Family Support in Advanced Cancer

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ABSTRACT Changes in the health care system have resulted in a shift of cancer care from the in-patient arena to ambulatory and home settings. This shift has likewise translated into increased family involvement in the day-to-day care of the person with cancer. Cancer patients have multifaceted needs, including disease and treatment monitoring, symptom management, medication administration, emotional support, assistance with personal care, and assistance with instrument care. Family caregivers may be ill prepared to assume these tasks, requiring information on the disease and treatment, as well as instruction in technical and care skills. Moreover, caregiving must be balanced against already established roles and role responsibilities. In addition, family caregivers have their own emotional responses to the patients' diagnosis and prognosis, and may require coaching and emotional support themselves.

The health care system can facilitate positive outcomes by embracing the family caregiver as a partner in the health care team, providing instruction and guidance to the caregiver as he/she assumes this role, and evaluating the home care situation. Research to date has only scratched the surface of testing interventions that meet the needs of the cancer caregiver.

A research agenda is proposed to more fully elucidate the cancer caregiver’s experience throughout the illness and treatment trajectory, and identify the means to effecting positive outcomes for the person with cancer, their family caregiver, and the health care system. (CA Cancer J Clin 2001;51:213-231.)

INTRODUCTION

Oncology services have not escaped the changes occurring in the delivery of health care in the United States. The most significant of these changes has been the transfer of care from the hospital to outpatient and ambulatory settings, with a shift in responsibility for the day-to-day care of the patient to the family. These changes in the health care system have been well documented by shortened lengths of hospital stay and concern for productivity and effectiveness. A significant result of these changes has been the increased role of families in caring for cancer patients at home.15

Families and their patients with advanced cancer are particularly vulnerable to these shifts in care. Patients with advanced disease are likely to receive aggressive therapy and frequently report considerable numbers of side effects. Alternatively, their care may be shifting from active treatment with the goal of cure, to symptom management with the goal of comfort. In either scenario, patients are likely to experience symptoms from the treatment as well as from the disease itself.
Family members may need to devote more time to caring for their patient and often react to the strains that patient care introduces into their daily lives. Most pressing, however, will be concerns about the patient: How to maintain comfort, how to manage equipment, and when to report changes in their patient’s status. Moreover, family members may be concerned about their abilities to balance the demands of care with other responsibilities and wonder what the immediate future will be like for them and their patient with advanced cancer.

It is against this backdrop that the support needed by family caregivers for persons with advanced cancer should be viewed. The role of family caregivers has shifted from one of custodial care to a complex, multifaceted role that includes symptom management, monitoring for changes in hallmark symptoms, equipment care (e.g., infusion pumps or IVs), patient transport and advocacy, and management of activities/responsibilities the patient has foregone because of illness. Due to advances in treatment, the cancer care trajectory has increased from days and weeks to months and years.

Few Strategies for Family Care

To date, the oncology care system has not fully incorporated “family care” for patients at home. There are few documented, effective strategies to guide family members caring for patients with advanced cancer. The absence of strategies persists despite the fact that burden and distress on family caregivers has been studied since the early 1980s. Most research reflects family caregivers’ abilities to help patients through the early phases of diagnosis and initial treatment.6-8 While there is considerable literature on the demands faced by family caregivers at the end of the patients’ lives, few descriptions of the actual care requirements for patients with advanced and recurrent disease exist. Concern for family caregivers and the quality of their care is essential; their care will have a significant effect both on costs to the health care system and to families who may withdraw from the labor force to provide care. Helping family members learn how to prioritize and manage problems, and work collaboratively with the health care system is important. The perspective becomes one of how health care professionals can provide support to family members so that they can effectively make the transition from a “cure” to a “care” focus.

Given the transfer of daily care for patients with advanced disease to the home, a perspective on supportive care by family members will be presented. Issues that family members face as they begin supportive care is the focus of the first part of this article. Discussion related to the needs of family members for support and assistance with care follows. Based upon work in progress and the research literature on family caregiving, the needs of patients and how information and communication by health professionals can assist family caregivers in addressing these needs, is the anchoring perspective. If health care professionals recognize the home care needs of patients, they can teach family members how to provide effective care. And, if family members are informed and supported while delivering care, they, in turn, will be less anxious, better able to integrate care into their lives, and will see the experiences of caring in a more positive light. Maintaining the health and well-being of the caregivers must also be considered in the health care design. Family caregivers must be considered as an integral part of the advanced cancer care partnership.

Support for the Family Caregiver

As used in this discussion, the term “support” describes meeting family caregivers’ needs for assistance in providing optimal care to the patient with advanced cancer. As such, the focus is not only on the disease and treatment, but also on the interplay between
how the disease affects the patient and the demands it imposes on the caregiver. Support from health care professionals, family, and friends can help family caregivers expand their capacities to respond to care demands. The goals of support should be to enable family caregivers to maintain the patient's comfort and enhance the patient's quality of life, and to prevent or minimize unnecessary caregiver distress. Generally, support should balance the psychosocial needs of the caregiver and promote the caregiver's physical and emotional well-being so that he or she can more effectively attend to the physical and emotional needs of the patient with advanced cancer.

The oncology health care team can improve patient outcomes and reduce caregivers’ anxiety, depression, and sense of frustration by identifying patients’ home care needs, tailoring plans of care, and then instructing family members about how to implement them. Also, the team must assume that family members’ capacities to provide care vary; these variations must be considered and interventions tailored for each situation. The interventions designed by oncologists and delivered to family caregivers should emphasize improving patient comfort and satisfaction, reducing unnecessary hospitalizations, and managing patient care across the advanced disease trajectory.

