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# THE IMPACT OF CAREGIVING ON THE PSYCHOLOGICAL WELL-BEING OF FAMILY CAREGIVERS AND CANCER PATIENTS

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**OBJECTIVES:** *To provide an overview of patient and caregiver emotional distress; examine the sources of their distress, review evidence-based interventions that can reduce distress, and provide guidelines for assessment and intervention.*

**DATA SOURCES:** *Peer-reviewed publications.*

**CONCLUSION:** *There is a significant, reciprocal relationship between patient and caregiver emotional distress. Sources of distress vary by phase of illness. Evidence-based interventions can reduce distress and anxiety, but often are not implemented in practice.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Nurses need to assess patients and family caregivers for distress and intervene to reduce distress by fostering patient-caregiver teamwork, communication, and self-care; providing information; and referring to resources as needed.*

**KEY WORDS:** *Emotional distress, anxiety, family caregivers, assessment, intervention*

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CANCER affects the quality of life of family caregivers in many ways, but takes its greatest toll on their psychological well-being. Family caregivers are expected to provide complex care in the home with little preparation or support.<sup>1</sup> When the demands placed on caregivers exceed their resources, caregivers feel overwhelmed and report high stress. The stress has a negative effect *initially* on the caregiver's psychological well-being, but as the stress continues it can negatively affect their physical well-being as well. The effects of stress on the psychological domain of quality of life appear as increased emotional distress, anxiety, and/or depression; feelings of helplessness and loss of control; and difficulty in coping with caregiving roles.<sup>2</sup>

High emotional distress reported by family caregivers is a significant problem that needs to be addressed for a number of reasons. First, longitudinal studies indicate that when family caregivers are highly distressed, it has a negative effect on the patient's long-term adjustment.<sup>3</sup> Over time, a highly anxious partner can increase the anxiety experienced by the patient.<sup>4</sup> Second, distressed caregivers have more difficulty providing optimal patient care<sup>1</sup> and administering medications to patients.<sup>5</sup> Third, caregivers who have high distress also have changes in their immune system that can lead to flare-ups in auto-immune diseases, worsened glucose control in the body, and increased vulnerability to cardiovascular diseases.<sup>6</sup> These changes increase the likelihood that the caregiver's own health will suffer and, subsequently, hinder their capacity to provide care.

To gain a broader understanding of the effects of cancer on caregiver's psychological well-being, this review addresses the following: 1) provides an overview of patient and caregiver emotional distress, 2) examines the sources of their distress by phase of illness, 3) reviews evidence-based interventions that can reduce patient and caregiver distress, and 4) provides guidelines for assessing and intervening with patients and caregivers in practice settings.

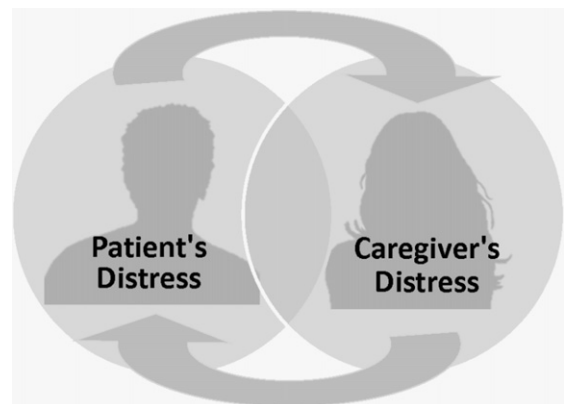
### OVERVIEW OF PATIENT AND CAREGIVER EMOTIONAL DISTRESS

For many years, it was assumed that cancer had little effect on the well-being of family caregivers because caregivers were not the ones diagnosed

with cancer. However, as studies examined the impact of cancer on the family over time, health professionals and others became more aware of the emotional distress experienced by family members as well as patients.

