The Crisis of Cancer: Psychological Impact on Family Caregivers

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Cancer causes changes in the family's identity, roles, and daily functioning. Studies document that spouses are as distressed as cancer patients and that spousal and patient distress are correlated. Three major areas of caregiver concern are: fear of cancer and its spread, helping patients deal with the emotional ramifications of the disease, and managing the disruptions caused by cancer. From 20% to 30% of partners suffer from psychological impairment and mood disturbance as a result of the spouse's cancer. Factors that may predict high levels of spousal distress include: disease stage; emotional adjustment of the patient; gender, age, and other characteristics of the spouse; marital adjustment; and family functioning. Studies show that interventions do not reduce spousal distress. Future studies should explore the role of mediating factors, such as coping style, marital adjustment, and family functioning, on the relationship between illness demands or prognosis and distress. Interventions could then be targeted to high-risk individuals. [ONCOLOGY 11(2):189-194, 1997]

Introduction

"Families matter. They matter because they provide the context of adjustment in which the person with cancer responds to his or her disease. This context is known to affect self-care behaviours and adjustment. Families also matter because family members, and not just the patient, are directly confronted with the illness experience."[1]

When a person develops cancer, it is family members who provide the context for this experience, but they themselves are often profoundly affected by the disease. This article will focus on the second reason that families matter—the impact that cancer has on the entire family. This impact has been compared to the result of dropping a stone in a pond. The illness causes a ripple effect that results in changes to the family's identity and to daily routines.[1]

These changes have long-lasting effects, regardless of the outcome of the disease. Although the effects generally are perceived to be negative, involving different types of losses, it should be remembered that many families describe the positive effects and resulting strengths of coping with the crisis of cancer.

Studies Documenting Caregiver Stress

For many years, studies on cancer-related stress focused on patient adjustment, with little attention paid to the family, except for how the social support given (particularly by the spouse) affected patient adjustment (see reference 2 for reviews of this subject). During the 1970s and early '80s, descriptive studies provided evidence that family members of the cancer patient also suffer from stress. These studies, conducted in spouses (primarily of breast cancer patients), documented that partners often experience sleep disturbances and eating disorders,[3] heightened anxiety and depression,[4] a pervasive sense of helplessness,[5] and fears about cancer and its treatment.[6]

These investigations highlighted the need for additional research. Reports then began to use standardized instruments to quantify the level of stress experienced by spouses. Results of these studies reinforced the earlier findings by reporting that spouses were as distressed as patients[7,8] and that levels of patient and spousal distress were correlated,[9,10] so that when one was having difficulty adjusting so was the other.

Major Caregiver Concerns
Having documented that caregivers experience stress, several investigators turned to an examination of the specific concerns of families of cancer patients. In a recent review of the literature on caregiver needs, Northouse and Peters-Golden[11] concluded that these concerns can be categorized into three basic areas. The first and major concern is fear of cancer and its spread. Spouses worry about the extent of disease at the time of diagnosis and about the ultimate outcome. In a recent study of spousal care-givers, Toseland, Blanchard, and McCallion[12] reported that fear of the spouse dying was the major concern of spouses, even when the patients were essentially asymptomatic. Similarly, in a study of breast cancer patients and their husbands, Northouse[13] found that an even greater concern among patients and husbands than the loss of a breast was the fear of cancer itself. The sense of unpredictability and heightened uncertainty of the disease course and the experience of the disease itself add to the lack of control and resulting helplessness felt by the patient and spouse.

The second category of concern relates to helping the patient deal with the emotional ramifications of the disease. Zahlis and Shands[14] and Toseland, Blanchard, and McCallion[12] have documented that dealing with the patient's emotional needs is one of the most difficult areas for the spouse. Spouses often do not know how to help and may feel unprepared to meet the patient's demands. They may also deny their own feelings while trying to provide support for the patient. This can result in heightened anxiety and depression. The emotional needs of other well family members also pose challenges for the spouse, particularly when the couple has young children.