To provide this support, a partnership and collaboration must be developed between health professionals and family caregivers around the patient's plan of care. Professionals should develop a patient-family member focused plan for care that recognizes the caregiver’s capabilities. Such a plan should begin with a focus on illness-related patient needs.

**PATIENT ILLNESS-RELATED NEEDS**

For patients with advanced disease, the goal of treatment may shift from cure to comfort. At this point, the oncology specialty care system may continue to care for the patient or may refer the patient and family back to the primary care physician. These care transitions occur at a time when families may be experiencing not only the shock, anger, and depression associated with realizing that treatments are no longer effective, but also increased care responsibilities. This may place family caregivers in a particularly difficult situation, without a consistent provider to turn to for advice and direction regarding the plan of care for their patient.

Patients’ needs are influenced by age, number of comorbid conditions, psychological disposition, cultural traditions, cancer stage, and phase of treatment. Caregivers, in turn, may perceive these patient needs as demands, based in large measure on past interactions with the patient, as well as on the family history and the complexity of the cancer treatment. Thus, the demands of caregiving result from complex interactions and perceptions that may not address the priority needs of the patient (Table 1). Within this complex set of familial relationships and needs, family members face certain key issues when caring for patients with advanced cancer.

**Direct Versus Indirect Care**

Care may be classified as “direct care” or “indirect care,” depending on its focus. This classification affects the demands of caregiving. Direct care is care carried out directly with the patient, such as symptom management, emotional support, administration of medications, and assistance with mobility or bathing. Indirect care is carried out on behalf of the patient and includes activities such as

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obtaining medications, transportation, errands, scheduling and coordinating appointments, and assisting with the medical bills and finances. Supervision of care and anticipating patient needs are also considered indirect care. Family members can render direct and indirect care, both of which become increasingly more complex with advanced disease.

As the disease progresses, cancer patients often report increases in pain and other symptoms, such as nausea, fatigue, shortness of breath, or anorexia, and increased functional dependence on others. The patient’s psychological symptoms and distress, which are heightened in advanced disease, also affect the care demands on the caregiver, who experiences his or her own emotions and reactions to the prognosis.

There is mounting evidence that during advanced stages of illness, changes in family roles and the burden placed on family caregivers may negatively affect quality of life for cancer patients, as well as their caregivers. These effects arise from two different sources: 1) Patient needs for comfort, i.e., symptom management for which caregivers must become involved, and 2) Family members’ own needs for information, support, and assistance.

### Patient Needs for Comfort

To assure that caregivers’ perceptions are congruent with patient needs and that direct and indirect care needs are addressed, health care professionals need to provide caregivers with appropriate information to manage patients’ symptoms. Symptom management for patient comfort is a fundamental need and becomes a major concern as the disease progresses and treatments become less effective. Health care providers should assess family members’ abilities to recognize symptoms and to gauge the circumstances under which the patient should be referred to the health care system.

Tailoring a plan of care involves providing information to enhance family caregivers’ levels of knowledge so that they are able to identify symptoms early, manage them effectively, and recognize when to seek assistance from the formal system, i.e., when symptoms appear out of control or current measures are ineffective. Additionally, family members need to know how to report symptoms in ways that are useful to health care professionals in making effective decisions. Symptom control can become a major struggle for patients with advanced disease and their family caregivers. Pain management, in particular, often becomes a pervasive and

| TABLE 1 | Factors That Influence Demands of Caregiving |
| --- | --- |
| **Patient Characteristics** |  |
| Age |  |
| Other Roles (occupation, etc.) |  |
| Sex |  |
| Cultural Background |  |
| **Caregiver Characteristics** |  |
| Age |  |
| Other Roles (occupation, family, social) |  |
| Living Arrangements |  |
| Sex |  |
| Cultural Background |  |
| Reactions to Care |  |
| Relationship to Patient |  |
| Information Needs |  |
| **Disease Situation** |  |
| Stage |  |
| Cancer Site |  |
| Treatment |  |
| Disability and Self-Care Needs |  |
| Direct Care Demands |  |
| Indirect Care Demands |  |
| Symptoms and Comfort |  |
intractable problem for family caregivers, contributing to care demands as well as to their own distress.\textsuperscript{23,24}

**Pain Control as a Model**

There are pharmacologic and nonpharmacologic components to pain control that involve both direct and indirect care demands on the family caregiver.

**Pharmacologic Pain Control**

The pharmacologic-specific demands on the family caregiver relate to deciding what medication to use for pain relief; when to give the medication (around the clock versus as needed); monitoring for side effects; reminding the patient about medication; keeping records; controlling dosage; assessing efficacy of pain control; and noting when and how to report negative results or ineffectiveness.\textsuperscript{23,25}

**Nonpharmacologic Pain Management**

Nonpharmacologic activities related to pain management may include distraction, such as talking with the patient or playing music; emotional support; positioning; or complementing drug therapy with heat or cold therapy. Although health care professionals usually help family members understand pharmacologic issues and medication instructions, nonpharmacologic strategies, such as distraction or complementary approaches, are not as frequently discussed. Patients/caregivers report that they learn these management skills through trial and error and would like more assistance from the formal health care system.\textsuperscript{23,25,26}

Family members can soon become anxious from the stress of administering narcotics, managing infusion pumps, making decisions about dosages and effectiveness of medicines, monitoring for side effects, and delivering multiple medications to a loved one who is continuing to deteriorate physically.\textsuperscript{23,26}

Sarna and Brecht\textsuperscript{9} studied women with advanced lung cancer, finding that fatigue was not only the most prevalent symptom, but was also perceived as the most severe and most distressing, outranking pain, nausea, and breathing difficulties.

