

# Quality of Life of Family Caregivers of Patients With Cancer: A Literature Review

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**Purpose/Objectives:** To systematically review literature regarding the quality of life (QOL) of family caregivers of patients with cancer and evaluate the instruments measuring family caregivers' QOL.

**Data Sources:** PubMed, CINAHL®, PsycINFO, ISI Web of Science®, and EBSCO electronic databases; published literature.

**Data Synthesis:** Overall, the QOL of family caregivers of patients with cancer varied. Influences related to family caregivers' QOL were identified. Global and generic measures have been used because of the lack of specific instruments. Comparisons are complicated because several measures were used at different times along the illness trajectory with caregivers caring for people with various types and stages of cancer.

**Conclusions:** A more explicit definition of QOL for family caregivers of patients with cancer and specific instruments suitable for different cultures are needed to enhance knowledge.

**Implications for Nursing:** Maintaining the QOL of caregivers is important in their ability to provide the care required to keep family members with cancer in the community. Nurses must provide care to maintain caregivers' QOL.

## Key Points . . .

- ▶ Providing care for patients with cancer has an impact on caregivers' quality of life (QOL).
- ▶ QOL among family caregivers of patients with cancer varies.
- ▶ Various instruments have been used to assess the different aspects and overall QOL of family caregivers of patients with cancer.
- ▶ Defining the QOL of family caregivers of patients with cancer and developing a specific instrument will enhance research and assist healthcare professionals to understand needs and more effectively support family caregivers.

Longer survival, increasing incidence, and a growing trend toward outpatient treatment have made family caregivers increasingly important in providing support for and managing the care of patients with cancer (Given, Given, & Kozachik, 2001). Providing care for long periods at home can impose considerable demands and cause stress that dramatically can affect family caregivers' quality of life (QOL) (Weitzner, Jacobsen, Wanger, Friedland, & Cox, 1999).

QOL is a complex and multifaceted concept that is studied widely by social scientists, psychologists, and healthcare professionals. Conceptualizations of QOL have objective and subjective aspects (Day & Jankey, 1996). Objective aspects include physical functioning and economic factors, such as income and housing. Subjective aspects include attitudes, feelings of well-being, and the ability to achieve personal goals. In addition, QOL can be a unidimensional or multidimensional concept (Frank-Stromborg, 1997). When viewed as unidimensional, QOL is evaluated by using one global indicator of well-being. QOL defined as a multidimensional concept can be assessed by using a number of criteria that typically consist of as many as five domains: physical, psychological, social, economic, and spiritual well-being (Ferrans, 2000; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Padilla & Frank-Stromborg, 1997).

Definitions of QOL have been based primarily on research with people who are ill. However, healthcare professionals know that assuming caregiving responsibility greatly influ-

ences the QOL of family caregivers, particularly as cancer care shifts from inpatient to outpatient. The QOL of family caregivers of patients with cancer is important. Extending the conceptualization of QOL to caregivers requires considering domains specific to them. For example, Stetz (2003) suggested assessing families' social interactions or emotional functioning. Economic functioning is an additional aspect to consider because a primary role of the family is to provide financially for its members (Wietzner, Meyers, Steinbruecker, Saleeba, & Sandifer, 1997). Nevertheless, to date, few researchers have explored QOL issues of family caregivers of patients with cancer. This review of the literature aimed to assess instruments of QOL used in family caregivers of patients with cancer and describe results from QOL research among caregivers.

## Methods

The authors performed a literature search of the PubMed, CINAHL®, PsycINFO, ISI Web of Science®, and EBSCO electronic databases with no date limitations. Searches used

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Digital Object Identifier: 10.1188/06.ONF.625-632

combinations of the following key words: *caregiver*, *carer*, *spouse*, or *partner*; *quality of life*; *caregiving*; and *cancer*. Reference lists of the articles found were scanned to identify additional articles. Inclusion criteria were articles published in English of studies that measured QOL of unpaid respondents who were adult family caregivers providing care for adult patients with cancer.

## Findings

### Study Characteristics

The search netted 28 studies meeting the inclusion criteria. The studies were from the disciplines of nursing, medicine, and psychology and were published from 1991–2004. The majority of studies were conducted in the United States and Canada. Sixteen studies included various groups of family caregivers, and 12 studies focused on spouses or partners. Nearly half of the studies involved family caregivers of patients with multiple cancer diagnoses. The sample sizes ranged widely from 40–401.

