The Caregiving Journey for Family Members of Relatives With Cancer: How Do They Cope?

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Family caregivers need adequate support from healthcare professionals to complete the demands associated with caregiving with minimal impact on their own health and well-being. An optimal balance of provision of care between family and support services has not been achieved; therefore, this literature review investigates how family caregivers endure and cope with the challenges of caring for an adult relative with cancer. This review considered the characteristics of caregivers and their functioning, the external and internal supports that help them cope, the ongoing challenges as they journey along the caregiving trajectory, the personal costs of caregiving, and how caregivers cope with supporting their family members through to the end of their journeys. The literature provides an abundance of research on the numerous challenges encountered by families living with cancer; however, little research has been conducted on the coping strategies used by family caregivers at specific stages along the illness trajectory that either optimize or hinder personal recovery. Even less information is available on interventions nurses can introduce to ease the caregiving burden. Improving nurses’ understanding of the stressors and unmet needs associated with caregiving is fundamental to the development of effective family-focused clinical interventions.

According to the World Health Organization ([WHO], 2007), cancer is the leading cause of death worldwide and will cause the deaths of as many as 84 million people through 2015. The increasing incidence and mortality of cancer worldwide has led to a greater demand for the provision of health care and palliative care services in all developed countries (WHO, 2002, 2007). According to the WHO (2000), the cost of caring for such a significant number of people has overwhelmed many hospital services and promoted the movement of health care into the community. As a result of such resource constraints, inadequate, intermittently available, and potentially inaccessible services exist, which often fail to meet the needs of family members caring for loved ones with cancer. Consequently, the provision of home care relies heavily on the willingness of a family member to become an informal caregiver to a close relative (WHO, 2000).

Many family caregivers believe that their duty is to be present, to offer emotional support, and to provide their relatives with physical assistance in everyday tasks (Perreault, Fothergill-Bourbonnais, & Fiset, 2004). However, the role of the caregiver often is overwhelming and can be a physically demanding and emotionally draining experience, particularly for caregivers of patients with cancer. The financial constraints and the lack of social support can cause family caregivers to feel helpless and leave them little time to appropriately complete personal responsibilities (Grunfeld et al., 2004). In addition, caregivers often feel a moral obligation to continue to care for relatives in the home. This obligation is influenced by cultural beliefs, gender role, and perceptions of institutional constraints on care (Sellappah, 2000).

At a Glance

- Little is known about the coping strategies used by caregivers of adult family members with cancer.
- The role of the family caregiver often is overwhelming and can be a physically demanding and emotionally draining experience.
- Caregivers need adequate assistance from nurses and various support services to meet the demands of caregiving.

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Digital Object Identifier: 10.1188/10.CJON.567-577
Kristjanson, & Maltby, 2001). The purpose of this literature review was to identify how family members of relatives with cancer cope with the caregiving journey.

### Methods and Process

Key words used to search for literature were cancer, caregiver, adult, nursing, survivorship, coping, stress, and caregiver burden. Electronic databases searched included the OVID platform (PubMed, PsycINFO, and CINAHL®), SocioFile, ProQuest HealthSM, Wiley Interscience, Internurse, Science Direct, Health Sciences, SAGE Journals Online, Australian Public Affairs Full Text, Family and Society Plus, Academic Search Complete, and Web of Science®, which produced 103 articles for evaluation regarding the primary question of the review: How do family members of relatives with cancer cope with the caregiving journey? Criteria for inclusion in the review included that the article was published in an English-language, peer-reviewed journal from 2000–2009; that the study was conducted in a developed country; that the study addressed adults with cancer (any type) and their caregivers; and that the study was either quantitative or qualitative and focused on the psychosocial, physical, or financial impact of a cancer diagnosis on families and discussed caregiver stress and coping during the caregiving trajectory. Exclusion criteria from the review included any articles that focused on caregivers coping with death and bereavement of a patient with cancer and articles concerning caregivers of children and young adults. After application of the inclusion and exclusion criteria, 70 articles were reviewed. The literature was grouped into articles that reflected the characteristics of caregivers and their functioning, the external and internal supports that help them cope, the ongoing challenges as they journey along the caregiving trajectory, the personal costs of caregiving, and how the caregivers cope with supporting their loved ones as they reach the end of their journeys.

### Caregivers’ Characteristics and Functioning

#### Caregiver Gender

Inherent traits and adopted family roles have clearly influenced which family member becomes the primary caregiver (Feldman & Broussard, 2006; Kris et al., 2006; McClement, Degner, & Harlos, 2004). The gender of the caregivers and their associated familial responsibilities play a significant role in the decision to begin and then continue to care for a relative with cancer (Bernard & Guarnaccia, 2003; Feldman & Broussard, 2006; WHO, 2000). Kim and Schulz (2008); Papastavrou, Charalambous, and Tsangari (2009); and Wells, Cagle, Bradly, and Barnes (2008) found that, within Western society, women are generally expected by their families to continue to provide the nurturing and caregiving role when a relative is diagnosed with cancer. Similarly, Bernard and Guarnaccia (2003) noted that, although spouses are most likely to care for their partners, daughters frequently feel societal pressure to take on caregiving duties for their parents. All societies around the world assign gender roles that instruct the behavior of women and men (Akyüz, Güvenç, Ustünsöz, & Kaya, 2008). In traditional countries, the female members of a family feel an obligation to provide physical care for the ill relative (Akyüz et al., 2008).