The demands of caring for patients with advanced disease extend beyond symptom management and direct care to indirect care, including evaluation and decision-making about changes in patients’ conditions. The complexity of the demands of care is influenced by the frequency with which tasks have to be completed, i.e., hourly versus once daily; the predictability of the task, (e.g., cooking versus dealing with diarrhea or vomiting); and the nature of the skill required for the task. Hours of care required each day also add to the complexity and demands of care.\textsuperscript{20}

Support received from other family members or a formal care system, such as visiting nurses, while often welcome, also adds to the complexity of the care plan because family caregivers must manage home-health professionals and coordinate all activities. Being on duty, “standing by,” i.e., being available for care as needed 24 hours a day, and coordinating the care of others causes considerable caregiver strain.\textsuperscript{12,19,27}

**Coordinating Care**

Among patients with advanced disease, an often unrecognized and complex demand relates to coordination and structuring of care. Family caregivers must interact and negotiate with the formal care system to schedule appointments, report changes in condition, change medications, or ask for assistance.
TABLE 2

Demands of Caregiving

| Direct Care                     | Indirect Care                                      |
|--------------------------------|---------------------------------------------------|
| Administration of Medications   | Obtaining Medications                              |
| Wound Care and Dressings       | Scheduling Appointments and Coordinating Care     |
| Bathing                        | Assistance with Medical Bills and General Finances |
| Dressing                       | Observing for Side Effects                         |
| Assistance with Mobility       | Supervising Care                                   |
| Emotional Support              | Standing By (Vigilance)                            |

Symptom and Comfort Management

- Nonpharmacological Approaches
- Administration of Medications
- Titrating Doses of Medication
- Observing for Side Effects
- Observing for Complications
- Keeping Records of Symptoms and Medications
- Reporting Untoward Effects and Treatment Effectiveness
- Determining Need for Altered Medications

Information Needed

- Disease
- Treatment
- Symptom Management
- Expected Trajectory of Illness
- Emotional Distress Management
- Coordination of Care Activities
- Household Management
- Problem-Solving Strategies
- Community Resources
- Financial Management
- Mobility

Gatekeepers in the health care system sometimes make this difficult for family members. As the sheer number of tasks increases, the primary caregiver may have to seek informal assistance from other family members. Obtaining cooperation from other family members can sometimes be difficult. Unemployed caregivers, for example, are less likely to be able to recruit assistance from secondary caregivers, as they are perceived as having fewer outside responsibilities. In contrast, persons caring for patients with high levels of physical disability are likely to receive more secondary care assistance, especially for those patients with high levels of immobility.

Spouse caregivers consistently get less assistance from secondary caregivers than non-spouses. Given, Given, Stommel, and Lin and Stommel and colleagues indicate that patterns of cooperation between primary caregivers and secondary helpers are influenced by the sheer number and types of tasks that must be performed. Supplementation of care (the addition of others who assume some of the tasks) rather than abdication of tasks seems to be the standard practice when the primary caregiver can no longer manage all care demands, although there are no reports in the literature describing caregivers’ acquisition of assistance as disease progresses and the demands of care increase.

Health professionals need to recognize that primary family caregivers often are gatekeepers themselves and may be reluctant to seek assistance even when they feel inadequately prepared to provide care and report both informational and skill deficits. Some caregivers do not have the capacity to carry out the full range of care activities successfully. Others have difficulty with making decisions and problem-solving. Still others become stressed dealing with multiple health care providers and coordinating the tasks of both professionals and other family caregivers.
FAMILY CAREGIVER NEEDS FOR INFORMATION, SUPPORT, AND ASSISTANCE

A family caregiver concern that has been reported consistently in the literature is the need for information about the dimensions of care to be provided,15, 26 such as information and assistance regarding the disease; physical care; comfort measures; what symptoms to expect, their causes, and how to manage them; treatment regimens; expectations for future care; patients’ emotional responses; household management procedures; finances; and community resources.17,19,27,30,31

Caregivers report needing assistance about how to structure such care activities as transportation, monitoring and reporting symptoms, providing personal care (bathing, walking, and dressing), nutritional considerations, coordination of care (scheduling appointments and calling a physician), monitoring disease status, and financial activities.31 Hileman, Lackey and Hassanein32 indicate that caregivers also seek information on strategies for reassuring patients with decreased energy, as well as about managing other symptoms.

Demands on caregivers escalate as treatment plans shift, the disease progresses, and the patient’s functional capacity deteriorates.2,19,24,27, 32,33 Thus, continued guidance and support from health care professionals will assist caregivers in coping with these aspects of care, which, in turn, will help to alleviate some of the stress, burden, and depression that caregivers experience.

Hileman, Lackey and Hassanein32 found that caregivers have many unmet psychological and social needs. Although current care programs for family caregivers focus on physical problems, supplies, and equipment, many specific caregiver concerns go unattended. Caregivers want detailed and specific information tailored to their unique situations and psychosocial needs, as well as to the physical care needs of their patients. In summary, patients with advanced disease require not only direct care but indirect care, which involves coordination with health professionals and health care systems that may not be receptive to the needs of families. The complexity of caregiving is influenced by the quantity of required tasks, many of which are not predictable. These tasks may require insights and abilities that caregivers do not possess, adding to caregivers’ anxiety and frustration. Information thus becomes a key resource for family caregivers (Table 2).

| TABLE 3 | Caregiver Responses to Demands of Caregiving |
|----------------------------------------|-----------------------------------------------|
| **Mental and Emotional Health** | |
| Depression | Anxiety |
| Burden | Role Conflict |
| Uncertainty | |
| **Physical Health** | |
| Fatigue | Insomnia |
| Physical Health Decline | Lack of Exercise |
| Poor Nutrition | Use of Medications (hypnotics, tranquilizers) |
| Morbidity | |

In summary, patients with advanced disease require not only direct care but indirect care, which involves coordination with health professionals and health care systems that may not be receptive to the needs of families. The complexity of caregiving is influenced by the quantity of required tasks, many of which are not predictable. These tasks may require insights and abilities that caregivers do not possess, adding to caregivers’ anxiety and frustration. Information thus becomes a key resource for family caregivers (Table 2).