Eighteen studies reviewed were prospective and assessed QOL of family caregivers only one time, varying from when patients with cancer were in active treatment through hospice care. Seven studies discussed the work in terms of a theoretical framework. Lazarus' model of stress and coping was used most commonly to illustrate the relationships among stressors, appraisal, coping, and QOL.

### Instrument Characteristics

Thirty instruments were used to evaluate QOL of family caregivers of patients with cancer in the 28 studies (see Table 1). They can be classified into three categories: population-specific ( $n = 3$ ), global ( $n = 5$ ), and generic instruments ( $n = 22$ ).

Population-specific instruments were developed focusing on QOL relevant to a particular population (e.g., family caregivers of patients with cancer). Global QOL tools used a single item to measure overall QOL across different populations. Generic instruments, based either on aspects of QOL or other concepts relating to QOL that are common across diverse population, were most commonly used in these reviewed studies. Many instruments emphasized assessment of physical, psychological, and social well-being, whereas financial and spiritual aspects were included less often. Seven studies administered multiple generic instruments. Several studies did not present the results of reliability testing.

### Quality of Life of Family Caregivers of Patients With Cancer

The reviewed studies, which are summarized in Table 1, included three aspects of QOL of family caregivers of patients with cancer. These were (a) descriptions of QOL of family caregivers, (b) influences associated with family caregivers' QOL, and (c) interventions for enhancing QOL of family caregivers.

**Descriptions of quality of life of family caregivers of patients with cancer:** Because QOL was measured with several instruments, the findings include overall QOL and different domains of QOL (physical, psychological, social, and spiritual) for family caregivers. After reviewing the descriptions, comparisons among QOL of family caregivers, patients with cancer, and healthy populations are reported.

**Overall quality of life:** Overall QOL of family caregivers varied. Husbands of women with gynecologic cancer and wives of testicular cancer survivors were satisfied with their QOL (Tuinman, Fleer, Hoekstra, Sleijfer, & Hoekstra-Weebers, 2004; Zacharias, Gilg, & Foxall, 1994). In longitudinal studies, the moderate to relatively high scores of QOL for caregivers of patients receiving treatment remained stable over time when measured before and after therapy and until patients' deaths (Gill, Kaur, Rummans, Novotny, & Sloan, 2003; Kornblith et al., 2001). Others found that family caregivers' QOL improved after patients completed chemotherapy and surgery (Le et al., 2004; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).

Nevertheless, low overall QOL was found in caregivers while patients were receiving radiation, bone marrow transplantation, and hospice care (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Iconomou, Viha, Kalofonos, & Kardamakis, 2001; Meyers & Gray, 2001). QOL also deteriorated over time among caregivers before and after patients received brachytherapy or palliative surgery (Borneman et al., 2003; Koot et al., 2004).

**Physical aspects:** Physical symptoms such as tiredness, trouble sleeping, lack of appetite, and need for rest were reported by wives of men with prostate cancer (Kornblith, Herr, Ofman, Scher, & Holland, 1994). Axelsson and Sjoden (1998) found that spouse caregivers had insomnia and needed assistance with patients' hygiene and dressing, which increased during the last month compared to 7–12 weeks before patients' death.

**Psychological aspects:** Most wives of men with prostate cancer described emotional turmoil, stress, worry, nervousness, anger, concern for their husbands, feelings of devastation, and depression (Crowe & Costello, 2003; Kornblith et al., 1994). Vickery, Latchford, Hewison, Bellew, and Feber (2003) reported that anxiety scores of partners of patients with head and neck cancer were in borderline clinical range, but their depression scores were in the normal range. In a longitudinal study, Borneman et al. (2003) found that family caregivers also had worsening psychological problems after patients' palliative surgery.

**Social relationships:** Caregivers of survivors of autologous bone marrow transplantation perceived insufficient family support, fluctuation in role responsibilities at home, continued demands in caregiving, and a return to normalcy within the family (Boyle et al., 2000). The item about sex life was scored the lowest among the aspects of QOL of husbands of women with gynecologic cancer (Zacharias et al., 1994). Wives of men with prostate cancer reported a decrease in sexual activity and wanted information about sexual function but had no change in their relationships with their spouses (Crowe & Costello, 2003). A longitudinal study reported that relationships of family caregivers who shared worries with patients and had contact with friends were stable over time at the end of patients' lives (Axelsson & Sjoden, 1998).

