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Abstract

Family caregivers provide uncompensated care and assistance to a family member who has cancer. When patients move through the care trajectory into the survivorship phase, roles and demands of caregivers change and caregivers assume responsibility to assist with coordination of ongoing care. The goal of this article is to describe aspects of caregiver experiences and the roles of caregivers as patients transition from active cancer treatment into the first and early phase of cancer care. Residual problems for patients and caregivers remain for some period of time. *Cancer Epidemiol Biomarkers Prev; 20(10); 2015–21. ©2011 AACR.*

Introduction

Family caregivers are individuals who provide uncompensated care or assistance to a family member who has cancer. This care goes beyond the usual family activities, such as household chores. Research has documented the negative effects of providing care to someone who has cancer. Family caregivers are at risk for developing side effects such as fatigue and sleep disturbances (1), lower immune functioning, slower wound healing, higher blood pressure, and altered lipid profiles (2, 3). Positive effects of providing care have also been reported such as rewards, self-esteem, support, uplifts, and satisfaction, which may provide a buffer to the residual negative effects of caregiving (4–6). Caregivers report life changes, appreciation of life, acceptance, reprioritization of values, increased self-confidence, stronger interpersonal relationships, and strengthened spirituality (7–9). Most research, in oncology, has focused on caregivers' reactions to providing care during active treatment or at the patient's end of life. However, care activities, and thus the negative effects of providing care, do not end with the completion of the patient's active treatment.

Although more than 65% of cancer patients now survive for more than 5 years, quality-of-life issues for patients and their families continue even after active treatment ends (10, 11). When patients move through the care trajectory into the survivorship phase, roles and demands of caregivers change and caregivers assume responsibility to assist with coordination of ongoing care, but, as research shows, care needs remain for a large number of patients (12–14). Preparing the family member for the transition into survivorship is a vital part of the provider's role. Access to the health care system for assistance decreases after active treatment. Issues such as slow or nonresolving symptoms and side effects, residual limitation in physical function, and adherence to ongoing medication and follow-up care remain The patient's adjustment to the survivorship phase can affect the role (15). On the basis of assessments of the patient's posttreatment needs, information and support can be provided and appropriate referrals for continuing care may be made. Return to primary care providers for ongoing care may be the posttreatment expectation or there may be a shared care approach with both primary care and oncology providers involved with the posttreatment care.

The goal of this article is to describe aspects of caregiver experiences and the roles of caregivers as patients transition from active cancer treatment into the early survivorship phase of cancer care, which may be the first year or two. The focus is on the group of patients who have care needs and prior to any return to active treatment. The team for effective transition cancer care for patients and their caregivers involves not only physicians and nurses but may also include dieticians, nutritionists, physical therapists, case workers, social workers, and psychologists (16, 17). Family caregivers continue to be concerned about patients but have their own transitions as well. Finally, dyads should be aware that the end of active treatment does not signal return to precancer existence (18).

Transition for Patients and Caregivers Posttreatment

When active treatment ends, caregivers are often responsible for coordinating care with a new set of care activities and with differing resources, as patients shift from the oncology team as their primary source of support back to their primary care providers. New information

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and skills are vital for the transition to early survivorship, yet caregivers often receive little help and guidance to maximize patients' recovery and reintegration into their previous roles and patterns. Unfortunately, transition care is often fragmented, uncoordinated, and without an analysis of services based on needs of the patient, their recovery, and the sequela and posttreatment toxicities or the late effects of cancer treatment.