CAREGIVERS’ REACTIONS TO DEMANDS OF CARE

Caregivers’ reactions to the demands of care stem from the ambiguity and uncertainty associated with organizing and addressing multiple tasks and responsibilities in the face of increasing patient disability.15,34-36 (Table 3).

Stommel and colleagues57 found that patients’ dependencies in tasks of daily living,
symptom severity, and immobility had a direct effect on the burden and depression experienced by family members providing care. Sales and colleagues\textsuperscript{13} and Given and Given\textsuperscript{1} found that older caregivers seem to have difficulty with tasks and physical demands of spouse illness, whereas the difficulties of younger couples are in the affective domain. These younger individuals may feel angry, frustrated, and depressed. Other studies report that females experience more distress than males.\textsuperscript{36, 39}

Although there are few data related to socioeconomic status, Mor, Guadagnoli, and Wool\textsuperscript{40} and Oberst and colleagues\textsuperscript{31} found that caregivers with low socioeconomic status report more problems because of limited resources and a reduced capacity to provide adequate care. Weitzner et al.\textsuperscript{41} found that caregivers with lower levels of education reported poorer physical health.

In a review article, Schulz, O’Brien, Bookwala, and Fleissner\textsuperscript{42} report that virtually all studies found elevated levels of depressive symptomatology among family caregivers. Using “clinical diagnostic evaluations,” researchers report high rates of clinical depression and anxiety, as well as psychosomatic symptoms, restrictions of roles and activities, and diminished physical health.\textsuperscript{13, 43} Weitzner, McMillan, and Jacobsen\textsuperscript{41} report that family caregivers of patients receiving palliative care had significantly lower quality of life, which they suggested was a reflection of their patients’ poor performance status.

Cochrane, Gaering, and Rogers\textsuperscript{44} found that among caregivers, the odds of anxiety disorders are 1.7 times and the odds of depression were 1.5 times those of non-caregivers. The evidence is more equivocal and generally weaker for the association between caregiving and physical morbidity, such as self-rated health or number of illnesses. Physical morbidity in caregivers has most often been associated with patient problem behaviors, patient cognitive impairment, and with caregiver’s own depression and anxiety.\textsuperscript{42}

Caregivers report fatigue and inadequate time for sleep and self-care.\textsuperscript{7} Compared with non-caregivers, family members involved in high levels of care have significantly increased odds of not getting enough rest, not having time to exercise, not having leisure activities, and forgetting to take prescription drugs.\textsuperscript{45} Some reports reveal that caregivers have higher levels of prescription medication use, such as antidepressants and hypnotics, have higher levels of health care utilization, and do not engage in preventive health behaviors. The rate of use of mental health services by caregivers was reported by Cochrane and colleagues\textsuperscript{44} to be twice that of non-caregivers. Strained caregivers rate their health as lower. Finally, Schulz and Beach,\textsuperscript{46} in a four-year follow-up study found that caregivers had increased mortality.

Caregivers are clearly at risk for negative physical health effects, and these effects emerge as the demands for care increase and caregiving extends through time.\textsuperscript{19, 41, 45, 47, 48} Because family members experience distress, their quality of life needs to be addressed as an important avenue to enhanced patient care.\textsuperscript{2, 41, 49, 50} Supportive interventions should be developed to ensure that family caregivers are able to find time to care for themselves and for respite from caregiving.

Conclusions in the literature are mixed regarding whether or not the “level of patient care needs,” i.e., the quantity of work, relates to caregiver distress. Mor, Guadagnoli and Wool,\textsuperscript{40} Oberst and colleagues,\textsuperscript{31} Siegel and colleagues,\textsuperscript{51} and Weitzner et al.\textsuperscript{41} relate caregiver distress to the level of physical care demands. Weitzner suggests that this may be due to increasing demands as caregivers assume more responsibility for family and social functioning. Others, however, such as Given and colleagues\textsuperscript{10} and Kurtz, Kurtz, Given, and Given\textsuperscript{52} suggest that it is neither the amount nor the level of
Caregiver Burden

The majority of caregivers report that their caregiving responsibilities are experienced as a burden. Caregiver burden is the distress that caregivers feel as a result of providing care. It is specific to care and differs from anxiety, depression, and other emotional and more general responses. Disease and treatment each impact the prevalence and intensity of caregiver burden. This burden may arise as a result of increased caregiver demands that accompany the progressive deterioration of the patient.50,53,54

There is general agreement that women’s traditional roles in home health care are more normatively expected and more encompassing than the traditional gender role of men; thus, wives may experience burden equal to that of husbands.7,55 Men may more narrowly define their care roles and have more resources provided to them, and, as a result, are less likely to be the sole caregiver. Caregivers of younger, especially male, patients report more distress than caregivers of older patients.20,56 Some researchers report that spouses experience as much, if not more, distress as patients.49

Siegel, Raveis, Mor, and Houts51 found that a substantial majority of caregivers reported objective social and employment-related burdens. There was no difference in intensity of subjective burden between husbands and wives. Those caring for patients who had advanced disease had more physical, social, and time burdens than those whose patients had early-stage disease. Physical burdens were higher for husbands when spouses were bedridden and disabled in the previous two weeks. Wives had more time-related burdens. The most intense burdens were financial, physical, and time-related. Sales56 and Blanchard et al.56 support the notion that caregiver distress is due to metastatic disease, grave prognosis, and increased length of illness.