**Spiritual aspects:** Spiritual well-being, which included feeling spiritual support, usefulness, hopefulness, sense of purpose, and overall satisfaction with life (Matthews, Baker, & Spillers, 2004), was the highest-rated dimension of QOL for caregivers of cancer survivors. Axelsson and Sjoden (1998) found that meaningfulness of caregivers was fairly stable from 7–12 weeks to less than 6 weeks before patients died.

**Palliative versus curative treatment:** Weitzner, McMillan, and Jacobsen (1999) found that family caregivers of palliative

**Table 1. Studies of Quality of Life of Family Caregivers of Patients With Cancer**

Reference	Design	Instruments	Findings
<b>Prostate and testicular cancer</b>			
Kornblith et al., 1994	Cross-section	European Organization for Research and Treatment of Cancer Quality-of-Life (QOL) Questionnaire C-30 <sup>a</sup> Marital Communication Problem Scale <sup>a</sup> Intrusion Subscale of the Impact of Event Scale <sup>a</sup> Selby's Quality of Life Uniscale <sup>b</sup>	Spouses had physical, psychological, and sexual symptoms. Spouses had greater psychological distress than patients.
Crowe & Costello, 2003	Cross-section	Functional Assessment of Cancer Therapy (FACT)–Prostate <sup>a</sup>	Partners had loss of sexual activity. Partners had greater stress than patients.
Campbell et al., 2004	Cross-section	Profile of Mood States–Short Form <sup>b</sup> Caregiver Strain Index <sup>a</sup>	Patients' and partners' self-efficacy were positively correlated with partners' QOL.
Tuinman et al., 2004	Cross-section	Rand Short Form–36 (SF-36) <sup>a</sup>	Spouses who had relationships with patients after treatment had more psychological and health problems than spouses who had relationships with patients before diagnosis. Time since completion of treatment and type of treatment were not related to spouses' QOL.
Kornblith et al., 2001	Longitudinal	Mental Health Inventory–17 <sup>a</sup> Caregiver Burden Interview <sup>a</sup>	Partners' QOL was not changed. Patients' and partners' QOL were correlated. Patients' clinical response was negatively related to partners' mental problems and positively correlated with partners' psychological well-being.
<b>Breast and gynecologic cancer</b>			
Zacharias et al., 1994	Cross-section	Quality of Life Index–Cancer Version (QLI-CV) <sup>a</sup>	Spouses' QOL was high but the item about sex life was low. No differences existed between patients' and spouses' QOL. Spouses' self-blame was negatively related to their QOL.
Northouse et al., 2002	Cross-section	FACT–General Scale <sup>a</sup> Medical Outcomes SF-36 <sup>a</sup>	Patients had lower QOL than caregivers. Caregivers had lower mental health than healthy people. Caregivers' symptom distress, concerns, hopelessness, and negative appraisal of caregiving had negative effects on their QOL, but caregivers' self-efficacy, social support, and family hardiness were positively related to their QOL.
Gaston-Johansson et al., 2004	Cross-section	QLI-CV <sup>a</sup>	Caregivers' QOL was low. Subjective caregiver burden was related to caregivers' QOL.
Kershaw et al., 2004	Cross-section	Medical Outcomes SF-36 <sup>a</sup>	Caregivers' avoidant coping predicted the mental aspect of caregivers' QOL.
Le et al., 2004	Longitudinal	Caregiver of Quality of Life Index–Cancer (CQOLC) <sup>c</sup>	Caregivers' QOL improved.
<b>Brain and head and neck cancer</b>			
Mathieson et al., 1991	Cross-section	Happiness Scale <sup>b</sup>	Spouses' satisfaction with sexual relationships and the effect of laryngectomy on relationships between patients and spouses predicted spouses' QOL.
Hahn et al., 2003	Cross-section	Visual Analog of Mood Scale <sup>a</sup> Miller Hope Scale <sup>a</sup> Hassles and Uplifts Scale <sup>a</sup> Linear Analog Self-Assessment <sup>b</sup>	Patients' QOL was correlated with caregivers' QOL. Miller Hope Scale, Confusion Subscale, and Sadness Subscale were correlated with caregivers' QOL.
Vickery et al., 2003	Cross-section	Hospital Anxiety and Depression Scale <sup>a</sup> Dyadic Adjustment Scale <sup>a</sup>	Partners had higher anxiety than patients. The scores of the quality of relationships between partners and patients were similar to those of healthy people.
Koot et al., 2004	Longitudinal	Extension of Rotterdam Symptom Checklist <sup>a</sup>	Partners' QOL decreased. Patients' QOL was correlated with partners' QOL.
<b>Mixed cancer</b>			
Weitzner et al., 1999	Cross-section	CQOLC <sup>c</sup>	Palliative caregivers had lower QOL than curative caregivers.

