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# Family Caregivers in Cancer: Roles and Challenges (PDQ®)

## Health Professional Version

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This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about challenges and helpful interventions for caregivers of cancer patients. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions.

This summary is reviewed regularly and updated as necessary by the PDQ Supportive and Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health (NIH).

## Overview

More than 1.7 million new cases of cancer are expected to be diagnosed in the United States in 2019.[1] Many patients diagnosed with cancer will eventually require support from a family caregiver. In fact, family caregivers form the foundation of the health care system in the United States, supporting advances in treatment such as multimodality treatment protocols given in outpatient and home settings.[2]

### Definition: Who Is the Caregiver?

Also referred to as *informal caregivers*, family caregivers provide a complex array of support tasks that extend across physical, psychological, spiritual, and emotional domains.[3] Generally speaking, more women than men become caregivers, most caregivers are related to the person who has cancer, and most caregivers are aged 55 years or older. [4,5]

Family caregivers play an important role in the management of cancer; enlisting their cooperation and including them as the unit of care from the outset are considered critical ingredients to effective cancer management. Most oncology teams recognize this and try to include family caregivers in treatment planning, decision making, and implementation. [6] However, for interventions to be feasible, they must be appropriate within the constraints of busy oncology practices and service delivery environments.[7] Short-term hospital admissions may also restrict the time available to implement supportive strategies for caregivers.

Information about the following is included in this summary:

- An overview of the caregiver's perspective across the illness trajectory in cancer.
- Typical caregiver roles and concerns.
- Helpful interventions.

In this summary, unless otherwise stated, evidence and practice issues as they relate to adults are discussed. The evidence and application to practice related to children may differ significantly from information related to adults.

When specific information about the care of children is available, it is summarized under its own heading.

## References

1. American Cancer Society: Cancer Facts and Figures 2019. Atlanta, Ga: American Cancer Society, 2019. Available online. Last accessed June 7, 2019.
2. Schumacher KL, Stewart BJ, Archbold PG, et al.: Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncol Nurs Forum* 35 (1): 49-56, 2008. [PubMed: 18192152]
3. Honea NJ, Brintnall R, Given B, et al.: Putting Evidence into Practice: nursing assessment and interventions to reduce family caregiver strain and burden. *Clin J Oncol Nurs* 12 (3): 507-16, 2008. [PubMed: 18515250]
4. Alecxih LMB, Zeruld S, Olearczyk B: Characteristics of Caregivers Based on the Survey of Income and Program Participation. National Family Caregiver Support Program: Selected Issue Briefs. Washington, DC: U.S. Department of Health and Human Services, Administration on Aging, 2001.
5. Sherwood PR, Given BA, Given CW, et al.: Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Res Nurs Health* 29 (2): 105-20, 2006. [PubMed: 16532486]
6. Glajchen M: The emerging role and needs of family caregivers in cancer care. *J Support Oncol* 2 (2): 145-55, 2004 Mar-Apr. [PubMed: 15328817]
7. Hudson PL, Aranda S, Kristjanson LJ: Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *J Palliat Med* 7 (1): 19-25, 2004. [PubMed: 15008126]

## The Caregiver's Perspective: Across the Illness Trajectory

Caregivers have their own emotional responses to patients' diagnoses and prognoses, and they may require coaching and emotional support separate from that offered to patients.[1,2] Caregiver roles and caregiver burden are profoundly affected by a patient's prognosis, stage of illness, and goals of care. The existing body of work on family caregivers of patients with cancer focuses primarily on a caregiver's adjustment during the acute survivorship phase, from the time of diagnosis to 2 years postdiagnosis.[3]

As open communication and diagnostic disclosure for patients have gained in popularity, studies have focused on the impact of truth-telling on patients, and guidelines for such communication have been developed.[4,5] Although caregivers are sometimes included in these studies, little attention has been paid to caregivers' specific informational needs and preferences for diagnostic information or to caregivers' readiness or willingness to integrate this new medical information. Yet a caregiver is expected to learn new illness-related terminology, enter the new treatment setting with the cancer patient, and participate actively in treatment decision making. For all of these reasons, caregivers experience a complex array of powerful emotions that may equal or surpass those experienced by the patient during diagnosis and treatment.[6-8]

### At Diagnosis

Family caregivers in the United States are expected to take an active role in decision making related to treatment options, beginning during the diagnostic phase. The caregiver is expected to do the following:[8]

- Integrate new medical information.
- Learn new illness-related terminology.
- Enter a new treatment setting.
- Find the time to accompany the patient to medical appointments.

### During Hospitalization and Treatment

Caregivers play an important role in making decisions about treatment and care. The family often steps in as a patient's advocate and primary decision maker at the request of the patient. How well a caregiver fulfills that role may depend on his or her preexisting relationship with the patient and the level of agreement between caregiver and patient. Disagreements and conflicts can complicate decision making and affect treatment choices.[9] In addition, disagreement within the family about the most appropriate treatment options for the patient can cause excessive stress for both patients and caregivers, resulting in diminished quality of life.[10]

The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) is an instrument that assesses congruence in patient-caregiver communication. The tool can be used on patients, caregivers, or both and identifies specific areas of conflict that may be amenable to intervention. In the initial validation study, higher CCAT-PF scores were significantly correlated with the following:[11]

- Greater patient depression.
- Higher perceived family conflict.
- Lower patient and caregiver well-being.
- Less expressiveness.
- Lower perceived family cohesion.

The CCAT-PF can be administered by any member of the oncology team.

During the active treatment phase, caregivers report difficulties in juggling the competing demands of providing emotional and tangible support to patients while meeting the ongoing obligations of home, work, and family. The demands of providing transportation, scheduling and making hospital visits, arranging for home care, and dealing with insurers may be physically and emotionally exhausting for both cancer patients and their caregivers.[8]

## Planning the Transition Home

Transitions between care settings are particularly stressful for both cancer patients and their caregivers. The immediate posthospitalization period may be the most precarious for caregivers, filled with mounting concerns about managing patients at home while also attending to their own health.[12] A study involving 518,240 elderly couples enrolled in Medicare found that the hospitalization of a spouse was associated with an increased risk of death for elderly caregivers.[13] The cancer patient usually prefers to be at home, where he or she can resume a sense of normalcy in a familiar and comforting environment.

## Home Care

If the cancer patient is receiving home care, the caregiver is responsible for managing home care professionals, organizing necessary medical and food supplies, managing any medical emergencies that may arise, and generally navigating the health care system. In addition to assuming many of the patient's domestic responsibilities, the family caregiver may have to forgo social activities and work duties to assume the primary caregiver tasks of providing companionship, accompanying the patient to medical appointments, and running personal errands.

## Surviving Beyond Treatment

Persistent psychological distress and role adjustment problems experienced by caregivers have been reported up to a year after patients have completed treatment for cancer, with levels of distress far higher than those found in healthy controls.[14,15] Much of this distress is attributed to elevated fears of recurrence and sexual difficulties.[16,17] At 2 years postdiagnosis, however, studies do not indicate long-term psychological distress.[18-20]

Generally speaking, factors that may predict a caregiver's poor adjustment over the long term include the following:

- Strain in the relationship between caregiver and patient.[18,19]
- Negative communication patterns between caregiver and patient.[20]
- Less social support.[21]
- Role overload.[22]

## End of Life

Caregiver quality of life has been found to be influenced by the cancer patient's stage of illness and goals of care. Caregivers of patients at the end of life have been shown to have significantly lower quality-of-life scores and health scores than do caregivers of patients who are in active/curative treatment.[23,24]

The physical and emotional demands of caregiving reach their peak as the disease progresses to the terminal phase. The period during which patients enter hospice is often characterized by profound unrest and intense strain. In the context of recurrent illness, terminal illness, or the dying process, the caregiver must meet a new set of challenges in dealing with increasing functional limitations, increasing dependence of the patient, and greater symptom burden. [25,26] If treatment is prolonged, the capacity of caregivers to meet the daily needs of patients is severely strained.

Caregivers providing end-of-life care have been shown to experience increased emotional distress, regardless of the amount of care provided, when they are limited in their ability to participate in valued activities and interests.[26] Research had suggested that caregivers of cancer patients were at risk of developing a variety of psychological and physical problems, including anxiety, depression, fatigue, reduced self-esteem, and somatic health problems.[27,28] A well-designed study examined the prevalence of psychosocial variables associated with anxiety and depression in 436 caregivers of cancer survivors at 6 and 12 months postsurvivorship. Outcomes show that anxiety and depression often coexist, and that while anxiety abated over time, the percentage of those who were depressed remained stable. Partners and caregivers of survivors with lung, hematological, or head and neck cancer showed the highest levels of anxiety and depression. High use of avoidant coping and interference in regular activities were associated with both anxiety and depression. This included lower emotional/informational support and lower positive social interaction. Additional variables associated with anxiety and depression at 12 months included higher unmet needs and more caregiver involvement in personal and medical tasks. Even at the 12-month postsurvivor diagnosis, almost one-third of participants reported anxiety. Understanding the variables associated with caregivers' anxiety and depression can lead to earlier identification, more specific assessment, earlier referral, and more tailored caregiver interventions.[29] [Level of evidence: II] However, the landscape has changed since the development of hospice and palliative medicine as a medical specialty, the availability of specialist-level palliative care consultation teams, and the equal focus on the cancer patient and family caregiver as the unit of care.

Hospital palliative care programs have been shown to improve caregiver well-being, family satisfaction, and physical and psychological symptom management for patients and caregivers alike. In a retrospective study involving 524 caregivers, palliative care consultation was associated with higher scores in nine caregiver-related domains of care during the last month of life.[30] These differences were attributable primarily to improvements in communication and emotional support.

Generally speaking, the hallmarks of palliative care that relate to caregivers include the following:[31]

- An interdisciplinary focus.
- Concern for quality of life of both patients and family caregivers.
- Involvement of caregivers in symptom management, communication, and medical decision making.