#### Family Dynamics

The family role of caregivers directly affects their ability to endure new responsibilities and adjust to living with constant uncertainty. Prior to becoming caregivers, many women already carry a double burden of working as paid employees and acting as voluntary care providers to family and friends (WHO, 2000). These women who care for one or more of their parents report that caregiving has a detrimental effect on their own marital families’ functioning, more so than effects reported by husbands who care for their spouses (Bernard & Guarnaccia, 2003). However, such a comparison may be considered inequitable as the findings of the study clearly reflect the differing ages and life stages of both caregiver groups. In addition, daughter caregivers reported greater feelings of anxiety and depression than husband caregivers, which the authors assumed was caused by their numerous concurrent noncaregiver duties (Bernard & Guarnaccia, 2003; Grunfeld et al., 2004). Daughter caregivers strongly based their self-worth on their household income and either caring for a child or being employed, thereby indicating that multiple familial roles affected their self-esteem in several ways (Bachner, Karus, & Raveis, 2009).

For husband caregivers, Feldman and Broussard (2006) and Fergus, Gray, Fitch, Labrecque, and Phillips (2002) argued that many men purposefully deny feelings of depression as they fear such an admission may discredit their role as provider and protector of the family. This denial has a negative effect on family dynamics. Husband caregivers have a need to be strong for their families as they complete their daily tasks (Akyüz et al., 2008). This situation also exists, in reverse, when the husband is cared for by his spouse. Fergus et al. (2002) found that some wife caregivers expressed emotional distress in response to their husbands’ lack of communication about negative feelings. The wife caregivers interpreted the lack of open communication as signs of depression. Based on traditional gender roles, men may be better off than women as caregivers because research shows they selectively define their new role, receive more resources, and are less likely to be the only caregiver (Given, Given, & Kozachik, 2001).

In contrast, many daughter caregivers showed signs of poor endurance when the demands of various roles overlapped and caused conflict within the family (Bernard & Guarnaccia, 2003; Spillers, Wellsch, Kim, Matthews, & Baker, 2008). This viewpoint is based on the historical role of women taking care of the household and looking after children as well as caring for other family members. Nevertheless, Bachner et al. (2009) suggested that daughter caregivers’ existing myriad of familial roles could act as a buffer against the strain associated with their new caregiving commitments by providing them with welcome distraction from their cancer-related concerns.

The level of family functioning and closeness prior to the patient’s diagnosis of cancer affects the caregiver’s ability to survive the experience (Palm & Friedrichsen, 2008). Kissane et al. (2005) found that 71% of families in their study had greater levels of psychosocial morbidity as a result of poor family functioning. Hostile, paranoid, psychotic, and sullen behaviors; frequent
expressions of anger; and unresolved conflict all contributed to the caregiver’s increased risk of developing grief-related health complications.

Grbich, Parker and Maddocks (2001); Palm and Friedrichsen (2008); and Patterson and Dorfman (2002) found that caregivers valued the opportunity to experience greater closeness with their partners during the palliative care stages. Direct communication, physical contact, laughter, effective problem solving, and spending time together all were identified as activities that strengthened the caregiver/patient relationship (Edwards & Clarke, 2004; Palm & Friedrichsen, 2008). Caregivers in Akyüz et al. (2008) also reported an overwhelming sense of being “a team at war” (p. 245) against the cancer, which took priority over thinking about the future and provided daily motivation.

Cultural Background

The degree of influence culture has on family members’ ability to adapt to caring for a loved one with cancer is very difficult to determine. However, the cultural beliefs of some people may hinder their willingness to actively seek professional help and resultant support services (Sellappah et al., 2001). Weinland (2009) found that most African American men acting as caregivers refused the entry of formal support services into their homes because of financial or privacy concerns. In another study, professionals provided useful psychoeducational support to some Mexican American families; however, others in that cultural group did not choose to accept services outside of the family even when the services could have aided their limited financial resources (Wells et al., 2008). Similarly, Costantini, Beccaro, Merlo, and the ISDOC Study Group (2005) concluded that the primary support person of patients of Italian descent was predominantly a child or spouse, with very few caregivers or patients accepting or seeking any kind of support outside the family. In a small study by Sellappah et al. (2001), six Western Australian Indian families indicated that the provision of cancer care in the home environment allowed cultural rituals to be maintained with ease within the family when compared to a hospital setting.

Some Mexican American women acting as caregivers associated emotional, intellectual, and spiritual growth with their caregiving journeys as they chose to move forward with positivity and “fight it as the enemy” (Wells et al., 2008, p. 228). In particular, they described a sense of “becoming stronger” (p. 227) through discovering their life values, gaining a sense of self-worth, and receiving spiritual rewards and appreciation from others for their caregiving efforts. Other benefits included a renewed faith in God and a greater closeness within the family obtained by presenting a united front against cancer. However, by primarily acting as caregiver, the women had less time with their own children and spouses, which sometimes developed into family conflict (Wells et al., 2008). Many families also expressed distress about the lack of access to an interpreter to aid communication and the need to rely on a family member to regularly leave work and act as the family spokesperson in the hospital (Wells et al., 2008). Notably, no caregivers in this study identified caregiver burden, despite its prevalence in other research. However, the sample did express negative experiences when asked about the difficulties of caregiving (Wells et al., 2008).