*(Continued on next page)*<sup>a</sup> Generic instrument<sup>b</sup> Global instrument<sup>c</sup> Population-specific instrument

**Table 1. Studies of Quality of Life of Family Caregivers of Patients With Cancer (Continued)**

Reference	Design	Instruments	Findings
Boyle et al., 2000	Cross-section	Rand SF-36 <sup>a</sup> FACT–Bone Marrow Transplantation <sup>a</sup>	Caregivers had concerns about social adjustment; survivors worried about dealing with physical compromise. No difference existed in the well-being of survivors and caregivers.
Hagedoorn et al., 2000	Cross-section	A global QOL scale (Cantril, 1965) <sup>b</sup>	Wives of patients with cancer had lower QOL than husbands of patients with cancer and wives of healthy people. Male patients from a cancer association had lower QOL than husbands of patients from a cancer association.
Iconomou et al., 2001	Cross-section	Global QOL scale (a one-item linear visual analog scale) <sup>b</sup>	Caregivers' anxiety, depression, impact of caregiving on caregivers' life, and psychological distress were negatively related to caregivers' QOL.
Chen et al., 2004	Cross-section	Caregivers QOL Index (CQLI) <sup>c</sup>	Caregivers' QOL was low. Patients' QOL was positively related to caregivers' QOL. Shortened patients' hospitalization, marital satisfaction, and caregiving self-esteem were related to caregivers' QOL.
Matthews et al., 2004	Cross-section	QOL–Family (QOL-F) <sup>a</sup>	Caregivers' health protective behaviors and emotional strain were inversely related to caregivers' QOL.
Nijboer et al., 1999	Longitudinal	QOL scale (a one-item linear visual analog scale) <sup>b</sup>	Partners' QOL improved. Partners' initial QOL, income, loss of physical strength, self-esteem, and quality of relationship between partners and patients predicted partners' QOL.
Borneman et al., 2003	Longitudinal	QOL-F <sup>a</sup>	Caregivers' QOL worsened. No gender differences existed in caregivers' QOL.
<b>Terminal cancer</b>			
Meyers & Gray, 2001	Cross-section	CQOLC <sup>c</sup>	Caregivers' QOL was low; being retired and length of time as a caregiver were related to caregivers' QOL.
McMillan & Mahon, 1994	Longitudinal	CQLI <sup>c</sup>	No change occurred in caregivers' QOL. Patients' QOL correlated with the caregivers' QOL. Caregivers' age and education were not related to their QOL.
McMillan, 1996	Longitudinal	CQLI <sup>c</sup>	Caregivers' QOL remained stable. Caregivers' education was negatively related to their QOL. Caregivers' age and patients' functional status were not related to caregivers' QOL.
Axelsson & Sjoden, 1998	Longitudinal	Assessment of QOL at the End of Life <sup>c</sup>	Spouses' physical well-being worsened. Patients' QOL was lower than spouses' QOL. Items of caregiver meaningfulness, feelings of security, contact with friends, and hours they were able to leave patients unattended were positively related to caregivers' QOL, and caregivers' depression was negatively related.
Smeenk et al., 1998	Longitudinal	Overall QOL Index <sup>a</sup>	The transmural intervention contributed positively to caregivers' QOL.
Gill et al., 2003	Longitudinal	Linear Analog Self-Assessment Scales <sup>a</sup>	Caregivers' QOL remained stable. Patients' QOL was correlated with caregivers' QOL.

<sup>a</sup> Generic instrument<sup>b</sup> Global instrument<sup>c</sup> Population-specific instrument

patients with cancer had significantly lower QOL, greater impairment in physical functioning, and worse overall physical health than caregivers of curative patients with cancer. No significant differences existed in mental and social well-being.