The need for caregiver involvement following active patient treatment may continue for several years, as patients have residual symptoms, late effects, and disability (13, 14, 19). Caregiver activities, roles, and demands during posttreatment depend on the residual impact and the treatment the patient has received as well as the long-term expectation of survival and outcome of treatment (13, 14, 20–22). From our work, we have found that 60% of 143 patients who were from 2 to 6 weeks posttreatment reported substantial problems (23). These problems included depression scores above 16 on the Center for Epidemiologic Studies Depression Scale, 3 symptoms with a severity score above a threshold of 4 on a 10-point scale, 2 or more comorbid conditions, and a physical function score of the 36-Item Short Form Health Survey in the mid to high 60s. For the most part, these characteristics persisted 6 weeks later. Together, the data indicate that the proportion of patients leaving treatment with residual problems is substantial and poses a challenge for their family caregivers. This transition period causes caregivers to adapt to an ongoing or new set of patient care needs with uncertainty about the patient's future (13, 14, 24, 25). For some patients, there is disease progression or recurrence, or a second cancer that further complicates the disease trajectory. For others, treatment continues for the duration of the patient's life, with treatment-related side effects left to the patient and family to manage. Unfortunately, there has been little research examining family caregivers in the early transition/survivorship period (20, 22, 26, 27).

Multiple factors can affect how family caregivers respond emotionally and physically to changes in the patient's treatment and thus changes in care demands. The relationships depicted in this article as well as the cyclical nature of the care situation are supported within the Adapted Pittsburgh Mind Body Center Model (28). In this model, both patient characteristics (e.g., the patient's functional ability) and caregiver characteristics (e.g., the availability of social support and gender) affect caregivers' emotional responses to providing care (e.g., depressive symptoms, anxiety, and burden). These emotional responses, in turn, may alter biological responses (initiating and prolonging the physiologic stress response), which ultimately lead to poor overall health. The cyclical nature of the model is vital to understanding caregiver demands and health as patients transition out of active treatment into the survivorship phase. During this transition, patient characteristics will change (e.g., changes in symptom severity) and new care demands may arise (e.g., surveillance for symptom recurrence).

Reintegration Following the End of Treatment

The caregiver's "new normal" or reintegration following the cancer experience will vary depending on the patient's disease trajectory. One patient may have a well-controlled disease with maintenance therapy, whereas others experience progressive, residual symptoms such as fatigue or pain (29), or the risk for late treatment effects. In each of these scenarios, both patients and family caregivers must adapt to this new phase often with less direct care from oncology health care professionals.

For caregivers, tasks during the patient's transition from active treatment turn to monitoring and surveillance of late effects, recurrence, and/or disease progression. In addition, caregivers coordinate care by making and keeping medical appointments and continue to maintain insurance and billing paperwork. When the active treatment ends, patients may be transferred from cancer specialists to primary care providers. Often there is a disconnect between providers, and fragmented care may ensue. Frequently, family caregivers become responsible for the coordination of care during this period. Primary care providers prefer not to manage ongoing cancer-related issues but instead prefer to focus on issues such as routine screenings and treating comorbid conditions (30).

Caregivers often have fears about recurrence and the future, a sense of loss of control, and anxiety about lack of contact with oncology practitioners. Caregivers centered their life activities around providing care, adjusting their schedules and relinquishing valued personal activities. When the treatment is over, they may have a difficult time restoring these activities, as the relationships may no longer exist; friends, social support, and opportunities may have moved on (4, 31). Both patients and caregivers may have reintegration problems in resuming social relationships, establishing communication patterns, dealing with problems involving family and children, and financial and employment difficulties (32, 33). Caregivers' routines must be reorganized and reprioritized to compensate for the long-term impact that cancer and treatment have had on the family (33, 34). Caregivers want to return to "normal" and resume their lives but must often establish a new normal. Reintegration to "normal life" may be difficult, as both patients and family caregivers try to move forward with their lives. Caregivers may have neglected their own health problems and need to resume screening for age/sex-appropriate conditions, management of their own chronic conditions, or resume healthily lifestyle activities such as exercise regimens or better diets. For employed caregivers, renewing attention to jobs and reestablishing relationships with co-workers may be important. Evidence from the caregiving literature indicates that family members may have difficulty withdrawing from caregiving roles, particularly for those who have become enmeshed in caring (17).