Caregiving External Supports: Reaching Out for Help

Hospice and Community Care Services

Many cultures choose not to seek help outside the family despite the acceptance of professional assistance from healthcare services being essential for the well-being of many caregivers. To receive professional care, the caregiver needs to be willing to reach out and accept help from others (Riess-Sherwood, Given, & Given, 2002). Several studies have shown that caregivers who do not accept help suffer physical and psychological ailments as a result of their ongoing personal sacrifices (Bernard & Guarinaccia, 2003; Clukey, 2007; Kris et al., 2006). Healthcare professionals should encourage caregivers to request and receive assistance from family, friends, and formal caregivers (Given et al., 2001) (see Figure 1).

The support services of a hospice were vital to four family caregivers in Sellappah et al. (2001). One participant reported that hospice nurses provided therapeutic contact and were very sensitive toward the family’s needs. Clukey’s (2007) study supported this idea when participants said the 24-hour availability of a hospice service provided reassurance, even if the services were not accessed. Caregivers identified the community hospice service as an essential support that not only supplied financial relief and around-the-clock service availability, but also eased the caregiver burden and provided security of care (Clukey, 2007).

Ryan, Howell, Jones, and Hardy (2008) examined the impact of providing nonclinical social support services to caregivers of at-home patients with lung cancer. Caregivers reported feeling reassured that they had a source of support and received benefits, including information and financial, emotional, and practical support. Caregivers did not feel pressed for time when receiving support and associated this with social workers’ relaxed approach, which differed, in their opinion, from the approach of other healthcare professionals (Ryan et al., 2008). Similarly, home-based caregivers expressed improvement in their preparedness, knowledge, and practical caregiving after attending a three-week psychoeducational group program (Hudson et al., 2008). The authors found that caregivers were able to seek validation of their feelings by sharing their emotions with similarly affected individuals (Hudson et al., 2008; O’Connor, 2008).

Group programs: help caregivers validate their feelings and emotions by offering a setting with similarly affected individuals

Hospice: Nurses in a hospice setting can provide therapeutic contact to at-home caregivers and are sensitive toward the family’s needs. Caregivers cite around-the-clock support as being reassuring.

Social worker: provides nonclinical information on financial, emotional, and practical support.

Support person: family member or friend who provides sporadic relief from caregiving duties

Figure 1. Social Support Services for Family Caregivers

Note. Based on information from Clukey, 2007; Hudson et al., 2008; O’Connor et al., 2009; Ryan et al., 2008; Sellappah et al., 2002.
Gardner, Millar, & Bennett, 2009). In addition, when respite support was provided, it allowed the caregiver to continue engaging in existing interests (e.g., hobbies), go for a walk, talk to family or a priest, or simply enjoy some alone time (Given et al., 2001; Grbich et al., 2001). The ease of accessing the hospice service (i.e., only a phone call away) and the role of the hospice service in delivering and supplying medication and equipment were benefits of particular importance to the caregivers in Clukey (2007).

In comparison, Hudson (2004), O’Connor et al. (2009), and Perreault et al. (2004) found that community nursing failed to significantly lighten the load of caregiving tasks. Caregivers complained of poor availability of services at night and in rural areas, little continuity of care, limited respite, and a lack of accessibility to regular care provision from healthcare services to meet their considerable care needs. Despite the positive reports in Clukey (2007), many participants in these three studies stated that they were unaware of the extent of hospice services available in their area until they began receiving community care support. It appears, therefore, that available community care services do not always meet the needs of families affected by cancer (Hudson, 2004; Perreault et al., 2004). In addition, several caregivers who wished to continue to care for their relatives at home chose to admit their family members into institutional care after a lack of professional support in the community left them with no other alternative (Perreault et al., 2004).

Healthcare Professionals

Healthcare professionals have the potential to make a significant difference in the way caregivers cope. Family members often receive no preparation for their role as a caregiver and often need support from others to develop their skills and find their way through the confusion of watching their relatives receive treatments (e.g., chemotherapy) and suffer from a disease of which they have little understanding (Given et al., 2001; Hudson et al. 2008; McClement et al., 2004; Riess-Sherwood et al., 2002; Taylor, 2008). Nurses have the unique opportunity to introduce interventions aimed at reducing caregiver burden and strain when they believe the individual needs it most.

Caregivers have a variable need for information across all stages of the journey, and healthcare professionals should be encouraged to provide patients and their families with honest, personalized information regarding their prognoses without creating false hope (Given et al., 2001; O’Connor et al., 2009). The amount and timing of the information play an important role in the caregivers’ retention and application of this new knowledge (Riess-Sherwood et al., 2002). Group education sessions have been found to be a valuable intervention for families facing palliative care (Hudson et al., 2008); however, these programs are underdeveloped and a lack of evidence-based research exists on effective clinical interventions in cancer caregiver populations (Harding & Higginson, 2003; Honea et al., 2008). By introducing potentially beneficial coping skills to the individual (such as emotional reactivity management and problem-solving strategies), nurses can promote greater caregiver health, confidence, and self-efficacy (Doorenbos et al., 2007; Given et al., 2001; Honea et al., 2008).

Caregivers experiencing anticipatory grief claimed that the presence of healthcare professionals provided caregivers with reassurance and someone to talk to about caregiving tasks (Clukey, 2007). Conversely, the absence of healthcare professionals dampened the caregivers’ hopes and prompted them to be concerned about the level of care and support being provided (Abma, 2005; Clukey, 2007). Caregivers also reported that healthcare professionals often did not provide emotional support through all stages of care (Grbich et al., 2001). Clukey (2007) emphasized that the phrase “the art of being present is a skill” (p. 153) is critical to the success of hospice care as an avenue of reassurance and support for patients and their families (Perreault et al., 2004). Clukey (2007) further stressed that being present is the most important support that human beings can provide to each other during times of suffering.

