

---

---

# ENHANCING THE SOCIAL WELL-BEING OF FAMILY CAREGIVERS

---

---

SHIRLEY OTIS-GREEN AND GLORIA JUAREZ

---

---

**OBJECTIVES:** *To provide an overview of key issues and resources useful for oncology professionals to support the social well-being of patients and their families. A caregiver narrative highlights examples of the importance of addressing the social impact of illness.*

**DATA SOURCES:** *Review of the literature and Web sites related to social well-being of oncology patients and families.*

**CONCLUSION:** *Culture influences social well-being and impacts caregiving across the life span. Coping with cancer creates a myriad of social implications with potentially significant impacts on communication; sexuality, intimacy and sexual expression; education, finances, work, and leisure.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Nurses spend the greatest amount of time with patients and their families and therefore have an especially important role in identifying and addressing social needs. An interdisciplinary approach to care that includes the assessment of those at high risk and family meetings increases opportunities to address the complex multidimensional social concerns associated with oncology care.*

**KEY WORDS:** *Social well-being, family caregiving, roles, culture, family meetings, financial resources, bereavement support*

CARING for a loved one with a cancer diagnosis has multidimensional and synergistic implications influencing every aspect of the family's well-being and quality of life (QOL).<sup>1</sup> Although this article

focuses on the social impact of the cancer experience with special attention to the roles of caregivers, it is important to recognize the inter-connectedness of each domain within the quality-of-life model. This article discusses the benefits, burdens, and

---

Shirley Otis-Green, MSW, ACSW, LCSW, OSW-C: Senior Research Specialist, City of Hope National Medical Center, Duarte, CA. Gloria Juarez, RN, PhD: Assistant Professor, City of Hope National Medical Center, Duarte, CA.

Address correspondence to Shirley Otis-Green, MSW, ACSW, LCSW, OSW-C, Senior Research

---

Specialist, Division of Nursing Research and Education, Department of Population Sciences, City of Hope National Medical Center, 1500 East Duarte, Road, Duarte, CA 91010-3000. e-mail: Sotis-green@coh.org

© 2012 Elsevier Inc. Open access under CC BY-NC-ND license. 0749-2081/2804

<http://dx.doi.org/10.1016/j.soncn.2012.09.007>

cultural influences that contribute to social well-being, emphasizing the challenges encountered and the evolutionary nature of caregiving over the trajectory of illness and in the life-span of the families who care for a loved one with cancer. Additionally, this review will explore the evidence to guide clinicians in providing culturally sensitive, individualized quality care for patients and families with a focus on strategies that enhance social well-being.

Attention to the social well-being concerns of family caregivers includes consideration of the impact of cancer on the patient's social network; possible changes in family roles; social support; communication; sexuality and intimacy; education; employment and leisure activities; as well as possible financial burden. Programs that support the social well-being of family caregivers must consider these concerns.

### CULTURAL INFLUENCE

The impact of caregiving on the social well-being of family caregivers is significant throughout the cancer trajectory.<sup>2</sup> The social structure and integrity of the family may be threatened when a member has a life-threatening illness. Multidimensional elements of culture, including language, environment, social structure, spirituality, religion, existential worldview, and economy interact to influence health status, disease perception, and medical care.<sup>3</sup> Caregiving is learned within the family, which is a cultural environment.

Caregivers may perform similar activities in all ethnic groups, but culture influences the way caregiving is defined by family members.<sup>3</sup> One's culture significantly influences reactions to a diagnosis of cancer and provides the foundation for the response to illness. The capacity for people to give meaning to suffering and reach transcendence is intimately related to cultural beliefs and values.<sup>4</sup> Cultural norms and values have a substantial effect on how caregivers perceive their own caregiving experiences and their roles as caregivers. Culture helps create meaning or structure with events that seem uncontrollable, such as a cancer diagnosis of a loved one.

Caregivers for whom English is not their primary language face unique challenges when caring for a loved one with cancer, based on language and health literacy barriers that may make medical information more difficult to navigate.<sup>5</sup> Other contextual factors,

such as financial and insurance barriers, immigration status, lack of social or emotional support, social isolation, and language translation or living in communities with inadequate resources provide additional potential burdens. These barriers affect access to quality cancer care and underscore the importance of providing culturally congruent and linguistically appropriate support for treatment decision-making. Communication with caregivers who primarily speak a language other than English requires special sensitivity regarding the use of medical interpreters.<sup>6</sup>

Unfortunately, disparities in access to care (eg, inadequate pain treatment) continue, with minority patients facing twice the likelihood that they will experience under-treatment for their cancer-related pain compared with non-Hispanic white patients.<sup>7</sup> Family caregivers suffer when their loved ones are in distress, and feelings of hopelessness or anger with an unresponsive health care system contribute to worsened QOL.

### CHANGES WITH RELATIONSHIPS/ROLES

Cancer has a serious impact on the entire family and does not occur as an individual, isolated experience. Family caregivers may experience conflict among their changing family roles and responsibilities, restrictions of their activities, strain in marital and family relationships, and struggle to maintain robust systems of social support.<sup>8-10</sup> Marital relationships can be strained, and research has found that depression in both patient and spouse negatively affected marital relationships.<sup>11,12</sup> Family communication patterns, roles, and coping methods are crucial components of family functioning, and difficulties in these components can be exacerbated by cancer and increase caregiver burden.