Caregivers who lack adequate resources or who are insufficiently prepared for their new and complex role, have pre-existing mental health difficulties, or have strained family relationships are most at risk for experiencing caregiver burden.57 Mor and colleagues,8 Blank and Longman,17 Stetz,19 Hileman and Lackey,30 Oberst and colleagues,31 and Schulz and colleagues42 suggest that it is the “strained” caregiver who experiences the most negative health effects.

Financial concerns and problems related to women’s dependence on their husbands have often resulted in overwhelming burden and feelings of instability, uncertainty, and helplessness among female partners. Morse and Fife47 found that partners of patients who were experiencing a recurrence of their illness or who were in the metastatic stage of the disease were more vulnerable to increased distress, caregiver strain, and problems of adjustment than were partners of patients at earlier stages of disease. Social support from all sources correlated significantly with the positive adjustment of these caregivers. Finally, changes in the patients’ mental status are a distressing part of caregiving.39,58 It appears that mental deterioration raises awareness of the patient’s downward trajectory and adds to the
There is mounting evidence that patients and family members have different perceptions of care needs during the cancer care trajectory. These differences may be the result of long-standing family roles and communication patterns. If these patterns are not appreciated, they may contribute to caregivers’ reactions and sense of burden, add to the conflict, and hence to caregiver distress. Open communication about illness and care may facilitate family coping. The added stress of caring for a patient with advanced cancer exacerbates problems in family relations and personal mental health problems. Lewis, Woods, Hough, and Bensley found that the number of illness demands experienced by the male spouse of a female patient living with chronic illness was a significant predictor of spousal depression. Subsequently, marital adjustment was affected significantly by the male partner’s level of depression as well as by the problems associated with the wife’s illness.

Northouse and Northouse studied families of women with metastatic breast cancer and reported that “conspiracies of silence” among family members may impede coping. Knowing prior communication patterns among family members helps one understand family functioning during the cancer illness. Families that communicated effectively prior to the illness seem to cope more effectively during the illness than those with histories of less functional communication. Family communication patterns, roles, and coping methods are components of family functioning, and difficulties and impaired relationships are exacerbated by cancer. In transferring care responsibilities to families and developing a therapeutic plan, providers need to consider the family’s communication patterns.

Archbold and colleagues showed that mutuality and preparedness to care could contribute to ameliorating caregiver distress. Further, the ability to control emotional distress and maintain a positive cognitive response appear to be important factors in the prevention of caregiver burden. Caregivers’ optimism was found to be predictive of overall caregiver mental health and positive reactions to the impositions associated with caregiving. Another factor that can affect caregivers’ adjustment is the availability of adequate social support, which can serve to buffer stress.

Literature focused on how family cancer care for those with advanced disease actually alters family functioning is limited and inconclusive, raising several issues for future research. For example, how can families be helped to prevent caregiver burden? What supportive care strategies can be developed for family caregivers? What constitutes a therapeutic “dose” of social or instrumental support to enable family members to continue to give quality care to those with advanced cancer?

Summary of Caregiver Burden

In summary, it appears that most caregivers are plagued by anxiety, depression, and caregiver burden. Most evidence indicates that home care has a greater impact on caregiver depression and burden than upon caregivers’ physical health, although the recent study by Schulz and Beach suggests that poor caregiver physical health results from caregiver distress. Interestingly, some research shows similarities between the levels of distress experienced by patients and their family caregivers. Changes in the degree of distress and adjustment problems tend to become more intense for the caregiver as the patient’s condition deteriorates. At such times, a serious assessment of the family caregiver’s support needs should be documented and the capacity to care for the patient evaluated. Appropriate support from health care providers and others may help families to prioritize and manage...
patients’ problems, while at the same time lowering the burdens associated with the uncertainty of caring. If families can acknowledge the value of their care, their sense of burden is likely to be lower.

**SUPPORTIVE INTERVENTIONS FOR FAMILY MEMBERS**

**Planning and Implementing Patient Care**

If health care providers are to be supportive of caregivers and to facilitate quality care for patients with advanced disease, they have to implement interventions that address caregivers’ priority needs, such as the need for information and education; the ability to mobilize formal and informal sources of assistance; and strategies for maintaining physical health, positive attitudes, and well-being. In tailoring such interventions, providers must recognize that caregivers possess different levels of knowledge and skill, differ in their level of burden, experience different levels of care demands, and differ in the amount of support and assistance they receive from other family members (Table 4).

In the following sections, we will discuss some of the supportive interventions for caregivers—educational interventions and programs, psychotherapeutic interventions to manage caregiver distress and enhance coping skills, and strategies to assist caregivers in mobilizing resources on behalf of their patients—that can be developed and implemented.

**Educational and Informational Interventions**

It is clear from a review of literature that education and information are essential if family caregivers are to participate effectively in the home care of patients. Families report providing much care by trial and error. This creates a sense of uncertainty that makes caregiving more time-consuming and stressful. Information that is tailored to the problems that caregivers face would provide them with guidance for implementing care but more importantly, would reduce the stresses of caregiving and the associated burdens and feelings of inadequacy and helplessness arising from ambiguity. Therefore, educational interventions will be reviewed first, recognizing that effective education will produce important secondary benefits for caregivers and reduce the necessity for psychotherapeutic interventions.

There are personal as well as structural reasons why caregivers of patients with advanced disease often do not have appropriate information to care for their patients.