Caregiver/patient needs during transition

It is important to assess the care at the transition phase and then find strategies to support caregivers who remain involved. Caregivers' needs, resources, and capabilities will be influenced by multiple factors such as gender, age, culture, education, economics, and geographic location. Residual effects from disease and treatment, late effects, altered household and family roles, along with altered communication patterns adopted during treatment, remain a source of anxiety for caregivers as they seek to reinstate work and secondary roles (5, 35). Caregivers assist patients with persistent symptoms, emotional distress (anxiety, fears, worry, and depression), medical problems, social needs, need for information, and coordination of care services (14, 21, 36). In addition, economic and financial stressors are common after active treatment due to the high cost of cancer care or loss of employment for either the patient or the caregiver (20, 24, 37, 38). Some targeted therapies and biological agents may costs more than $60,000 to $100,000 per year, and insurance coverage varies for these agents. Caregivers report using financial resources, selling homes, taking out loans, and even declaring bankruptcy as a result of expensive care (39).

Continued involvement of caregivers following transition

Although caregivers report unmet needs decreasing after active treatment, they also cite that some needs remain even at 5 years (14). One study reported that 60% of caregivers had at least one unmet psychosocial need at 2 years after active treatment and 36% still claimed unmet needs at 5 years. The prevalence of medical support needs was 49% at 2 years and 28% at 5 years (14). On average caregivers provided 8.3 hours per day of care for 13.7 months after "active treatment," which varied by cancer diagnosis and caregiver education. Caregivers whose financial needs were not met reported poorer mental health at 2 years and the prevalence of financial unmet needs was 27% at 2 years and 19% at 5 years (14, 21).

Unmet needs often take the form of assisting patients with residual symptoms such as pain, fatigue, cognitive issues, sleep disturbance, and depression. Late effects such as lymphedema, cardiac changes, pulmonary fibrosis, constipation, diarrhea, incontinence, and/or anorexia also occur (4, 11, 29, 40, 41). The severity of patients' functional impairment or disability can increase care demands and restrict caregiver activities (7). As the number and/or severity of long-term late effects increase and the patient becomes more dependent, the caregiver's level of distress may increase (4, 42). Family members continue to be patient advocates, interacting with the health care system to obtain information and support services, as well as to negotiate with the system.

Health promotion

Caregivers may forego their own health needs to focus on providing care during active treatment (11). Health care professionals need to encourage caregivers to return to usual activities and maintain their own physical and mental health. Healthy living and lifestyle recommendations for nutrition, exercise, and stress management should be provided. Health-promoting behaviors and how current distress affects both the long-term health and well-being of caregivers need to be examined. The prevalence of the unhealthy behaviors such as limited physical activity, poor nutrition, obesity, alcohol consumption, and smoking among family caregivers in the survivorship phase is not well established (11). Both patients and caregivers should be guided to return to a healthy lifestyle.

In one of the few studies in this area, Beesley and colleagues (11) followed caregivers of ovarian cancer patients over approximately 3 years following their cancer diagnosis to examine current health patterns and weight changes. More than half of the caregivers did not meet physical activity guidelines, and 71% were overweight; 40% ate less than 2 servings of fruit, and 80% less than 5 servings of vegetables. Beesley and colleagues also reported that 37% consumed alcoholic drinks and 10% were smokers. Fifty-six percent reported more than one negative change in lifestyle, 42% decreased physical activity, and 35% gained weight since the patient's diagnosis. Caregivers reported more unhealthy behaviors when they had fewer years of education, were limited in daily activities, or reported high levels of depressive symptoms (11). Beesley and colleagues did not have a comparison group, but they argue that in their study, changes occurred to a greater extent in subgroups with increased physical and emotional demands (11), suggesting that the change in behaviors were not normal changes of aging.

Consideration of the caregiver's health maintenance, physical activity, nutrition, stress management, smoking cessation, chronic disease management, and comorbid conditions is important during the transition phase. Caregivers may experience changes in physical health, which can be complicated by their own comorbid conditions (4, 14), particularly if they are physically inactive (43). Follow-up care by primary care providers is vital.

Difficulty in family relationships may add to the distress of caregivers during the posttreatment phase. Preexisting discordance in family relationships may be aggravated and manifest after active treatment (33, 38, 43). Among caregivers in less mutually satisfying relationships, any residual or late effects may cause negative responses (31, 44). Caregivers may need guidance and counseling, enabling them to return to effective relationships. There is some evidence that benefit finding evolves from the family care role and may contribute to positive relationships (7, 9).

