

Putting Evidence Into Practice[®]: Nursing Assessment and Interventions to Reduce Family Caregiver Strain and Burden

**Norissa J. Honea, RN, AOCN[®], CCRP,
RuthAnn Brintnall, PhD, AOCN[®], CHPN, APRN-BC,
Barbara Given, PhD, RN, FAAN, Paula Sherwood, PhD, RN, CNRN,
Deirdre B. Colao, RN, BSN, OCN[®], Susan C. Somers, BA, RN, BSN, OCN[®],
and Laurel L. Northouse, PhD, RN, FAAN**



Family caregiving often is associated with multiple rewards, yet the diversity and intensity of caregiving roles also can result in caregiver strain and burden. Using interventions to reduce the strain and burden on caregivers of patients with cancer is an important role nurses play. This article is a critical review and synthesis of the evidence regarding assessment tools and interventions aimed at reducing caregiver strain and burden in the oncology population. Although the striking finding is the limited number of interventions targeted toward oncology caregivers, suggestions from the literature are offered to support and promote healthy outcomes for family caregivers.

An interest in caregiver burden dates back to the 1950s (Townsend, 1957; Yin, Zhou, & Bashford, 2002). Although the caregiving role often is associated with multiple rewards (Picot, 1996), existing research now suggests that the diversity and intensity of caregiving roles also may result in caregiver strain and burden. Although difficult to define, caregiver strain and burden are terms used to describe what occurs when the emotional or physical health of caregivers is compromised or when the demands of care outweigh available resources (Given et al., 1992). Strain and burden, along with depression, are common in family caregivers and, if left untreated, can result in poor physical and mental health (Goode, Haley, Roth, & Ford, 1998). Because nurses spend a great deal of time with patients and families, they are in a unique position to assess caregiver strain and burden and to provide appropriate interventions. Among professional care providers, oncology nurses are ideally positioned to assist patients and their families to recognize and reduce the strain and burden of caregiving. Reducing caregiver strain and burden supports the mission of professional nursing through efforts to improve quality of life and other health outcomes for patients with cancer and their caregivers. This systematic review of the literature evaluates and synthesizes the existing assessment tools and evidence regarding caregiver strain and burden to make practice recommendations to help reduce those effects on caregivers of patients with cancer.

At a Glance

- ◆ Family caregiver strain and burden are common and can lead to poor health outcomes for caregivers if left unchecked.
- ◆ Caregiver strain and burden often are unrecognized.
- ◆ Education, support, psychotherapy, and respite interventions have demonstrated the greatest effect in reducing caregiver strain and burden.

Norissa J. Honea, RN, AOCN[®], CCRP, is a clinical research nurse at Arizona Oncology Services Foundation in Phoenix and a doctoral candidate in the College of Nursing at the University of Utah in Salt Lake City; RuthAnn Brintnall, PhD, AOCN[®], CHPN, APRN-BC, is an assistant professor in the Kirkhof School of Nursing at Grand Valley State University in Grand Rapids, MI; Barbara Given, PhD, RN, FAAN, is a university distinguished professor in the College of Nursing at Michigan State University in East Lansing; Paula Sherwood, PhD, RN, CNRN, is a research assistant professor in the School of Nursing at the University of Pittsburgh in Pennsylvania; Deirdre B. Colao, RN, BSN, OCN[®], is the director of the Thoracic Oncology Program at the Heart and Lung Institute at St. Joseph's Hospital and Medical Center in Phoenix; Susan C. Somers, BA, RN, BSN, OCN[®], is an oncology staff nurse at Spectrum Health Services in Grand Rapids; and Laurel L. Northouse, PhD, RN, FAAN, is the Mary Lou Willard French Professor of Nursing at the University of Michigan in Ann Arbor. No financial relationships to disclose. (Submitted September 2007. Accepted for publication November 19, 2007.)

Digital Object Identifier: 10.1188/08.CJON.507-516

Background

An estimated 1.4 million new cases of cancer will be diagnosed in 2008 (American Cancer Society, 2008), and many of those diagnosed with cancer will eventually require support or care from an informal caregiver. An informal caregiver is a person who is not paid and provides physical, emotional, financial, or other support to a patient with cancer. Women are caregivers more often than men, and more than one-third of those living with and providing routine care for patients are aged 55 or older (Alexih, Zeruld, & Olearczyk, 2001). Immediate family members serve as informal caregivers most often; however, other people who share a significant bond with the patient also may serve in caregiving roles (Sherwood et al., 2006). According to Arno (2006), the total value of uncompensated informal care in the United States is more than \$306 billion, more than two times the cost of nursing home services and home care. However, most care services by informal caregivers are not financially compensated (Arno). Because the anticipated need for caregivers is expected to grow as Americans live longer, a critical need exists to define and implement interventions that reduce caregiver strain and burden.

The complexity of caregiver roles often is variable and difficult to define. Caregiving for patients with cancer often requires multidimensional support that extends across physical, psychological, spiritual, and emotional domains. For example, caregiving may be solely limited to physical care, such as help with toileting or eating, or extend to multiple areas, such as providing intense 24-hour care, emotional support, or financial assistance. In an effort to fully appreciate possible burdens associated with caregiving, exploring other terms associated with the caregiving role is important. *Caregiver strain*, an evolving term, occurs when caregivers perceive difficulty performing roles or feel overwhelmed by their tasks (Archbold, Stewart, Greenlick, & Harvath, 1990). Other terms, such as *objective burden*, describe events or activities associated with the caregiving role. These activities include delivering practical physical care on a day-to-day basis or managing challenging behavioral changes in the patient. By contrast, *subjective caregiver burden* often is less apparent and describes emotional reactions of the caregiver to the caregiving role, such as worry, anxiety, frustration, or fatigue (Pinquart & Sorenson, 2003).

It is important to acknowledge the fact that health hazards are associated with caregiving and that they can lead to an increased risk of caregiver mortality (Beach, Schulz, Yee, & Jackson, 2000; Schulz & Beach, 2000; Vitaliano, Zhang, & Scanlan, 2003). Nurses need to recognize caregiver strain and burden and, in turn, implement effective interventions aimed at reducing them.