Family caregivers may experience "role overload" when providing cancer care while taking on the patient's household or family responsibilities in addition to their own. The more social roles a caregiver carries out, the more likely the caregiver is to experience stress and negative affect that may result in diminished QOL.<sup>10,13</sup> Cultural beliefs and norms may define the meaning of caregiving in certain cultures.<sup>14</sup> Where intergeneration caregiving is a cultural expectation, an inherent part of the role of wife or daughter may be the perception of a filial responsibility. In other cultural groups, the responsibility for caregiving may be determined by birth order.

## SOCIAL SUPPORT

Social support is a highly variable and multidimensional construct, and often the designated caregiver does not receive what they perceive to be adequate support from others.<sup>14</sup> Research suggests that social support accounts for a significant amount of variance in the family caregiver's QOL.<sup>15</sup> Real or perceived lack of support by family caregivers has been found to correlate with high levels of physical as well as psychological exhaustion, with many caregivers reporting that their social support decreases over time.

Family members are an especially important source of social support across the cancer trajectory for ethnic groups with strong collectivistic values.<sup>16,17</sup> Certain ethnic or cultural groups prefer relying on family members rather than professional caregivers.<sup>18</sup> This reliance on family support may precipitate delaying access to external resources. Reasons for underutilization of support services include the cultural belief that caregiving is a personal responsibility. Lack of financial resources, literacy, health literacy, other language issues, lack of culturally congruent interventions, and availability of community and institution-based resources all contribute to an underutilization of formal support.<sup>19</sup>

## ISOLATION

Social isolation has a negative impact on health and well-being. Despite having family support, both patients and family caregivers may continue to report feelings of increased isolation, which may contribute to distress and impact QOL for all involved.<sup>20,21</sup> Family caregivers may be so involved providing care for their loved one that socialization is rare or nonexistent. Caregivers may benefit from face-to-face peer support (from another caregiver) or from Web-based support groups, social networks, and social media.<sup>22</sup>

## CAREGIVER BENEFITS AND BURDENS

There is a growing recognition that patients and family caregivers exist within a social system that is intimately impacted by diagnosis, treatment, survivorship, and palliative care. Caregiver burden contributes to poorer social well-being and patient outcomes.<sup>23</sup> Caregiver burden has been defined as

the distress that caregivers feel as a result of providing care; this distress is different from depression, anxiety, and other emotional responses.<sup>24</sup>

Montgomery et al<sup>25</sup> describe three dimensions of caregiver burden. *Objective burden* is defined as the perceived infringement or disruption of tangible aspects of a caregiver's life. *Subjective demand burden* is defined as the extent to which the caregiver perceives care responsibilities to be overly demanding. Finally, *subjective stress burden* is the emotional impact of caregiving responsibilities on the caregiver.<sup>25</sup> Other factors that affect caregiver burden are patient characteristics, caregiver characteristics, and characteristics of the care situation.<sup>26</sup> Patient characteristics include diagnosis, treatment, advanced stages of disease, and increased number of care tasks.<sup>24,27</sup> Caregivers of patients receiving palliative care have been shown to have significantly higher burden than caregivers of patients receiving potentially curative treatments.<sup>23,26</sup>

Research suggests that the intensity and the relationship of the caregiver to the care recipient may result in caregiver burden. Providing care to an adult with cancer is a dynamic process. Consequently, perceived burden and social concerns differ across the phases of the patient's illness. There is evidence of psychological, occupational, and economic burdens associated with caregiving at the outset of life-limiting illness that increase as the patient's functional status declines and death approaches.<sup>28</sup>

Family caregiving often entails intense emotional burdens in dealing with patient depression and anxiety, which are common patient problems. Distress from caregiving may be expressed differently among people of different ethnic backgrounds and cultural beliefs.<sup>29</sup> Culture shapes the perceptions of familial responsibilities and consequently influences the way caregiver burden is perceived among ethnic minorities.

Conversely, there are well-established findings in the literature on the positive benefits of caregiving.<sup>30</sup> If adequately supported, family caregivers can succeed in meeting patient needs and caregiving can become a rewarding experience.<sup>30</sup> This experience can result in increased caregiver satisfaction throughout the trajectory of illness. Caregivers who feel well-prepared for their experience and have adequate resources to meet the patient's needs report emotional satisfaction and positive well-being related to being able to skillfully assist their loved one through a difficult experience. Successful caregiving can result in more intense relationships and reinforced social bonds.

## CAREGIVING ACROSS THE ILLNESS TRAJECTORY AND INTO BEREAVEMENT

Family caregivers face numerous challenges and opportunities for growth as their loved one's illness progresses along the illness trajectory and they seek to cope with and make meaning from the experience.<sup>31</sup> From the onset of the first symptoms, through the identification of an oncology diagnosis and the selection of treatment, family members typically accompany their loved one on an emotional roller coaster with implications for their QOL and social well-being. Increasing symptoms and physical concerns are often accompanied by feelings of fear and anxiety for both patients and their loved ones. As the illness progresses and treatment continues, it is not surprising that families find that adjusting to their role as a caregiver can impact every aspect of their life.

Caring for a loved one undergoing active treatment requires many adjustments in roles to sustain their ability as a caregiver over time. The chronic nature of caregiving requires a certain nimbleness to be successful. Caregivers who identify role models and feel that they have a robust system of support are the most likely to succeed in their role, while those who lack such support are at increased risk for difficulty.<sup>32</sup> For example, many caregivers report benefits from sharing care tips with others caregivers in busy clinic waiting rooms or from attending structured caregiver support groups or educational programs. These informal networks of support can supplement the isolation and alienation associated with chronic caregiving and can provide important opportunities for self-care. As the caregiver becomes a source of support of others, the caregiver benefits from increasing self-efficacy in their role.