Support Person and Social Network

Many individualized strategies exist to support caregivers. Some studies have mentioned the value to a caregiver of a support person, such as a family member or friend, who provided sporadic relief from caregiving duties as well as psychological support to both the patient and the caregiver (Perreault et al., 2004; Sellappah et al., 2001). Several caregivers admitted that the role of the support person was imperative to their ability to maintain a positive attitude (Houldin, 2007). Two types of social support were identified: emotional (e.g., companionship) and instrumental (e.g., practical assistance). Coupled with problem-solving support, the moderating effects of both resources depend on each caregiver’s unique situation (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001). In Perreault et al. (2004), caregivers asserted their inability to continue providing care without the assistance of a close family friend who gave them respite and emotional support. Clukey (2007) corroborated the findings, emphasizing that a supportive social network provided the caregiver with someone to share emotional suffering and experiences with, which reduced feelings of isolation. In comparison, caregivers without nearby friends and family experienced significant loneliness (Grbich et al., 2001).

Internal Supports: Looking After the Self

Dyadic Coping

Everyone experiences loss at some stage in their lives, and people deal with grief using various coping methods. The ability of caregivers to look after themselves depends on their development of self-awareness and use of personal strategies to support their needs and make room for grief in their lives (Moules, Simonson, Prins, Angus, & Bell, 2004). A couple’s functioning is dependent on the reciprocal nature of their coping strategies and their ability to embrace and accept each other’s coping methods (Feldman & Broussard, 2006). Dyadic coping strategies are tools a couple uses to conjointly cope with a common problem. Couples may employ positive (e.g., communication of stress) and negative styles of coping (e.g., hostile behavior toward partner). Some evidence exists of poor psychological adjustment in men who employ negative dyadic coping methods while caring for their partners (Feldman & Broussard, 2006).
The ability of each partner to provide mutual support during stressful experiences directly affects the stability and well-being of their relationship (Feldman & Broussard, 2006). Reliance on less functional coping strategies (such as focusing on getting over a loss) can lead to poorer outcomes in the caregiver’s mental and physical health (Moules et al., 2004; Wells et al., 2008). Many husband caregivers expressed concern about their ability to fulfill a new nurturing role and felt that they should hide their true feelings of anxiety and helplessness from their partners (Feldman & Broussard, 2006). Similarly, many male caregivers employed denial as a way of coping with their new caregiving duties and ongoing concerns about the future (Hilton, Crawford, & Tarko, 2000). Caregivers should be given nursing support to help them disregard the common societal discourse that grief must be conquered or hidden from public view. Moules et al. (2004) argued that, by making room for grief, caregivers’ burdens are lightened and they are able to move forward and reflect on their journey without fear of public scrutiny.

**Personal Beliefs**

Family members were encouraged to find a positive meaning from the illness together, which relied on their ability to maintain hope and optimism about the future (Koldjeski, Kirkpatrick, Everett, Brown, & Swanson, 2007; Mellon & Northouse, 2001; Spillers et al., 2008). Meaning-based coping is a concept supported by Ayers (2000), who believed that the meaning of an illness can be redefined when caregivers use expectations, explanations, and strategies to make sense of their new role within their lives. Nursing interventions, such as cognitive appraisal exercises, could help improve the caregiver’s awareness of personal philosophies and promote the discovery of alternate illness meanings or strategies that provide more positive perceptions of the situation. In a study by Downe-Wamboldt, Butler, and Coulter (2006), some caregivers chose to view the disease as a challenge or hurdle to overcome rather than a threat, which reportedly increased spiritual satisfaction. Similarly, most families experiencing ovarian cancer accepted the illness as a part of life and embraced the opportunity to redefine their situation, which ultimately helped their coping ability (Koldjeski et al., 2007). In addition, caregivers of patients with short, terminal diagnoses either chose to view the situation as a privilege to spend time together with their loved ones or as a loss of a future life with the patients (Sherwood et al., 2004). Some caregivers had difficulty accepting the diagnosis and suspected they were being punished for past actions (Grbich et al., 2001).

Fenix et al. (2006) found that caregivers who considered themselves to be religious suffered a lower incidence of major depression. This population said that beliefs aided their ability to cope and that faith motivated their decision to endure many of the hardships of caregiving (Papastavrou et al., 2009; Wells et al., 2008). Meditation, prayer, Bible readings, and pastoral care services all were acknowledged avenues of support (Akyüz et al., 2008; Houldin, 2007; Koldjeski et al., 2007; Sellappah et al., 2001). In contrast, Pearce, Singer, and Prigerson (2006) found that positive and negative religious coping strategies existed; with the former related to greater levels of caregiver satisfaction and the latter associated with a poorer quality of life and an increased risk of developing mental health disorders. Positive religious coping included belief in a meaning in life and seeking help from the church community; negative religious coping involved a struggle to find hope and a sense of abandonment and punishment by God (Pearce et al., 2006). Many Mexican American caregivers perceived God as “the ultimate decision maker” on the patient’s future and believed healthcare workers were acting under his guidance (Wells et al., 2008, p. 229).

