See page E57 for suggested questions to begin discussion in your journal club.

Caring for the Caregiver

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Purpose/Objectives: To describe the quality of life (QOL) and well-being of caregivers of patients receiving outpatient chemotherapy for leukemia and to identify strategies to promote the best possible QOL and well-being for the caregivers.

Design: Descriptive, cross-sectional study.

Setting: Ambulatory treatment center of a major comprehensive cancer center in the southern United States.

Sample: Convenience sample of 194 caregivers of patients receiving chemotherapy for leukemia.

Methods: Participants completed the Caregiver Quality-of-Life–Cancer Scale, the Caregiver Well-Being Scale, and the Learning Needs Questionnaire developed by the authors. Descriptive statistics were used to summarize the demographic characteristics of the caregivers, and exploratory factor analysis was performed to identify meaningful factors.

Main Research Variables: QOL, well-being, and learning needs.

Findings: Caregivers identified burden as their most important concern for QOL. Key factors identified with caregivers' well-being were expression of feelings and household maintenance. Caregivers identified giving medications and managing the side effects as crucial to learning needs. Communication, positive attitudes, support, and education were important in promoting QOL for the caregivers.

Conclusions: Caregiving for a patient receiving chemotherapy for leukemia influences the QOL and well-being of the caregiver.

Implications for Nursing: This study highlights the need for better nurse-caregiver communication and education, particularly in the areas of symptom management and medication administration. Additional research should focus on factors that affect caregivers' QOL, their educational needs, and improved interventions for delivering new information or reinforcing old information.

As cancer care increasingly shifts from inpatient settings to outpatient settings, patients often receive complex treatments at home or in local oncologists' offices. Family members may be called on to provide primary care at home when a patient receives aggressive or disabling treatment in an outpatient setting or when treatment has transitioned into palliative care. In caregiving for patients with different types of cancer, several commonalities can create caregiver burden and strain. Extremely high physical and emotional demands are placed on caregivers, and the disease itself creates major cognitive and emotional disruptions of normal behavior in patients (Gozum & Ackay, 2005; Lloyd-Williams, Dennis, & Taylor, 2004; McIlfatrick, Sullivan, & McKenna, 2005). Age, gender, cultural background, ethnicity, socioeconomic status, educational level, personal health, and family dynamics work together as integral factors in predicting the caregiver's reaction to this demanding role (Baider & Bengel, 2001; Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000; Langer, Abrams, & Syrjala, 2003; Northouse, Mood, Templin, Mellon, & George, 2000).

In addition, family caregivers often report deficits in education and skills related to their patients' care, a lack of assistance from healthcare professionals, an absence of social support, and increasing stress associated with the patient's advancing cancer, subsequent disability, and increasingly complex care demands (Crowe & Costello, 2003; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Gozum & Akcay, 2005). Therefore, the additional responsibility can result in added strain on the physical and mental well-being of caregivers and patients.

Patients with leukemia may receive a number of various chemotherapies in the outpatient setting (Savoie et al., 2006). Success in the management of expected treatment complications, such as pancytopenia and metabolic abnormalities, requires early therapeutic interventions (Savoie et al.); therefore, patients with leukemia being treated in outpatient settings require close monitoring and management at home by their primary caregivers.

Patients with leukemia receiving chemotherapy develop significant side effects, which may result in extremely high physical and emotional strain on the caregiver. Prior studies have been conducted with caregivers of patients with solid tumors, including those actively receiving treatment through hospice. A review of the literature failed to identify any studies that describe the quality of life (QOL) and well-being of caregivers of patients with leukemia receiving any type of therapy.

Identifying and addressing the numerous variables leading to improved or decreased QOL and well-being in caregivers early in the treatment plan would benefit caregivers and patients. Identifying the needs of caregivers will enable healthcare providers to develop interventions to enhance the QOL and well-being of caregivers of patients with cancer. As a result, the authors designed a study to describe QOL and well-being of family caregivers of patients with leukemia receiving outpatient chemotherapy to identify strategies to promote optimal QOL and well-being in these caregivers.

Variables

Quality of Life

QOL is multidimensional in nature and can be considered an outcome of health care and rehabilitation or a health status. Poor QOL can be a sign of functional disability, a sign of disease progression or regression, or a manifestation of negative social circumstance. QOL can be considered with subjective internal constructs of self-evaluation and psychological well-being (Ferrans, 2005).