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**TABLE 4**

| Interventions and Strategies in Support of Family Caregivers |
|-------------------------------------------------------------|
| **Information**                                             |
| Family Conferences                                          |
| Skills Training                                             |
| Problem-Solving Strategies                                  |
| Caregiver Training                                          |
| Books, Videos, CD ROMs, Web Pages                           |
| Help Sheets                                                 |
| **Psychotherapeutic**                                       |
| Support Groups                                              |
| Psychologists/Counselors                                    |
| Psychiatric Referral                                        |
| Counseling Sessions                                         |
| Telephone                                                   |
| In Person                                                   |
| **Mobilize Resources**                                      |
| Support Groups                                              |
| Caregiver Classes                                           |
| Visiting Nurses                                             |
| Chore Services                                              |
Moreover, caregivers are often not perceived as partners in developing the patients’ plans of care. Caregivers may not be involved in physician–patient conferences and, when they are present, their perspectives and questions are neither acknowledged nor addressed. When caregivers are included, they may be overwhelmed by the care situation and may not have prepared their questions or may be unaware of what questions should be asked. In addition, patients with advanced disease may have wide fluctuations in disease and treatment status and needs for care.

Another more difficult issue involves establishing the linkages between primary care providers and oncologists that make devising a coherent plan of care possible. Caregivers may simply be overwhelmed by the issues of caring and may not recognize that it is appropriate for health professionals to address their informational and psychological issues. Against this backdrop, we offer suggestions about how professionals might direct care through family caregivers.

**Providing Specific Guidelines**

Health care professionals need to establish a structured and ongoing dialogue with family members about treatment goals, plans of care, and expectations regarding patient outcomes. They may find it useful to develop protocols or “help sheets” to meet the informational needs of caregivers. Having specific guidelines or suggestions for care provides caregivers with a sense of control, and monitoring patients according to specific limits (such as “report to the health care professional a temperature of 101°F that persists for 36 hours”) helps them evaluate the need for assistance. Wherever possible, professionals need to distribute written, individualized, guidelines that caregivers can follow with specific actions when a criterion is reached. Caregivers report that specific and tailored direction is supportive and reduces the uncertainty they experience as they provide care. They do not, however, want to be overwhelmed with massive amounts of nonspecific information. 53,54,71

Acquiring information regarding disease and treatment-related expectations from health care providers can help caregivers plan care, anticipate possible problems, and detect changes in the trajectory of the illness. In general, the reasons family caregivers give for their lack of sufficient information include:

1. Inability of family members to ask questions (they may lack the social skills).
2. Inability to obtain specific information from providers.
3. Limited contact with providers.
4. Too many intermediaries between the treating oncologist, the patient, and the caregiver.
5. Primary care physicians who do not understand cancer, cancer treatment, or cancer care needs.
6. Providers who talk only to the patient and do not relate to the family.
7. Receiving only filtered information from providers.
8. Being overwhelmed due to distress and having attention or comprehension deficits. 72

While books, videos, and mass-produced materials are useful, family members want “patient-specific and tailored” information based on their particular situation that can only be provided by their health care team. Information may be customized by addressing 1) What family caregivers can expect about the patients’ symptoms, disability, reactions to treatment, and disease trajectory; 2) What patients and caregivers can expect from their health care provider; and 3) How different types of supportive community care services can assist them, as well as the situations in which these services are most useful. 53

Clinicians need to be cognizant of how the course of the disease and treatment will affect caregiving situations, anticipate the problems and needs of family caregivers during these
transitions, and provide anticipatory guidance to family members. Restrictions on time, personal activities, and privacy may increase during the advanced disease phase, and family caregivers need to be informed to anticipate these changes and restrictions.

**Formal Programs to Help Family Caregivers—Two Models**

There are very few programs or interventions for family caregivers of cancer patients reported in the literature; two examples will be described. Houts and colleagues\(^7\) have designed a program of support for family caregivers.

**The COPE Model**

The Prepared Family Caregiver model, which is summarized by the acronym COPE (Creativity, Optimism, Planning, and Expert Information), helps uninformed family caregivers who are assuming caregiving responsibilities. Houts and colleagues\(^7\) indicate that a lack of information increases the risk not only of significant caregiver burden, but of compromising the quality of care for the patient. They argue that increasing caregiver competence requires training family caregivers in the skills they need to provide comprehensive care, including information about the illness, about caregiving itself, and problem-solving approaches. Problem-solving is both a way of changing the situation and of changing how caregivers react to situations.

While the COPE model has not undergone rigorous testing, caregivers have responded positively to it. The process was found to be useful in helping family caregivers learn to carry out their caregiving responsibilities and to evaluate the effectiveness of their actions.

Family caregivers have dual needs: To solve caregiving problems successfully and to cope with the cancer experiences of their patients. Educational approaches should be designed to be supportive of these two needs. Solutions that use problem definition and formulation, generation of alternatives, decision-making, and implementation of strategies provide burdened caregivers with specific information and skills. Houts and colleagues\(^7\) conclude that this model supports family caregivers to maximize caregiving effectiveness and the family caregiver’s sense of efficacy. Expert information empowers caregivers. A problem-solving approach can help reduce a family caregiver’s sense of uncertainty and accompanying feelings of stress and burden, enhancing positive patient outcomes.

**A Program for Health Care Teams**

Barg and colleagues\(^7\) and Barg\(^5\) report on a psychoeducational program designed for health care professionals so that they can respond more effectively to the needs of family caregivers. This program (six-hour curriculum) is designed to prepare nurse and social worker teams to teach family members to care for patients at home. This program focuses on symptom management, technical competence, and medication administration for the patient, but it also includes components specific to the caregiver, such as stress reduction, depression, managing his or her own health, and bereavement.