The third area of concern relates to managing the disruptions in family routines and daily living caused by the cancer. Many spouses must assume additional responsibilities and balance these duties with any needed care of the patient, as well as with other roles and duties outside of the home. Oberst and James[4] found that almost half of the spouses of newly diagnosed cancer patients "complained" of disruptions in their employment, household and child-care schedules, and recreational and domestic activities. Providing needed transportation to therapy or assisting in the management of side effects means the disruption of daily schedules for spouses as well as patients. Furthermore, daily routines and schedules may need to be rearranged as often as the disease status changes.

If the patient is able to assume previous roles, he or she may feel more in control and more "normal." If roles cannot be reassumed, others will need to assume the duties and roles that the patient held in the household system. If some family members prefer the new arrangement, it may be difficult to return to the old routines. This may be a relief to the patient or it may make the patient feel like he or she is needed less or is a burden.

In a review of studies of family caregiver needs, Laizner et al[15] suggested various barriers that may prevent caregivers from successfully addressing these concerns. These included lack of awareness or knowledge, financial constraints, stigma of accepting help, family resistance, transportation issues, depletion of existing services, and incongruent goals between the health-care providers and the patient.

**Extent and Duration of Distress**

Given the impact of cancer on every aspect of the family's life, it is not surprising that most studies have documented that family members experience significant distress. Although the majority of spouses appear to adapt to the stress of cancer without exhibiting clinically significant levels of psychological distress,[16] it is estimated that a significant minority of spouses, 20% to 30%, suffer from mood disturbance and psychological impairment.[3,14,17] Toseland and colleagues[12] reported that cancer patients and spousal caregivers were significantly less depressed than psychiatric inpatients but were significantly more depressed (as measured by the Center for Epidemiologic Studies Depression Scale [CES-D]) than samples of people in the community who did not have cancer. The Dyadic Adjustment Scale was used to assess the impact of cancer on the marital relationship of participants. Both spouses and patients reported significantly lower scores on marital consensus, marital satisfaction, and marital cohesion when compared to a community sample of married respondents. State anxiety (measured by the State-Trait Anxiety Inventory [STAI]) was assessed for spousal caregivers only and was found to be significantly greater than the values reported in a community sample.

Interestingly, even though the spouses in the study by Toseland et al[12] were more distressed than samples of people from the community, the spousal caregivers in this study felt that they were dealing effectively with their major concerns (fear of the patient's dying, living with uncertainty, and meeting the patient's emotional needs). Similar findings were reported by Carter and associates.[18]
Although they found breast cancer patients and spouses to be maladjusted on measures of marital adjustment, videotapes of interactions, as well as individual measures, did not support these findings. Perhaps the spouses in these studies were reporting normal responses to a life-threatening illness.

Northouse and Peters-Golden[11] have suggested that the stress of cancer extends over time for caregivers. Northouse[17] found no change over 18 months in husbands' level of distress despite improvements in mood and role functioning. In a study of spouses of patients with lung, breast, or colon cancer, Ell, Nishimoto, and Mantell[19] reported that partners experienced an increase in levels of distress from diagnosis to 1-year follow-up. These results can be explained, at least in part, by a study by Oberst and Scott,[20] which found that stress levels of spouses varied, depending on the ongoing demands of the illness.

The changing demands of the illness have led Lewis[21] to suggest that psychosocial transitions occur as the family attempts to cope with the disease. These transitions include a new pattern of communication within the family, the development of new self-concepts by each family member, the relinquishing of old roles and the assumption of new ones, shifts in status and social structures affecting the person or the family experiencing cancer, and the management of the family's routines, patterns, and basic maintenance functions in light of the demands of the illness.

Factors Affecting Spousal Distress

Given that not all spouses experience clinically significant psychological distress, researchers have turned their attention to identifying factors that may predict those at highest risk for distress. Two major factors have been identified: illness-related variables and contextual variables (Table 1).