Two meta-analyses examined the emotional distress reported by cancer patients and their family members.<sup>7,8</sup> Hodges et al<sup>8</sup> conducted a meta-analysis of 21 studies, with a combined sample of 1,098 patient-caregiver dyads, to determine if there was a relationship between the distress reported by cancer patients and their family caregivers. They found a moderate, significant relationship between their distress scores ( $r = 0.35$ ,  $P < .0001$ ), indicating that their emotional responses to the illness were interrelated. When patients were distressed, it was likely that their caregivers were distressed, and vice versa. Hagedoorn et al<sup>7</sup> conducted a meta-analysis of 46 studies that examined distress in couples coping with cancer ( $N = 2,468$  dyads). They found a significant correlation between patient's and their spouse caregiver's level of distress ( $r = 0.29$ ,  $P < .001$ ), even after controlling for illness-related factors such as the patient's stage of disease. Their findings suggest that couples react to cancer as an "emotional system," and that the patient-caregiver dyad must be viewed as the unit of care (see Fig. 1).

Even though patient and caregiver distress is related, some investigators have questioned, "Who has more emotional distress—the patient or the caregiver?" When this question was examined in two meta-analyses, investigators found no significant difference in the amount of distress



**FIGURE 1.** Reciprocal relationship between patient and caregiver emotional distress. Each partner affects the other throughout all phases of illness.

reported by patients and their caregivers.<sup>7,8</sup> They also found no significant differences in their emotional distress by phase of illness. One meta-analysis found a tendency for caregivers to report more distress during the treatment phase ( $P < .08$ ) when physical and emotional caregiving demands were high, and a tendency for patients to report more distress 1 and 2 months following diagnosis ( $P < .08$ ) as they continued to struggle with the new diagnosis.<sup>8</sup>

The distress reported by couples facing cancer was compared with couples who were not facing cancer. Investigators found that cancer patients and their spouse/partners had significantly higher distress than the comparison group.<sup>7,9</sup> Couples facing cancer had “modestly elevated” levels of distress that, on average, was below cut-off points indicating high distress or clinical depression on established instruments.<sup>7</sup> However, there is a subgroup of patients and caregivers who do report higher distress or more depression than others. Zabora et al<sup>10</sup> examined the distress levels of a large sample of cancer patients ( $N = 4,496$ ) and found the rate for high distress in the sample was 35.1%. While the rate of distress ranged from a low of 29.6% (gynecological cancer patients) to a high of 43.4% (lung cancer patients), these levels of distress are very significant. The incidence of high distress or depression in caregivers has been estimated at approximately 20%.<sup>11-13</sup> However, the incidence is higher when patients have high symptom distress, poor physical functioning, and advanced disease,<sup>14</sup> and also when caregivers report high caregiver burden and little support from others.<sup>14</sup>

Gender is a key factor associated with distress in patients and caregivers. Female patients and female caregivers report more distress than their male counterparts.<sup>15</sup> Female caregivers, however, have the highest distress of all.<sup>16</sup> In contrast to male caregivers, female caregivers spend more time providing care,<sup>17</sup> provide more complex care,<sup>17</sup> perceive less support from others,<sup>16</sup> and have more noncancer-related stress, in addition to the stress of cancer.<sup>16</sup>

### **SOURCES OF DISTRESS BY PHASE OF ILLNESS**

There are many sources of emotional distress and they can vary according to the phase of illness. The sources of distress for patients and caregivers are briefly described for the following six phases during the cancer trajectory: 1) prediagnosis, 2) diagnosis,

3) treatment, 4) survivorship, 5) recurrent, and 6) advanced and end of life. Table 1 highlights the major sources of emotional distress by phase.