The instructor team teaches the caregiver about talking with health care providers, managing the health care system, handling family role and relationship changes, caring for equipment, managing jobs and other roles, caring for the patients’ and their own emotional reactions (especially anxiety and depression), asking for assistance, and self-care. Finally, this program has a module that specifically addresses the supportive needs of caregivers.

This program prepares caregivers to master the techniques and strategies of care. Family caregivers describe how a sense of competency, mastery, preparedness, and a sense of control and confidence in care roles imparts feelings of satisfaction, alters misconceptions,
reduces uncertainty, enhances coping, and provides a sense of meaning associated with providing care.\textsuperscript{69,74-77} Recent evidence suggests that caregivers who receive psychoeducational interventions during the course of their patients’ illnesses recover sooner following a patient’s death.\textsuperscript{12} Becoming an accomplished and successful caregiver can contribute to a sense of pride and overall well-being that enable a caregiver to continue care as long as needed.\textsuperscript{77,78}

Lewis and colleagues\textsuperscript{65} identified nine types of support services that may help caregivers challenged by multiple care demands. The areas identified were:

1. Diagnostic and medical treatment information.
2. Interpretation of the course of illness and anticipatory guidance.
3. Interpretation of patients’ emotions to the caregiver.
4. Interpretation of illness to school-aged children.
5. Cognitive process of the meaning of illness.
6. Access to services for physical care.
7. Skill-building services.
8. Problem-solving services.
9. Referral services for the distressed family caregivers.

Studies show that if caregivers receive information that is tailored to the priority problems they face and is provided in a manner they can comprehend, then they will become active members of the health care team, contributing both to higher quality patient outcomes and reductions in the cost of care for patients with advanced disease.

**PSYCHOTHERAPEUTIC INTERVENTIONS**

Psychotherapeutic interventions for family caregivers are designed to enhance morale, self-esteem, coping, sense of control, and problem-solving abilities, and to decrease caregiver emotional distress while caring for patients at home. These interventions are not designed to inform caregivers regarding specific aspects of delivering care; instead, these interventions focus on helping caregivers psychologically adjust to the demands of caring.

Family caregivers should be assessed periodically for psychological/emotional distress, and the specific sources of this distress should be identified. In addition, assessment of the quality of the family relationship and communication patterns is necessary if interventions are to be effective. If warranted, a referral should be made to outside expert resources (e.g., counselor, psychologist). During visits, health care providers need to devote time to candid discussions with caregivers so that questions and concerns can be freely expressed. Health care providers must plan patient care based on the assumption that the family is a system and that the behavior and response of one member affects the family as a unit. Both the patient and the caregiver may need psychological support. Emotional distress of the caregiver must be addressed.

Some researchers have reported on the use of telephone counseling to assist family caregivers in coping with demands of care, increase their confidence in care management, identify resources and support, and assist them in problem-solving.\textsuperscript{79} Toseland and colleagues,\textsuperscript{43} using telephone intervention directed toward caregivers, demonstrated an improvement in the latter’s physical role and social functioning, as measured by the Medical Outcomes Study 36-Short Form instrument (SF-36). Burdened caregivers also showed an improvement in their ability to cope. Individual intervention produced more positive effects on caregivers’ psychological functioning and well-being than did a group intervention.

In a more recent study, Blanchard, Toseland, and McCallion\textsuperscript{80} tested the effectiveness of a randomized counseling intervention program for spouses of cancer patients when compared with usual care. At six months, spouses who
received the intervention were less depressed, and there were no other effects on coping, social support, or psychological well-being. Research on psychotherapeutic approaches should be directed to study the effects of acknowledging the caregivers’ feelings about the difficulty of the situation, and of offering specific strategies for managing their emotional reactions and coping with the more difficult dimensions of caring. Psychotherapeutic approaches can help caregivers identify support groups and the need for assistance in maintaining their own mental health and well-being.

Although psychotherapeutic interventions may be important for some family caregivers, most clinical oncology settings do not include such services. Nevertheless, problem-solving and stress management are important components of psychological support for caregivers81 and health professionals need to recognize when family caregivers may benefit from such interventions.

MOBILIZING RESOURCES AND SUPPORT SERVICES

Because of the nature and stages of the disease, and the use of multimodal treatments in advanced disease, caregivers are frequently confronted with changing conditions and new problems. The approach to formal and informal support should be directed to controlling caregiver distress as related to the demands and ambiguity of patient care.

Providers need to be aware that the more dependent patients become, the more likely the caregiver will need, and perhaps accept, formal assistance. Even if at earlier points in the care trajectory, families would not accept assistance, this option needs to be re-evaluated as the illness progresses.29,82

How to Ask for Help

It is important to help families mobilize existing resources, such as chore services, or to mobilize additional resources, such as other family members.55 Studies suggest that only 15% to 20% of caregivers utilize formal services.20,83 It is not clear from the sparse literature on the use of community services whether this lack of use is due to lack of referral, lack of acceptability, lack of knowledge, or lack of awareness of potential benefits.

Some caregivers need direction from health professionals about how to ask family and friends for assistance and how to obtain referrals for formal care. Fink84 suggests that

A problem-solving approach can help reduce a caregiver’s sense of uncertainty and accompany feelings of stress and burden enhancing positive patient outcomes.

Highly stressed family caregivers may need to be assisted with mobilizing community resources, while those with lower levels of strain may be able to take a more active role in enlisting such resources. Likewise, caregivers with high social skills may be able to mobilize social support quite effectively. McCorkle and colleagues85 reported that home care services helped patients forestall distress-related symptoms and enabled them to remain independent. This independence reduced demands on the caregiver.