Methods

To develop an evidence-based approach to evaluating and relieving caregiver strain and burden, an Oncology Nursing Society (ONS) Putting Evidence Into Practice® (PEP) project team was formed. The team composition was based on guidelines developed by ONS and mirrored previous PEP teams. It consisted of one senior researcher and two advanced practice/staff nurse dyads. Other content-based expert researchers worked parallel

to the resource team to develop recommendations for research and practice that could be used by oncology nurses at various points of care.

Assessing Caregiver Burden

Measuring caregiver burden presents unique challenges to both clinicians and researchers. Several instruments have been developed to assess the burden of providing care to a family member with cancer (see Table 1). Clinicians and researchers should consider the information provided in Table 1 when choosing a tool for use. The instrument should measure multiple aspects of burden, have established reliability and validity in the oncology caregiver population, be easily obtained and scored, and be brief enough to prevent respondent and administrator burden. Once these criteria are satisfied, users must decide whether their measure of burden will be objective, subjective, or both.

An objective measurement of caregiver burden is comprised of variables, such as the number of hours that care is provided or the number of tasks the caregiver performs on behalf of the patient (Bookwala & Schulz, 2000; Gaugler et al., 2005). An advantage of objective measures is that they are less susceptible to response bias resulting from caregivers' feelings of distress (Porter et al., 2002). Objective measures often are short, are easily administered, and provide a straightforward way to identify tangible areas for intervention. In addition, using objective measures may be easier for caregivers than rating their own emotional responses to providing care. The primary disadvantage to using a strictly objective measure of caregiver burden is that the impact of providing care on the caregivers' lives is not assessed. Therefore, such measures provide an assessment of one component of caregiver burden that may not accurately represent the complexity of caregivers' distress and may overlook areas that cause the greatest distress.

Subjective measures of caregiver burden examine the degree of emotional distress that providing care has on the caregiver (Given et al., 1992; Robinson, 1983; Zarit, Reever, & Bach-Peterson, 1980). Subjective measures of burden may be considered more accurate representations of caregivers' emotional reactions to the impact of providing care, particularly in relationship to the development of depressive symptoms (Sherwood, Given, & von Eye, 2005). In addition, several researchers have suggested that objectively measured tasks do not lead to caregiver distress but, rather, it is the way in which caregivers perceive the bother associated with those tasks (Schulz & Beach, 2000). The researchers suggest that strictly objective measures of caregiver burden may not accurately identify caregivers at risk for negative consequences from providing care.

Limitations exist for using a strictly subjective measure of caregiver burden. Items on subjective measures may be more difficult for caregivers to answer and the instruments typically contain multiple items, which may increase their length and limit their clinical applicability. To improve clinical applicability, use of a brief screening tool or selected subscales of a longer instrument may be beneficial. Several instruments have been developed that concomitantly assess both subjective and objective burden (Portenoy et al., 1994; Stetz, 1987). The measures ask caregivers to indicate a patient issue or task with

Table 1. Caregiver Measurement Instruments and Administration

TOOL	SOURCE	DOMAINS OR FACTORS	NUMBER OF ITEMS	SCALING	SCORING	LANGUAGE
Zarit Burden Inventory	Zarit et al., 1980	Burden related to health, psychological well-being, finances, social life, and relationship with patient	22	Five grade ratings from 0 (never) to 4 (nearly always)	Items are summed to provide subscale scores.	English, Hebrew, Spanish, Japanese, Turkish, Spanish, French, Swedish, and Chinese
Caregiver Strain Index	Robinson, 1983	Burden related to employment, financial, physical, social, and time constraints	13	Yes or no	Items are summed to provide subscale scores and a total score.	English
Caregiver Reaction Assessment	Given et al., 1992; Stommel et al., 1992	Burden related to self-esteem, lack of family support, impact on finances, impact on schedule, and impact on health	24	Five grade ratings from 1 (strongly agree) to 5 (strongly disagree)	Items are summed to provide subscale scores.	English, Japanese, Thai, Dutch, Norwegian, and Korean
Memorial Symptom Assessment Scale	Portenoy et al., 1994	Burden related to frequency, severity, and distress of patient symptoms	24	Four grade ratings from 1 (rarely, slightly severe, no distress at all) to 4 (almost constantly, very severe, very much distress)	Items are summed to provide subscale scores in severity, frequency, and distress.	English
Caregiver Demands Scale	Stetz, 1987	Burden related to meals, intimate care, movement and comfort, medications and treatments, supervision, rest, and acquisition of new skills	46	Five grade ratings from 1 (not at all difficult) to 5 (extremely difficult)	Items are summed to provide total scores.	English
Appraisal of Caregiving Scale	Oberst et al., 1989	Burden related to harm/loss, threat, challenge, and benefit	72	Five grade ratings from 1 (very untrue) to 5 (very true)	Items are summed to provide subscale scores.	English

which they provided assistance and then ask caregivers to rate the amount of distress or degree of difficulty associated with that issue or task. The primary advantage of using such measures is that multiple aspects of burden can be assessed, which is important because objective and subjective levels of burden often change over time as a result of changes in care demands. The downside of using such measures is that they, too, can be cumbersome and difficult to complete in busy clinical settings.

Measuring caregiver burden in the clinical and research arena should ideally be done with a multidimensional, valid, reliable, and clinically relevant tool. Continuing to implement and evaluate how the measures perform is crucial in determining their applicability to caregivers of patients with cancer. Once a caregiver is assessed to have strain or burden, focus should be placed on applying interventions to reduce such effects.