If treatments are successful and the patient experiences remission or cure, caregivers may be surprised to find that their loved one's return to health requires a period of adjustment. Relinquishing "control" for another may be as challenging as adopting the role was in the beginning of treatment. Returning to work or school and re-engaging with social activities that had been put aside may be more difficult than had been anticipated.

Insights learned from the caregiving experience may have led to re-prioritizations and deeper introspection regarding what matters most in life. There are numerous examples of former caregivers volunteering in hospitals out of a desire "to give

back" in appreciation of the wonderful experience that they had while a loved one was ill. The relationships formed throughout treatment can become some of the most valued and intense of the former caregiver's life, and so it is perhaps not surprising that many will desire to maintain these nurturing bonds even after treatment ends.

Should the loved one's illness relapse or progress, the caregiving role typically intensifies, with resultant social life restrictions. Worsening illness is often associated with loss of function and increased need for caregiving and support. Loved ones who provided care earlier in the illness may find their reserves of energy are depleted and may need to rely on others to assist them in meeting the patient's needs for care and support. If there are adequate resources, care may be supplemented through formal networks (hiring additional assistance), but for many, limited resources will restrict opportunities for caregivers to obtain the additional services needed.

If the patient's illness continues to deteriorate, family caregivers may find that their ability to care for their loved one at home becomes overwhelming. The toll of chronic caregiving for those with advanced cancer may result in health complications for caregivers and may lead to placement of the patient in a skilled nursing facility. The needs of family caregivers with a loved one who is institutionalized require attention to assess for feelings of guilt or inadequacy.<sup>33</sup>

Progressive illness makes programs such as hospice become more valuable. Hospice provides not only expert assistance to meet symptom needs, but also provides a team of health care professionals who offer invaluable social support to beleaguered family caregivers. Visits from the hospice service ensure that social interactions continue even when patients and caregivers have become increasingly isolated because of the intensity of the illness. Importantly, hospice volunteers can provide respite for family caregivers to leave the home knowing that their loved one is well cared for while they take time for self-management.

Following the death of the patient, loved ones find themselves required to adjust to the loss of their role as caregivers. Depending on the nature of the relationship and the death experience, the caregiver may have difficulty transitioning from this role and be at risk for complicated bereavement.<sup>34</sup> If the experience of caring for a loved one was ultimately positive, personal growth can be reported.<sup>35</sup>

Exquisite attention to pain and symptom management at the end of life promotes adjustment to bereavement, while a traumatic or unexpected death is associated with an increased risk for complications within bereavement.

Bereaved caregivers may report that their experience in caring for their loved one was a high point in their life and offered opportunities for increased closeness and intimacy that heightened their bonds and was an experience that they will treasure for the rest of their lives. Conversely, if the experience was not perceived as being meaningful, the bereaved caregiver may voice regret and be at increased risk for symptoms of complicated grief. Ongoing assessment of the caregiver's experience is vital to allow opportunities to identify areas of potential regret and to minimize risk for complicated grief.

### **SOCIAL IMPLICATIONS FOR CAREGIVING**

Although parents typically accept that they will be caregivers for their children, the special circumstances associated with caring for a child with cancer create a very different dynamic, impacting everyone in the family setting.<sup>36</sup> The responsibilities associated with caring for a seriously ill child can take an enormous toll on the parents, grandparents, siblings, and friends – all of whom may be called into the caregiving role. Social implications of these converging roles can be significant. Parents may find that the sheer physical act of providing care can limit the energy that is available for sexual expression with their partners, time for leisure activities, and limit employment outside of the home. Each of these has social repercussions that influence QOL of family caregivers. There are social repercussions among the siblings of the ill child, with potential of resentment for the attention that the patient receives or the “extra” responsibilities that well children are asked to bear. There can even be feelings of guilt for one's own health when a brother or sister is so ill. Family roles are likely to be perceived as different from peers without an ill child, making the normal adolescent adjustments even more fraught with developmental challenges.

There are social implications for caregivers who are intimate partners as well. Providing care for a loved one outside of the norms of one's cohort offers its own set of challenges. Being the youngest one in the family waiting room, or the only one of your generation who seems to face these concerns may be especially difficult for the young adult

caregiver. Older persons may find challenges in caregiving, especially if they are members of the “sandwich generation,” with caregiving responsibilities for both older parents as well as for their own children, while still actively engaged in the workforce. More senior caregivers may find that their own health conditions limit the endurance and strength needed to provide sustained caregiving. Assessing for the specific developmental needs of caregivers is crucial to provide comprehensive care to these vulnerable populations.

### **Sexuality and Intimacy**

Illness changes a “partner” into a “patient,” with subsequent implications on body image and vulnerability for both the person with the illness and for those who will assist in caring for the patient. Some patients report taking enormous efforts to maintain privacy and independence from their sexual partners, while others welcome their partners into the role of caregiver. In a single patient support group facilitated by the author (S.O.), a woman with breast cancer reported that she had never allowed her spouse of 25 years to see her naked following her mastectomy some 3 years prior, while another woman spoke lovingly of how her spouse gently emptied her drains and provided wound care within hours of her surgery. Partners vary in their acceptance of the physical changes of illness and treatment, with some candidly reporting that they have a difficult time feeling aroused by a body that has so dramatically been altered by the illness experience, while others report feeling even more intensely close with a loved one who is perceived to have been in danger.