#### ***Prediagnosis Phase***

With advances in genetic testing, more people are learning about the possibility of hereditary cancer in their own families. Genetic testing identifies at-risk individuals and provides them with information about strategies they can use to lower their risk of developing cancer, such as risk-reducing surgery and intensive surveillance. A recent study found that mutation carriers did not differ significantly from non-carriers in psychological distress at the time of test results and at short-term follow-up. However, both groups showed an increase in anxiety and depression from 1 to 3 years after test disclosure.<sup>18</sup>

There are many sources of distress for families with hereditary cancer, such as learning about the risk of hereditary cancer in the family, deciding whether or not to seek genetic testing, determining whether or not to disclose test results to family members, and deciding how to manage this risk if they test positive.<sup>19</sup> Even relatives who test negative for a deleterious mutation identified in their family, experience guilt about communicating their results to untested siblings, who may still face a 50% chance of harboring the same mutation.<sup>20</sup>

Partners also experience distress when their loved ones are at greater risk for rare hereditary cancer syndromes.<sup>21</sup> Approximately one in three partners (28%) had clinically relevant levels of distress, which correlated significantly with the distress reported by the person at risk of rare hereditary cancer. Partners with higher distress were generally younger than other partners and lacked adequate social support. Enhancing family support and family communication about cancer risk and ways to manage it are important areas for intervention.<sup>22</sup>

#### ***Diagnosis Phase***

Many studies have documented the emotional distress reported by cancer patients and their family caregivers following the diagnosis of cancer. Findings indicate that both patients and caregivers report shock and anxiety at the time of diagnosis. Kim et al<sup>23</sup> assessed the needs of three cohorts of caregivers who were 2 months, 2 years, and 5 years following diagnosis. Caregivers of newly diagnosed patients (ie, 2-month cohort) had more unmet

**TABLE 1.**  
**Sources of Caregiver Distress Through the Phases of Illness**

Pre-diagnosis	Diagnosis	Treatment	Survivorship	Recurrence	Advanced/End of Life
Awareness of hereditary cancer in family Involvement in decisions about genetic testing Difficulties with family communication regarding cancer risk Worry about offspring and dealing with issues of guilt	Unmet needs: psychosocial, medical, financial and informational Uncertainty about how to address patient's emotional concerns Feelings of being overwhelmed and powerless Multiple role demands of household, work, providing care	Worry about effectiveness of treatment Difficulties managing side effects of treatment Lack of preparation for providing complex care Juggling multiple demands without help from others Social isolation	Fear of recurrence Multiple family stressors on top of history of cancer Inability to find some benefit or meaning in the illness	Increased uncertainty and hopelessness Period of emotional turmoil and increase in perceived threat Higher symptom distress and more role limitations for patient Fewer sources of support	High symptom distress in patient Difficult family relationships Feelings of abandonment Competing outside demands (work) Lack of financial and community support Poor self-care (exercise, diet, substance misuse)

psychosocial, medical, financial, and informational needs than caregivers in the other two cohorts. Younger caregivers reported substantially more unmet needs in all domains than older caregivers.

A major concern for caregivers during this phase is helping patients deal with emotional distress associated with their new diagnosis of cancer. Partners of breast cancer patients reported that at the same time their lives were shattered by the cancer diagnosis, they did not know what to do to support their distressed wives and had to guess.<sup>24</sup> Spouses often kept their worries to themselves because they did not want to add to their wives' burden.

Caregivers convey that helping patients to cope with emotional distress (eg, anger, anxiety, depression, fear, and resentment) is one of their highest unmet needs following diagnosis.<sup>23</sup> Caregivers reported less confidence helping patients with their emotional needs, than with their physical needs.<sup>1</sup> Partners often want to do the "right thing" but are unsure what that is. Others, including health professionals, may erroneously assume that family caregivers who have a close relationship with the patient will automatically know what to do or say. However, as research indicates, family caregivers often feel unprepared to deal with the array of intense emotions surrounding the diagnosis. Helping patients and caregivers to manage acute distress is a critical need during this phase of illness.

**Treatment Phase**

Just after diagnosis, patients and caregivers are confronted with new and unfamiliar treatments for the cancer. Sources of distress during this time are related to their worry about the patient's ability to tolerate the treatment, if the treatment will be effective, and if side effects and symptoms associated with the treatment will be manageable. During this phase, caregivers are more involved in providing physical care and managing treatment-related symptoms. In a study where caregivers were responsible for monitoring changes in the patient's condition and providing care, half of the caregivers reported that they did not get the training they needed to provide high quality care.<sup>1</sup> One fourth of the caregivers were concerned that their care was less than optimal.