Religion differs from spirituality, which provides individuals with purpose in their lives and is based on their personal morals and their relationship with a higher power or life force (Sherman et al., 2005). This set of personal beliefs acts as a guide throughout life; provides a sense of hope, conviction, and trust; and can be communicated through relationships, art, or music (Sherman et al., 2005). Many caregivers have no specific religious backgrounds; however, they may still have spiritual needs as individuals often question purpose in life when a loved one is faced with illness (Sherman et al., 2005). Low spiritual well-being levels existed in caregivers at all stages of the illness trajectory; however, caregivers not receiving support from hospice services were the most negatively affected. Research suggests that health professionals should introduce interventions to improve caregiver spiritual well-being, including the practices of unconditional love and forgiveness, reflection, and experiencing nature.

**Ongoing Challenges: Learning to Ride the Waves**

**Concurrent Responsibilities**

The caregiver’s experience of coping with ongoing challenges could be likened to the experience of “riding waves” (Moules et al., 2004, p. 104). If the caregiver fights the wave or swims against it, he or she can be pulled under. But if the caregiver moves with the ongoing challenges of the changing, relentless waves, buoyancy and predictability in the ride can be found (Moules et al., 2004). Scrambling to meet the emotional and physical needs of everyone else in the family is a continual challenge for countless caregivers (Bernard & Guarinacci, 2003; Carter & Acton, 2006; Grbich et al., 2001; Kim & Schulz, 2008). Many caregivers also are parents, spouses, siblings, or adult children who have daily commitments to work, household duties, and transportation for others. Therefore, that many caregivers admit to feeling helpless, exhausted, and overwhelmed and often operating “on automatic” (Grbich et al., 2001, p. 34) to get through the day is not surprising (Cotrim & Pereira, 2008; Feldman & Broussard, 2006; Perreault et al., 2004).

A range of coping methods can be used by family caregivers to cope with concurrent responsibilities. For example, family caregivers of patients with colorectal cancer in Houldin (2007) found that they were able to maintain a positive attitude and survive while juggling many responsibilities by sharing the burden. Communicating honestly and openly with friends and family, maintaining a daily focus on life, refusing to blame anyone for the cancer, not dwelling on thoughts too much, and focusing on the positives were some of the coping skills employed (Feldman & Broussard, 2006; Houldin, 2007; Palm & Friedrichsen, 2008). Numerous stressors and responsibilities experienced by caregivers may be softened by the opportunity to bond, become closer,
enjoy more sexual intimacy, and argue less about the small things with their spouses or partners during the cancer journey (Houl-

din, 2007). Some caregivers stated that being healthy and alive were more important than having sexual intercourse (Akyüz et

al., 2008); however, high importance was still placed on spend-
ing time together (Hudson, 2004). Similarly, Fergus et al. (2002) found that patients who actively considered the impact of their

illness on their spouse caregivers and took deliberate action to reduce the associated demands on their loved ones significantly decreased caregiver stress and reciprocal suffering.

Desire to Be Present

Caregivers often described a need to be present with the pa-
tients to feel they had fulfilled their role or achieved a personal connection (Hudson, 2004; Perreault et al., 2004; Wells et al., 2008). This desire is no doubt related to caregivers’ expressed wish to be there for the patients (even after hospice admission) to finalize and strengthen their relationships (Clukey, 2007).

Some caregivers also admitted to spending any remaining spare time gathering information, contacting organizations, and reading about cancer and treatments to support the patients through the illness experience (Houl-
din, 2007; Sellappah et al., 2001). Others chose to revisit places of special significance to life events to remind the patients of the good times they shared together. Sharing these intimate experiences with the patients illustrates the love for the individual and demonstrates the magnitude of the anticipated loss (Clukey, 2007).

Many caregivers in Clukey (2007) were able to experience posi-
tive interactions from the anticipatory grief process by touching or holding the patients, expressing their love or thanks, listening to their loved ones, or just being there to cherish the privileged experience. These beneficial outcomes occurred while being present with the patients and were strongly dependent on the rela-
tive’s ability to communicate with the caregiver (Clukey, 2007).
In other studies (Koldjeski et al., 2007; Palm & Friedrichsen, 2008; Perreault et al., 2004), several family caregivers described the experience of being present as a means of spending more time together, reminiscing, and becoming closer to the patients.

Response to the Disease Process

Watching a loved one face life with cancer-induced health changes that vary over time can cause distress, anxiety, and anger in the caregiver based on the perceived causes of the disease (Ostroff, Ross, Steinglass, Ronis-Tobin, & Singh, 2004). Many caregivers considered their relatives’ weight loss and state of terminal cachexia to be symbolic of their approaching death (Mc-
clement & Harlos, 2008). Similarly, caregivers strongly disliked the patients’ changed appearance and decreased level of physical functioning during the terminal stages of the disease (Doorenbos et al., 2007; Hudson, 2004) and expressed distress at watching the patients’ bodies “go to waste” (Berry, 2007, p. 24).

Caregivers said that patients with gynecologic cancer cited specific problems related to fertility, femininity, and sexual-

ity (Akyüz et al., 2008). Caregivers of patients with colorectal cancer who received a colostomy experienced greater levels of caregiver burden, depression, and anxiety when compared with spouse caregivers of nonstoma patients (Cotrim & Pereira,

2008). After surgery, many couples struggled to achieve inti-
macy and marital satisfaction because of the physical and psycho-
logical impact of living with a stoma. Other couples found changes in the patient’s ability to swallow and the occurrence of facial disfigurement (from head and neck cancer) very difficult to accept (Ostroff et al., 2004).