Glozman (2004) described primary stressors that affect the QOL of caregivers, including caregiving demands, patient impairment, duration and intensity of care, activities of daily living, dependency, recurrence of illness, and problem behavior in the care recipient. The relationship between primary stressors and QOL is under debate. Vedhara, Shanks, Anderson, and Lightman (2000) reported decreased QOL associated with these stressors, and other studies found no association between primary stressors and QOL (Cameron, Franche, Cheung, & Stewart, 2002; Nijboer et al., 2000). Secondary stressors include role change, responsibility, caregiving experience, and lifestyle interference (Glozman). Again, the effect of secondary stressors is unknown, with a significant relationship between secondary stressors and QOL reported in some studies in contrast to studies that revealed no association (Boyle et al., 2000; Nijboer et al.).

Weitzner, McMillan, and Jacobsen (1999) described the QOL of caregivers of patients with cancer in palliative and hospice settings. Caregivers of patients in the palliative group reported lower QOL scores than their counterparts in a curative group, primarily because of the palliative patients' worse performance status and outcomes.

Caregiver Well-Being

Goldstein (1990) described well-being as a periodic state of security and structure within the turbulence of life. Well-being measures focus on the strength of the caregiver as opposed to QOL measures that assess stress and burden (Berg-Weger, Rubio, & Tebb, 2000). A caregiver's well-being is dependent on the patient's condition as well as the individual characteristics of the caregiver (Weitzner & McMillan, 1999). Few studies have described the well-being of caregivers of patients with cancer.

Caregivers of Patients With Cancer

As patients move through the cancer trajectory, and as disease progresses, the needs of patients and caregivers increase exponentially (Giarelli, Pisano, & McCorkle, 2000). Recognition of the caregivers' future needs before patients have advanced disease could facilitate much-needed support for family caregivers early in the process. One venue for assessing caregivers' needs is the outpatient chemotherapy setting; however, few studies have addressed the needs of family caregivers of patients with cancer who are being actively treated in the outpatient setting.

Kitrungote and Cohen (2006) reviewed caregiver QOL literature and evaluated the instruments used to measure QOL in studies published from 1991–2004. Sixteen of the 28 studies identified included a variety of groups of family caregivers, and 12 focused on partners or spouses as caregivers. Sample size in the reviewed studies ranged from 40–401. The patients were diagnosed with different types of cancer and included patients actively receiving treatment through hospice. In the 28 studies reviewed, 30 different instruments were used to measure caregiver QOL. The instruments measured overall caregiver QOL and included different domains of QOL, such as psychological, physical, social, and spiritual. Several studies described positive and negative influences associated with QOL, including caregiver factors, patient- and treatment-related factors, social factors, and caregiving-related factors. Overall caregiver QOL was described as low, stable, or high, based on the type of cancer and whether the patient was receiving treatment or in-hospice care.

In another study, younger caregivers were affected more by disruptions in their schedules than older caregivers, who viewed the experience as less negative over time. A caregiver's age, the patient's health issues, depression, anger, and anxiety also significantly reduced caregiver QOL (Nijboer et al., 2000). Schumacher (1996) reported the emergence of caregiving patterns that changed in response to variations in the patient's care situation.

Family caregivers can affect the patients' positive adaptation related to their disease; therefore, promoting the QOL of caregivers of patients with cancer is definitely a concern of healthcare providers (Iconomou, Vagenakis, & Kalofonos, 2001). Caregivers managing patients with cancer at home require healthcare professionals to provide support through education, resources, and communication (Northouse et al., 2007).

Methods

Subjects

Two hundred twenty-eight patients with leukemia receiving chemotherapy in the ambulatory treatment center (ATC) of a major comprehensive cancer center in the southern United States were approached with information about this study. Thirty-four patients refused to identify a caregiver, did not have a primary caregiver, or did not have the primary caregiver available during the treatment. One hundred ninety-four patients (85%) agreed to identify a caregiver, all of whom completed the questionnaires. The study inclusion criteria were that the patient had a diagnosis of leukemia and was receiving chemotherapy or monoclonal antibody therapy in the ATC, the patient was willing to identify a primary caregiver, the caregiver agreed to participate, and the patient and the caregiver were aged 18 years or older and fluent in English. Participants who were unable to understand the purpose of the research study were excluded. Participating caregivers were given a packet with questionnaires to complete.