It is not surprising that during the treatment phase caregivers often report greater caregiver burden and strain than they do in some of the other phases of illness. The majority of caregivers (67%) in a large study reported that they were the

sole providers of care and received no informal help from others.<sup>1</sup> Caregivers who reported a greater impact of caregiving on their day-to-day schedules and social functioning, and who felt abandoned by others, experienced more emotional distress.<sup>14</sup> These caregivers are likely to benefit from more information and support from health professionals.

### **Survivorship Phase**

The survivorship phase is characterized as the time when the cancer is in remission or when the patient is considered cured. The quality of life of cancer survivors and their caregivers was comparable to the normal population in two studies of couples who were approximately 2 years<sup>25</sup> or 4 years post-diagnosis.<sup>26</sup> Survivors and their family caregivers had normal levels of distress<sup>25</sup> and depression rates that were consistent with community samples.<sup>26</sup> Approximately 70% of the survivors and caregivers were able to identify some positive aspect associated with their cancer experience (eg, realizing how precious life is, appreciating relationships).<sup>26</sup>

A number of factors are related to a higher quality of life in survivors and their family caregivers during this phase. Mellon and Northouse<sup>27</sup> assessed the quality of life of survivors and their family caregivers. Survivors, randomly selected from a national cancer registry, were disease-free and approximately 3 years following diagnosis. Higher quality of life of the family overall (combined patient-family member scores) was associated with higher family hardiness, more social support, greater ability to find meaning in illness, and with the survivor being employed at the time of the interview. Lower quality of life was associated with more concurrent stress in the family, somatic concerns in survivors, and higher fear of cancer recurrence in survivors and family members.<sup>27</sup>

A universal concern during survivorship is the fear that the cancer will recur. Family caregivers often report more fear of recurrence than survivors,<sup>28</sup> possibly because they interact less with health professionals than patients, and have fewer opportunities to obtain information that could lessen their fears. There is a fairly strong correlation between the levels of fear of recurrence reported by survivors and their family caregivers, suggesting that they mutually influence one another's fear.<sup>28</sup> Helping survivors and caregivers to manage fear of recurrence is an important area for intervention during this phase.

### **Recurrent Phase**

When the cancer returns, it is a devastating time for patients and their family caregivers. Recurrence shatters their hope that the cancer was cured, and it often requires patients to receive treatment again—which in many cases is palliative rather than curative. Studies that compared the quality of life of patients with recurrent versus newly diagnosed cancer report that recurrent cancer patients have significantly lower quality of life, more pain, more role limitations, higher symptom distress, and a more negative appraisal of the illness.<sup>29</sup> Their family caregivers report more uncertainty, hopelessness, and adjustment problems,<sup>30</sup> and a lower mental quality of life.<sup>29</sup>

Although recurrence can be a devastating blow, Andersen et al<sup>31</sup> assessed women with recurrent breast cancer from diagnosis through 8 years follow-up, and found that they were very resilient. According to the investigators, these women were knowledgeable about cancer from their initial diagnosis, were familiar with the medical system, and had established relationships with their oncology staff, all of which may have lessened their anxiety and stress at the time of recurrence. Of the women who had a recurrence (13.5%), their level of cancer-specific stress was equivalent to the level of distress at the time they were initially diagnosed. Although survivors with recurrent disease in this study were resilient, more information is needed about the resilience of family caregivers who were not assessed in this study. In other studies, family caregivers during the recurrent phase report higher uncertainty and fewer sources of support than survivors.<sup>29</sup>

It is important to note that the recurrent phase of cancer can lead to very different outcomes in patients and their families over time. Some survivors experience long disease-free remissions, while others face a steady progression of their cancer, in spite of having undergone multiple unsuccessful treatments. These two scenarios can have very different effects on the quality of life and distress levels of cancer patients and their family caregivers during recurrence, and they will require different interventions from health professionals.