Caregivers felt a sense of control over the disease if they chose to actively fight against the patients’ poor nutritional intake and weight loss by bringing them favorite homemade meals, begging them to eat more, and insisting on feeding them during meal times. Some caregivers also chose to petition healthcare profes-
sionals to include complementary therapies in the treatment regimens, believing they would improve the patients’ condition (McClement et al., 2004). Several family members expressed a sense of failure when they were unable to provide adequate care, relieve their loved ones’ pain, or help them gain weight (Spillers et al., 2008). Healthcare professionals should help care-
givers realize that these efforts may be futile at the end of the cancer journey and encourage them to shift their care involve-
mnt to other areas (e.g., physical and verbal support, hygiene care) (McClement & Harlos, 2008). Caregivers in Taylor (2008) reported difficulties in understanding and accepting the need for a possible ileostomy and use of chemotherapy and surgery to treat patients’ colorectal cancer.

Myriad Emotions

Providing care to relatives with cancer frequently stimulates feelings of sadness, anxiety, hurt, helplessness, and fear in family caregivers for themselves and their loved ones (Clukey, 2007; Given et al., 2001; Sellappah et al., 2001). Sadness, anxiety, and fear often are expressed in connection with the patient’s expected death, as well as in the loss of shared dreams for the future (Clukey, 2007; Grbich et al., 2001; Perreault et al., 2004). Emotional hurt is experienced when the caregiver witnesses suffering and is unable to relieve physical discomfort or psycho-
logical distress (Clukey, 2007; Perreault et al., 2004; Sellappah et al., 2001). The psychological components of the disease experience trigger the greatest amount of distress in families (Wong, Liu, Szeto, Sham, & Chan, 2004). Some caregivers continually tried to hide their feelings of loss (Grbich et al., 2001; Houl-
din, 2007; Sherwood et al., 2004; Wells et al., 2008) and grief from the patients, something Clukey (2007) referred to as “bridled griev-
” (p. 156). Several studies indicated that such behavior can cause caregivers to feel isolated and depressed and may result in an overwhelming sense of misery when the caregivers finally allow themselves to grieve (Moules et al., 2004; Wells et al., 2008).

Financial Strain

Several studies confirmed that a number of family caregivers suffered from financial difficulties as they were forced to reduce time at work or quit altogether to attend to patients’ needs (Hudson, 2004; Papastavrou et al., 2009; Sellappah et al., 2001; Sherwood et al., 2007; Wong et al., 2004) and spend savings on treatment (Sellers & Loney, 2002). Surprisingly, Abernethy, Burns, Wheeler, and Currow (2009) found a minority of caregivers in their study reported a severe financial burden on the family and
even fewer gave up work or used their savings to fund patient care. These results differ from several studies in which many caregivers reported lost hours from work, decreased retirement benefits, little or no money for medical expenses, and reliance on other relatives for financial aid (Sellers & Loney, 2002; Sherwood et al., 2004, 2007; Wells et al., 2008). Abernethy et al. (2009) suggested that their results may be related to differing government and health policies between Australia (site of Abernathy et al.’s study) and the United States. Grunfeld et al. (2004) estimated that the average burden of treatment-related costs in Canada to be $8,292 (Canadian) (without health insurance) for caregivers who looked after relatives with breast cancer over a three-year period. A study by the WHO (2000) highlighted the severity of this problem, which found that many caregivers suffer from long-term financial strain that profoundly affects their lifestyles. This appears to be related to the time-consuming nature of the caregiving role, difficulties accessing health care, wage losses, and transportation costs to and from the hospital, which leaves the individual caregiver with limited earning opportunities (Kim & Schulz, 2008; Lauzier et al., 2004; WHO, 2000) while meeting ongoing expenses from the patient’s illness experience.

**Personal Costs of Caregiving: Providing Unconditional Love**

**Health Complications**

Providing unconditional love could be an analogy to describe the immeasurable amount of love and energy caregivers invest in caring for their relatives, without remuneration or incentive. However, the caregivers have to accept their own physical limitations or they can become overwhelmed by their circumstances and, consequently, suffer from health complications (Spillers et al., 2008; Waldrop, 2007). The concurrent balance of work, unpaid care provision, and other roles (e.g., spouse, parent) compete for the caregiver’s time.

The relationship between the personality and coping skills of caregivers and the development of depression and sleep issues was explored by Carter and Acton (2006). Quantitative methods were used to analyze the personalities of the caregivers to determine their levels of optimism, mastery, neuroticism, coping, depression, and sleep issues. The caregiver’s personality was found to be predictive of the individual’s likelihood of developing negative health outcomes. Both Nijboer et al. (2001) and Carter and Acton (2006) found that the majority of caregivers with a neurotic personality reported experiencing symptoms commonly associated with clinical depression. Similarly, Kim, Duberstein, Sörensen, and Larson (2005) found that caregivers experiencing such symptoms had high levels of neuroticism or low levels of self-efficacy, perceived less social support to be available, and reported greater personal and role strain.