While the oncologist and other team members cannot be expected to address the symptoms of psychological distress in family caregivers, it is nonetheless helpful to recognize and identify such symptoms so that caregivers can be referred to any services they may need. (Refer to the PDQ summary on [Last Days of Life](#) for more information about end-of-life care.)

## References

1. Given BA, Given CW, Kozachik S: Family support in advanced cancer. *CA Cancer J Clin* 51 (4): 213-31, 2001 Jul-Aug. [PubMed: 11577488]
2. Kozachik SL, Given CW, Given BA, et al.: Improving depressive symptoms among caregivers of patients with cancer: results of a randomized clinical trial. *Oncol Nurs Forum* 28 (7): 1149-57, 2001. [PubMed: 11517848]
3. Kim Y, Given BA: Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 112 (11 Suppl): 2556-68, 2008. [PubMed: 18428199]
4. Innes S, Payne S: Advanced cancer patients' prognostic information preferences: a review. *Palliat Med* 23 (1): 29-39, 2009. [PubMed: 18952746]
5. Back AL, Arnold RM, Baile WF, et al.: Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* 167 (5): 453-60, 2007. [PubMed: 17353492]
6. Zabora JR, Smith ED, Baker F, et al.: The family: the other side of bone marrow transplantation. *Journal of Psychosocial Oncology* 10 (1): 35-46, 1992.
7. Yeager KA, Miaskowski C, Dibble SL, et al.: Differences in pain knowledge and perception of the pain experience between outpatients with cancer and their family caregivers. *Oncol Nurs Forum* 22 (8): 1235-41, 1995. [PubMed: 8532548]
8. Glajchen M: Role of family caregivers in cancer pain management. In: Bruera ED, Portenoy RK, eds.: *Cancer Pain: Assessment and Management*. 2nd ed. New York, NY: Cambridge University Press, 2009, pp 597-607.
9. Siminoff LA, Rose JH, Zhang A, et al.: Measuring discord in treatment decision-making; progress toward development of a cancer communication and decision-making assessment tool. *Psychooncology* 15 (6): 528-40, 2006. [PubMed: 16206332]
10. Fried TR, Bradley EH, Towle VR: Valuing the outcomes of treatment: do patients and their caregivers agree? *Arch Intern Med* 163 (17): 2073-8, 2003. [PubMed: 14504121]
11. Siminoff LA, Zyzanski SJ, Rose JH, et al.: The Cancer Communication Assessment Tool for Patients and Families (CCAT-PF): a new measure. *Psychooncology* 17 (12): 1216-24, 2008. [PMC free article: PMC2830149] [PubMed: 18504807]
12. McCorkle R, Benoliel JQ, Donaldson G, et al.: A randomized clinical trial of home nursing care for lung cancer patients. *Cancer* 64 (6): 1375-82, 1989. [PubMed: 2670188]
13. Christakis NA, Allison PD: Mortality after the hospitalization of a spouse. *N Engl J Med* 354 (7): 719-30, 2006. [PubMed: 16481639]
14. Mellon S, Northouse LL, Weiss LK: A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nurs* 29 (2): 120-31; quiz 132-3, 2006 Mar-Apr. [PubMed: 16565621]
15. Northouse LL, Templin T, Mood D, et al.: Couples' adjustment to breast cancer and benign breast disease: a longitudinal analysis. *Psychooncology* 7 (1): 37-48, 1998 Jan-Feb. [PubMed: 9516649]
16. Walker BL: Adjustment of husbands and wives to breast cancer. *Cancer Pract* 5 (2): 92-8, 1997 Mar-Apr. [PubMed: 9110645]
17. Ganz PA, Coscarelli A, Fred C, et al.: Breast cancer survivors: psychosocial concerns and quality of life. *Breast Cancer Res Treat* 38 (2): 183-99, 1996. [PubMed: 8861837]
18. Nijboer C, Triemstra M, Tempelaar R, et al.: Patterns of caregiver experiences among partners of cancer patients. *Gerontologist* 40 (6): 738-46, 2000. [PubMed: 11131090]
19. Gritz ER, Wellisch DK, Siau J, et al.: Long-term effects of testicular cancer on marital relationships. *Psychosomatics* 31 (3): 301-12, 1990. [PubMed: 2167494]

20. Lewis FM, Hammond MA: Psychosocial adjustment of the family to breast cancer: a longitudinal analysis. *J Am Med Womens Assoc* 47 (5): 194-200, 1992 Sep-Oct. [PubMed: 1460225]
21. Kim Y, Carver CS: Frequency and difficulty in caregiving among spouses of individuals with cancer: effects of adult attachment and gender. *Psychooncology* 16 (8): 714-23, 2007. [PubMed: 17096451]
22. Tuinman MA, Fleer J, Hoekstra HJ, et al.: Quality of life and stress response symptoms in long-term and recent spouses of testicular cancer survivors. *Eur J Cancer* 40 (11): 1696-703, 2004. [PubMed: 15251159]
23. Weitzner MA, McMillan SC, Jacobsen PB: Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage* 17 (6): 418-28, 1999. [PubMed: 10388247]
24. McMillan SC, Small BJ, Weitzner M, et al.: Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer* 106 (1): 214-22, 2006. [PubMed: 16329131]
25. Sales E: Psychosocial impact of the phase of cancer on the family: an updated review. *Journal of Psychosocial Oncology* 9 (4): 1-18, 1992.
26. Cameron JI, Franche RL, Cheung AM, et al.: Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer* 94 (2): 521-7, 2002. [PubMed: 11900237]
27. Kinsella G, Cooper B, Picton C, et al.: Factors influencing outcomes for family caregivers of persons receiving palliative care: toward an integrated model. *J Palliat Care* 16 (3): 46-54, 2000. [PubMed: 11019507]
28. Baider L, Kaufman B, Peretz T, et al.: Mutuality of fate: adaptation and psychological distress in cancer patients and their partners. In: Baider L, Cooper CL, Kaplan De-Nour A, eds.: *Cancer and the Family*. Chichester, England: John Wiley & Sons, 1996, pp 173-86.
29. Lambert SD, Girgis A, Lecathelinais C, et al.: Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support Care Cancer* 21 (1): 75-85, 2013. [PubMed: 22661096]
30. Casarett D, Pickard A, Bailey FA, et al.: Do palliative consultations improve patient outcomes? *J Am Geriatr Soc* 56 (4): 593-9, 2008. [PubMed: 18205757]
31. Morrison RS, Meier DE: Clinical practice. Palliative care. *N Engl J Med* 350 (25): 2582-90, 2004. [PubMed: 15201415]

## Physicians Interacting With Family Caregivers

Patients and caregivers may present with different needs, making it difficult to decide whose needs take priority.[1] This situation is especially common when it comes to truth-telling, with family members asking the health care team to keep bad news a secret from the cancer patient, or vice versa.

## Communication With Caregivers

Cultural differences can profoundly affect communication with the patient and family. For example, some Asian Americans believe that talking about death or dying is bad luck.[2] Such differences complicate discussions about prognosis, treatment choices, and even the use of terms such as *chemotherapy*, *radiation*, and *hospice*. [3] Keeping a life-threatening diagnosis a secret from the patient and avoiding discussions of disease progression further add to a caregiver's sense of burden, isolation, and responsibility. A cross-sectional study was conducted in Taiwan to determine the frequency and difficulty of decisions encountered by bereaved caregivers of terminally ill patients who had died in one university hospital.[4] In Asian cultures, it is not uncommon for health care providers to refrain from telling the complete truth to patients, especially in the case of terminal disease, with the responsibility often left to family caregivers. In this study, truth-telling was the most common difficult decision experienced by family caregivers. Health care providers should be aware of such cultural differences from the Western notion of truth-telling to provide culturally competent care to such patients.

## Breaking Bad News

Delivering bad news to patients and caregivers is an essential skill for oncologists, palliative care physicians, and other members of the health care team. To do this well, the physician should:[5]

- Become comfortable with end-of-life issues.
- Understand the range of options available for families.
- Let caregivers know what can, rather than what cannot, be done for the patient.
- Share and receive information in a compassionate manner.

Oncotalk is a teaching program designed to improve communication skills for postgraduate medical trainees.[6] The program covers essential communication skills such as the "Ask-Tell-Ask" principle and the "Tell me more" principle, and communication tasks are linked to the illness trajectory:[7]

- The first visit.
- Making anticancer treatment decisions.
- Offering clinical trials.
- Completing anticancer therapy.
- Discontinuing palliative chemotherapy.

### **Responding to Difficult Situations**

Family caregivers may believe that their concerns are inevitable and their needs cannot be met.[8] In an ideal setting, the social worker or psychologist should be present at meetings with family caregivers to assist with follow-up and support.

Just as a patient's family can appoint a spokesperson, the oncology team can designate a family liaison. However, most family caregivers prefer direct access to the treating oncologist; in fact, active listening by physicians may reduce caregiver burden. One study found that caregivers experienced less burden and distress if they felt that the treating physician listened to their needs and opinions.[8] The oncology team should maintain frequent communication to ensure that messages and other information delivered to the family are consistent and that treatment goals are clear to all concerned.

### **Responding to Family Conflict**

Some families may have less-than-optimal internal relationships, which may lead to communication difficulties within the family and with health care professionals. Many families are not happy, tight-knit units, and the stress of caring for a relative with cancer can reignite unresolved conflicts or create new conflicts.[9] It may be beyond the scope of the oncology team to resolve long-standing family conflict. Use of the family meeting and one family-appointed spokesperson as a communication liaison with the oncology team can help to ameliorate some of these difficulties.