There are numerous resources<sup>37-39</sup> available for health care providers to assist patients and loved ones in navigating the challenges of maintaining sexual expression throughout advancing illness. Coping with normal fears of hurting a loved one who may seem more fragile following treatment and offering strategies to maintain sexual activity when fatigued can be especially beneficial.

### **Leisure Activities**

Illness takes a toll on the time and energy that caregivers have to pursue leisure activities.<sup>40</sup> Feelings of guilt or shame may also influence a caregiver's willingness to engage in pleasurable activities when a loved one is unable to do so because of illness. Although there is a growing literature<sup>41,42</sup> that emphasizes the importance of self-care for caregivers, family members may lack cultural and community support to take time away from their

caregiving responsibilities. Health care providers who offer specific suggestions regarding self-care strategies and who explicitly recommend continued engagement in leisure activities provide a powerful incentive for loved ones to consider the benefits of self-care to sustain their energies as a caregiver.

**Impact on Education and Employment**

It is not unusual for progressive illness to impact the employment not just of the person with cancer, but for their caregivers as well. As illness worsens, the sheer number of hours required to care for a loved one increases, resulting in less time for outside employment.<sup>43</sup> This has implications on each aspect of the patient and family’s QOL. Employment offers opportunities for social interaction and creates significant networks of support. As caregiving responsibilities increase, time at work can become compromised, with fewer opportunities to benefit from the support of work colleagues and friends.

This same phenomenon can be seen related to school. Caregivers who attend school may find that their social interactions are curtailed by their caregiving duties and eventually may need to cut back on their education or quit school altogether. The implications of this depend on the age and developmental stage of the caregiver. Not surprisingly, children and adolescents who report caregiving expectations limiting their time at school experience more impact than those who do not. Teenagers may feel embarrassed by their role as a caregiver, and limit their social interactions, eg, not wanting to invite friends to their home.

**Financial Burden**

Rising health care costs and inadequate insurance coverage result in a potentially devastating financial burden for many families as a result of a loved one’s illness.<sup>44</sup> Growing numbers of foreclosures and bankruptcies are attributable to the

**TABLE 1.**  
**Resources to Assist with Financial Concerns**

American Bar Association Commission on Law and Aging. (2009). *Legal Guide for the Seriously Ill: Seven Key Steps to Get Your Affairs in Order*. American Bar Association & National Hospice and Palliative Care Organization.

American Cancer Society. (2011, June 27). Medical Insurance and Financial Assistance for the Cancer Patient. Retrieved from <http://www.cancer.org/acs/groups/cid/documents/webcontent/002562-pdf.pdf>

American Cancer Society. (2002). *Coping Financially With the Loss of a Loved One*. National Endowment for Financial Education.

America’s Health Insurance Plans. (2004). *Guide to Long-Term Care Insurance*. Washington, DC: America’s Health Insurance Plans.

Brumley RD, Hillary K. (2002). *The TriCentral Palliative Care Program Toolkit*. Kaiser Permanente.

Centers for Medicare and Medicaid Services. (2011, September 20). Health insurance reform for consumers. Retrieved from <http://www.cms.hhs.gov/healthinsreformforconsume>

Dolan SR, Vizzard AR. (2009). *The End of Life Advisor: Personal, Legal, and Medical Considerations for a Peaceful Dignified Death*. New York, NY: Kaplan Publishing.

Dratch D. (2008, August 20). 16 ways to slash your insurance rates. Retrieved from <http://articles.moneycentral.msn.com/Insurance/InsureYourHealth/16waysToSlashYourInsuranceRates.aspx?page=2>

Harpham WS. (2003). *Diagnosis: Cancer. Your Guide to the First Months of Healthy Survivorship* (3rd ed.). New York, NY: W.W. Norton & Company.

Harwell A. (1995). *Ready to Live: Prepared to Die*. Wheaton, IL: Harold Shaw Publishers.

Hoffman B (editor.). (2004). *National Coalition for Cancer Survivorship. A Cancer Survivor’s Almanac: Charting Your Journey* (3<sup>rd</sup> ed.). Hoboken, NJ: John Wiley and Sons.

Hogan M. (2010). *Final Business: A Family Guide to Taking Care of Personal and Business Affairs Before and After the Death of a Loved One*. Ashland, OR: Sacred Vigil Press.

Information Strategies, Inc. (2007). 2007 HAS Primer For Employees/Individuals/Families. Retrieved from [http://www.4hsausers.com/pdf/HSA\\_Primer\\_Individual\\_2007.pdf](http://www.4hsausers.com/pdf/HSA_Primer_Individual_2007.pdf).

Landay DS. (1998). *Be Prepared: The Complete Financial, Legal and Practical Guide to Living with Cancer, HIV and Other Life-Challenging Conditions*. New York, NY: St. Martin’s Press.

Messner C, Vera V. (2011). Cancer and the Workplace. *The Oncology Nurse*, 4(6):24-26.

MSN Money. (2008, September 2). 9 keys to choosing the right health plan. Retrieved from: <http://articles.moneycentral.msn.com/Insurance/InsureYourHealth/9KeysToChoosingTheRightHealthPlan.aspx?page=1>.