Literature Review

To ensure optimal study retrieval related to caregiver strain and burden, multiple databases were searched, including Ovid's MEDLINE®, PubMed, PsycINFO, and the *Cumulative Index to Nursing and Allied Health Literature (CINAHL®)*. The search

was limited to studies of adult oncology populations published in English in peer-reviewed journals from 1995–2006. Key search terms included *caregivers*, *caregiving*, *family*, *spouse*, *burden*, *strain*, *cancer*, *oncology*, *intervention*, *randomized controlled trial*, and *review* or *meta-analysis*. Review or meta-analysis articles were included only if they covered oncology populations. Finally, to ensure a comprehensive search, a medical librarian was consulted and a manual search was performed to evaluate the reference lists of retrieved sources.

To begin the review process, the senior researcher guided the PEP team through several literature reviews using the Critical Appraisal Skills Program (CASP®, Public Health Resource Unit) evaluation guide adapted by Guyatt, Sackett, and Cook (1993, 1994). The CASP tool guided the team through a critical review of a study using specific criteria. Tables of evidence were created to identify key points of each study for consistency throughout the review (see tables posted at www.ons.org/outcomes/volume2/caregiver.shtml). The use of consistent and objective criteria added structure to the synthesis process and trustworthiness to conclusions for the team (Cooper, 1998).

Following each guided critique using the CASP tool, studies were ranked from level 1 to 8 by rigor of the evidence, with level

1 indicating optimal evidence (Ropka & Spencer-Cisek, 2001). To ensure clarity and consistency across topics, the assigned levels of evidence were validated with a leader/researcher dyad from another ONS PEP team who agreed with the team's analyses and conclusions.

Attention was then focused on rating the effectiveness of interventions in reducing caregiver burden. Accordingly, each intervention was given a weight of evidence to reflect its usefulness and value in making recommendations for practice (Mitchell & Friese, n.d.). Interventions were assigned to one of six weight-of-evidence categories, *recommended for practice, likely to be effective, benefits balanced with harms, effectiveness not established, effectiveness unlikely, or not recommended for practice* to be consistent with previous PEP resources (see Table 2).

Results

Interventions

Although caregiver burden carries considerable interest in the literature, a striking finding of this review was the limited number of studies addressing interventions for caregiver strain and burden in oncology. An extensive literature search yielded only 20 intervention studies and only eight specifically cited outcome measures for strain and burden. Of those, four studies were published from 1995–2000 and four were published from

2001–2006. In addition, two systematic reviews (Harding & Higginson, 2003; Pasacreta & McCorkle, 2000) and two meta-analyses (Martire, Lustig, Schulz, Miller, & Helgeson, 2004; Sorenson, Pinqart, & Duberstein, 2002) met study inclusion criteria. Both systematic reviews (22 and 29 studies, respectively) exclusively examined cancer and/or palliative care samples. However, 90% of the caregiver samples in the meta-analyses (70 and 78 studies, respectively) represented mixed samples of caregivers dealing with a variety of chronic illnesses, therefore limiting their use in the review. An effort was made to seek published guidelines; however, none was found.

To be consistent with previous research, the team used intervention categories and definitions (see Table 3) parallel to those established in the meta-analysis by Sorenson et al. (2002). This approach was established in consultation with expert researchers in an attempt to achieve optimal consistency in reporting. Categories reflected the focus of the intervention that was developed for caregivers and included psycho-educational, supportive, psychotherapy and/or cognitive behavioral, massage or healing touch, multicomponent, respite or adult day care, and interventions to improve recipient competence.

Psycho-educational: Psycho-educational interventions in this review described structured programs of information for caregivers. A psycho-educational intervention might provide information about a patient's disease process or delineate available resources, services, or training that might assist caregivers. Some psycho-educational interventions were individual

Table 2. Putting Evidence Into Practice® Weight-of-Evidence Classification Schema

WEIGHT-OF-EVIDENCE CATEGORY	DESCRIPTION	EXAMPLES
Recommended for practice	Effectiveness is demonstrated by strong evidence from rigorously designed studies, meta-analyses, or systematic reviews. Expected benefit exceeds expected harms.	At least two multisite, well-conducted, randomized, controlled trials (RCTs) with at least 100 subjects Panel of expert recommendation derived from explicit literature search strategy; includes thorough analysis, quality rating, and synthesis of evidence
Likely to be effective	Effectiveness has been demonstrated by supportive evidence from a single rigorously conducted controlled trial, consistent supportive evidence from well-designed controlled trials using small samples, or guidelines developed from evidence and supported by expert opinion.	One well-conducted RCT with fewer than 100 patients or at one or more study sites Guidelines developed by consensus or expert opinion without synthesis or quality rating
Benefits balanced with harms	Clinicians and patients should weigh the beneficial and harmful effects according to individual circumstances and priorities.	RCTs, meta-analyses, or systematic reviews with documented adverse effects in certain populations
Effectiveness not established	Data currently are insufficient or are of inadequate quality.	Well-conducted case control study or poorly controlled RCT Conflicting evidence or statistically insignificant results
Effectiveness unlikely	Lack of effectiveness is less well established than those listed under not recommended for practice.	Single RCT with at least 100 subjects that showed no benefit No benefit and unacceptable toxicities found in observational or experimental studies
Not recommended for practice	Ineffectiveness or harm clearly is demonstrated, or cost or burden exceeds potential benefit.	No benefit or excess costs or burden from at least two multisite, well-conducted RCTs with at least 100 subjects Discouraged by expert recommendation derived from explicit literature search strategy; includes thorough analysis, quality rating, and synthesis of evidence

Note. Based on information from Mitchell & Friese, n.d.