### **Appointing a Family Spokesperson**

Oncology clinicians can be frustrated by having to provide the same information to family caregivers repeatedly. A caregiver's ability to absorb and retain information may be compromised by depression, fear, anxiety, and sleep deprivation.[10] It is advisable for clinicians to request that the family appoint a spokesperson through whom information can be delivered. In addition, the oncology team should try to promote an environment that is conducive to information exchange (i.e., a quiet, private place with minimal interruptions).[11] To ensure that caregivers have

heard and understood the information, they should be prompted to ask questions and should be provided with written backup notes, user-friendly articles, or a list of websites for later reference.

### Convening a Family Meeting

The family meeting is a valuable clinical tool for communicating medical information, delineating the goals of care, and facilitating decision making in cancer treatment. Outcome studies validating the effectiveness of the family meeting are beginning to emerge, especially from the intensive care unit literature. The family meeting is an ideal forum for:

- Eliciting caregiver concerns.
- Providing clear information about treatment.
- Facilitating end-of-life care decisions.
- Deciding to avoid inappropriate treatment options.

In addition, caregivers can receive reassurance that symptoms will be adequately managed and patient preferences will be respected.[12]

Successful family meetings promote a safe setting in which caregivers can process emotions and have their concerns validated. Family meetings are most effective when:[11,13]

- The agenda is transparent to patients, families, and professional staff.
- There is a clearly designated staff person in the role of leader.
- Family caregivers are given the opportunity to ask questions, express concerns, and confront painful emotions with the help of trained and compassionate professionals.

(Refer to the PDQ summary on [Communication in Cancer Care](#) for more information about communication among clinicians, patients, and families.)

### Dealing With Psychological Issues

Patients facing the end of life face enormous physical and existential challenges. Enhanced understanding of the common psychological concerns of patients with serious illness and their caregivers can improve not only clinical care but also the physician's sense of satisfaction and meaning in caring for the dying patient.[14] Physicians also must be attentive to their own needs, which may include feelings of grief and loss, compassion fatigue, and a sense of detachment. In addition to caring for the patient and family, oncologists are advised to pursue healthy venues that promote adaptive coping.[15]

### References

1. Hudson PL, Aranda S, Kristjanson LJ: Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *J Palliat Med* 7 (1): 19-25, 2004. [PubMed: 15008126]
2. Ngo-Metzger Q, McCarthy EP, Burns RB, et al.: Older Asian Americans and Pacific Islanders dying of cancer use hospice less frequently than older white patients. *Am J Med* 115 (1): 47-53, 2003. [PubMed: 12867234]
3. Pinquart M, Sörensen S: Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist* 45 (1): 90-106, 2005. [PubMed: 15695420]
4. Huang HL, Chiu TY, Lee LT, et al.: Family experience with difficult decisions in end-of-life care. *Psychooncology* 21 (7): 785-91, 2012. [PubMed: 22619164]



5. Arnold RL, Egan K: Breaking the "bad" news to patients and families: preparing to have the conversation about end-of-life and hospice care. *Am J Geriatr Cardiol* 13 (6): 307-12, 2004 Nov-Dec. [PubMed: 15538066]
6. Back AL, Arnold RM, Baile WF, et al.: Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Arch Intern Med* 167 (5): 453-60, 2007. [PubMed: 17353492]
7. Back AL, Arnold RM, Baile WF, et al.: Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 55 (3): 164-77, 2005 May-Jun. [PubMed: 15890639]
8. Emanuel EJ, Fairclough DL, Slutsman J, et al.: Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med* 341 (13): 956-63, 1999. [PubMed: 10498492]
9. Harris KA: The informational needs of patients with cancer and their families. *Cancer Pract* 6 (1): 39-46, 1998 Jan-Feb. [PubMed: 9460325]
10. Radwany S, Albanese T, Clough L, et al.: End-of-life decision making and emotional burden: placing family meetings in context. *Am J Hosp Palliat Care* 26 (5): 376-83, 2009 Oct-Nov. [PubMed: 19571324]
11. Gueguen JA, Bylund CL, Brown RF, et al.: Conducting family meetings in palliative care: themes, techniques, and preliminary evaluation of a communication skills module. *Palliat Support Care* 7 (2): 171-9, 2009. [PubMed: 19538799]
12. Boyle DK, Miller PA, Forbes-Thompson SA: Communication and end-of-life care in the intensive care unit: patient, family, and clinician outcomes. *Crit Care Nurs Q* 28 (4): 302-16, 2005 Oct-Dec. [PubMed: 16239819]
13. Azoulay E: The end-of-life family conference: communication empowers. *Am J Respir Crit Care Med* 171 (8): 803-4, 2005. [PubMed: 15817804]
14. Block SD: Perspectives on care at the close of life. Psychological considerations, growth, and transcendence at the end of life: the art of the possible. *JAMA* 285 (22): 2898-905, 2001. [PubMed: 11401612]
15. Kutner JS, Kilbourn KM: Bereavement: addressing challenges faced by advanced cancer patients, their caregivers, and their physicians. *Prim Care* 36 (4): 825-44, 2009. [PubMed: 19913188]

## Potential Roles for the Family Caregiver

Caregivers of cancer patients are expected to function broadly, providing direct care, assistance with activities of daily living, case management, emotional support, companionship, and medication supervision.[1] Many caregivers of cancer patients perform multiple roles, including those of employee, parent, and caregiver for the elderly. The theory of role strain suggests that having a great number of social roles is associated with increased stress and burden. One study found that employed caregivers who were also caring for children reported higher levels of stress, while employed caregivers without parenting responsibilities reported an increased sense of caregiving as meaningful. These distinctions are important for assessment and targeted intervention for oncology caregivers.[2][Level of evidence: II] Caregivers of cancer patients generally undertake multifaceted responsibilities for tasks such as the following:[3]

- Administrative tasks (case management, management of insurance claims, bill payment).
- Instrumental tasks (accompanying the cancer patient to medical appointments; running personal errands; managing cooking, cleaning, and other housekeeping tasks).
- Navigation tasks (seeking information that may be difficult to find, finding a doctor).
- Social support activities (providing companionship, socializing).

## Decision Maker

The caregiver faces an overwhelming array of decisions during the course of a patient's illness. Decisions about treatment options, role changes, and finances generally are made by the patient-family unit.[4,5]

Even in the context of a strong doctor-patient relationship, caregivers may be more open to receiving information from other sources, both informal (family, friends) and formal (the Internet, Cancer Information Service, support groups). Families may make erroneous decisions based on biased information found in the media and on the Internet. In studies involving cancer patients and their caregivers, it is common for patients and their families to report the following:[6]

- Using the Internet to search for more information on the patient's cancer and its treatment.
- Checking the information given by the doctor.
- Researching other treatment options.
- Seeking information on alternative treatments.
- Seeking input from family and friends.

In a study involving 731 cancer patients, higher levels of education were associated with more active information seeking, and women with breast cancer were found to be more active in seeking information than were other patients. [7]

Information needs among cancer patients are many and wide-ranging, with most patients reporting unmet needs for more information about tests and treatments, health promotion, side effects and symptoms, and interpersonal and emotional issues. Information needs among cancer caregivers are also varied and may differ from those of the patient.

### **Advocate**

Caregivers often become advocates for the patient with cancer. This role may include administrative tasks such as the following:[3,8]

- Seeking information.
- Managing insurance claims.
- Paying bills.
- Renewing prescription medication.
- Exercising increased vigilance over the patient.
- Reporting new symptoms or side effects.
- Requesting symptom relief.
- Incorporating lifestyle changes.
- Encouraging treatment compliance.
- Promoting healthy behaviors by the patient.

### **Communicator**

An important goal for oncologists is to improve the ability of patients to (1) understand symptoms and treatment decisions and (2) communicate their ongoing needs and preferences for support.[9] However, communication problems can arise within certain patient groups, including older patients, patients with lower levels of education, and culturally disparate groups.

The family caregiver will often undertake the role of communicator for the patient. For both patients and caregivers, communication is affected by the family members' health information processing style and ability to manage sometimes threatening health information.[9] Decision making can be complicated by serious gaps in recall and understanding that can occur during psychological and physical health crises and by differences in the communication styles of patients, family caregivers, and health care professionals.[10]

### Hands-on Care Provider

Pain and symptom management is a major focus of the caregiver's role. Caregivers frequently dispense pain medication or remind the patient to take a scheduled dose, which requires making decisions about which medication to give, when to give it, and what dose to give.[11] It often falls to the caregiver to keep records and control the technical aspects of managing pain and other symptoms.

If the patient is homebound or unable to move around with ease, the caregiver will often fill and refill medication prescriptions, try to follow medical instructions, and anticipate the need for medication refills ahead of time.[12] In addition to managing the patient's treatment regimen, the caregiver is expected to identify and report treatment side effects or new symptoms.

As they move along the disease trajectory, cancer patients may face an array of other side effects and symptoms:[13]

- Fatigue, drowsiness, and sleep problems have been reported in 51% to 68% of cancer patients. (Refer to the PDQ summaries on [Fatigue and Sleep Disorders](#) for more information about fatigue and sleep problems in cancer patients.)
- Nausea, vomiting, anorexia, and cachexia have been reported in 10% to 40% of patients. (Refer to the PDQ summaries on [Treatment-Related Nausea and Vomiting and Nutrition in Cancer Care](#) for more information about nausea and vomiting, anorexia, and other nutrition needs.)
- Reports of anxiety, mood disorder, and depression are well documented in 25% to 50% of cancer patients. (Refer to the PDQ summaries on [Adjustment to Cancer: Anxiety and Distress](#) and [Depression](#) for more information about anxiety, depression, and mood disorders.)

Management of these complicated side effects frequently falls to the caregiver in the outpatient setting.