Nijboer et al. (2001) examined the relationship between a group of caregivers’ social and psychological resources and the development of depression over a six-month period. The authors found that those who experienced little everyday emotional support perceived caregiving with negativity, had low levels of mastery, and were more depressed over time. Clear correlations also were discovered between the caregiver’s lack of optimism and mastery and the incidence of sleep issues (Carter & Acton, 2006). Gaugler et al. (2009) found that caregivers who experienced greater levels of mastery and optimism, or expressed considerable pride in their caregiving role, subsequently experienced less negative health complications. Ryan et al. (2008) agreed that caregivers who are emotionally resilient; have an open, friendly persona; maintain a realistic and practical approach to care; and feel confident in their capabilities cope best with any negative health outcomes. Caregivers who received greater levels of daily support and reported experiencing less disruption to their daily schedules also expressed lower levels of depression over time (Nijboer et al., 2001). Bachner et al. (2009) also suggested that employment can be associated with a greater sense of mastery and self-worth, as well as providing caregivers with an avenue for social support.

These studies suggest that the social and personal resources of each individual have a significant impact on the individual’s ability to adapt to the caregiving role. However, caregivers can develop health complications regardless of their personalities. A number of authors found that caregiver burden can cause health complications in many caregivers, including sleeping difficulties, depression, hypertension, weight gain, and exacerbation of chronic conditions (Carter & Acton, 2006; Grunfeld et al., 2004; Hearson & Clement, 2007; Hudson, 2004; Sherwood et al., 2008). In particular, the traditional nurturing role expected of women can place a female caregiver in a position likely to induce high stress levels from the physically demanding nature of her duties (Carter & Acton, 2006; Spillers et al., 2008; Wells et al., 2008). Two studies found that caregivers expressed physical exhaustion and were too fatigued to cook or maintain good nutrition and lacked time to relax, relying on counseling or medications for relief (Grbich et al., 2001). Caregivers in Riess-Sherwood et al. (2002) and Sherwood et al. (2008) admitted to an increase in alcohol and tobacco use, lack of sleep and exercise, and decreased visits to preventive health services as a direct result of their new caregiving role. The interaction of the body and mind creates profound consequences on caregivers’ health as they come to terms with the present, experience various losses, and adapt to the demands of their new role. This transitional process of change requires caregivers to seek and accept professional help and assistance from others to achieve their own needs and responsibilities (Kris et al., 2006; Perreault et al., 2004).

**The End of the Journey: Living on the Edge**

**Admission to the Hospice or Palliative Care Unit**

Literature about hospice or palliative care indicated that caregivers feel like they are living on the edge when their loved ones enter end-stage care. Thulesius, Håkansson, and Petersson (2003) stated that caregivers are “walking a fine line” (p. 1353) when faced with the challenges of end-of-life care, balancing between receiving bad news, weighing the wishes of patients with available resources, transferring care, and maintaining hope. The transitional changes from their role as caregiver to their usual family positions and the difficult experience of admitting a relative into hospice care creates mixed emotions. Such feelings
promote caregivers to exist within a state of heightened sensitivity, feeling fragile and uneasy about hospice care particularly if they have a lack of understanding about the resources available and the goals of end-of-life care (Stajduhar, Allan, Cohen, & Heyland, 2008; Waldrop, 2007). Family conferences can be useful in helping caregivers assess their responsibilities and gain greater insight into the goals of care for the multidisciplinary team (Given et al., 2001). Hospice care has been found by several studies to provide caregivers of terminally ill relatives with benefits, including an increased level of family functioning, greater role satisfaction, more time for personal needs, and increased ability to survive the experience (Christakis & Iwashyna, 2003; Perreault et al., 2004). However, one could feasibly argue that such benefits could be experienced within the home if the provision of healthcare services was adequate.

Despite these findings, Kris et al. (2006) noted that 28% of study participants showed clinical signs of major depression during their relatives’ stay in hospice care. This may be caused by feelings of guilt associated with feeling responsible for falling short of their own expectations about how one should live or behave (Spillers et al., 2008). Guilt can be induced by the caregivers themselves or others, such as relatives with cancer who may show strong animosity toward families for admitting them into a hospice (Berry, 2007). Whether guilt also has a positive influence on the caregiver/patient relationship by motivating both individuals to spend more time together as the palliative stage of care nears is unclear (Spillers et al., 2008). At the end of the journey, several caregivers also spoke of feeling physically winded by the reality before them and experienced a whirlwind of emotions (i.e., anger, hostility, anxiety, and sadness) that affected their ability to concentrate and complete tasks (Clukey, 2007; Waldrop, 2007). This phenomenon highlights the need for psychological caregiver support services, particularly at the point of hospice admission.

### Considerations for Healthcare Professionals

Most healthcare professionals providing terminal care perceive their role as controlling symptoms (Grbich et al., 2001; Kris et al., 2006), promoting patient independence in functioning, strengthening their connection with the patient’s family and friends, and assisting the patient with finding meaning in the illness experience (Wong et al., 2004). Two studies, in contrast, found that many nurses direct their care toward the physical symptoms of the patient only, particularly when stretched by limited time and resources, rather than considering the person from a more holistic and interconnected perspective (Mitchell, Sakraida, Dysart-Gale, & Gadmer, 2006; Ryan et al., 2008). In contrast, many family members viewed the relative as someone at the end of a lifelong journey and considered their loved one’s needs based on a lifetime of recollections (Abma, 2005; Wong et al., 2004). This mismatch of caregiving goals can result in a poor nurse/family member relationship that lacks open communication, trust, understanding, and reciprocal support (Abma, 2005). In addition, Grbich et al. (2001) discovered that many health professionals feel they lack skills in providing emotional care and feel extremely uncomfortable in this role, with most providing only patient-focused support in the later stages.