Table 3. Interventions to Reduce Family Caregiver Strain and Burden

INTERVENTION	DESCRIPTION
Psycho-educational	Uses a structured program geared toward providing information about the patient's disease process, available resources and services, and training for caregivers so they can effectively respond to disease-related issues in individual ^a or group formats. In the group format, a trained leader lectures, encourages group discussions, and provides written materials. Support may be a part of a psychoeducational group, but it is secondary to the educational content.
Supportive	Supportive interventions can be offered in an individual ^a or group format and led by either a professional or a peer. Focus is placed on building rapport and creating opportunity in which to discuss issues, successes, and feelings regarding caregiving. Supportive interventions may include teaching problem-solving skills and how to use them to meet care demands.
Psychotherapy	A therapeutic relationship between the caregiver and a trained professional is created. The caregiver identifies strategies for managing distress.
Cognitive behavioral	Teaches self-monitoring; challenges negative thoughts and assumptions that maintain the caregiver's difficult behavior; helps caregivers develop problem-solving abilities by focusing on time management, overload, and emotional reactivity management; and helps the caregiver reengage in pleasant activities and positive experiences
Massage	Involves the therapeutic manipulation of the soft tissues of the body by various hand movements (e.g., rubbing, kneading, pressing, rolling, etc.) to induce relaxation
Healing touch	Biofield therapy consists of a group of noninvasive techniques that make use of the hands to clear, energize, and balance the human and environmental energy fields.
Respite or adult day care	Includes in-home or site-specific supervision, assistance with activities of daily living, or skilled nursing care designed to give the caregiver time off
Multicomponent	Interventions include various combinations of educational, supportive, psychotherapy, and respite approaches.
Interventions to improve recipient competence	Interventions are directed to the patient and include memory clinics for patient competence, particularly those with dementia, and activity therapy programs designed to improve everyday competence.

^a Based on information from McMillan et al., 2006

Note. From "How Effective Are Interventions With Caregivers?" by S. Sorenson, M. Pinquart, and P. Duberstein, 2002, *Gerontologist*, 42(3), pp. 357–358. Copyright 2002 by the Gerontological Society of America. Adapted with permission.

(McMillan et al., 2006) and others were offered in a group format (Sorenson et al., 2002). Within a group format, a trained leader may lecture, encourage group discussions, or provide written materials. Support may or may not be a part of a psycho-educational intervention. Most interventions reported in the review were psycho-educational strategies. In fact, seven of the eight studies found employed psycho-educational approaches (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Harding et al., 2004; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Keefe et al., 2005; McMillan et al.; Pasacreta, Barg, Nuamah, & McCorkle, 2000; Toseland, Blanchard, & McCallion, 1995). Psycho-educational interventions from these studies include

- Teaching symptom management
- Discussing psychosocial issues
- Identifying resources
- Discussing coordination of services
- Teaching caregiver self-care.

Supportive: Supportive interventions aimed at caregivers were offered in individual or group formats and were led by a professional or a peer (McMillan et al., 2006; Sorenson et al., 2002). Supportive interventions focused on building rapport and creating an opportunity and forum to discuss difficulties, successes, and feelings regarding caregiving. Conclusions from the meta-analysis by Sorenson et al. suggest that supportive interventions were effective in reducing caregiver burden among

caregivers from heterogeneous chronic illness populations (e.g., patients with dementia, elderly patients with physical or mental disabilities, those suffering from stroke or cancer). Supportive interventions (Sorenson et al., 2002) from these studies

- Allowed participants in group settings to provide mutual support to one another
- Provided opportunities to share ways to deal with caregiving difficulties
- Identified strategies to incorporate these ideas into care.

Psychotherapy and cognitive behavioral: Psychotherapy and cognitive behavioral approaches for caregivers facilitate the development of a therapeutic relationship between the caregiver and a trained professional. The professional therapist helps the caregiver identify strategies to manage personal distress, whereas, in cognitive behavioral approaches, caregivers are taught to develop self-monitoring skills. Sorenson et al. (2002) concluded that these types of interventions are likely to reduce caregiver burden. Examples include

- Challenging negative thoughts or assumptions that encourage difficult behaviors
- Using strategies that help develop problem-solving abilities
- Focusing on time management, work overload, or emotional reactivity management
- Encouraging caregivers to re-engage in pleasant activities and positive experiences.

Massage or healing touch: One study examined the benefit of massage therapy or healing touch on caregivers of patients with cancer in an outpatient clinic. The massage and healing interventions were delivered by a certified therapist but failed to demonstrate effectiveness in reducing caregiver strain and burden. However, a significant decline was observed in the depression and anxiety scores of caregivers in the treatment group receiving massage therapy (Rexilius, Mundt, Erickson Megel, & Agrawal, 2002).

Respite or adult day care: Interventions that made use of respite or adult day care were designed to give caregivers important time away from caregiver demands, such as the activities of daily living, supervision, or more skilled nursing care. The benefit of adult day care in variable settings was examined in a multicomponent meta-analysis by Sorenson et al. (2002). In the analysis, 13 of 78 studies described some component of respite care. Because populations in the analysis were not limited to patients with cancer, the benefit of respite care for patients with cancer was not established, although some preliminary results suggest that respite care may indeed reduce caregiver strain and burden in the oncology population (Sorenson et al.).

Multicomponent: Multicomponent interventions for caregivers incorporate various combinations of psycho-educational, supportive, psychotherapy, and respite interventions (Sorenson et al., 2002). These interventions are likely to be most effective at reducing caregiver strain and burden because they use a variety of techniques to address the caregivers' needs. Multicomponent interventions in two meta-analyses had a moderate effect on reducing caregiver burden, whereas when interventions focused on a single therapeutic activity, such as supportive interventions (e.g., support groups) or psycho-educational interventions, only a small burden reduction was realized (Martire et al., 2004; Sorenson et al.).

The effects of the Coping With Cancer Program (Toseland et al., 1995) were compared to standard care in helping spouses cope with the stress of caring for a partner with cancer. Six individual, one-hour sessions were delivered by an oncology social worker focused on support, problem-solving, and coping skills. No significant difference in caregiver burden was found between caregivers who received the intervention and caregivers who received standard care. However, for caregivers who reported high levels of burden at baseline, the intervention led to significant improvements in their ability to cope with pressing issues.

Interventions to improve recipient competence: Interventions aimed at improving recipient competence included interventions such as memory clinics for those with dementia or activity therapy programs designed to improve affect and daily competence. One meta-analysis (Martire et al., 2004) of five randomized, controlled trials in dementia populations found no effect from this type of intervention on caregiver burden; therefore, the value to patients with cancer is uncertain.