### Social Support

The social impact of cancer and pain can be ameliorated by social support, financial security, and stability at work. Given the increasingly chronic nature of cancer, caregivers may find that support in all of these areas erodes over time. The desire for additional help from family and friends has been identified as an indicator of caregiver burden. [14][[Level of evidence: II](#)] Encouraging caregivers to network with other families and linking them with formal resources can help augment informal sources of social support. Caregivers can be encouraged to search for national caregiver groups and disease-specific organizations online.[15]

### References

1. Caregiving in the U.S. Bethesda, Md: National Alliance for Caregiving, 2004. [Also available online](#). Last accessed February 28, 2019.
2. Kim Y, Baker F, Spillers RL, et al.: Psychological adjustment of cancer caregivers with multiple roles. *Psychooncology* 15 (9): 795-804, 2006. [[PubMed: 16502472](#)]
3. Glajchen M: Role of family caregivers in cancer pain management. In: Bruera ED, Portenoy RK, eds.: *Cancer Pain: Assessment and Management*. 2nd ed. New York, NY: Cambridge University Press, 2009, pp 597-607.

4. Vachon ML: Psychosocial needs of patients and families. *J Palliat Care* 14 (3): 49-56, 1998. [PubMed: 9770922]
5. Ferrell BR, Rhiner M, Cohen MZ, et al.: Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. *Oncol Nurs Forum* 18 (8): 1303-9, 1991 Nov-Dec. [PubMed: 1762971]
6. Warner JE: Involvement of families in pain control of terminally ill patients. *Hosp J* 8 (1-2): 155-70, 1992. [PubMed: 1286848]
7. Ehemann CR, Berkowitz Z, Lee J, et al.: Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. *J Health Commun* 14 (5): 487-502, 2009 Jul-Aug. [PMC free article: PMC3024551] [PubMed: 19657928]
8. Bowman KF, Rose JH, Deimling GT: Families of long-term cancer survivors: health maintenance advocacy and practice. *Psychooncology* 14 (12): 1008-17, 2005. [PubMed: 15818596]
9. Rose JH, Radziewicz R, Bowmans KF, et al.: A coping and communication support intervention tailored to older patients diagnosed with late-stage cancer. *Clin Interv Aging* 3 (1): 77-95, 2008. [PMC free article: PMC2544372] [PubMed: 18488881]
10. Siminoff LA, Graham GC, Gordon NH: Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns* 62 (3): 355-60, 2006. [PubMed: 16860520]
11. Ferrell BR, Dow KH, Grant M: Measurement of the quality of life in cancer survivors. *Qual Life Res* 4 (6): 523-31, 1995. [PubMed: 8556012]
12. Glajchen M: The emerging role and needs of family caregivers in cancer care. *J Support Oncol* 2 (2): 145-55, 2004 Mar-Apr. [PubMed: 15328817]
13. Hickok JT, Morrow GR, Roscoe JA, et al.: Occurrence, severity, and longitudinal course of twelve common symptoms in 1129 consecutive patients during radiotherapy for cancer. *J Pain Symptom Manage* 30 (5): 433-42, 2005. [PubMed: 16310617]
14. Burton AM, Sautter JM, Tulsy JA, et al.: Burden and well-being among a diverse sample of cancer, congestive heart failure, and chronic obstructive pulmonary disease caregivers. *J Pain Symptom Manage* 44 (3): 410-20, 2012. [PMC free article: PMC3432705] [PubMed: 22727950]
15. Surbone A, Baider L, Weitzman TS, et al.: Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. *Support Care Cancer* 18 (2): 255-63, 2010. [PubMed: 19609571]

## Impacts of Caregiving on the Caregiver's Quality of Life

Caregiver burden is commonly used to describe multiple dimensions of distress that result from an imbalance between care demands and the availability of resources to meet those demands. Although quality of life is a multidimensional construct, the most studied aspect of quality of life in caregivers is psychological distress.[1] Most family caregivers do not experience clinically significant levels of depression when providing care, but some studies report levels of depressive symptoms in caregivers that are similar to, or even higher than, those in patients with cancer.[2][Level of evidence: II]

### Physical Impact

The physical aspects of caregiving have rarely been studied. Caregiving may be solely limited to physical care such as helping with toileting or eating but can also include lifting, positioning, transferring, massaging, and operating medical equipment. The physical demands of caregiving are closely related to medical variables such as the following:

- Disease stage.
- Level of symptomatology.

- Functional ability.
- Fatigue level.
- Side effect profile.

Cancer patients require varying levels of practical assistance during the course of their illness. Cumulative sleep disruption and fatigue are common among caregivers who are on duty 24 hours a day or only during nighttime hours. Behaviors such as not getting enough rest or exercise and neglecting their own health can mimic depression in caregivers but can also contribute to the impairment of their health and quality of life.[3];[4][Level of evidence: II]

### **Social Impact**

Social roles and relationships are profoundly affected by cancer. The nature and quality of the preexisting patient-caregiver relationship are important considerations in the assessment and treatment of caregiver burden. If marital or relationship strain predates the onset of cancer or pain, the caregiver may approach caregiving grudgingly. In addition, caregiving is time consuming and can lead to feelings of social isolation.

The social impact of cancer and pain can be ameliorated by social support, financial security, and stability at work. Given the increasingly chronic nature of cancer, caregivers may find that support in all of these areas erodes over time. Encouraging caregivers to network with other families and linking them with formal resources can help augment informal sources of social support.

### **Financial Impact**

The financial impact and hidden costs of cancer may affect caregiver burden. Families can incur financial burden from insurance deductibles, copayments, uncovered services such as transportation and home care, and lost salaries. Additional costs to caregivers, in terms of time associated with caring for a patient with cancer, include the following: [5]

- Traveling to and from medical appointments.
- Waiting with patients for appointments.
- Missing work.
- Preparing for surgery and medical procedures.
- Neglecting their usual activities and relationships.
- Attending to patients who are hospitalized.

Other social costs include time spent at home during a patient's recovery, time spent addressing insurance issues, and disruptions of companionship, emotional support, conversation, and other forms of distraction.[6]

### **Psychological Impact**

Family members confronting serious illness have been found to experience as much distress as, if not more distress than, the patient with cancer. This distress arises from the caregiver role itself as well as witnessing the patient's suffering.[7] A meta-analysis of psychological distress among cancer patients and family caregivers found that both members of the dyad experienced similar levels of distress.[8]

Related personality characteristics such as optimism and pessimism affect the psychological impact of caregiving. A family caregiver burdened by loss, stressful life events, or strife in the relationship with the patient may enter the new caregiving role already overwhelmed. Although meeting the psychological needs of the caregiver may fall outside the

scope of the oncology team, these needs are significant insofar as they affect the quality of caregiving as well as the likelihood of premature and unnecessary hospital admissions.[9]

A caregiver's quality of life has been found to be influenced by the cancer patient's stage of illness and goals of care.[10][Level of evidence: I] One prospective population-based cohort study found that caregiver strain increased mortality risk by 63% within 5 years.[11][Level of evidence: II]

## Spiritual Impact

The spiritual aspect of caregiver quality of life has been inadequately studied.[9] A few studies have shown patients and caregivers to have parallel spiritual tasks when dealing with cancer, such as finding meaning and hope in the disease process while also posing existential questions about the meaning of life.[12]

Spiritual well-being may provide a stress-buffering effect for caregivers. Higher levels of spirituality are associated with lower psychological distress and improved well-being for caregivers.[13] In addition, maintaining faith and finding meaning have been shown to mitigate the adverse effects of caregiving stress on mental health.[14] Spirituality can fortify caregivers against hopelessness, help caregivers derive meaning from the cancer experience, and provide an existential perspective on hope and suffering.[15] Any member of the oncology team can explore the spiritual or religious values that inform a person's response to caregiving, but generally speaking, the social worker and chaplain are most adept in this area. (Refer to the PDQ summary on [Spirituality in Cancer Care](#) for more information about spirituality and religion in cancer care.)

## Positive Aspects of Caregiving

Caregivers assume their tasks for reasons that include a sense of familial obligation and loyalty and altruism in the face of their loved one's suffering; more practical reasons include lack of paid help and lack of insurance coverage for services.[16] Other positive rewards of caregiving include the following:

- Discovery of personal strength through adversity.
- Improved sense of self-worth.
- Deepening of the relationship with the cancer patient.
- A sense of personal growth.

Studies have shown that caring for a patient with cancer has rewards such as satisfaction, closeness with the cancer patient, and a sense of fulfilling an obligation. Positive and negative aspects of caregiving are associated with psychological well-being and the caregiver's willingness to continue providing care.[17]

The positive aspects of caregiving can be strengthened by psychological support and practical assistance with problem solving from health care professionals.[18] Direct professional validation of caregivers and indirect support through the patient's medical care are associated with higher caregiver satisfaction and the willingness to continue providing care.[18,19]

To reduce the stress of frequent clinic visits, caregivers should also be provided with options such as using long-acting medication regimens or telephone triage. Educating caregivers about pertinent aspects of cancer management and available community resources can be accomplished through individual contact with health care professionals or through more formal educational programs.