Procedures

Following approval by the cancer center's institutional review board, patients who were checking in to the ATC for their chemotherapy treatment and who met the eligibility criteria were given a screening tool by ATC nursing personnel. If patients did not wish to identify a caregiver, they marked the appropriate box on the form and returned it to the clinic nurse. If a patient identified a primary caregiver, a member of the research team gave the caregiver a packet of instructions and surveys. The cover letter in the packet explained the purpose and objectives of the study, provided instructions for the surveys, and described how confidentiality would be preserved. Included in this letter was a statement explaining that completion of the survey implied consent to participate in the study. Study participants returned the completed surveys in sealed envelopes to a staff nurse in the ATC. One of the authors collected the surveys on a daily basis.

Caregiver participants completed a demographic information sheet, the Caregiver Quality-of-Life–Cancer (CQOL-C) scale, Caregiver Well-Being (CWB) scale, and the Learning Needs Questionnaire developed by the authors. Participants were instructed not to write their names or initials on the surveys. Each set of surveys was coded with an assigned number.

Measures

The CQOL-C and the CWB were used to measure QOL and caregiver well-being. The CQOL-C is a multidimensional questionnaire that assesses the issues and needs afflicting caregivers, and the CWB assesses caregivers' well-being. The instruments were selected because they have been used in studies of caregivers of patients with cancer and have established validity and reliability. Demographic data were collected from the primary caregiver.

A questionnaire was developed by the authors to identify and determine the importance of learning needs, giving medication, managing side effects of medication, and symptoms such as pain, nausea and vomiting, and fatigue. In addition, an open-ended question was included to obtain comments or ideas for nurses to improve the QOL of the family caregiver. Caregivers were asked to "write anything else you feel nurses could do for you that would improve your quality of life as a caregiver."

Data Analysis

Individual CQOL-C factor (burden, disruptiveness, positive adaptation, and financial concerns) scores were obtained by summing the responses to the items that load on the particular factor. Total CQOL-C scores were obtained by summing scores for all 35 items. The maximum score was 140, with higher scores indicating better QOL. Several items were not included in an individual factor but were included in the total CQOL-C score.

The CWB scale includes basic human needs composed of three factors (expression of feelings, attendance to physical needs, and self-security), and activities of daily living, composed of five factors (time for self or leisure activities, household maintenance, maintenance of functions outside the home, household tasks, and family support). The scales were computed by averaging the scores for each response on each factor. Nine scores were calculated for each participant.

Exploratory factor analysis was performed using squared multiple correlations as prior commonalities estimates. The maximum likelihood method was used to extract the factors and was followed by a promax rotation. A scree plot of the eigenvalues (Cattell, 1966) obtained from the exploratory factor analysis suggested four meaningful factors. Kaiser's (1970) measure of sampling adequacy was used to determine the appropriateness of the common factor model. In interpreting the rotated factor pattern, an item was said to load on a given factor if the factor loading was greater than 0.4 for that factor and less than 0.4 for the other factors (Stevens, 1996). Setting the critical value at 0.4 ensures

Table 1. Demographic Characteristics of Caregivers

Variable	Men n	Men %	Women n	Women %	Total n	Total %
Age (years)						
Younger than 30	6	14	11	8	17	9
30–39	4	10	14	10	18	10
40–49	6	14	27	20	33	18
50–59	5	12	34	25	39	22
60–69	12	29	38	27	50	28
70 and older	9	21	14	10	23	13
Race						
Asian or Pacific Islander	2	5	2	2	4	2
Black non-Hispanic	–	–	7	5	7	4
Hispanic	5	12	14	10	19	11
Native American or Alaskan	–	–	4	3	4	2
White non-Hispanic	35	83	106	79	141	80
Other	–	–	1	1	1	1
Religious background						
Protestant	18	51	67	52	85	52
Catholic	12	34	39	30	51	31
Jewish	2	6	5	4	7	4
Other	3	9	18	14	21	13
Marital status						
Married	35	95	114	92	149	92
Single	2	5	7	6	9	6
Divorced	–	–	1	1	1	1
Separated	–	–	2	1	2	1
Household income ($)						
50,000 or more	24	63	85	64	109	64
40,000–49,999	3	8	16	12	19	11
30,000–39,999	6	16	9	7	15	9
Less than 30,000	5	13	22	17	27	16
Employment status						
Full-time	17	47	36	29	53	34
Part-time	–	–	15	12	15	9
Unemployed	6	17	52	43	58	37
Other	13	36	19	16	32	20
Education						
High school or less	19	45	47	34	66	37
College or technical school	12	29	57	41	69	38
Graduate school	11	26	34	25	45	25
Residence						
Coresident	31	94	100	86	131	88
Not a coresident	2	6	16	14	18	12
Relation to care recipient						
Spouse	35	92	103	77	138	80
Daughter	–	–	19	14	19	11
Son	–	–	–	–	–	–
Other	3	8	12	9	15	9
Courses of chemotherapy						
Less than five	25	66	87	68	112	68
More than five	13	34	40	32	53	32