Illness-Related Variables

Disease Stage—In view of the central importance of stage of the disease on treatment and prognosis, it is not surprising that this factor relates to psychological distress. (For a review of the literature relating to shifts in family issues across disease stages, see reference 22.) Studies have consistently shown a close association between disease stage and emotional distress. Not surprisingly, more severe mood disturbances and feelings of being overwhelmed have been found in partners of patients with advanced disease, as compared with spouses of those with localized disease.[6,10,19,23] Mor, Guadagnoli, and Wool[24] concluded, "The burden of caretaking in the context of extended illness, advanced stage of cancer, and poor prognosis not infrequently leads to emotional conflict, strain, and guilt."

At present, it is impossible to ascertain whether the psychosocial problems are related to increased caregiving responsibilities or to the anticipated loss of the loved partner.[16] Commenting on the inconsistent impact that the duration of the illness has had on distress, Sales and associates[16] suggested that the length of the terminal illness rather than the time since diagnosis may be the more important factor contributing to the distress.

The impact of cancer treatment on the spouse has been studied primarily for breast cancer. Although the focus has often been on the impact of surgery on the couple's intimate relationship, radiation therapy and chemotherapy each create disruptions in daily routines, uncertainty about the outcome, and, often, difficult side effects. Studies are inconsistent with regard to the problems associated with adjuvant chemotherapy, but difficulties appear to increase with the length of treatment, whether it be given for cure or palliation.[25,26] It may be that disruptions in normal routines cannot be tolerated after a limited amount of time.

Patient's Emotional Adjustment—The spouse's emotional state is related closely to the patient's emotional adjustment throughout the illness. Corresponding levels of distress have been found in breast cancer patients and their spouses, as well as in colon cancer patients and their spouses.[7,27] Thus, Wellisch et al[28] concluded that patient adjustment may be a major determinant of family adjustment. However, this relationship between patient and spousal adjustment may be mediated by other factors. For example, both patient and spouse may be responding to an increase in symptoms, a poor prognosis, or other factors in their relationship.[29]

Contextual Variables

Several studies have examined a variety of individual spousal variables that may predict those at highest risk for distress. More recently, family functioning, or relational variables, have been emphasized. We will discuss each of these contextual variables.
Spousal gender has been studied as a predictor of distress. Sales, Schulz, and Biegel[16] concluded that studies generally showed that adult female family members exhibit more emotional distress than do adult male family members, and they provide more physical and emotional support to their male spouses. Baider and colleagues[30] have pointed to the importance of gender in understanding the relationship between distress of the spouse and that of the patient. They reported that psychological distress of women, whether patients or spouses, was significantly influenced by the distress of their husbands. In contrast, distress of men, whether sick or healthy, was only marginally influenced by the distress of their wives. They postulated that society traditionally casts men in instrumental (task-centered roles) and problem-solving roles, whereas women are taught not only to guard their health but also to nurture and attend to the needs of their spouse. On the other hand, Keller and colleagues[31] found that the impact of cancer differed depending on the patient's gender. When the wife was ill, her emotional response and that of her husband were closely correlated, reflecting a high degree of mutuality and interdependence. If she was adjusting well, the couple might be able to manage the crisis of cancer without major psychological problems. The more she exhibited anxiety or depression, the more difficult was the adjustment for the couple. Interestingly, as long as the wife was stable emotionally, the husband suffered less from her physical condition. When the patient was a male, however, the couple's emotional relationship was less closely correlated. The patient's physical status seemed to be a major factor in predicting the wife's emotional distress. The wife's distress was explained, in part, by concrete needs related to the increasing demands of the illness. Perhaps this reflected her lack of experience in dealing with these needs.

Spousal age has also been studied as a possible predictor of distress. Younger spouses react more emotionally than older ones to the partner's illness,[16] but older patients may experience more difficulty dealing with home care,[23] or they may need significantly more physical and administrative services.[24] Little is known about the impact of the age of the children on family adjustment, although Cooper[32] found that adolescents reported more maladaptive responses to a parent's cancer than younger children. The degree to which children of any age (including adult children) participate in care is unknown.