## References

1. Kim Y, Given BA: Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 112 (11 Suppl): 2556-68, 2008. [PubMed: 18428199]
2. Kim Y, Duberstein PR, Sørensen S, et al.: Levels of depressive symptoms in spouses of people with lung cancer: effects of personality, social support, and caregiving burden. *Psychosomatics* 46 (2): 123-30, 2005 Mar-Apr. [PubMed: 15774950]
3. Carter PA: Caregivers' descriptions of sleep changes and depressive symptoms. *Oncol Nurs Forum* 29 (9): 1277-83, 2002. [PubMed: 12370697]
4. Travis LA, Lyness JM, Shields CG, et al.: Social support, depression, and functional disability in older adult primary-care patients. *Am J Geriatr Psychiatry* 12 (3): 265-71, 2004 May-Jun. [PubMed: 15126227]
5. Yabroff KR, Davis WW, Lamont EB, et al.: Patient time costs associated with cancer care. *J Natl Cancer Inst* 99 (1): 14-23, 2007. [PubMed: 17202109]
6. Glajchen M: Role of family caregivers in cancer pain management. In: Bruera ED, Portenoy RK, eds.: *Cancer Pain: Assessment and Management*. 2nd ed. New York, NY: Cambridge University Press, 2009, pp 597-607.
7. Weitzner MA, McMillan SC, Jacobsen PB: Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage* 17 (6): 418-28, 1999. [PubMed: 10388247]
8. Hodges LJ, Humphris GM, Macfarlane G: A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med* 60 (1): 1-12, 2005. [PubMed: 15482862]
9. Ferrell BR, Dow KH, Grant M: Measurement of the quality of life in cancer survivors. *Qual Life Res* 4 (6): 523-31, 1995. [PubMed: 8556012]
10. McMillan SC, Small BJ, Weitzner M, et al.: Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer* 106 (1): 214-22, 2006. [PubMed: 16329131]
11. Schulz R, Beach SR: Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 282 (23): 2215-9, 1999. [PubMed: 10605972]
12. Taylor EJ: Nurses caring for the spirit: patients with cancer and family caregiver expectations. *Oncol Nurs Forum* 30 (4): 585-90, 2003 Jul-Aug. [PubMed: 12861319]
13. Kim Y, Wellisch DK, Spillers RL, et al.: Psychological distress of female cancer caregivers: effects of type of cancer and caregivers' spirituality. *Support Care Cancer* 15 (12): 1367-74, 2007. [PubMed: 17516094]
14. Colgrove LA, Kim Y, Thompson N: The effect of spirituality and gender on the quality of life of spousal caregivers of cancer survivors. *Ann Behav Med* 33 (1): 90-8, 2007. [PubMed: 17291174]
15. Ward SE, Berry PE, Misiewicz H: Concerns about analgesics among patients and family caregivers in a hospice setting. *Res Nurs Health* 19 (3): 205-11, 1996. [PubMed: 8628909]
16. Feinberg LF, Wolkwitz K, Goldstein C: *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*. Washington, DC: AARP Public Policy Institute, 2006. Issue Paper No. 2006-09. Also available online. Last accessed February 28, 2019.
17. Balducci C, Mnich E, McKee KJ, et al.: Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. *Gerontologist* 48 (3): 276-86, 2008. [PubMed: 18591353]
18. Haley WE: Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *J Support Oncol* 1 (4 Suppl 2): 25-9, 2003 Nov-Dec. [PubMed: 15346997]
19. Kim Y, Schulz R, Carver CS: Benefit-finding in the cancer caregiving experience. *Psychosom Med* 69 (3): 283-91, 2007. [PubMed: 17420443]

## Factors to Consider in Caregiver Assessment

To be effective, caregiver assessment should take into account what the caregiver is able and willing to provide. Gender stereotyping may lead the oncology team to assume that women are more able to perform tasks such as wound dressing, feeding, bathing, and wheelchair manipulation, but this is not always the case.[1] Caregiving may be influenced by gender and by the expected caregiver roles within a family unit. A meta-analysis of 84 studies of

caregiver burden found that spousal caregivers were more distressed than other caregivers and that women were more distressed than men.[2] The reasons for gender differences may include the following:[3]

- Women tend to perform more personal care tasks.
- Women are more likely to assume the primary caregiver role.
- Women are less likely to obtain formal help.
- Women are more likely to experience cultural and social pressure to become caregivers.

Ideally, caregiver burden should be measured in the clinical and research arenas with a multidimensional, valid, reliable, and clinically relevant tool (see table below). However, most tools measure objective or subjective burden rather than both types simultaneously. Objective measures of caregiver burden comprise variables such as the number of hours spent providing care or the actual count of tasks the caregiver performs.[4][Level of evidence: II][5] Objective measures are usually short and easy to answer, often pointing to a clear direction for problem solving and direct intervention.[6]

### Instruments for Evaluating Caregiver Burden

Reference Citation(s)	Instrument Name	Description
[7]	Brief Assessment Scale for Caregivers (BASC) of the Medically Ill	14-item rating scale measuring burden and quality of life, plus 8-item subscale measuring negative personal impact
[8,9]	Caregiver Quality of Life Index—Cancer (CQOLC) Scale	35-item rating scale measuring physical, emotional, family, and social functioning burden
[10]	Caregiver Reaction Assessment (CRA)	24-item rating scale measuring burden in self-esteem, lack of family support, finances, schedule, and health
[11]	Caregiver Strain Index (CSI)	13-item rating scale measuring employment, financial, physical, social, and time constraint burden
[12]	Zarit Burden Interview (ZBI)	22-item rating scale measuring burden in health, psychological well-being, finances, social life, and relationship with patient
[13]	CareGiver Oncology Quality of Life questionnaire (CarGOQoL)	29-item rating scale measuring psychological well-being, burden, relationship with health care, administration and finances, coping, physical well-being, self-esteem, leisure time, social support, and private life
[14]	Care of My Child with Cancer (CMCC)	28-item rating scale measuring caregiving tasks for a child completed by family members

*Caregiver strain*, an evolving term, occurs when caregivers perceive difficulty in performing their roles or feel overwhelmed by their tasks.[15] Also known as *subjective burden*, this term is used to describe the emotional reactions that may accompany caregiving. Anxiety, worry, frustration, and fatigue may contribute to caregiver burden and strain and may not be visible to members of the treatment team.[2]

Demographic and psychosocial characteristics associated with caregiver distress (e.g., depression, general psychological distress, and cancer-specific distress) include the following:[16]



- Being a woman.
- Being younger.
- Being the patient's spouse.
- Having lower socioeconomic status.
- Being employed.
- Lacking personal and social support.

Factors specific to the caregiving situation that also are related to caregiver distress include caregiving burden, self-efficacy for caregiving, types of care provided, and the survivor's functional status.[16]

Family caregivers report various problems with their caregiving experiences, including conflict among their social roles, restrictions on activities, strain in marital and family relationships, psychological distress, and diminished physical health.[17]

### Timing of the Assessment

Caregiver assessment can be performed at any point of contact within the health care system. Ideally, a comprehensive caregiver assessment should be performed when the patient is first diagnosed with cancer, when the patient presents in the emergency department, and when a major transition is planned. In systems where caregivers are assessed, caregivers can be acknowledged by practitioners as valued members of the health care team. Caregiver assessment can identify family members most at risk for health and mental health difficulties so that additional services can be planned accordingly.[18]

### Culture

Caregiver assessment needs to be multidimensional and reflect culturally competent practice.[19] Studies have shown that cultural beliefs play a part in influencing family emotions and concerns in the cancer experience.

In a meta-analysis of 116 empirical studies, Asian American caregivers were found to provide more caregiving hours than white, African American, and Hispanic caregivers; to use lower levels of formal support services; and to have fewer financial resources, lower levels of education, and higher levels of depression than the other subgroups.[19] These findings are important for the oncology team because caregivers with no outside help are more depressed than those who receive help. A study involving unmet needs and service barriers among Asian American caregivers found that caregivers refused outside help because they “felt too proud to accept it” or “didn't want outsiders coming in”; other reported barriers included “bureaucracy too complex” or “can't find qualified providers.”[20]

Access to care may be compromised by the family's reluctance to discuss the disease among themselves. Some Asian Americans believe that talking about death or dying is bad luck, which greatly complicates discussions about prognosis and informed consent.[21] Keeping a cancer diagnosis secret from a patient and avoiding discussions of disease progression can add to a caregiver's sense of burden and responsibility. Early in the initial assessment, cultural beliefs about illness and caregiver roles should be identified and discussed.

Studies show that Hispanic and African American patients and caregivers underutilize community health resources, including counseling and support groups, home care, residential care, and hospice services. There are many reasons for this underutilization. One important reason is that strong family ties may prevent minority caregivers from seeking help outside of the family unit.[22] A study that compared African American, white, and Hispanic caregivers found that 75% of Hispanic patients and 60% of African American patients lived with the family of the primary caregiver. The minority families relied more on informal caregiving from friends and relatives and had larger social support networks than the white families. However, this increased sense of obligation to provide care for older family

members was associated with more caregiving hours, greater resignation about caregiving, higher levels of caregiver strain, and a larger reduction in household income than that reported by white caregivers.[22,23]

Another study analyzed reports of employment loss due to caregiving. Results showed that African American and Hispanic caregivers were more likely than white caregivers to reduce their work hours to care for patients. In addition, minority caregivers were reluctant to use formal nursing home services for their loved ones. The decision to reduce work hours rather than place a relative in a nursing home was associated with increased psychological, social, and financial burden.[24]

Accepting the burden of caregiving may lead to depression in caregivers. Caregivers who have no outside help are more depressed than those who receive help from secondary informal caregivers or from formal resources. Despite reporting stress, many Hispanic and African American caregivers do not seek outside help, even when they are aware of support groups and other resources. This barrier to care may be a reluctance to share familial problems with outsiders. Other barriers include the following:[25]

- Lack of availability of outside help.
- Lack of community awareness.
- Lack of trust in social service providers.
- Misperceptions of the role of hospice services.