Tolley DP. (2001). *Finding the Money: A Guide to Paying Your Medical Bills*. Bend, OR: Diane Pammenter Tolley.

US Department of Labor. (2004). The Health Insurance Portability and Accountability Act (HIPAA) Fact Sheet. Retrieved from <http://www.dol.gov/ebsa/newsroom/fshipaa.html>.

Weston LP. (2007, January 31). A survival guide for the uninsured. *MSN Money*. Retrieved from <http://articles.moneycentral.msn.com/Insurance/InsureYourHealth/AsurvivalGuideForTheUninsured.aspx>.

uncompensated cost of coping with a serious illness. In the United States, insurance is often tied to employment, and if advancing illness limits one's ability to work, one's insurance coverage is in jeopardy. This "Catch 22" is associated with a great deal of anxiety among families who face enormous challenges related to the cost of caring for an ill family member, with difficult decisions regarding whether to pay for rent, food, or medications.<sup>45</sup> Table 1 offers resources to assist families in addressing these economic issues. Close collaboration with social workers and financial counselors can be helpful for those with limited financial resources.

### INTERDISCIPLINARY TEAM APPROACH

Each member of the health care team has a responsibility to offer education and support to the patient and caregiver. Table 2 offers a listing

of national Web sites currently available to assist health professionals in identifying and addressing the social needs of caregivers. Dynamic communication among an interdisciplinary team increases the likelihood that patient and family caregiver needs will be identified before the problem escalates and causes additional suffering.

Because the multidimensional needs of a loved one's illness creates a plethora of potential concerns for family members, an interdisciplinary team approach to providing social care is vital.<sup>46,47</sup> Harnessing the skills of a collaborative team of professionals offers the greatest likelihood that the needs of caregivers will routinely be included in care planning. Nurses spend the greatest amount of time with patients and their families and therefore have an especially important role in identifying and addressing social needs. Sensitive medical assessments can recognize those at risk for experiencing the burdens of caregiving instead

**TABLE 2.**  
**Web sites to Enhance Quality of Life and Social Well-Being**

<p>Agency for Healthcare Research and Quality. <i>Health Insurance/Access to Care</i> - <a href="http://www.ahrq.gov/news/pubcat/c_hins.htm">http://www.ahrq.gov/news/pubcat/c_hins.htm</a>  American Cancer Society (ACS) - <a href="http://www.cancer.org">http://www.cancer.org</a>  Beyond the Cure - <a href="http://beyondthecure.org">http://beyondthecure.org</a>  Cancer Hope Network - <a href="http://www.cancerhopenetwork.org">http://www.cancerhopenetwork.org</a>  Cancer Legal Resource Center (CLRC) - <a href="http://www.disabilityrightslegalcenter.org">http://www.disabilityrightslegalcenter.org</a>  CaringBridge - <a href="http://www.caringbridge.org">http://www.caringbridge.org</a>  City of Hope Pain &amp; Palliative Care Resource Center - <a href="http://prc.coh.org">http://prc.coh.org</a>  Gilda's Club Worldwide - <a href="http://www.gildasclub.org">http://www.gildasclub.org</a>  Health Insurance Resource Center - <a href="http://www.healthinsurance.org/">http://www.healthinsurance.org/</a>  Job Accommodation Network - <a href="http://www.jan.wvu.edu">http://www.jan.wvu.edu</a>  Joe's House - <a href="http://www.joeshouse.org">http://www.joeshouse.org</a>  Last Acts Partnership - <a href="http://www.lastactspartnership.org">http://www.lastactspartnership.org</a>  Life and Health Insurance Foundation for Education - <a href="http://www.life-line.org">http://www.life-line.org</a>  LIVESTRONG Cancer Survivor's Health Journal - <a href="http://www.cancersupportcommunity.org/mm/Treatment-Ends/medicalmanagement/Journal.pdf">http://www.cancersupportcommunity.org/mm/Treatment-Ends/medicalmanagement/Journal.pdf</a>  LIVESTRONG Navigation Services - <a href="http://www.livestrong.org/get-help">http://www.livestrong.org/get-help</a>  National Association of Health Underwriters. <i>Consumer Guide to Group Health Insurance</i> - <a href="http://nahu.org/consumer/GroupInsurance.cfm">http://nahu.org/consumer/GroupInsurance.cfm</a>  National Coalition for Cancer Survivorship (NCCS) - <a href="http://www.canceradvocacy.org">http://www.canceradvocacy.org</a>  Personal Health Record - <a href="http://www.myphr.com">http://www.myphr.com</a>  The Ulman Cancer Fund for Young Adults - The Barbara Palo Foster Memorial Scholarship Award - <a href="http://www.ulmanfund.org/University-Outreach/College-Scholarship-Program/The-Barbara-Palo-Foster-Memorial-Scholarship-Award.aspx">http://www.ulmanfund.org/University-Outreach/College-Scholarship-Program/The-Barbara-Palo-Foster-Memorial-Scholarship-Award.aspx</a>  The Ulman Cancer Fund for Young Adults - The Marilyn Yetso Memorial Scholarship Award - <a href="http://www.ulmanfund.org/University-Outreach/College-Scholarship-Program/The-Marilyn-Yetso-Memorial-Scholarship-Award.aspx">http://www.ulmanfund.org/University-Outreach/College-Scholarship-Program/The-Marilyn-Yetso-Memorial-Scholarship-Award.aspx</a>  The Ulman Cancer Fund for Young Adults. The Vera Yip Memorial Scholarship Award - <a href="http://www.ulmanfund.org/University-Outreach/College-Scholarship-Program/The-Vera-Yip-Memorial-Scholarship-Award.aspx">http://www.ulmanfund.org/University-Outreach/College-Scholarship-Program/The-Vera-Yip-Memorial-Scholarship-Award.aspx</a>  The Wellness Community - <a href="http://www.thewellnesscommunity.org">http://www.thewellnesscommunity.org</a>  U.S. Equal Employment Opportunity Commission - <a href="http://www.eeoc.gov">http://www.eeoc.gov</a>  U.S. Department of Health and Human Services. <i>Office for Civil Rights – HIPAA, Medical Privacy - National Standards to Protect the Privacy of Personal Health Information</i> - <a href="http://www.hhs.gov/ocr/hipaa">http://www.hhs.gov/ocr/hipaa</a>  U.S. Institutes of Health – National Cancer Institute (NCI) - <a href="http://www.cancer.gov">http://www.cancer.gov</a>  Vital Options - <a href="http://www.vitaloptions.org">http://www.vitaloptions.org</a>  WebMD. <i>Choosing and Using a Health Plan</i> - <a href="http://www.webmd.com/healthy-aging/guide/choosing-using-health-plan">http://www.webmd.com/healthy-aging/guide/choosing-using-health-plan</a></p>
--