Discussion and Recommendations

Nurse clinicians often intuitively assess for and use many of the previously described interventions to reduce caregiver strain or burden. The lack of evidence demonstrating the

effectiveness of such interventions for oncology caregivers is disappointing. Perhaps the way caregiver strain or burden was assessed (i.e., how it was measured in the tool) played a role in this. The tool may not have captured or may not given a true reflection of caregiver strain and burden. Strain and burden are only two of a host of caregiver outcomes. As such, caregiver strain and burden may be less amenable to intervention because of their multidimensional nature.

Although no intervention can be *recommended for nursing practice* as an evidence-based strategy to reduce strain and burden in caregivers of patients with cancer, nurses should not be deterred from employing interventions as caregiver research progresses. Although interventions in the *likely to be effective* category (psycho-educational, psychotherapy, supportive) had only a small effect on reducing caregiver burden in cancer populations, the interventions can be used across settings and can be applied with individuals or groups. When personal interventions are not available or possible, telephone conversations, tape-recorded information, or printed materials can be made available. Nurses also are encouraged to employ these interventions with family caregivers because they may have other positive effects, such as less anxiety, greater knowledge, self-efficacy, and confidence in performing caregiving roles (Ferrell et al., 1995; Pasacreta et al., 2000; Rexilius et al., 2002). Nurses can further assist caregivers by

- Encouraging them to challenge negative thoughts
- Engaging in pleasant and positive activities
- Developing problem-solving abilities that focus on time management, role overload, and emotional control
- Incorporating problem-solving and coping skills into day-to-day care demands.

Certain interventions may benefit some caregivers more than others. Multicomponent interventions may be most valuable for caregivers who report greater burden. Multicomponent interventions are more likely to be effective at reducing burden when they are directed to caregivers who are older, are female, and report greater subjective burden (Sorenson et al., 2002; Toseland et al., 1995). Additionally, the interventions are more likely to be effective when offered to individual caregivers rather than to a group. Interventions offered to spouses alone or to a combination of family members are effective in reducing caregiver burden. Furthermore, including the patient in the caregiver intervention does not change the effectiveness of the intervention (Martire et al., 2004). Overall, interventions have a stronger effect in reducing burden when relationship issues between patients and caregivers are addressed (Martire et al.).

Both systematic reviews in the current synthesis (Harding & Higginson, 2003; Pasacreta & McCorkle, 2000) exclusively examined studies of caregivers in oncology or palliative care populations. However, most study designs were qualitative, descriptive, cross-sectional, or nonexperimental designs; as such, many of the interventions proposed (e.g., competence, support, respite or adult day care) were listed as *effectiveness not established* until further evidence can be obtained with randomized clinical trials. Despite the fact that some of the interventions studied had positive psychosocial outcomes, they could not document a reduction in caregiver burden. Therefore, those particular strategies require further testing before effec-

tiveness can be established in reducing caregiver burden. Lastly, interventions not found to have an effect on reducing caregiver burden were listed as *effectiveness unlikely*.

Several studies examined interventions for which insufficient data or data of inadequate strength was noted. The studies often were limited by small sample size and/or attrition of subjects (i.e., in palliative care). It is unknown whether increasing the amount of intervention, allowing more time for caregivers to practice new skills, or using resources after an intervention would change the outcome (Keefe et al., 2003). Therefore, the effectiveness of the interventions in reducing caregiver strain and burden could not be established and, as reported, they could not be weighted as *recommended for practice*. These strategies may still be used by caregivers. Potentially valuable interventions include strategies that teach caregivers about pain and other symptoms; discuss psychosocial issues; employ massage or healing touch; teach caregiver competence; and identify resources and coordinate existing care, including respite or adult day care. Looking at other populations, such as caregivers of patients with dementia, may reveal interventions that have been tried and found to be successful.

Only two oncology studies in the current review showed *effectiveness likely*; one in hospice (McMillan et al., 2006), and one in caregivers reporting greater subjective burden (Toseland et al., 1995). Most of the other studies were not able to establish the effectiveness in reducing caregiver burden; therefore, those interventions were categorized as *likely to be effective* and *not established* at this time. Other meta-analyses of caregivers of patients with chronic illness exist and there may be some information missing from this review because the search criteria was limited to caregivers of patients with cancer.

Conclusion

Caregivers of patients with cancer often face substantial challenges in their caregiving roles, despite a paucity of evidence-based interventions that can be endorsed for practice. Therefore, nurses should continue their efforts to explore and test interventions targeted at reducing strain or burden in caregivers. Measurement tools that screen for caregiver burden must be thoughtfully considered and refined and demonstrate sensitivity to objective and subjective burden (distress) in the caregiver. More research needs to be done, particularly in the oncology population. Defining the mediators to caregiver strain and burden may better explain the effect of interventions on the outcomes of strain and burden. Until evidence-based interventions are unveiled, clinicians should make recommendations based on the limited evidence presented in this review to reduce caregiver strain and burden. Interventions without strong evidence may still be useful and can be recommended for caregivers. Other benefits to caregivers, such as enhanced caregiver self-efficacy, self-esteem, and greater confidence in the caregiver role, were demonstrated with certain interventions and may be valuable for other caregivers. Time and study will determine whether the interventions ultimately reduce caregiver strain and burden in the oncology setting.

The authors gratefully acknowledge the expert reviewers of the caregiver strain and burden PEP resources and cards. Their

critique and suggestions helped make this project a success. We also would like to thank the ONS staff for their guidance and assistance as the project took form.

Author Contact: Norissa J. Honea, RN, AOCN®, CCRP, can be reached at norissa@azoncology.com, with copy to editor at CJONEditor@ons.org.