Because African Americans rely heavily on closely knit groups of friends and family, they are less inclined to welcome strangers such as home care workers into their networks.[25]

In addition, a prerequisite for obtaining hospice care is the presence of a primary caregiver in the home. Because African American family members often must work outside the home, no one is available to care for the patient, and the patient may thus be barred from hospice care. Members of the African American community may also be uncomfortable with the concept of palliative care, which seems to encourage the patient to give up and stop fighting. [25] These cross-cultural issues are important in assessing caregiver needs and in designing clinical and educational programs to meet those needs.[26]

### **Caregiver Age and Health Status**

Family caregivers often feel unprepared, have inadequate knowledge, and receive little guidance from the oncology team for providing care to the cancer patient.[27] Older caregivers are especially vulnerable because they may present with comorbidities, they may be living on fixed incomes, and their available social support networks may have shrunk. In addition, older caregivers of cancer patients may neglect their own health needs, have less time to exercise, forget to take their own prescription medications, and become fatigued from interrupted sleep. It is therefore common for caregiving by older people to lead to poor physical health, depression, and even increased mortality.[28,29]

Younger caregivers must generally juggle work, their own family responsibilities, and sacrifices involving their social lives. Middle-aged caregivers typically worry about missed workdays, interruptions at work, taking leaves of absence, and reduced productivity.[30,31]

### **Socioeconomic Background**

Substantial out-of-pocket costs involved in caregiving can create financial strain for the families of patients with cancer. Higher income can mitigate some of these effects because wealthier families are better able to purchase care and external support services, which can lower feelings of distress. On the other hand, low personal and household incomes and limited financial resources may also place families at risk for treatment compliance or treatment-related decisions that are made on the basis of income.[32]

## The Family and Medical Leave Act

The Family and Medical Leave Act of 1993 (FMLA) was designed to give employees the option of taking time off from work for their own serious medical condition or that of a relative without losing their benefits or their jobs. Family members are entitled to a maximum of 12 weeks' leave under the law; however, since its implementation, FMLA has been met with resistance from employers and underutilization by employees. In an exploratory study involving 45 caregivers of children with chronic illnesses, FMLA was least used by unmarried women with annual incomes lower than \$35,000.[33]

## Norms, Roles, and Expectations

The original theoretical models for understanding caregiver burden highlighted caregiver appraisal and role strain. [34,35] Multiple roles performed by caregivers of cancer patients can compete with each other in relation to caregivers' physical and emotional resources.

Role strain theory has been used to explain caregiver burden in numerous studies. Results of a study of 457 middle-aged caregivers showed that the more social roles a caregiver performed, the more likely the caregiver was to experience stress and negative affect.[36] Employed caregivers who were also caring for children reported higher levels of stress; however, employed caregivers benefited from the respite provided by work and from the support of employers and co-workers, which enabled them to replenish their psychological resources. Encouraging caregivers to maintain their roles as employees might therefore be helpful.

Focus has shifted to the treatment of caregiving as a dyadic phenomenon, based on the recognition that family caregiver roles are complex and overlapping. By its nature, caregiving is fundamentally relational [37] and often reciprocal.[38,39] To be effective, any assessment should take into account not only what the care recipient requires but also what the caregiver is able and willing to provide.

## References

1. Levine C: Nursing and social work leadership. *Am J Nurs* 108 (9 Suppl): 13-5, 2008. [PubMed: 18797213]
2. Pinquart M, Sörensen S: Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 18 (2): 250-67, 2003. [PubMed: 12825775]
3. Yee JL, Schulz R: Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 40 (2): 147-64, 2000. [PubMed: 10820918]
4. Bookwala J, Schulz R: A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives: the Caregiver Health Effects Study. *Psychol Aging* 15 (4): 607-16, 2000. [PubMed: 11144320]
5. Gaugler JE, Hanna N, Linder J, et al.: Cancer caregiving and subjective stress: a multi-site, multi-dimensional analysis. *Psychooncology* 14 (9): 771-85, 2005. [PubMed: 15750995]
6. Honea NJ, Brintnall R, Given B, et al.: Putting Evidence into Practice: nursing assessment and interventions to reduce family caregiver strain and burden. *Clin J Oncol Nurs* 12 (3): 507-16, 2008. [PubMed: 18515250]
7. Glajchen M, Kornblith A, Homel P, et al.: Development of a brief assessment scale for caregivers of the medically ill. *J Pain Symptom Manage* 29 (3): 245-54, 2005. [PubMed: 15781175]
8. Weitzner MA, Jacobsen PB, Wagner H, et al.: The Caregiver Quality of Life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Qual Life Res* 8 (1-2): 55-63, 1999. [PubMed: 10457738]
9. Weitzner MA, McMillan SC: The Caregiver Quality of Life Index-Cancer (CQOLC) Scale: revalidation in a home hospice setting. *J Palliat Care* 15 (2): 13-20, 1999. [PubMed: 10425873]
10. Given CW, Given B, Stommel M, et al.: The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 15 (4): 271-83, 1992. [PubMed: 1386680]

11. Robinson BC: Validation of a Caregiver Strain Index. *J Gerontol* 38 (3): 344-8, 1983. [PubMed: 6841931]
12. Zarit SH, Reever KE, Bach-Peterson J: Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 20 (6): 649-55, 1980. [PubMed: 7203086]
13. Minaya P, Baumstarck K, Berbis J, et al.: The CareGiver Oncology Quality of Life questionnaire (CarGOQoL): development and validation of an instrument to measure the quality of life of the caregivers of patients with cancer. *Eur J Cancer* 48 (6): 904-11, 2012. [PubMed: 22033328]
14. Wells DK, James K, Stewart JL, et al.: The care of my child with cancer: a new instrument to measure caregiving demand in parents of children with cancer. *J Pediatr Nurs* 17 (3): 201-10, 2002. [PubMed: 12094361]
15. Archbold PG, Stewart BJ, Greenlick MR, et al.: Mutuality and preparedness as predictors of caregiver role strain. *Res Nurs Health* 13 (6): 375-84, 1990. [PubMed: 2270302]
16. Kim Y, Given BA: Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 112 (11 Suppl): 2556-68, 2008. [PubMed: 18428199]
17. Pitceathly C, Maguire P: The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer* 39 (11): 1517-24, 2003. [PubMed: 12855257]
18. Feinberg LF: Caregiver assessment. *Am J Nurs* 108 (9 Suppl): 38-9, 2008. [PubMed: 18797223]
19. Pinquart M, Sörensen S: Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *Gerontologist* 45 (1): 90-106, 2005. [PubMed: 15695420]
20. Li H: Barriers to and unmet needs for supportive services: experiences of Asian-American caregivers. *J Cross Cult Gerontol* 19 (3): 241-60, 2004. [PubMed: 15243200]
21. Ngo-Metzger Q, McCarthy EP, Burns RB, et al.: Older Asian Americans and Pacific Islanders dying of cancer use hospice less frequently than older white patients. *Am J Med* 115 (1): 47-53, 2003. [PubMed: 12867234]
22. Guarnaccia PJ, Parra P: Ethnicity, social status, and families' experiences of caring for a mentally ill family member. *Community Ment Health J* 32 (3): 243-60, 1996. [PubMed: 8790967]
23. Cox C, Monk A: Strain among caregivers: comparing the experiences of African American and Hispanic caregivers of Alzheimer's relatives. *Int J Aging Hum Dev* 43 (2): 93-105, 1996. [PubMed: 8945642]
24. Covinsky KE, Eng C, Lui LY, et al.: Reduced employment in caregivers of frail elders: impact of ethnicity, patient clinical characteristics, and caregiver characteristics. *J Gerontol A Biol Sci Med Sci* 56 (11): M707-13, 2001. [PubMed: 11682579]
25. Gordon AK: Deterrents to access and service for blacks and Hispanics: the Medicare Hospice Benefit, healthcare utilization, and cultural barriers. *Hosp J* 10 (2): 65-83, 1995. [PubMed: 7557934]
26. Glajchen M: The emerging role and needs of family caregivers in cancer care. *J Support Oncol* 2 (2): 145-55, 2004 Mar-Apr. [PubMed: 15328817]
27. Scherbring M: Effect of caregiver perception of preparedness on burden in an oncology population. *Oncol Nurs Forum* 29 (6): E70-6, 2002. [PubMed: 12096297]
28. Given CW, Stommel M, Given B, et al.: The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychol* 12 (4): 277-85, 1993. [PubMed: 8404801]
29. Schulz R, Beach SR: Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA* 282 (23): 2215-9, 1999. [PubMed: 10605972]
30. Cameron JI, Franche RL, Cheung AM, et al.: Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer* 94 (2): 521-7, 2002. [PubMed: 11900237]
31. Given B, Sherwood PR: Family care for the older person with cancer. *Semin Oncol Nurs* 22 (1): 43-50, 2006. [PubMed: 16458182]
32. Hayman JA, Langa KM, Kabeto MU, et al.: Estimating the cost of informal caregiving for elderly patients with cancer. *J Clin Oncol* 19 (13): 3219-25, 2001. [PubMed: 11432889]
33. Roog SA, Knight TA, Koob JJ, et al.: The utilization and effectiveness of the Family and Medical Leave Act of 1993. *J Health Soc Policy* 18 (4): 39-52, 2004. [PubMed: 15447880]

34. Lazarus RS, Folkman S: *Stress, Appraisal, and Coping*. New York, NY: Springer Publishing Co, 1984.
35. Pearlin LI, Mullan JT, Semple SJ, et al.: Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 30 (5): 583-94, 1990. [PubMed: 2276631]
36. Kim Y, Baker F, Spillers RL, et al.: Psychological adjustment of cancer caregivers with multiple roles. *Psychooncology* 15 (9): 795-804, 2006. [PubMed: 16502472]
37. Sanders SJ, Kittay EF: Shouldering the burden of care. *Hastings Cent Rep* 35 (5): 14-5, 2005 Sep-Oct. [PubMed: 16295259]
38. Feld S, Dunkle RE, Schroeffer T, et al.: Expansion of elderly couples' IADL caregiver networks beyond the marital dyad. *Int J Aging Hum Dev* 63 (2): 95-113, 2006. [PubMed: 17137029]
39. Lingler JH, Sherwood PR, Crighton MH, et al.: Conceptual challenges in the study of caregiver-care recipient relationships. *Nurs Res* 57 (5): 367-72, 2008 Sep-Oct. [PMC free article: PMC2875992] [PubMed: 18794721]

## Interventions for Caregivers

Caregivers usually define the onset of caregiving as the time of the patient's first cancer diagnosis; ideally, interventions for the caregiver should begin then. However, no validated model exists that can be applied to understanding the family caregiver experience, and few settings perform routine caregiver assessment—making the job of oncology practitioners more difficult, as they have no suitable framework for guiding their care decisions.[1]

Generally speaking, interventions for the caregiver include the following:

- Education and information.
- Counseling and psychotherapy.
- Home care services for the cancer patient.
- Hospice care for the cancer patient.
- The family meeting.
- Psychoeducation.