### **Advanced and End-of-Life Phase**

Advanced cancer is often characterized by high symptom distress in patients and high caregiver burden in their family members. Some patients are informed that they have advanced cancer at the time of their diagnosis, but for many patients

the cancer progresses to an advanced phase over time. Researchers in one study found that caregivers of patients with a short time interval between diagnosis and death experienced more symptoms of depression.<sup>32</sup>

As the end of life approaches, caregivers in some studies reported depressive symptoms that equaled or exceeded thresholds for clinical depression.<sup>32</sup> Sources of caregiver depression are related to more negative family relationships,<sup>33</sup> including a sense of abandonment,<sup>32</sup> more outside demands related to their employment, and more symptom distress in patients.<sup>32,34</sup> In one study, the majority of caregivers (71%) needed substantial help with managing the patient's symptoms, and this need remained unmet for 43% of the caregivers through the end of the patient's life.<sup>34</sup> Caregivers who had substantial unmet needs related to symptom management, and difficulty obtaining financial and community support, were more likely to report that the patient received lower quality of care at the end of life than caregivers who had fewer unmet needs.<sup>34</sup>

As the patient nears the end of life, another concern is that the caregiver's health may decrease as they engage in fewer healthy lifestyle behaviors. In a study of caregivers of patients who had mostly advanced ovarian cancer, 42% reported a decrease in physical activity, 35% gained weight, and 12% reported an increase in alcohol intake.<sup>11</sup> Caregivers who reported more distress and more caregiving demands had more negative changes in their health behaviors. Although this is an area for primary prevention, few interventions have been designed to help caregivers of seriously ill patients to maintain their own health.

Effective interpersonal relationships among family members, between patients and caregivers, and with health professionals are especially important as patients near the end of life and caregiver burden increases. In families that are more cohesive and have less conflict, caregivers report less caregiver burden, in part because they are likely to get more help from other family members.<sup>33</sup> In couples with better marital relationships, caregivers have less depression and less difficulty providing care.<sup>35</sup> In addition, when caregivers have better interpersonal relationships with health professionals, caregivers report better health and feel less abandoned.<sup>33</sup> Although maintaining family relationships is important, very few interventions try to strengthen these relationships as a key component of end-of-life care.

### EVIDENCE-BASED INTERVENTIONS TO REDUCE EMOTIONAL DISTRESS IN PATIENTS AND FAMILY CAREGIVERS: META-ANALYSIS FINDINGS

There is evidence that interventions can reduce emotional distress in patients and their caregivers. One meta-analysis examined the outcomes of 29 randomized clinical trials that delivered psychosocial interventions to cancer patients and their family caregivers, or to caregivers alone.<sup>36</sup> The investigators pooled the data from these 29 studies and then analyzed it to determine if the interventions had any effects on several different caregiver outcomes. Findings from the meta-analysis indicated that the interventions had a number of positive outcomes for caregivers. They reduced caregivers' burden, increased caregivers' knowledge and perceived benefits of caregiving, enhanced caregivers' coping resources and self-efficacy, and improved many aspects of the caregiver's quality of life.

The interventions reported in the 29 studies were examined for content, dose, and delivery format. The types of interventions were classified into three groups: 1) psycho-educational (57.1%); 2) skills training (25.7%); or 3) therapeutic counseling (17.1%). The dose of the interventions ranged from two to 16 sessions, with the average number being 6.7 sessions. In regard to delivery format, two thirds were delivered jointly to patients and their caregivers and one third to caregivers only. Most interventions were offered in a face-to-face format (68.6%), some were delivered by phone (20%), and only a few in a group format (11.3%). Two studies used a combination of face-to-face and phone interventions. No studies used Web-based interventions.<sup>36</sup>

