
	Daily activities
Current caregivers	Meeting patient’s complex care demands
	Communication with medical health care professionals,family, and friends
	Managing daily activities
	Maintaining intimacy with partner
	Responding to potential change in patient condition
	Managing emotions about prognosis
	Balancing own needs and patient’s needs
	Impact of caring on work
	Making decisions in the context of uncertainty
	Materials and information
	Financial
Bereaved caregivers	Managing psychological distress
	Reintegrating daily life
	Managing the loss of the patient