## Education and Information

Clinicians generally agree on the value of providing information to caregivers. Information tailored to a caregiver's situation provides guidance for implementing care. Information may also help reduce the stress of caregiving and associated feelings of inadequacy and helplessness.[2] Information about the patient's disease trajectory, anticipated course of disease, and the range of emotions experienced by families helps normalize the experience and enhances a caregiver's sense of control.

Caregivers and cancer patients may experience stress related to meeting new oncology clinicians and being introduced to new treatment facilities. One review of the effects of programs that provide information to cancer patients and caregivers about the cancer therapy facility and available services was undertaken. Reviews of randomized controlled trials (RCTs), cluster RCTs, and quasi-RCTs related to the effects of interventions designed to help orient caregivers and patients to the cancer care facility revealed only four studies with 610 participants. Results from two RCTs showed significant benefit related to reduction of distress levels but nonsignificant benefit to anxiety levels. Other positive benefits included increased knowledge about the cancer center and cancer therapy and improved coping abilities, with no harmful or adverse effects. However, the authors concluded that the studies were generally of poor quality with low numbers of participants, resulting in potential bias.[3][Level of evidence: I]

Caregivers want factual information about cancer and its treatment, related symptoms, and side effects. They need specific details about what to do and how a particular cancer is likely to behave. In one survey, priority areas of

information and education needs identified by cancer outpatients and their caregivers included management of pain, weakness, and fatigue, followed by the types of services available to facilitate patient care at home.[4] The most important time periods during the patient's disease trajectory for caregivers to receive information appear to be the following:[5]

- At diagnosis.
- During hospitalization.
- At the start of new treatments.
- At recurrence.
- During the dying phase.

However, because of the chronic nature of cancer and the range of tasks that need to be mastered at different times, the nature of a caregiver's information needs changes over time.[4]

In the area of pain management, caregivers need to understand pharmacologic issues and medication instructions. Specifically, caregivers have shown a need for instructions in the following:[6]

- Which medications to use for pain relief.
- When to give a medication.
- How to assess the efficacy of pain control.
- How to monitor for side effects.
- How to identify negative results or ineffectiveness.

A caregiver's knowledge of and attitudes about symptoms such as pain and fatigue may influence the patient. A caregiver who harbors fears of causing addiction, overdosing, or indirectly causing discomfort through side effects may guard the medication supply, limit its use, and undermedicate the patient.[7] Caregivers need to be trained in managing the side effects of treatment because the experience of side effects can cause cancer patients to abandon their treatment regimens.

Caregivers report learning most of their caregiving skills through trial and error and would like more assistance from the formal health care system.[2] Caregivers have benefited from training in nonpharmacologic strategies for symptom management, including the following:

- Massage.
- Use of heat and cold compresses.
- Energy conservation.
- Rest and restoration strategies.
- Relaxation.
- Distraction.

Skills in positioning the patient with pillows, mobilizing the patient, and assisting the patient with ambulation in an effort to promote pain relief and reduce fatigue can also be taught.[6]

Dealing with the impairment of mobility is ranked by caregivers and cancer patients alike as one of the most difficult caregiver responsibilities. Caregivers must frequently help patients with their mobility issues and bear the responsibility for minimizing the risk of falls. A feasibility study demonstrated the ability to increase caregiver knowledge and skills related to safe mobility and decrease fall risk through the use of an educational video viewed when convenient for caregiver and patient. Use of this DVD technology to educate has proven effective in other studies.[8]

A pilot study using online intervention was successful in helping caregivers find information specific to their needs. Participants reported positive well-being, in large part resulting from the intervention.[9] Other types of intervention that are frequently used but less well described in the literature include the following:[4]

- Coaching patients and families to ask questions.
- Booklets, pamphlets, fact sheets, and information cards.
- Touch-screen information systems.
- Webcasts.
- Computerized information systems.

Accurate information helps reduce uncertainty and empowers caregivers by giving them a sense of control. In addition, caregivers derive emotional support from time spent with the pain professional. Caregivers report needing information about the following:[10,11]

- The patient's cancer.
- Symptom etiology.
- What to expect in the future.
- Treatment side effects.
- Management of medical emergencies.

Although several descriptive investigations have reported on the value of educational programs for caregivers, there is a paucity of outcome data. Many of the studies have important methodological flaws, especially in delineating outcome variables.

The availability of informational tools such as written materials, audiotapes, and videotapes for caregivers has lagged behind the availability of comparable tools for cancer patients. Family caregivers of cancer patients need their own educational materials that include problem-solving strategies, specific caregiving strategies, and self-care.[12]

Few available data examine the relationship between caregiver interventions and increases in care provided to patients. In a randomized trial involving patients with stage III and stage IV cancers who were receiving chemotherapy and experiencing pain and fatigue, patients and their caregivers were randomly assigned as a dyad to a symptom management intervention delivered by a nurse or to a coach-led intervention conducted by a member of the research staff.[13][Level of evidence: I] A total of 225 caregiver-patient dyads were enrolled in the study. The purpose of the trial was to determine which intervention more effectively increased caregiver involvement in assisting with patient symptom care and improved caregiver emotional health.

The caregiver portion of the study was designed to help caregivers learn to support patients and understand the role of helping patients implement self-care strategies. Caregivers assigned to a symptom management problem-solving intervention group received three phone contacts from an oncology nurse, who:

- Solicited information regarding roles in symptom assistance and care tasks.
- Discussed the importance of providing emotional support to the patient and managing symptoms.
- Assisted in problem-solving techniques.

A toolkit for symptom management was also provided and referenced.

The coach-led information group also received three phone contacts from a research staff member, who provided no instruction or assistance with problem solving but referred caregivers to the toolkit for specific symptom management.

Results of the study showed no significant main effect of the problem-solving intervention arm on assistance provided by caregivers who exhibited symptoms at 10 weeks. However, caregivers with lower levels of depressive symptoms in the nurse-delivered intervention group were more likely to provide patient assistance. There was no effect seen on caregiver emotional health in either arm.

The authors concluded that nurse-delivered problem-solving interventions increase family caregiver assistance in those with lower levels of depressive symptoms. They also concluded that interventions focused solely on patient symptom management may not improve caregiver emotional health.[13]

### **Counseling and Psychotherapy**

Counseling and psychotherapy are designed to reduce distress by helping caregivers adjust psychologically to the demands of caregiving.[2] These interventions are typically designed to enhance morale, self-esteem, coping, and sense of control while reducing anxiety and depression. Individual counseling is designed to provide caregivers with support, education, and problem-solving or coping skills. However, these interventions are expensive and may prove too time-consuming for working or highly distressed caregivers.[14]

### **Home Care Services for the Cancer Patient**

Home care services provided for the cancer patient generally include caregiver support as part of the plan of care. Caregivers report high rates of satisfaction with such services and describe them as useful.[15][Level of evidence: I] At the same time, however, studies continue to show high levels of psychological morbidity and unmet needs among caregivers of cancer patients using home care services, suggesting that generic supportive nursing care does not fully meet caregiver needs.[14]

One group of investigators studied whether specialized oncology home care services provided to lung cancer patients influenced bereavement and psychological distress among survivors.[16][Level of evidence: I] Participants were randomly assigned to an oncology home care group, a standard home care group, or an office care control group. Spouses of patients in the oncology home care group had significantly lower psychological distress than did spouses of patients in either of the other groups.[16] These findings have been corroborated by others.

### **Hospice Care for the Cancer Patient**

Family caregivers of home-based palliative care patients report the need for coaching in practical nursing skills and more access to professional advice to increase their self-confidence and ability to perform the practical aspects of home-based care.[17] In addition, caregivers assisting patients in the final stages of life experience as much distress as patients do, if not more. A meta-analysis of psychological distress among cancer patients and family caregivers found that both members of the dyad experienced similar levels of distress.[18] For these reasons, there is a strong correlation between quality-of-life scores for patients and their caregivers in hospice home care programs; caregivers continue to report high rates of burden.[19-22]



## Psychoeducation

Psychoeducational programs provide caregivers of cancer patients with a variety of skills, resources, and problem-solving strategies to help them cope with caregiving. For example, the problem-solving model summarized by the acronym COPE (creativity, optimism, planning, and expert information) is designed to maximize a caregiver's effectiveness, sense of efficacy, and satisfaction.[23] Caregivers are encouraged to develop creative solutions to challenging situations. The COPE problem-solving model:

- Addresses the emotional aspect of problem-solving, combining optimism with realism.
- Helps caregivers develop specific plans to meet their individual situations.
- Teaches caregivers the rationales for what they do.

The authors of the COPE study contend that their model moderates caregiver stress through empowerment and training.[23]

Skills training for caregivers has proven effective in improving their quality of life, reducing the burden associated with symptom management, and in strengthening caregiving tasks. Such programs are effective for caregivers of patients at all stages of cancer, including end-of-life care and hospice.[22] The most effective skills training programs tend to be nursing intervention programs, which combine guidance, support, and nursing home visits.[6] Nurse-led transition coaching programs prepare patients and caregivers for the next level of care, teach communication skills, and follow patients to the home. In addition, the nurses initiate phone calls at 2, 7, and 14 days after discharge, thereby providing continuity of care through a single point of contact.[24]

The effectiveness of psychoeducational programs for caregivers of cancer patients has been mixed. For example, a 6-week problem-solving intervention with spouses of cancer patients was successful at reducing depression; however, there were no effects on coping, social support, or psychological well-being.[25] In another study, 237 cancer patient/caregiver dyads were randomly assigned to one of two groups: a conventional care group or a 20-week experimental group. The focus of the intervention was improving the caregiver's ability in symptom management and reducing their distress. Although the intervention improved caregivers' symptom management abilities, it was not effective in decreasing their depression.[26]

It is possible that interventions with multiple components are more effective in assisting caregivers. For example, the Family Caregiver Cancer Education Program targets education about symptom management along with skill-building in communication, managing roles and relationships, managing finances, and maintaining self-care.[27] Caregivers' sense of confidence and being well informed increased after participation in the program, while perceptions of their own health improved over time.