*Family caregivers' characteristic:* Using a global QOL tool, Iconomou et al. (2001) found that QOL was lower among female than male caregivers. Wives of hospitalized patients with cancer had lower QOL than husbands of hospitalized patients, but no gender differences were found in QOL of spouses of

patients from a cancer association who were assessed by Cantril's (1965) global QOL measure (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000). Likewise, Borneman et al. (2003) reported no gender difference in overall QOL of caregivers of patients with advanced cancer. In addition, spouses who had relationships with testicular cancer survivors that began after treatment had more psychological problems than spouses who had relationships with testicular cancer survivors that began before diagnosis (Tuinman et al., 2004).

*Family caregivers versus patients:* Comparison of overall QOL and aspects of QOL of family caregivers and patients with cancer were inconsistent. Hagedoorn et al. (2000) found that QOL of male patients from a cancer association was lower than QOL of husbands of patients from a cancer association. Northouse et al. (2002) reported that women with recurrent breast cancer had lower overall QOL than their caregivers. Tuinman et al. (2004) reported that cancer survivors who had relationships with spouses before their diagnosis had worse general QOL than their spouses.

Zacharias et al. (1994) reported that QOL scores of patients with gynecologic cancer were close to those of their caregivers. Northouse et al. (2002) found that women with recurrent breast cancer and family members equally reported impairment of their mental and social health. Emotional well-being and overall QOL ratings of survivors with autologous bone marrow transplantation were similar to caregivers' ratings (Boyle et al., 2000).

Nevertheless, spouses had greater psychological distress than patients with prostate cancer (Kornblith et al., 1994). A study of partners of patients with head and neck cancer who had combinations of surgery and radiation or brachytherapy or chemoradiation found that caregivers had significantly higher levels of anxiety than patients (Vickery et al., 2003). Spouses of hospice patients also were more anxious than patients (Axelsson & Sjoden, 1998).

*Family caregivers versus healthy people:* Caregivers of women with recurrent breast cancer reported that their mental health was worse than the mean of a healthy population, but the physical scale was similar to the mean for the healthy population (Northouse et al., 2002). Similarly, Vickery et al. (2003) found that the score of quality of relationships of partners who care for patients with head and neck cancer was in an average range when compared with scores of a healthy population.

*Summary:* The overall QOL of family caregivers of patients with cancer ranged from low to relatively high. These caregivers have physical concerns, decreased scores in psychosocial aspects, and positive spiritual well-being. Longitudinal studies have shown mixed results, including worsened, stabilized, and recovered patterns of QOL of caregivers. Evidence about QOL is suggestive rather than conclusive about differences among characteristics of caregivers and about comparisons between caregivers and patients with cancer. Findings are inconsistent about who is affected the most and to what extent. Comparisons across studies are complicated because researchers used several instruments at different times and studied different patients vis-à-vis their health status and treatments.

**Influences associated with quality of life of family caregivers of patients with cancer:** Positive and negative influences associated with QOL of family caregivers of patients with cancer can be categorized into four groups: patient- or treatment-related factors, caregiver factors, caregiving-related factors, and social factors.

*Patient- or treatment-related factors:* Several studies reported that earlier stage of patients' disease, efficacy, and QOL were positively associated with their caregivers' QOL (Campbell et al., 2004; Chen, Chu, & Chen, 2004; Gill et al., 2003; Hahn et al., 2003; Koot et al., 2004; Kornblith et al., 2001; Matthews et al., 2004; McMillan & Mahon, 1994). Shortened hospitalization and the treatment's effect on the

relationships between patients and caregivers had detrimental effects on caregivers' QOL (Chen et al.; Mathieson, Stam, & Scott, 1991). Patients' clinical responses were associated with decreases in their partners' anxiety, distress, and depression and with increases in psychological well-being (Kornblith et al., 2001). However, patients' functional status and type of treatment were not correlated with caregivers' QOL (McMillan, 1996; Tuinman et al., 2004).

*Caregiver factors:* Demographic factors may influence family caregivers' QOL. Retirement and income were associated with better caregivers QOL, and education was negatively related (McMillan, 1996; Meyers & Gray, 2001; Nijboer et al., 1999). However, McMillan and Mahon (1994) found that education and age were not related to caregivers' QOL.