References

- Alecxih, L.M., Zeruld, S., & Olearczyk, B. (2001). *Characteristics of caregivers based on the survey of income and program participation*. Retrieved September 5, 2007, from <http://www.lewin.com/NR/rdonlyres/249B1D52-EFCC-48D8-B9C7-86BB4A34E0C9/0/jan2001caregivers.pdf>
- American Cancer Society. (2008). *Cancer facts and figures 2008*. Atlanta, GA: Author.
- Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health, 13*(6), 375-384.
- Arno, P.S. (2006). *Economic value and informal caregiving*. Paper presented at the Care Coordination and Caregiving Forum, Department of Veterans Affairs, Bethesda, MD.
- Beach, S.R., Schulz, R., Yee, J.L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15*(2), 259-271.
- Bookwala, J., & Schulz, R. (2000). A comparison of primary stressors, secondary stressors, and depressive symptoms between elderly caregiving husbands and wives. *Psychology and Aging, 15*(4), 607-616.
- Cooper, H. (1998). *Synthesizing research* (3rd ed.). Thousand Oaks, CA: Sage.
- Ferrell, B., Grant, M., Chan, J., Ahn, C., & Ferrell, B. (1995). The impact of cancer pain education on family caregivers of elderly patients. *Oncology Nursing Forum, 22*(8), 1211-1218.
- Gaugler, J.E., Hanna, N., Linder, J., Given, C.W., Tolbert, V., Kataria, R., et al. (2005). Cancer caregiving and subjective stress: A multi-site, multi-dimensional analysis. *Psycho-Oncology, 14*(9), 771-785.
- Given, C., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing and Health, 15*(4), 271-283.
- Goode, K.T., Haley, W.E., Roth, D.L., & Ford, G.R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology, 17*(2), 190-198.
- Guyatt, G.H., Sackett, D.L., & Cook, D.J. (1993). Users guide to medical literature. *JAMA, 270*(21), 2598-2601.
- Guyatt, G.H., Sackett, D.L., & Cook, D.J. (1994). How to use an article about therapy or prevention. *JAMA, 271*(1), 59-63.
- Harding, R., & Higginson, I.J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine, 17*(1), 63-74.
- Harding, R., Higginson, I.J., Leam, C., Donaldson, N., Pearce, A., George, R., et al. (2004). Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service. *Journal of Pain and Symptom Management, 27*(5), 396-408.
- Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychosocial status. *Image—Journal of Nursing Scholarship, 31*(2), 115-120.

- Keefe, F.J., Ahles, T.A., Sutton, L., Dalton, J., Baucom, D., Pope, M.S., et al. (2005). Partner-guided cancer pain management at the end of life: A preliminary study. *Journal of Pain and Symptom Management, 29*(3), 263-272.
- Martire, L.M., Lustig, A.P., Schulz, R., Miller, G.E., & Helgeson, V.S. (2004). Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology, 23*(6), 599-611.
- McMillan, S., Small, B., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L., et al. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer, 106*(1), 214-222.
- Mitchell, S.A., & Friese, C.R. (n.d.). Weight of evidence. Retrieved September 6, 2007, from <http://www.ons.org/outcomes/tables/sleep/woe.shtml>
- Oberst, M., Thomas, S., Gass, K., & Ward, S. (1989). Caregiving demands and appraisal of stress among family caregivers. *Cancer Nursing, 12*(4), 209-215.
- Pasacreta, J.V., Barg, F., Nuamah, I., & McCorkle, R. (2000). Participant characteristics before and 4 months after attendance at a family caregiver cancer education program. *Cancer Nursing, 23*(4), 295-303.
- Pasacreta, J.V., & McCorkle, R. (2000). Cancer care: Impact of interventions on caregiver outcomes. *Annual Review of Nursing Research, 18*, 127-148.
- Picot, S.J. (1996). Family care givers. Windows into their worlds. *Reflections, 22*(4), 13-14.
- Pinquart, M., & Sorenson, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 58*(2), P112-P128.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Coyle, N., et al. (1994). Symptom prevalence, characteristics and distress in a cancer population. *Quality of Life Research, 3*(3), 183-189.
- Porter, L., Keefe, F., McBride, C., Pollak, K., Fish, L., & Garst, J. (2002). Perceptions of patients' self-efficacy for managing pain and lung cancer symptoms: Correspondence between patients and family caregivers. *Pain, 98*(1-2), 169-178.
- Rexilius, S.J., Mundt, C., Erickson Megel, M., & Agrawal, S. (2002). Therapeutic effects of massage therapy and healing touch on caregivers of patients undergoing autologous hematopoietic stem cell transplant [Online exclusive]. *Oncology Nursing Forum, 29*(3), E35-E44. Retrieved April 15, 2008, from <http://ons.meta.press.com/context/n32p3381648866h8/fulltext.pdf>
- Robinson, B. (1983). Validation of a Caregiver Strain Index. *Journals of Gerontology, 38*(3), 344-348.
- Ropka, M.E., & Spencer-Cisek, P. (2001). PRISM: Priority Symptom Management Project phase I: Assessment. *Oncology Nursing Forum, 28*(10), 1585-1594.
- Schulz, R., & Beach, S.R. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging, 15*(4), 607-616.
- Sherwood, P.R., Given, B.A., Given, C.W., Schiffman, R.F., Murman, D.L., Lovely, M., et al. (2006). Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Research in Nursing and Health, 29*(2), 105-120.
- Sherwood, P.R., Given, C.W., Given, B.A., & von Eye, A. (2005). Caregiver burden and depressive symptoms: Analysis of common outcomes in caregivers of elderly patients. *Journal of Aging and Health, 17*(2), 125-147.
- Sorenson, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist, 42*(3), 356-372.
- Stetz, K. (1987). Caregiving demands during advanced cancer: The spouse's needs. *Cancer Nursing, 10*(5), 260-268.
- Stommel, M., Wang, S., Given, C., & Given, B. (1992). Confirmatory factor analysis (CFA) as a method to assess measurement equivalence. *Research in Nursing and Health, 15*(5), 399-405.
- Toseland, R., Blanchard, C., & McCallion, P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science and Medicine, 40*(4), 517-528.
- Townsend, P. (1957). *The family life of old people: An inquiry in East London*. London, England: Eoutledge and Kegan Paul.
- Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*(6), 946-972.
- Yin, T., Zhou, Q., & Bashford, C. (2002). Burden on family members: Caring for frail elderly: A meta-analysis of interventions. *Nursing Research, 51*(3), 199-208.
- Zarit, S., Reever, K., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist, 20*(6), 649-655.