Other spousal characteristics that have been found to influence the degree of distress include socioeconomic status and other life stressors. Families whose socioeconomic status is lower, who are in poor health, or who have experienced more life stressors exhibit the greatest strain.[16] A recent longitudinal study by Kurtz and associates [33] used the Life Orientation Test previously developed by Scheier and Carver [34] to measure the possible impact of a personality construct, termed "caregivers' optimism," on caregiver symptoms. Caregiver optimism was found to be a strong predictor of caregiver reactions to the burdens of caring, and it buffered the impact of patient variables on caregiver reactions (impact on schedule, physical health, and depression). A study of caregivers of patients receiving chemotherapy[35] found that perceived social support and coping explained, at least partially, the relationship among caregiver variables, patient functional status, and caregiver depression. Specifically, caregivers' perceived coping efficacy had a mediating effect on the relationship between caregiver strain and depression, whereas caregivers' perception of the adequacy of social support mediated the relationship between patients' functional status and caregiver depression.

Marital adjustment has been studied as one measure of the family environment. Vess, Moreland, and Schwebel[36,37] found that couples who communicated well were better able to cope with role demands than were other couples. They also were more cohesive and exhibited less role strain and family conflict. During the terminal phase of the illness, spouses who communicate closely with their loved one may experience more distress.[16] Alternatively, they may experience a higher degree of closeness, resulting in greater communication prior to the patient's death and a better adjustment afterward.[29]

Family Functioning—Another approach has been to examine family functioning as a predictor of distress. The circumplex family model of Olson created to describe family responses to crisis has been used by Schulz et al[38] to study 97 cancer patients and 162 family members. The model consists of two major dimensions: cohesion and adaptability. Cohesion is the emotional bonding among family members. Extremely high cohesion involves overidentification with the family and is termed enmeshment. Extremely low involvement is termed disengagement. Both extremes are considered to be pathological, whereas an average degree of...
cohesion is thought to be functional. Adaptability refers to the ability of a system (in this case, the family) to change its power structure, role relationships, and relationship rules in response to a stressor. The extremes are rigid and chaotic. Again, both extremes are pathological, and the middle ground between the two is functional.

Schulz and colleagues used a comprehensive approach to the measurement of distress, employing the European Quality of Life Questionnaire, the List of Complaints (used in many German studies), and an interview. They hypothesized that a medium degree of both adaptability and cohesion would be related to the lowest psychological distress in patients and family members. They found that distress was lower in spouses and children if their families were not at either extreme on the adaptability dimension. For patients, however, no differences in distress were seen on this dimension. The converse was true for cohesion. Patients who reported the lowest distress were from families with mid-range cohesion, but spouses and children did not show significant differences on this dimension.

Thus, for family members, a well-regulated system of managing roles and duties was more important in reducing distress than was emotional closeness. For the patient, on the other hand, mid-level cohesion seemed most important. Further analysis combining ratings of both partners showed that the partner also experienced less distress, provided that the couple exhibited mid-range cohesion. Additional studies are needed to further explore adaptability and cohesion as predictors of distress. Lewis[39] has conducted a number of studies examining the impact of breast cancer on children in the family. These studies showed that increased illness demands resulted in increased levels of depression for both the patient and husband. These depression levels negatively affected marital adjustment, as experienced by both spouses. Lowered marital adjustment caused the family to cope less frequently with their problems. When the couple reported lower marital quality or coped less frequently, the total household functioning declined.