Personal attributes have been found to affect caregivers' QOL. Caregivers' positive expectations, performances of protective behaviors, self-efficacy, and self-esteem were positively related to their QOL (Campbell et al., 2004; Chen et al., 2004; Matthews et al., 2004; Nijboer et al., 1999; Northouse et al., 2002). The use of more avoidant coping was related to poorer mental well-being, but use of less self-blame coping was correlated with better caregiver QOL (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Zacharias et al., 1994).

Individual aspects of caregivers' QOL also affected total QOL. Good initial QOL, good health status, sexual satisfaction, hope, and feelings of security and meaningfulness were positively related to caregivers' QOL (Axelsson & Sjoden, 1998; Hahn et al., 2003; Iconomou et al., 2001; Mathieson et al., 1991; Nijboer et al., 1999). In contrast, loss of physical strength, feeling of burden, emotional strain, psychological distress, confusion, sadness, anxiety, depression, concerns, hopelessness, and symptom distress were important factors in reducing caregivers' QOL (Gaston-Johansson et al., 2004; Hahn et al.; Iconomou et al.; Kershaw et al., 2004; Matthews et al., 2004; Nijboer et al.; Northouse et al., 2002).

*Caregiving-related factors:* Time in caregiving role, negative appraisal of caregiving, and impact of caregiving on caregivers' lives were related to lower caregiver QOL (Axelsson & Sjoden, 1998; Iconomou et al., 2001; Meyers & Gray, 2001; Northouse et al., 2002).

*Social factors:* Good relationships with patients, marital satisfaction, contact with friends, family hardiness, and social support contributed to positive caregiver QOL (Axelsson & Sjoden, 1998; Chen et al., 2004; Nijboer et al., 1999; Northouse et al., 2002).

**Intervention for improving the quality of life of family caregivers of patients with cancer:** Only one quasi-experimental longitudinal study was found of an intervention to enhance caregivers' QOL (Smeenk et al., 1998). The study tested a transmural homecare program for caregivers of terminally ill patients with cancer. The transmural program addressed the needs of patients with cooperation, coordination, and communication among the family and professional caregivers. The program consisted of four components: (a) a specialist nurse coordinator, (b) a 24-hour telephone service in the hospital with access to a transmural home team, (c) a collaborative home case dossier (case file), and (d) a protocol designed for each specific person. Family caregivers using transmural care had higher QOL one week after the intervention and three months after patients' death compared with caregivers of those receiving standard care.

## Discussion and Recommendations

Limitations in the studies indicate the need for caution in drawing conclusions and synthesizing information about QOL of family caregivers of patients with cancer. Restrictions in definition as well as conceptual and methodologic aspects of the literature are worth noting.

### Ambiguous Definition of Quality of Life

Perhaps because QOL is a complex and elusive concept, most researchers did not provide a conceptual definition of family caregivers' QOL and instead focused on measurement issues. Problems such as compromised validity may occur, and findings that cannot be interpreted adequately if the tools chosen do not fit with a conceptual definition of QOL (Waltz, Strickland, & Lenz, 1991). Without a definition in the reviewed literature, the linking of conceptual and operational definitions of QOL is questionable (Ferrans, 1990). Thus, explication of what QOL means for family caregivers of patients with cancer is needed. To reach agreement about QOL's definition in cancer settings, oncology nurses should have a consensus conference about its meaning to both family caregivers and healthcare professionals (Farquhar, 1995). National and international organizations can help to optimize this concept clarification. Moreover, as changes in healthcare occur with time and political shifts, nurses need to reexamine and update the concept to better understand and generate knowledge and research (Chung, Killingworth, & Nolan, 1997).

### Lack of a Theoretical Framework

A theoretical framework or model is essential at the beginning of a study to underpin research questions and select variables as well as at the end of a study to interpret the results. Most of the studies reviewed did not report use of a theoretical or conceptual framework. Using a theoretical model would guide advancement of the body of knowledge by explaining complex phenomena of caregivers. In addition, comparison among studies would be enhanced by the consistency a model would provide.

### Methodologic Issues

Methodologic flaws threaten validity and reliability. Limitations of the 28 studies included inappropriate QOL measurements, small sample size, and weak research designs.