Communication

Caregivers often need assistance to know "how" to communicate with their loved ones after active treatment. Changes in patients' personalities, priorities, and attitudes caused by the diagnosis and treatment may increase caregivers' need to be assertive and find new

communication patterns. There are supportive groups or educational sessions that might be helpful to caregivers. A family conference may benefit the patient, the caregiver, and the professional's ability to communicate (45). Web-based toolkits may become useful to improve communication among patients, caregivers, and professionals. These can be used to foster understanding, provide education, and facilitate care management through communication (46, 47).

Caregiver role activities

Caregivers may be at risk for increased distress in the transition period (13). Spouses have adapted to new roles during active treatment, and now there is a need for another set of role changes or adaptation that call for changes in the demands of social, work, and other relationships (4, 48). Spousal caregivers may have had to assume other role responsibilities for financial and household activities vacated by the individual with cancer and may not be willing to give them up. Adult children and other nonspousal younger caregivers often need to adjust their lifestyle to meet more competing demands, and, in return, exhibit lower levels of well-being (14). van Ryn and colleagues (13) found that 67% of caregivers had at least one competing demand that interfered with their care role.

The loss of employment of the caregiver and/or the patient and restrictions on health insurance due to involvement with cancer care pose a problem that continues into the early survivorship phase. There are the economic ramifications for the family members who have used savings or lost their jobs during treatment. A recent report finds higher bankruptcy roles in survival phase (49). How families at the end of active treatment deal with employment decisions made during active treatment may be problematic, and continuing insurance into survivorship is often a major challenge. Caregivers may find it necessary to find a job with health benefits. Medical insurance, Medicare, Medicaid, and Veteran's benefits all have restrictions to coverage that pose problems that continue into the transition phase. In addition, if providing care affected the caregiver's productivity, loss of promotions and job advancement opportunities may ensue. Caregivers (20%–30%) adapt employment obligations to manage care demands during treatment, and there may be residual effects into survivorship (50–52). These are usually described as missed days, interruptions at work, numerous phone calls, leaves of absence, reduced presenteeism, and reduced productivity (14).

Care plans should include family caregivers and should summarize residual symptoms, potential late effects, and future expectations needed for care coordination appropriate to the patient's health and treatment status. Recommendations for follow-up care, cancer screening (recurrence or new primary), psychosocial effects, and financial issues (work, insurance, and employment) should be a part of the plan. In addition, recommendations for a healthy lifestyle (for both the patient and the caregiver), referrals for follow-up care, and a list of needed support and community resources should be discussed. Referrals to primary care providers for both are important. The LIVESTRONG Care Plan or the Survivorship Care Plan as identified in the Institute of Medicine's publication *Lost in Transition* can be the basis for the plan (16, 53). The plan includes topics such as physical activities, nutrition, effective communication, prevention of substance abuse, staying informed, and stress management for both members of the dyad as appropriate and based on the assessment. Health care professionals need to assess caregivers in particular to identify those at risk for negative outcomes (burden or depression) in the transition phase.

Care plans should also highlight needed resources to assist in this phase. Some caregivers have ample personal, social, and economic resources, whereas others have few. Many caregivers have competing demands with employment, dependent care, and their own health issues. Care demands in this phase may differ from the active treatment phase and include limited physical care, encouragement of physical activity, nutrition, emotional and social support, symptom management, and financial assistance. van Ryn and colleagues (13) found more than 54% of patients in survivorship in high need and thus their caregivers were involved with clinical tasks. More than 68% focused on side effects, 47% spent time managing or controlling symptoms, and 30% assisted with decisions to call physicians. Unfortunately, 44% of caregivers indicated that they were not trained to administer medications and 49% were not trained to manage symptoms and side effects, thus indicating a need for preparation (13).