Follow-up studies at 8 months confirmed these findings about the relationship among depressed mood, active coping, and household functioning. For fathers, the more frequently the family coped with its problems, the better was the quality of the relationship between the father and the school-age child. For the mother, a better-adjusted marriage meant a better relationship with the child. Higher levels of depression in the mother were negatively associated with the child's coping and social acceptance and were positively associated with behavioral problems. More frequent coping by the family was positively associated with high self-esteem of adolescents. Higher levels of depression in the mother were associated with lower self-esteem of adolescents and were negatively associated with the quality of peer relationships and the quality of the parent-child relationship. Lewis suggested that programs are needed to help manage the mother's depression, reinforce the importance of parental support to children and adolescents, and minimize the stress in the marital relationship caused by the cancer.

In summary, factors influencing family distress include the disease status and treatment; individual variables, such as spousal age, gender, and, possibly, caregiver optimism; perceived coping efficacy and adequacy of social support; and variables reflecting the functioning of either the patient-spousal dyad or the entire family unit. The lack of consistent findings points to the need for continuing research to ascertain the relative importance of each of these variables in explaining and predicting family distress.

Interventions

The nature of the concerns expressed by spouses clearly has implications for interventions by a variety of health-care professionals. The importance of providing information can hardly be overemphasized as a major way to assist the patient and family in managing the anxiety resulting from the uncertainty of the disease and its treatment.[40] Information also assists the spouse in helping the patient make decisions, whether they involve the selection of treatment options, ways of managing side effects (eg, wigs, transportation), or rearrangement of roles and routines in response to changing demands of the illness. Spouses who are well-informed also are better prepared for the patient's long-term survival or know what to expect if the illness is terminal. Information can thus help the spouse and patient support each other. Albrecht and colleagues[41] have emphasized the value of understanding how information is communicated among patient, family members, and physician in a supportive environment.

Early studies of interventions with spouses documented the effectiveness of either support programs
or additional information, such as provided by the American Cancer Society's "I Can Cope" program. These studies suffered from the absence of a randomized control group design, small sample sizes, and the use of measures with untested psychometric properties.

Randomized Studies

Two studies using randomized control groups have been published. Neither reported positive results. Goldberg and Wool[42] studied the effectiveness of a 12-session counseling intervention with spouses and adult children of recently diagnosed cancer patients. Using a randomized control design, they assessed 53 caregivers prior to the intervention, immediately after treatment, and at a 2-month follow-up. They found no changes on measures of psychosocial or physical functioning for either patient or spouse.

Blanchard et al[43] reported on the effect of a six-session intervention with spouses of cancer patients. They used a problem-solving approach to assist spouses in devising, implementing, and assessing solutions to individually identified problems. Results at 6-month follow-up showed no significant impact of the intervention on spouses. This was also true for the most distressed spouses. Patients whose spouses received the intervention showed significantly lower depression, however. The researchers could not determine whether this finding represented changes in any interaction patterns due to the impact of the spousal intervention or whether patients were grateful that someone else was assisting the spouses in coping with the illness. These findings did, however, point to the advantage of studying the patient-spouse dyad, rather than just the patient or spouse.

Conclusions

Clearly, cancer raises a multitude of concerns for the entire family, and these concerns vary with the demands of the illness. Changes in the family's identity and roles occur as the family copes with the disease. The majority of families adapt to these challenges; however, we do not know whether adaptation would occur sooner with psychosocial intervention. When the demands of the illness increase, so do the strains on the family, although some families do report increased closeness and a refocusing of priorities.

Interventions are perhaps best aimed at the minority (20% to 30%) of spouses who experience greater distress. There is little consistency across studies with regard to the identification of factors that predict those at higher risk for distress. Clearly, additional work is needed in this area. The demands of the illness, and thus, stage of disease, appear to be key factors to consider, although their impact may be mediated, in part, by such variables as gender, personality construct or coping style, marital adjustment, or family functioning. We do not know whether instituting early intervention in those experiencing high levels of distress would prevent distress later in the course of the illness.

Another significant area for further study is the impact of ethnic differences on family functioning when a family member has cancer. Still another area for study is nontraditional family systems, eg, gay and lesbian couples and unmarried and cohabiting partners.

What is clear is that cancer is, indeed, a crisis that affects the entire family.

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