of the benefits. Social workers can offer deeper exploration into strengths and challenges, provide community resources, and develop targeted psycho-educational support services so necessary for increased social well-being. Chaplains can coordinate with community sources for social support within the family's spiritual community.

Integrating palliative care services early in the illness trajectory offers an opportunity for family needs to be assessed and anticipated.<sup>48</sup> Ensuring timely and effective family meetings are an important intervention to address caregiver concerns and should be made available at times of critical decision-making.<sup>49,50</sup> The family meeting may be the intervention most directly associated with addressing the social well-being of family caregivers in that it gathers relevant caregivers together to provide an opportunity for professionals and family members to identify concerns and address issues related to

care of the loved one. Earlier identification of family needs allows for customized interventions to address caregiver burden and promote benefit.

Comprehensive attention to the multidimensional impact of the illness on the QOL of each family member allows early recognition of the challenges and potential difficulties being faced by this particular family at this particular point in time. **Box 1** offers a composite caregiver narrative that highlights many social concerns and the positive impact that attention to social well-being can provide. The family meeting allows an opportunity to offer tailored psycho-educational support, identify appropriate referrals, and provide anticipatory guidance regarding next steps in the illness trajectory. Importantly, a family forum offers an opportunity to explore misconceptions, address misunderstandings identify priorities, and minimize regrets for the patient and caregivers and discuss goals of care.

### **Box 1.** **Caregiver Narrative: Mrs. G**

Mrs. G. is a 40-year-old Hispanic woman who has resided in Southern California for the past 20 years, having lived in Mexico before that time. She is married, has two school-aged girls, and is a stay-at-home mother. She is taking care of her 70-year-old mother who was recently diagnosed with advanced breast cancer. Although Mrs. G. has three sisters, she is her mother's primary caregiver. Mrs. G. accompanies her mother to all medical appointments and chemotherapy treatments. Because her mother speaks limited English, Mrs. G. often finds herself in the role of her mother's interpreter. She worries that she doesn't always fully understand what the health care team is asking of her mother and sometimes shares her concerns with the infusion nurse.

The nurse noticed that Mrs. G. has become more easily tearful and frequently sits in the clinic with her rosary on hand silently praying for her mother's recovery. In talking with her, she realized that Mrs. G.'s lifestyle has changed as a result of providing 24-hour care for her mother 7 days a week. The nurse recommended that Mrs. G. consider attending the hospital's caregiver support group.

The support group is co-facilitated by an oncology nurse and social worker. At the meeting, Mrs. G. shared what it has been like for her to manage the everyday work of caring for her mother in addition to her other responsibilities. Mrs. G. reports that her responsibilities include maintaining the household, cooking, cleaning, shopping, paying the bills, sorting out health insurance and Medicare forms, taking care of the children, keeping family members apprised of the patient's progress, and upholding the family's social obligations. She is also responsible for obtaining her mother's medications and ensuring that they are used appropriately, and despite her best attempts to care for her, is concerned that her mother's symptoms seem to be getting increasingly worse. Managing these many and varied obligations consumes most of Mrs. G.'s waking hours, interrupts her sleep, and robs her of her 'normal' daily work and social routines.

The co-facilitators offer to meet with Mrs. G. outside of the group to provide her with additional resources and support. They follow-up with her physician and encourage a referral to the hospital's palliative care team for a comprehensive pain and symptom management referral and encourage a 'goals of care' family conference with a certified medical interpreter present.

At a subsequent support group meeting, Mrs. G. reports that although her mother's status has continued to decline, her mother is markedly more comfortable. The family conference resulted in a referral to hospice and Mrs. G. tells the group that the entire family has benefited from the comprehensive care that has been provided. A chaplain has been especially valuable, and volunteers now come regularly to her home to offer respite services. The hospice nurse vigorously attends to her mother's symptom concerns and oversees her mother's medications. The hospice social worker meets regularly with her children and is helping Mrs. G. prepare them for their grandmother's continued decline. Mrs. G. says that her sisters also now have a better understanding of their mother's limited prognosis, and have been spending more time with the family.