## The Family Meeting

Refer to the [Convening a Family Meeting](#) section in the [Physicians Interacting With Family Caregivers](#) section of this summary for more information.

## Rehabilitation for the Caregiver

Although the subject of caregiver burden is well represented in the literature, one comprehensive review found a strikingly limited number of studies addressing interventions for caregiver strain and burden in oncology.[28] The extensive literature search yielded only 20 intervention studies, with only 8 studies that specifically cited outcome measures for strain and burden. Two systematic reviews [14,27] exclusively examined studies of caregivers in oncology or palliative care populations. However, most study designs were qualitative, descriptive, cross-sectional, or nonexperimental designs; therefore, many of the proposed interventions for caregivers (e.g., competence, support,

respite, or adult day care) are those whose effectiveness cannot be established until further evidence is obtained with randomized clinical trials.

Although some of the interventions studied had positive psychosocial outcomes, the studies could not document a reduction in caregiver burden. Therefore, those particular strategies require further testing before their effectiveness in reducing caregiver burden can be established.[28]

Few intervention studies have demonstrated efficacy in improving the quality of life of caregivers from the study entry point. Instead, most intervention studies have demonstrated efficacy in improving knowledge of and skills in caregiving. For example, interventions designed to educate caregivers about how to seek out medical information, identify psychosocial resources, or manage symptoms have helped improve caregivers' knowledge, confidence, and mood. Similarly, interventions designed to help caregivers develop problem-solving skills (e.g., coping with cancer) have demonstrated effectiveness in increasing caregiver self-efficacy in managing stress and in reducing psychological distress.[29]

In one study, the psychosocial needs of not only the caregiver but also other family members and people close to the dying patient—all defined in this study as "secondary survivors"—were examined. A qualitative assessment of the needs of the secondary survivors, which occurred after 8 weeks of group psychoeducational grief intervention, revealed a sense of powerlessness and isolation in these individuals. Also, support was identified as a need extending beyond the traditional needs associated with the care of dying patients. The authors concluded that intervention by social workers directed toward the needs of secondary survivors may be helpful.[30][Level of evidence: II]

## References

1. Hudson PL, Aranda S, Kristjanson LJ: Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *J Palliat Med* 7 (1): 19-25, 2004. [PubMed: 15008126]
2. Given BA, Given CW, Kozachik S: Family support in advanced cancer. *CA Cancer J Clin* 51 (4): 213-31, 2001 Jul-Aug. [PubMed: 11577488]
3. Chan RJ, Webster J, Marquart L: Information interventions for orienting patients and their carers to cancer care facilities. *Cochrane Database Syst Rev* (12): CD008273, 2011. [PubMed: 22161425]
4. Wong RK, Franssen E, Szumacher E, et al.: What do patients living with advanced cancer and their carers want to know? - a needs assessment. *Support Care Cancer* 10 (5): 408-15, 2002. [PubMed: 12136224]
5. McCorkle R, Pasacreta JV: Enhancing caregiver outcomes in palliative care. *Cancer Control* 8 (1): 36-45, 2001 Jan-Feb. [PubMed: 11252271]
6. Ferrell BR, Grant M, Chan J, et al.: The impact of cancer pain education on family caregivers of elderly patients. *Oncol Nurs Forum* 22 (8): 1211-8, 1995. [PubMed: 8532545]
7. Juarez G, Ferrell BR: Family and caregiver involvement in pain management. *Clin Geriatr Med* 12 (3): 531-47, 1996. [PubMed: 8853944]
8. Potter P, Olsen S, Kuhrik M, et al.: A DVD program on fall prevention skills training for cancer family caregivers. *J Cancer Educ* 27 (1): 83-90, 2012. [PubMed: 22057986]
9. Edgar L, Greenberg A, Remmer J: Providing internet lessons to oncology patients and family members: a shared project. *Psychooncology* 11 (5): 439-46, 2002 Sep-Oct. [PubMed: 12228877]
10. Ferrell BR, Taylor EJ, Grant M, et al.: Pain management at home. Struggle, comfort, and mission. *Cancer Nurs* 16 (3): 169-78, 1993. [PubMed: 8348524]
11. Nijboer C, Tempelaar R, Triemstra M, et al.: The role of social and psychologic resources in caregiving of cancer patients. *Cancer* 91 (5): 1029-39, 2001. [PubMed: 11251956]
12. Bucher JA, Houts PS, Nezu CM, et al.: Improving problem-solving skills of family caregivers through group education. *Journal of Psychosocial Oncology* 16 (3-4): 73-84, 1999.
13. Sherwood PR, Given BA, Given CW, et al.: The impact of a problem-solving intervention on increasing caregiver assistance and improving caregiver health. *Support Care Cancer* 20 (9): 1937-47, 2012. [PubMed:

22081056]

14. Harding R, Higginson IJ: What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 17 (1): 63-74, 2003. [PubMed: 12597468]
15. Grande GE, Todd CJ, Barclay SI, et al.: A randomized controlled trial of a hospital at home service for the terminally ill. *Palliat Med* 14 (5): 375-85, 2000. [PubMed: 11064784]
16. McCorkle R, Benoliel JQ, Donaldson G, et al.: A randomized clinical trial of home nursing care for lung cancer patients. *Cancer* 64 (6): 1375-82, 1989. [PubMed: 2670188]
17. Bee PE, Barnes P, Luker KA: A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 18 (10): 1379-93, 2009. [PubMed: 18624779]
18. Hodges LJ, Humphris GM, Macfarlane G: A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med* 60 (1): 1-12, 2005. [PubMed: 15482862]
19. McMillan SC, Mahon M: Measuring quality of life in hospice patients using a newly developed Hospice Quality of Life Index. *Qual Life Res* 3 (6): 437-47, 1994. [PubMed: 7866362]
20. McMillan SC, Small BJ: Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: a clinical trial. *Oncol Nurs Forum* 34 (2): 313-21, 2007. [PubMed: 17573295]
21. Meyers JL, Gray LN: The relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life, and burden. *Oncol Nurs Forum* 28 (1): 73-82, 2001 Jan-Feb. [PubMed: 11198900]
22. Haley WE: Family caregivers of elderly patients with cancer: understanding and minimizing the burden of care. *J Support Oncol* 1 (4 Suppl 2): 25-9, 2003 Nov-Dec. [PubMed: 15346997]
23. Houts PS, Nezu AM, Nezu CM, et al.: The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Educ Couns* 27 (1): 63-73, 1996. [PubMed: 8788750]
24. Naylor MD: Transitional care: a critical dimension of the home healthcare quality agenda. *J Healthc Qual* 28 (1): 48-54, 2006 Jan-Feb. [PubMed: 16681300]
25. Toseland RW, Blanchard CG, McCallion P: A problem solving intervention for caregivers of cancer patients. *Soc Sci Med* 40 (4): 517-28, 1995. [PubMed: 7725125]
26. Kurtz ME, Kurtz JC, Given CW, et al.: A randomized, controlled trial of a patient/caregiver symptom control intervention: effects on depressive symptomatology of caregivers of cancer patients. *J Pain Symptom Manage* 30 (2): 112-22, 2005. [PMC free article: PMC1805478] [PubMed: 16125026]
27. Pasacreta JV, Barg F, Nuamah I, et al.: Participant characteristics before and 4 months after attendance at a family caregiver cancer education program. *Cancer Nurs* 23 (4): 295-303, 2000. [PubMed: 10939177]
28. Honea NJ, Brintnall R, Given B, et al.: Putting Evidence into Practice: nursing assessment and interventions to reduce family caregiver strain and burden. *Clin J Oncol Nurs* 12 (3): 507-16, 2008. [PubMed: 18515250]
29. Kim Y, Given BA: Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 112 (11 Suppl): 2556-68, 2008. [PubMed: 18428199]
30. Clark PG, Brethwaite DS, Gnesdiloff S: Providing support at time of death from cancer: results of a 5-year post-bereavement group study. *J Soc Work End Life Palliat Care* 7 (2-3): 195-215, 2011 Apr-Sep. [PubMed: 21895437]

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## Changes to This Summary (03/06/2019)

The PDQ cancer information summaries are reviewed regularly and updated as new information becomes available. This section describes the latest changes made to this summary as of the date above.

## Overview

Revised text to state that more than 1.7 million new cases of cancer are expected to be diagnosed in the United States in 2019 (cited American Cancer Society 2019 as reference 1).

This summary is written and maintained by the [PDQ Supportive and Palliative Care Editorial Board](#), which is editorially independent of NCI. The summary reflects an independent review of the literature and does not represent a policy statement of NCI or NIH. More information about summary policies and the role of the PDQ Editorial Boards in maintaining the PDQ summaries can be found on the [About This PDQ Summary and PDQ® - NCI's Comprehensive Cancer Database](#) pages.

## About This PDQ Summary

### Purpose of This Summary

This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about challenges and helpful interventions for caregivers of cancer patients. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions.

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- be discussed at a meeting,
- be cited with text, or
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Changes to the summaries are made through a consensus process in which Board members evaluate the strength of the evidence in the published articles and determine how the article should be included in the summary.

The lead reviewers for Family Caregivers in Cancer are:

- Andrea Barsevick, PhD (Thomas Jefferson University)
- Larry D. Cripe, MD (Indiana University School of Medicine)
- Edward B. Perry, MD (VA Connecticut Healthcare System)
- Maria Petzel, RD, CSO, LD, CNSC, FAND (University of TX MD Anderson Cancer Center)
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