Nurses should consider the needs of the family caregiver during this stage. Admitting a relative into hospice care is a difficult time of transition for many families and stimulates mixed emotions, including feelings of exhaustion, guilt, urgency, hope, and forgiveness (Clukey, 2007; Kris et al., 2006; Sellappah et al., 2001). Many caregivers said that it was important to remain hopeful during the illness experience, despite their acknowledgment of their relatives’ terminal diagnosis (Clukey, 2007; Houldin, 2007). Family members also expressed a sense of urgency to spend more time with the patient, resolve any past disagreements, and strengthen the closeness of their relationships (Clukey, 2007; Palm & Friedrichsen, 2008; Perreault et al., 2004). Feelings of fatigue and guilt were described in connection with the decision to admit a relative into hospice care (Sellappah et al., 2001; Spillers et al., 2008). Important to note is that 95% of caregiver participants in Clukey (2007) who described such feelings also expressed positive evaluations of the care provided by community hospice services. Whether their assessments were based solely on the care provided to the patient or whether they included their own impressions of the hospice care is difficult to determine.

Oncology nurses should continue to develop and adopt a wide variety of strategies to assist individuals and families both in and outside the hospital (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003). Docherty et al. (2008) emphasized the information needs of caregivers (specifically relating to pain management) as palliative care shifts into the home environment. Wong et al. (2004) emphasized the fundamental need for nurses to provide psychological support to family caregivers and refer them to support services when necessary. In addition, nurses should involve the multidisciplinary team, particularly the palliative care team, as part of the caregiver and patient’s care, to meet their substantial needs (Waldrop, 2007; Wong et al., 2004). Many caregivers are in a state of heightened sensitivity during this transitional time, and the caring presence of the nurse can provide the encouragement and respite they need to continue functioning. Essentially, the key to providing effective and supportive nursing care is to walk side by side with patients and their families; to be there if and when they need assistance (Wong et al., 2004).

### Implications for Nursing Research, Education, and Practice

The caregiving experience is dependent on many factors unique to the individual’s gender, cultural background, relationships, and family roles and, therefore, cannot be predicted. Perreault et al. (2004) asserted that the caregiver and the patient share similar challenges and recommended additional research on this topic. Also, little evidence exists about how to provide families with spiritual support when caring for a loved one with cancer (Sellappah et al., 2001). Research on providing appropriate spiritual support to families receiving cancer care is needed for healthcare professionals to use effective interventions. In addition, a significant gap exists in the current literature regarding the challenges encountered during the illness experience by caregivers of people with the same type and stage of cancer. Another area of required research is how nurses can build trust with non-Western families so that they will be open to nurses providing in-home, culturally sensitive support services.

Cancer is an ambiguous, unpredictable, and intrusive illness that invokes pain and suffering in individuals and creates an
unknown future for themselves and their families. The burden of carrying these ongoing challenges summons nurses and healthcare professionals alike to recognize the need to treat family caregivers as pseudo patients (Perreault et al., 2004). By providing educational opportunities that increase nurses’ understanding of the physical, psychosocial, and spiritual impact of caregiving, future provision of nursing interventions can become more individualized and phase-specific. These personalized interventions would ideally assist caregivers to develop a greater capacity to accommodate to loss, grief, and life changes (Morse, 2001).

Oncology nurses have a significant influence on the family’s ability to survive and evolve throughout the cancer care experience. Cancer treatment should become more family-oriented to consider the needs and involvement of the primary caregiver (Feldman & Broussard, 2006; Riess-Sherwood et al., 2002) (see Figure 2). However, without adequate staff management, support, and education, the joint caregiver and patient approach to oncology nursing is unlikely to succeed (Gross et al., 2006; Sellers & Loney, 2002). The consequences of not providing caregiver- and patient-centered care in oncology and community settings are too costly for the individual and for healthcare services. Caregivers will most likely need clinical care themselves if inadequate support is provided by healthcare professionals during stressful stages along the cancer care journey (Kissane et al., 2003; Navaie-Waliser et al., 2002).

Conclusion

Many nurses working in oncology experience caring for terminal patients with cancer and their families at some stage in their careers, despite a lack of formal training in holistic end-of-life care (Sellers & Loney, 2002). The beginning of the caregiving journey stimulates a myriad of emotions in caregivers as they struggle to find meaning and hope in their relatives’ diagnoses. Their ability to cope has been enhanced by the presence of the nurse as a support person; however, coping also is dependent on many personal characteristics. Finally, admission to palliative or hospice care triggers mixed responses from caregivers who struggle to adapt to a life filled with many role and lifestyle changes.

The WHO (2000) asserted that current healthcare services fail to provide holistic care that satisfies the needs of patients with cancer and their care-providing families. This problem is magnified by the growing, aging global population, which is contributing to the escalating number of people living with cancer (WHO, 2000, 2007). This population is functionally de-

The authors take full responsibility for the content of the article. Northfield received honoraria for this work from Australian Catholic University. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the independent peer reviewers or editorial staff.

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References


• Provide approved healthcare information.
• Enhance critical thinking skills.
• Provide personalized psychosocial interventions.
• Recognize the warning signs of stress.
• Provide counseling to couples to support their life-changing journey.

Figure 2. Nursing Interventions to Support Family Caregivers

Note. Based on information from Riess-Sherwood et al., 2002; Strasser et al., 2007.

Clinical Journal of Oncology Nursing • Volume 14, Number 5 • Caregiving Journey for Family Members