**Inappropriate quality-of-life measurement:** Numerous studies reviewed assessed QOL of caregivers with global and generic instruments. Using global and generic tools limits the results. For example, global QOL instruments provide a restricted view of caregivers' QOL and lack psychometric properties. Although generic instruments work well with patients with cancer, using these instruments with caregivers can be problematic because some items are not relevant to caregivers. Moreover, none of the tools addressed every domain of QOL identified as important for caregivers; in particular, economic and spiritual well-being often were neglected. Furthermore, using multiple generic instruments targeted toward particular domains and summing all the dimensions to calculate caregivers' overall QOL does not take into account that caregivers differ in how each dimension contributes to their QOL. Interpreting relationships among variables in multiple generic instruments may be difficult because scores from various scales are weighted and dimensions overlap.

Therefore, using different generic instruments simply may increase confusion and also make comparisons across the reviewed studies difficult.

In addition, the studies reviewed were conducted in several countries, but most QOL measurement tools were developed in the United States. Tools may be specific to the culture in which they were developed and tested. Culturally appropriate and valid instruments to measure QOL are needed before cross-cultural studies can proceed. Moreover, because reliability estimates vary from sample to sample, instrument reliability should be reestimated for each study. However, many reviewed studies did not discuss reliability of instruments, leaving the consistency of the current results in question.

The fact that the reviewed studies employed diverse instruments may reflect the lack of suitable instruments available and failure to specify the ways in which QOL for caregivers most likely is affected. Therefore, using specific instruments with caregivers of patients with cancer is needed because these instruments allow researchers to tailor the questions to their unique population and are more sensitive to change of caregivers' QOL than are generic instruments. For novice users, choosing among existing specific instruments is needed and is best based on reading widely and thinking critically. Jacobson (2004) and Waltz et al. (1991) provided a description of how to evaluate existing tools. When assessing a tool, users should ascertain through extensive literature review that the instrument's conceptual basis fits with their theoretical conceptualization. In addition, a tool's reliability and validity, the purpose for which it was developed, population, setting, administration and scoring, sensitivity, comprehensibility, and feasibility all should be included in users' considerations. If the results of the assessment find that a tool meets users' needs, it can be used. If doubts exist about a tool's appropriateness, users may look for another tool or use it to conduct a pilot study to evaluate the tool.

**Small sample size:** Sample size is another methodologic issue. Most studies had small sample sizes, resulting in imprecise estimates of the caregiving effects. Attrition and decreased response rates are additional problems and raise questions about the representativeness of findings.

**Weak research designs:** Most of the 28 studies were cross-sectional, thereby limiting understanding of the evolution of the caregiving experience and the factors that contribute to its breakdown, maintenance, or improvement. Because changes occur in the role of caregivers, more longitudinal studies are needed. Moreover, only one intervention study was identified in the present review, so testing interventions for enhancing QOL of caregivers is important.

Despite the limitations of these studies, implications for research and practice can be drawn to inform healthcare professionals about ways to support and promote family caregivers' QOL. In current practice, although providing care impacts caregivers' lives, few assessments examine caregivers' QOL. Nurses should develop or use a standard tool to assess caregivers' QOL along the entire course of cancer care to identify potential caregivers who are vulnerable and in need of support.

The influences of caregivers' QOL identified previously allow healthcare professionals to establish synergistic interventions that integrate several strategies for caregivers

throughout patients' illness trajectory. These interventions are more effective in enhancing caregivers' QOL. In addition, to optimize caregivers' aims, intervention planning should be based on a theory, identify clear aims, focus on the caregivers' needs, address accessibility and acceptability, and assess the aims with rigorous evaluation methods (Harding & Higginson, 2003).

## Conclusion

The transition to community-based care has increased awareness of the extent and importance of family caregiving in keeping patients with cancer at home. Evidence from the 28 studies reviewed showed that providing care has an enormous impact on caregivers' QOL. Maintaining QOL of caregivers is a significant factor in their willingness to provide the care required to keep family members with cancer in the community

instead of in institutional settings. Providing care to maintain caregivers' QOL is a central nursing value.

Comparing studies and building knowledge are difficult because of the scant theoretical bases, diversity of instruments, culturally insensitive instruments and lack of consistency among them, and lack of specific timing when QOL is assessed in studies. Research needs to begin with clear definitions of QOL and specific indicators that are accurate and valid for family caregivers in different cultures. Such research would advance healthcare professionals' understanding of the caregiving process and would enable them to direct interventions to effectively help family caregivers to continue with their essential role while maintaining their own health and QOL.

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