Mrs. G. says that she is more confident in her ability to care for her mother and feels blessed to have this opportunity for her family to be together during this precious time. Mrs. G. is visibly relieved by the support that she is receiving and encourages others in the group to consider asking for support.



## RESEARCH IMPLICATIONS

Comparatively little research has been conducted to offer guidance regarding best practices as to how to meet the needs of family caregivers with insufficient resources, inadequate social support, and limited skills and knowledge regarding their caregiving role. More research is needed to provide guidance and information to assist health care professionals in supporting caregivers in their attempts to provide the best cancer care for their loved one. There is clear evidence that urgent interventions are needed to improve minority family caregiver outcomes and to support caregivers across the cancer trajectory. A recent meta-analysis of caregiver interventions in oncology conducted by Northouse and colleagues<sup>51</sup> found that only 16% of the study participants were self-identified as members of a minority group and only two studies were tailored for a particular ethnic group. The growing diversity of the population of the United States reflects the need for more caregiver research to address the needs of family caregivers from diverse cultural and multiethnic backgrounds to guide them through the caregiving cancer experience. It is also important to develop research studies that consider issues surrounding health literacy and low literacy in the development of caregiver interventions. Additionally, studies are needed that

address the ongoing under-treatment of pain for minority patients, which has tremendous social repercussions and lowers caregiver and patient QOL.

## CONCLUSION

Caregivers who fail to adequately care for themselves are at risk for diminished effectiveness in their role. Health care providers have an important opportunity to support family members as they transition into and out of their role as caregivers. Ultimately, with sufficient support and education, providing care for a vulnerable loved one can be viewed as a tremendously powerful life event that creates opportunities for meaningful memories that will be deeply treasured. The challenge for health care providers is to ensure that adequate resources are available to offer this level of support for all patients and caregivers.

## ACKNOWLEDGMENT

The authors gratefully acknowledge the family members who so lovingly have embraced their role as caregivers and have shared with us their insights, joys, and frustrations on this journey; and thank Licet Garcia for her generous assistance with this manuscript.

## REFERENCES

1. Adler N, Page A. Cancer care for the whole patient: meeting psychosocial health needs. Washington, DC: The National Academies Press; 2008.
2. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors. *Cancer* 2008;112(suppl 11):2556-2568.
3. Ayalong L. Cultural variants of caregiving or the culture of caregiving. *J Cult Divers* 2004;11:131-138.
4. Chiu L. Transcending breast cancer, transcending death: a Taiwanese population. *Nurs Sci Q* 2000;13:64-72.
5. Juarez G. Common English/Spanish terminology use in radiology. *J Radiol Nurs* 2011;30:9-14.
6. Otis-Green S. Working with cultural groups: some practical suggestions: an interview with Gloria Juarez and Virginia Sun. *Pain Pract* 2007;17:30-35.
7. Fisch MJ, Lee JW, Weiss M, et al. Prospective, observational study of pain and analgesic prescribing in medical oncology outpatients with breast, colorectal, lung, or prostate cancer. *J Clin Oncol* 2012;30:1980-1988.
8. Manne SL, Norton TR, Ostroff JS, et al. Protective buffering and psychological distress among couples coping with breast cancer: the moderating role of relationship satisfaction. *J Fam Psychol* 2007;21:380-388.
9. Northouse LL, Mood DW, Montie JE, et al. Living with prostate cancer: patients' and spouses' psychosocial status and quality of life. *J Clin Oncol* 2007;25:4171-4177.
10. Kim Y, Baker F, Spillers RL, et al. Psychological adjustment of cancer caregivers with multiple roles. *Psychooncology* 2006;15:795-804.
11. Chen ML, Chu L, Chen HC. Impact of cancer patients' quality of life on that spouse caregivers. *Support Care Cancer* 2004;12:469-475.
12. Northouse LL, Mood D, Kershaw T, et al. Quality of life of women with recurrent breast cancer and their family members. *J Clin Oncol* 2002;20:4050-4064.
13. Morris ME, Grant M, Lynch JC. Patient-reported family distress among long-term cancer survivors. *Cancer Nurs* 2007;30:1-8.
14. Juarez G. Perceptions of the caregiving experience and quality of life: Mexican/American caregivers providing care to adults with advanced cancer. *Dissertation Abstracts International* 2003;64(11B).
15. Deshields TL, Rihanek A, Potter P, et al. Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers. *Support Care Cancer* 2012;20:349-356.
16. Ruiz ME. Familismo and filial piety among Latino and Asian elders: reevaluating family and social support. *Hisp Health Care Int* 2007;5:81-89.
17. Phillips LR, Crist J. Social relationships among family caregivers: a cross-cultural comparison between Mexican

Americans and non-Hispanic White caregivers. *J Transcult Nurs* 2008;19:326-337.

18. Chadiha LA, Adams P, Biegel DE, et al. Empowering African American women informal caregivers: a literature synthesis and practice strategies. *Soc Work* 2004;49:97-108.

19. Lopez-Class M, Jurkowski J. The limits of self-management: community and health care system barriers among Latinos with diabetes. *J Hum Behav Soc Environ* 2010;20:808-826.

20. Juarez G, Ferrell B, Uman G, et al. Distress and quality of life concerns of family caregivers of patients undergoing palliative surgery. *Cancer Nurs* 2008;31:2-10.

21. Munoz C, Juarez G, Munoz ML, et al. The quality of life of patients with malignant gliomas and their caregivers. *Soc Work Health Care* 2008;47:455-478.