Caregiver Support Groups and Respite Services

Support groups may be beneficial, but many caregivers find them difficult to attend when care demands are high. While there is controversy regarding the value of support groups, they should be presented as an option to be considered.

If family caregivers become overwhelmed by the stress of providing care, respite services may be considered. In extreme cases, institutionalization of the patient may be necessary.
Respite may include relief from specific care tasks, such as laundry, cooking, shopping, or transportation, or it may involve short time periods on a weekly basis when the caregiver is relieved from all responsibilities and can leave the home. A few hours of respite scheduled each week allows the caregiver some personal time and may enable him or her to continue providing care.

Ideally, a case manager within the care system would be responsible for helping families utilize community resources. It is important that health care professionals appreciate the fluid nature of the care situation as the patient’s condition continues to deteriorate, and family caregivers adjust to meet the ever-changing care needs of their patients.

When anticipating support needs for the caregivers, health care providers should examine the demands of care, family roles, social and work roles, and available social resources. Sources of support may include the formal health care system, where health care professionals, skilled home care nurses, and chore workers provide support. Employed caregivers may need some formal assistance from home care agencies. At other times, family members may be able to assist caregivers. Assistance can be rendered on a regular basis, such as a daily chore service, or on an ad hoc basis, such as respite care.

The feasibility of maintaining the individual with advanced cancer in the home is largely dependent upon the availability, capacity, and willingness of the family caregiver to provide care. Health professionals need to develop risk profiles to anticipate which family members are likely to experience distress and then plan for services to support them. How complex is the care? What resources are needed? What are the risk factors that predispose caregivers to financial, emotional, social, and physical problems? When are teaching, structure, and formal support needed? Health professionals need to design and conduct supportive programs that decrease caregiver distress and burden, and enhance the quality of life for the family caregiver and the patient.

**FUTURE RESEARCH**

To date, research on caring for a person with cancer has explored the needs and reactions of the caregivers. Investigators have identified how patients’ symptoms, loss of functioning, and possible cognitive deterioration affect family caregivers. Future research is needed in at least four areas of family caregiving.

1) **Symptom Management Strategies.** Pharmacologic agents often cause side effects; families need to be aware of how to administer these agents and how to monitor patients for possible untoward effects. Nonpharmacologic approaches to symptom management are becoming more widely used and many of these approaches also have side effects that need to be monitored. Strategies need to be developed for both approaches so that families can more effectively administer them.

2) **Patient-Caregiver Communication.** Involvement in care at home presupposes that families have the time to care, the abilities to learn new skills, and the psychosocial capacity to reframe past issues. All parties need to recognize that after many years together, both

**BALANCING MULTIPLE ROLES**

Family caregivers often need assistance in evaluating their multiple roles to identify conflicts that are likely to arise, the sources of these conflicts, who can help alleviate them, and where role realignment can balance the demands of care with other roles, such as employee, parent, sibling, or friend. Family conferences may be useful in helping caregivers examine and address the demands of care and potential role conflicts.
patient and caregiver have evolving roles. Many families find this shift in role responsibilities difficult, and cooperation between the patient and caregiver becomes difficult to achieve. As a result, more research is needed to understand the key elements of a productive patient–caregiver relationship that leads to successful patient outcomes.

3) Defining Patient Outcomes. Many health care professionals give little thought to what constitutes good versus poor outcomes for patients being cared for at home. What are reasonable levels of symptom management? How precisely can family members monitor equipment and changes in critical parameters? Standards of care need to be developed that link improved home care with better outpatient outcomes. Improved patient outcomes will provide a form of positive feedback to family caregivers through perceived effectiveness or mastery. It is essential that some range of outcomes be described. Health care professionals need to know who is providing high quality home care, which patients and families need more information or skill building to achieve these outcomes, and which families may never be able to provide the level of home care that will lead to these outcomes for their patients.

4) Cost Effectiveness. Given that the shifts in the health care system that produced the need for greater involvement in home care were driven by a demand for greater cost savings and desire to improve productivity, how can providers realistically be asked to spend more time with patients and their families? Research is needed to demonstrate that investing time, providing information, and working with families to provide home care leads to demonstrably better patient outcomes at lower costs with less professional time overall. This research is needed if family care is to be included as part of the health care system. Research is needed to determine which patients can benefit from intense home care, which family members can, with a certain level of training, deliver at an acceptable level, and what are the overall benefits to the health care system.

Longitudinal studies are needed to document family responses to care and changes over time. Then, longitudinal studies should be conducted that link interventions to family adjustment to care and to determine the optimal timing of interventions. Prematurely delivered interventions, when families are not ready to accept assistance, may be perceived as too intrusive.

As health care continues to change, it is imperative that the burden of care for the family is considered and that a research agenda is developed to focus on clinically meaningful supportive strategies. The correlation between anxiety, mood disturbance, and global mental health for patients and their family members needs to be assessed to determine how and when support should be provided to the patient and caregiver, and how combined support enhances the outcomes, both separately and jointly.

In summary, caregiver intervention programs provide a wide range of services, including personal counseling and the identification of direct support services. Arno et al. estimated that the national economic value of all informal family caregiving (not just cancer care) was $196 billion in 1997. A large portion of this is for those individuals who have cancer.

The ability of the family caregiver to provide quality care is a vital health care resource. Health care providers must be supportive of family caregivers if they are to maximize patient care. Caregivers’ well-being must be our concern; family caregivers have a legitimate and crucial role in the cancer care team. Weitzner et al. suggest that more work is needed in educating health care providers in palliative care settings regarding the negative impact of unrelenting demands of care that are placed on family caregivers. Family members are partners in care and have much to contribute to the care for the individual with advanced cancer.
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