Receive free continuing nursing education credit for reading this article and taking a brief quiz online. To access the test for this and other articles, visit www.cjon.org, select "CE from CJON," and choose the test(s) you would like to take. You will be prompted to enter your Oncology Nursing Society profile username and password.

Put Evidence Into Practice

The Putting Evidence Into Practice® (PEP) resource card for caregiver strain and burden appears on the following pages. For more information about evidence-based interventions for caregiver strain and burden, including different versions of the card, definitions, evidence tables, and a complete list of references, visit www.ons.org/outcomes/volume2/caregiver.shtml. PEP resources for several other nursing-sensitive patient outcomes are available at www.ons.org/outcomes.

The *Clinical Journal of Oncology Nursing* wants to hear how you use the PEP resources to improve the quality of cancer care that you deliver. E-mail CJONEditor@ons.org to share your experiences with nurses everywhere.

Appendix. Putting Evidence Into Practice® Card on Caregiver Strain and Burden

What can nurses do to assist family caregivers of patients with cancer to reduce strain and burden?

RECOMMENDED FOR PRACTICE

Interventions for which effectiveness has been demonstrated by strong evidence from rigorously conducted studies, meta-analyses, or systematic reviews and for which expectation of harms is small compared with the benefits.

No intervention can be recommended for nursing practice as of September 30, 2006.

LIKELY TO BE EFFECTIVE

Interventions for which effectiveness has been demonstrated by supportive evidence from a single rigorously conducted controlled trial, consistent supportive evidence from well-designed controlled trials using small samples, or guidelines developed from evidence and supported by expert opinion.

Research in the area of caregiver burden has focused primarily on other chronic illness populations (e.g., dementia) rather than cancer populations (fewer than 10% of studies). Because of this, several interventions are listed as *likely to be effective* rather than *recommended for practice* at this time.

Psycho-Educational Interventions

Psycho-educational interventions involve structured programs that provide education to caregivers delivered in either an individual¹ or group format.² Groups are commonly led by a trained leader and may include lectures, group discussions, and written materials. Content in the psycho-educational interventions may include

- The patient's disease process
- Information about resources and services
- Training for caregivers to respond effectively to disease-related difficulties.

Support (which includes facilitating discussion of feelings about caregiving) may be a part of a psycho-educational intervention, but it is secondary to the educational content.²

Psycho-educational interventions are likely to be effective at reducing caregiver strain and burden, particularly when they

- Occur in multiple sessions over time^{1,2}
- Teach problem-solving skills¹⁻³
- Include patient symptom assessment and management¹
- Teach coping skills³
- Are directed to caregivers with greater burden.³

Psychotherapy Interventions

Psychotherapy involves a therapeutic relationship between the caregiver and a trained professional (special training is required) in which the caregiver identifies strategies to manage his or her distress. The conclusions from one meta-analysis point to psychotherapy interventions as likely to be effective in reducing caregiver burden.² This may include

- Teaching caregivers to monitor their own feelings
- Helping caregivers challenge negative thoughts that may create issues for them

- Helping caregivers develop problem-solving abilities by focusing on time management, role overload, and emotion management
- Helping caregivers engage in pleasant activities and positive experiences.

Supportive Interventions

Supportive interventions can be offered in an individual or group format led by either a professional or peer.^{1,2} These interventions focus on building rapport and creating opportunities in which to discuss issues as well as successes and feelings regarding caregiving. Findings from one meta-analysis indicate that supportive interventions are likely to be effective in reducing caregiver burden.² Supportive interventions that are likely to be effective include

- Teaching caregivers problem-solving skills
- Teaching caregivers coping skills.

Multicomponent Interventions

Multicomponent interventions use various combinations of competence, supportive, psychotherapy, respite or adult day care, and miscellaneous interventions.² These interventions are likely to be effective because they use a variety of techniques to reduce burden and are able to address a variety of caregiver needs. Multicomponent interventions also have a moderate effect on reducing caregiver burden, whereas interventions that focus on a single therapeutic activity, such as supportive interventions (e.g., support groups) and psychoeducational interventions, only have a small effect.^{2,4}

Specific situations exist in which multicomponent interventions are more likely to reduce caregiver burden. Greater reduction in burden may be seen when the intervention is directed or offered

- To older caregivers rather than to younger caregivers²
- To caregivers of older rather than younger patients²
- To female caregivers rather than to male caregivers²
- To caregivers who report greater subjective burden than to caregivers with less subjective burden^{2,3}
- To individual caregivers rather than to caregivers in a group setting²
- To spouses alone or to a combination of family members⁴
- To both patients and families' members or to family members alone⁴
- When relationship issues between patients and caregivers are addressed.⁴

EFFECTIVENESS NOT ESTABLISHED

Interventions for which there currently are insufficient or conflicting data or data of inadequate quality, with no clear indication of harm.

Discussing Psychosocial Issues

A nonrandomized, multiple-site trial examined a formalized intervention program, the Family Caregiver Cancer Education Program, which included strategies such as controlling symptoms, managing psychosocial issues, and identifying available resources. No overall improvement in caregiver burden was observed. However, the impact of caregiving on household finances and caregiver knowledge showed significant improvement, and caregivers perceived an improvement in their health.⁵ A second study explored informal short-term teaching and group support sessions aimed at self-care promotion for adult caregivers and found no significant difference in caregiver burden.⁶

Identifying Available Resources and Discussing Coordination of Services

Three studies⁵⁻⁷ used multicomponent interventions to examine the benefit of educational sessions on coping skills and on caregivers' ability to identify supportive resources. No significant difference was seen on outcome measures, suggesting that the interventions are not effective in reducing caregiver burden or strain. However, caregivers in one study reported feeling more confident in their ability to handle the caregiver role following the educational sessions.⁵

Massage or Healing Touch Interventions

One quasi-experimental study examined the benefit of massage therapy or healing touch on caregivers of patients with cancer.⁸ The intervention was not effective in reducing caregiver burden or strain. However, a significant decline was observed in depression and anxiety scores of caregivers in the treatment group receiving massage therapy.⁸

Respite or Adult Day Care Interventions

The benefit of respite or adult day care was examined in a multicomponent meta-analysis.² Preliminary results suggest that respite care may reduce caregiver burden and strain. However, as study populations were not limited to oncology, the benefit for caregivers of patients with cancer was not established.