Of the 29 studies included in this meta-analysis, 16 examined the caregiver's emotional distress or anxiety. Findings indicated that the interventions significantly reduced the caregiver's emotional distress and anxiety. Although the size of the intervention effect was small to medium (range, .16 to .29), the interventions had a clinically significant effect.<sup>36</sup>

The meta-analysis also examined the effects of the interventions on the caregiver's depression in 16 studies. Overall, findings from the meta-analysis indicated no significant reduction in caregiver depression.<sup>36</sup> However, this finding must be viewed with caution because in some studies caregivers had little depression at the start of the study,

and in other studies, caregivers who were more depressed dropped out of the study. Similarly, in a separate meta-analysis that examined the effect of interventions on depression in cancer patients, there was also no significant reduction in patient depression.<sup>37</sup> Findings from these meta-analyses suggest that it may be more difficult to reduce depression than to reduce emotional distress and anxiety, but this needs further research.

### GUIDELINES FOR ASSESSING AND INTERVENING WITH CAREGIVERS AND PATIENTS IN CLINICAL PRACTICE

Although a number of research-tested interventions have reduced emotional distress and anxiety in caregivers of cancer patients, few of these evidence-based interventions have been implemented in practice settings because of a number of challenges. Many of the effective intervention programs were conducted as part of randomized clinical trials that often consisted of six or more face-to-face intervention sessions, which are difficult to implement in busy practice settings. Furthermore, oncology nurses and others face time constraints in practice settings. Out of necessity, nurses often spend time completing physical assessments and treatments, leaving little if any time to address psychosocial concerns. There is a need for more efficient ways to assess the psychosocial concerns of family caregivers in practice settings and to make better use of interventions and referrals.

#### **Assessment**

It is important to assess the caregiver's concerns on a regular basis. Such an assessment could use a series of clinician-designed questions as illustrated in Table 2, or more formal assessment instruments such as the Distress Thermometer.<sup>38</sup>

We developed four questions to assess caregiver distress (see Table 2) that could be built into a patient assessment or that could be used separately to assess caregiver emotional distress. The questions center on whether caregivers: 1) have the tools to provide optimal care; 2) are able to juggle multiple responsibilities; 3) engage in self-care to maintain their health; and 4) are able to keep their spirits up as they deal with the stress associated with caregiving. There are many questions that could be used for a clinician-based assessment, but these key questions should be included in any assessment.

There are also established instruments to assess emotional distress. The Distress Thermometer is widely used and has been validated to assess patient distress<sup>38</sup> and caregiver distress.<sup>39</sup> It has established cut-off points that indicate when patients or caregivers have high levels of distress warranting professional intervention. Bevans and Sternberg<sup>40</sup> identified other formal ways to screen for distress in practice settings, such as using anxiety and depression items from PROMIS (the Patient Reported Outcomes Measurement Information System).<sup>41</sup> The advantage of using formal assessment tools is that they have established reliability and validity and can be compared with other normative data. Whether to use a formal instrument or a series of questions will depend on the clinician's preference and nature of the practice setting.

#### **Interventions for Caregivers and Patients**

The key approach to interventions designed to decrease emotional distress is to treat the patient-caregiver dyad as the unit of care. As indicated in this review, there is substantial, well-documented evidence that both patients and their family caregivers are affected by the illness, and each affects the other's emotional response to it. From a dyadic perspective, when caregiver's needs

**TABLE 2.**  
**T-A-S-K Questions to Assess for Caregiver Distress**

Tools?	Do you have what you need (the tools) to provide the best care possible to ____ (cancer patient)? (eg, knowledge, time, finances, outside support)
Able to juggle?	Are you able to juggle your caregiving responsibilities with your other day-to-day responsibilities?
Self-care?	Are you taking care of yourself? (eg, taking breaks from caregiving, following healthy lifestyle habits, keeping own health care appointments)
Keeping spirits up?	Are you keeping your spirits up? (eg, assess for sadness or depression)

Caregivers who answer "No" to any of the above questions may be at risk for caregiver strain and psychological distress.