22. Given BA, Given CW, Sherwood PR. Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol* 2012;10:57-64.

23. Sales E. Family burden and quality of life. *Qual Life Res* 2003;1(suppl):33-41.

24. Given BA, Given CW, Kozachik S. Family support in advanced cancer. *CA Cancer J Clin* 2001;51:213-231.

25. Montgomery RV, Gonyea J, Hooyman N. Caregiving and the experience of subjective and objective burden. *Family Relation* 1985;34:19-26.

26. Sharpe L, Butow P, Smith C, et al. The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their careers. *Psychooncology* 2005;14:102-114.

27. Andrews SC. Caregiver burden and symptom distress in people with cancer receiving hospice care. *Oncol Nurs Forum* 2001;28:1469-1474.

28. Williams AL, McCorkle R. Cancer family caregivers during the palliative, hospice, and bereavement phases: a review of the descriptive psychosocial literature. *Palliat Support Care* 2011;9:315-325.

29. Cagle CS, Wells JN, Hollen ML, et al. Weaving theory and literature for understanding Mexican American cancer caregiving. *Hisp Health Care Int* 2007;5:149-161.

30. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002;17:184-188.

31. Borneman T, Brown-Saltzman K. Meaning in illness. In: Ferrell BR, Coyle N, eds. *Oxford textbook of palliative nursing*. 3rd Edition. New York, NY: Oxford University Press; 2010: pp. 673-683.

32. Palos GR, Mendoza TR, Liao KP, et al. Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. *Cancer* 2011;117:1070-1079.

33. Kolb PJ. Identifying and addressing family members' psychological, spiritual, and existential issues related to having a loved one living and dying in a nursing home. In: Bern-Klug M, ed. *Transforming palliative care in nursing home*. New York, NY: Columbia University Press; 2010: pp. 186-210.

34. Lichtenthal WG, Prigerson HG, Kissane DW. Bereavement: a special issue in oncology. In: Holland JC, Breitbart WS, Jacobsen PB, Lederberg MS, Loscalzo M, McCorkle R, eds. *Psycho-Oncology*. First edition. New York, NY: Oxford University Press; 2010: pp. 537-546.

35. Otis-Green S. Grief and bereavement care. In: Qualls SH, Kasl-Godley J, eds. *The Wiley series in clinical geropsychology*:

end-of-life issues, grief and bereavement: what clinicians need to know. First Edition. Hoboken, NJ: John Wiley and Sons; 2011: pp. 168-180.

36. Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. *Cancer Nurs* 2010;33:110-118.

37. Gallo-Silver L. Sexuality, sensuality and intimacy in palliative care. In: Altilio T, Otis-Green S, eds. *Oxford textbook of palliative social work*. First Edition. New York, NY: Oxford University Press; 2011: pp. 261-270.

38. Smith L. Sexual function of the gynecologic cancer survivor. *Oncology* 2010;24:41-44.

39. Matzo M. Sexuality. In: Ferrell BR, Coyle N, eds. *Oxford textbook of palliative nursing*. 3rd edition. New York, NY: Oxford University Press; 2010: pp. 477-486.

40. Miedema B, Hamilton R, Tatemichi S, et al. Do breast cancer survivors' post-surgery difficulties with recreational activities persist over time? *J Cancer Surviv* 2011;5:405-412.

41. Survivorship NCI. Cancer survival toolbox: module 2 communications. Silver Spring, MD: National Coalition for Cancer Survivorship; 2009. Available at: <http://www.canceradvocacy.org/toolbox/communicating/> (accessed October 1, 2012).

42. Marcusen C, Walsh-Burke K. Self-advocacy training for cancer survivors: the cancer survival toolbox. *Cancer Pract* 1998;7:297-301.

43. American Cancer Society. Advanced illness: financial guidance for cancer survivors and their families. Available at: <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acsq-020184.pdf> (accessed October 1, 2012).

44. American Society of Clinical Oncology. Cancer survivorship: next steps for patients and their families. Alexandria, VA: American Society of Clinical Oncology; 2011.

45. Nekhlyudov L, Madden J, Graves AJ, et al. Cost-related medication nonadherence and cost-saving strategies used by elderly Medicare cancer survivors. *J Cancer Surviv* 2011;5:395-404.

46. Altilio T, Otis-Green S, Dahlin CM. Applying the National Quality Forum Preferred Practices for Palliative and Hospice Care: a social work perspective. *J Soc Work End Life Palliat Care* 2008;4:3-16.

47. Stark D. Teamwork in palliative care: an integrative approach. In: Altilio T, Otis-Green S, eds. *Oxford textbook of palliative social work*. First edition. New York, NY: Oxford University Press; 2011: pp. 415-424.

48. Smith TJ, Temin S, Alesi ER, et al. American Society of Clinical Oncology provisional clinical opinion: the integration of palliative care into standard oncology care. *J Clin Oncol* 2012;30:880-887.

49. Fineberg IC, Bauer A. Families and family conferencing. In: Altilio T, Otis-Green S, eds. *Oxford textbook of palliative social work*. New York, NY: Oxford University Press; 2011: pp. 235-250.

50. Fineberg IC, Kawashima M, Asch SM. Communication with families facing life-threatening illness: a research-based model for family conferences. *J Palliat Med* 2011;14:421-427.

51. Northouse LL, Katapodi MC, Song L, et al. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 2010;60:317-339.