Teaching Caregiver Self-Care

One randomized trial⁷ and one nonrandomized study⁵ taught self-care behaviors to caregivers. One of the studies also addressed common emotional reactions to caregiving, such as depression or anger.⁵ No difference in caregiver strain or burden was observed in either study, but other benefits, such as increased caregiver self-esteem and perceived competence, were reported.⁵

Teaching Pain Management

Two studies tested the impact of one-on-one pain management education on cancer caregivers' feelings of efficacy and reported subjective burden and strain. One study⁹ showed a trend in improvement for reported levels of caregiver strain, whereas the other¹⁰ reported that education improved caregivers' attitudes about pain management and about their ability to handle the patient's pain but led to no measurable change in caregiver strain or burden.

Teaching Symptom Management

One observational study,⁶ one nonrandomized study,⁵ and one randomized trial⁷ investigated the benefits of using supportive interventions, including teaching symptom management in the cancer caregiver population. Two studies used multisession group interactions,^{5,6} and the other used in-home and telephone educational interventions aimed at improving caregiver competency in dealing with the patient's symptoms. One study showed no improvement in reported caregiver burden or strain but demonstrated positive effects on other measured indicators.⁵ The other studies were inconclusive.^{6,7}

EFFECTIVENESS UNLIKELY

Interventions for which the lack of effectiveness is supported by evidence from a single rigorously designed controlled trial or consistent evidence from controlled trials using small samples, or where meta-analyses/systematic reviews using small samples or guidelines developed by consensus/expert opinion indicate a lack of effectiveness.

Interventions Directed at Improving Patient Competence

A meta-analysis found no effect on caregiver burden when the intervention was directed only toward the patient to improve their competence.²

Note. From "Caregiver Strain and Burden" [PEP card], by N.J. Honea, L. Northouse, R. Brintnall, D.B. Colao, S.C. Somers, B. Given, and P. Sherwood, 2007, Pittsburgh, PA: Oncology Nursing Society. Copyright 2007 by the Oncology Nursing Society. Reprinted with permission.

Examples of this intervention type include memory clinics for patients with dementia and activity therapy programs designed to improve everyday competence.

Authors: Norissa J. Honea, RN, AOCN®, CCRP, Laurel L. Northouse, PhD, RN, FAAN, RuthAnn Brintnall, PhD, AOCN®, CHPN, APRN-BC, Deirdre B. Colao, RN, BSN, OCN®, Susan C. Somers, BA, RN, BSN, OCN®, Barbara Given, PhD, RN, FAAN, and Paula Sherwood, PhD, RN, CNRN

Oncology Nursing Society
125 Enterprise Drive
Pittsburgh, PA 15275
412-859-6100

Definitions of the interventions and full reference lists are available at www.ons.org/outcomes. Literature search completed through September 2006.

This content published by the Oncology Nursing Society (ONS) reflects a scientific literature review. There is no representation nor guarantee that the practices described herein will, if followed, ensure safe and effective patient care. The descriptions reflect the state of general knowledge and practice in the field as described in the literature as of the date of the scientific literature review. The descriptions may not be appropriate for use in all circumstances. Those who use this card should make their own determinations regarding safe and appropriate patient care practices, taking into account the personnel, equipment, and practices available at their healthcare facilities. ONS does not endorse the practices described herein. The editors and publisher cannot be held responsible for any liability incurred as a consequence of the use or application of any of this content.

Copyright 2007 by Oncology Nursing Society.

References

1. Martire, L.M., Lustig, A.P., Schulz, R., Miller, G.E., & Helgeson, V.S. (2004). Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology, 23*(6), 599–611.
2. Sorenson, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist, 42*(3), 356–372.
3. McMillan, S.C., Small, B.J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L., et al. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer, 106*(1), 214–222.
4. Toseland, R.W., Blanchard, C.G., & McCallion, P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science and Medicine, 40*(4), 517–528.
5. Pasacreta, J.V., Barg, F., Nuamah, I., & McCorkle, R. (2000). Participant characteristics before and 4 months after attendance at a family caregiver cancer education program. *Cancer Nursing, 23*(4), 295–303.
6. Harding, R., Higginson, I.J., Leam, C., Donaldson, N., Pearce, A., George, R., et al. (2004). Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service. *Journal of Pain and Symptom Management, 27*(5), 396–408.
7. Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychosocial status. *Image—Journal of Nursing Scholarship, 31*(2), 115–120.
8. REXILIU, S.J., MUNDT, C., ERICKSON MEGEL, M., & AGRAWAL, S. (2002). Therapeutic effects of massage therapy and healing touch on caregivers of patients undergoing autologous hematopoietic stem cell transplant [Online exclusive]. *Oncology Nursing Forum, 29*(3), E35–E44. Retrieved April 15, 2008, from <http://ons.metapress.com/context/n32p3381648866h8/fulltext.pdf>
9. Ferrell, B.R., Grant, M., Chan, J., Ahn, C., & Ferrell, B.A. (1995). The impact of cancer pain education on family caregivers of elderly patients. *Oncology Nursing Forum, 22*(8), 1211–1218.
10. Keefe, F.J., Ahles, T.A., Sutton, L., Dalton, J., Baucom, D., Pope, M.S., et al. (2005). Partner-guided cancer pain management at the end of life: A preliminary study. *Journal of Pain and Symptom Management, 29*(3), 263–272.