**TABLE 3.**  
**Interventions for Patient-Caregiver Dyads that Help Decrease Caregiver Distress**

Intervention	Rationale	Specific Strategies to Offer Dyad or Caregiver
Encourage teamwork and mutual support	Increases family bonds Decreases stress Improves coping	Picture yourselves as a “team” that is facing cancer together Look for ways to support and help each other Be aware of each other’s strengths and make the most of them Express appreciation to each other Share problems and work together to figure out solutions Respect each other; take each other’s concerns seriously; value each other’s opinion even if different Don’t let cancer consume you; focus on what gives your lives meaning and purpose Recognize when you need outside help
Foster open communication	Increases understanding and feelings of connectedness Decreases stress Improves problem-solving	Talk about how things are going; share your feelings even if it’s hard at times Make time to talk; create a quiet setting (turn off phones and TV) Show you want to listen; keep your body relaxed and make eye contact Try to understand feelings along with words; ask if you’re not sure Try not to interrupt, argue or criticize Be patient and kind with each other. Show your affection –it costs nothing and means a lot to those you care about. Share your fears and worries; it makes them less overwhelming. Then you can deal with them together with each other’s support
Encourage caregiver self-care	Maintains caregiver’s physical and emotional ability to provide care	Set aside time to meet your own needs Schedule breaks away from caregiving demands Practice healthy lifestyle habits: sleep, physical activity, nutrition Keep your own health care appointments Talk to other caregivers; consider joining a support group
Provide information	Decreases stress Reduces uncertainty Increases caregiver competence	Obtain information to increase your knowledge and confidence Go to patient’s appointments together and bring a list of your questions View online caregiver resources. Some reliable websites are: National Cancer Institute: <a href="http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/">http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/</a> Cancer Care (also available by phone: 1-800-813-HOPE [4673]) <a href="http://www.cancercare.org/tagged/caregiving">http://www.cancercare.org/tagged/caregiving</a> Cancer Support Community <a href="http://www.cancersupportcommunity.org/MainMenu/Family-Friends/Caregiving">http://www.cancersupportcommunity.org/MainMenu/Family-Friends/Caregiving</a>
Refer	Provides additional resources Enhances caregiver’s capacity to continue providing care	Expand your informal support network (family, friends, neighbors) Identify other people who may be able to help you Utilize referrals to professional services: Counseling, therapy Social work, financial services Spiritual care Chore services Hospice



are not addressed, their mental and physical health is at risk, which leads to patients not receiving optimal care from a well-prepared, confident caregiver.<sup>36</sup>

Table 3 lists a series of interventions that focus on helping patient-caregiver dyads to decrease caregiver distress, which is the primary focus of this article. The areas of intervention are: 1) encourage teamwork and mutual support; 2) foster open communication; 3) encourage caregiver self-care; 4) provide information; and 5) refer as needed to additional resources. Specific strategies to offer the dyad or caregiver in each area are also listed in Table 3.

Because of scarce health care resources, innovative ways are needed to address caregiver as well as patient needs. The Internet, smartphones, and Facebook are all untapped ways of providing information and support. A large survey of caregivers in the United States indicates that they are particularly interested in using technology to gain information and to improve the quality of patient care.<sup>42</sup> Future research should determine the best way to use technology, while at the same time

preserving important patient-family-professional interpersonal relationships that are essential for managing the stress associated with cancer.

## CONCLUSION

This review of research confirms that cancer can affect the quality of life of family caregivers in many ways, but particularly in the psychological domain. Patient and caregiver emotional distress is evident in each phase of illness, but is greater in some phases (diagnosis) than others (survivorship). Although there are a number of research-tested interventions that can reduce the caregiver's emotional distress, a continuing challenge is finding ways to implement evidence-based interventions in the practice settings. An important first step is to assess the needs of family caregivers to assist them in reducing their emotional distress. The ultimate goal is for caregivers to continue to be effective caregivers without compromising their own health and well-being.

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