Interventions that have been successful in other phases such as cognitive behavior, problem solving, and psychoeducational could be adapted for this phase. Few dyadic assessments exist and provide little guidance for intervention. Care plans should include all care tasks that will be needed during the posttreatment phase. Interventions may be needed to support caregiver problem solving, decision making, and priority setting. Most cancer caregiver intervention studies have used a psychoeducational intervention that emphasizes the provision of information, problem-solving skills, and a psychologic/counseling approach to decrease caregiver distress (22). Interventions to increase support for family caregivers have lagged behind those for patients. There is a dearth of literature regarding intervention design and effectiveness for those who have moved past active treatment but are facing the threat of disease progression or recurrence or for some residual or late effects (17, 54). Although there are not clear interventions tested, consideration of caregiver interventions for other phases can be adapted for the needs identified.

With the advent of health care technology, consideration of technology use may be of benefit to support caregivers during this phase. Family caregivers use technology to help themselves with caregiving. Among the two-thirds who use the Internet, the most frequent source was for needed information or support. Caregivers

indicate that technology would be of benefit to them for personal health record tracking, monitoring symptoms and events, tracking or coordinating care (appointments), and reminding to take prescription medications (55, 56).

Research

An inception cohort of caregivers is needed to examine variations in care demands that extend from diagnosis into the transition to survivorship, to determine if there is a logical progression in the depth of complexity and judgment required for tasks of caregiving. There should be a special focus on transition points. In addition, how care responsibilities, decision making, and knowledge and skill change over time should be addressed. Intervention studies are needed that target caregivers at risk for negative outcomes during the transition into survivorship and provide needed support. A cumulative set of risk factors should be developed to identify levels of risk and problems for caregivers and then determine how negative caregiver responses relate to patient outcomes. Risk assessments should include physical and emotional status of patient and caregiver relationships, home assessment, social, spiritual, and legal dimensions (17). Future research should explore how including caregivers in Survivorship Care Plan explicitly maximizes both patient and caregiver outcomes at 1, 3, and 5 years posttreatment.

Research is needed to better describe the impact on caregiver health that result from residual or persistent patient symptoms (loss of voice, pain, lymphedema, sexual dysfunction, or neuropathy) or the late effects, or the types and level of care needed. Little is known about what areas cause the greatest degree of distress or the most lasting effect for caregivers during the care transitions and posttreatment period. More systematic and longitudinal follow-up of healthy patients and health promotion practice studies are needed to examine variations and changes that occur in caregivers as they assume and relinquish the care role. Finally, research should explore differences in problems and perceptions of caregiver experience from different cultural, ethnic, or socioeconomic backgrounds. There is a noticeable absence in inclusion of diverse populations in any of the caregiver studies of the survivorship phase.

Conclusion

In conclusion, there have been studies describing the negative responses of family members to caring for persons with cancer (such as burden and depression) during the treatment and palliative phases of care. However, as caregivers go through transitions into survivorship, research is limited and we know little about the nature of the knowledge and skills caregivers need at transition phases. Unfortunately, there has been little examination of potential variables such as prior family relationships, cultural variation, caregiver health status, residual effects from the cancer, comorbid conditions, late effects, second cancers, ongoing hours of care, or competing caregiver role demands. There is also little evidence of how the unmet needs of caregivers during transition phases vary by previous diagnosis, treatment modality, stage of disease, or as the patient's condition deteriorates. Knowledge of outcomes and effects of caregivers is limited to few studies (8, 13, 19, 40). Fragmentation and discordant expectations posttreatment between patients and their caregivers with respect to who is responsible for survivorship care (primary care provider or oncologist) can lead to challenges for caregivers. Including the caregiver and supporting a clear survivorship plan for both the patient and the caregiver should be a standard component of quality cancer care.

Health policy changes with regard to family caregiving need to be evidence based and linked to the continuing problems faced by patients. Cancer patients with evidence of depression need to be appropriately treated. Family members may need to be screened for depression as well. Patients with residual losses in physical function may benefit from rehabilitation. Family members can be informed about to their roles in engaging patients in these programs and assisted, if need be to schedule, and ensure their patients participate in these programs. At this point, we believe that performance incentives to primary care providers to teach and monitor family caregivers effective engagement will lead to improved long-term outcomes for patients, benefit caregivers by focusing their efforts on aspects of patient assistance with clearly demarcated outcomes, and benefit the health care system through lowering costs for extended care and use.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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