N = 194

Note. Information was not provided for all categories by all caregivers.

that an item will share at least 16% of its variance with the factor that it was used to help name.

The sum of the items loading on each factor was determined for each participant, and then the mean, standard deviation (SD), minimum, and maximum of the total scores were found. All participants in the sample are represented, but some patients did not respond to some items.

The total CQOL-C score also was determined. However, as previously stated, a few of the items did not load on any of the factors, explaining why the total score is larger than the sum of the scores for the individual factors. The scoring was somewhat different for the CWB scale. Instead of summing the scores that loaded on each factor, the items loading on each factor were averaged.

Results

Demographics

Consistent with other family caregiver studies (e.g., Gaugler et al., 2008; Mellon, 2002; Pinquart & Sorensen, 2005), most of the caregivers studied were women (76%), were Caucasian (80%), were the patient's spouse (80%), lived with the patient (88%), and had a gross yearly income greater than $50,000 (64%). The mean age was 54.6 years (SD = 13.7 years; median = 55.5 years; range = 20–88 years). Participants were working full-time (34%), working part-time (9%), or not currently working (37%), with none being retirees (see Table 1). Several respondents did not complete the demographic information.

Caregiver Quality-of-Life–Cancer Scale

The participants completing the CQOL-C indicated four meaningful factors: Burden ($\bar{X}$ = 28.55) was the highest concern, followed by disruptiveness ($\bar{X}$ = 21.60), positive adaptation or financial concerns ($\bar{X}$ = 12.67), and support ($\bar{X}$ = 6.05), with eigenvalues of 29.34, 6.79, 5.48, and 3.74, respectively.

Kaiser's measure of sampling adequacy was 0.841, suggesting that the data were appropriate for the common factor model. The proportion of variance accounted for by each factor was 52.2%, 12.1%, 9.8%, and 6.7%, for a total of 80.8%. The internal consistency of the CQOL-C was estimated using the Cronbach alpha coefficient, which suggested a high degree of internal consistency for the first (0.9) and second (0.84) factors, very good internal consistency for the fourth factor (0.74), and weak internal consistency (0.28) for the third factor.

Caregiver Well-Being Scale

The CWB scale is comprised of two scales: Basic Needs Scale and Activities of Daily Living Scale. The Basic Needs Scale identified four meaningful factors, including expression of feelings ($\bar{X}$ = 3.9), attendance to physical needs ($\bar{X}$ = 3.38), security ($\bar{X}$ = 3.41), and confidence ($\bar{X}$ = 2.39), with eigenvalues of 21.35, 3.54, 2.62, and 2.32, respectively.

Kaiser's measure of sampling adequacy was 0.886, suggesting that the data were appropriate for the common factor model. The proportion of variance accounted for by each factor was 68.9%, 11.4%, 8.5%, and 7.5%, for a total of 96.3%. The internal consistency of the Basic Needs Scale also was estimated using the Cronbach alpha coefficient, which suggested a high degree of internal consistency for the first factor (0.92), very good internal consistency for the second (0.8) and third (0.77) factors, and weak internal constancy for the fourth factor (0.58).

However, the Activities of Daily Living Scale identified four important factors, including household maintenance ($\bar{X}$ = 3.88), family support and self-care ($\bar{X}$ = 3.21), leisure activity ($\bar{X}$ = 1.99), and personal maintenance ($\bar{X}$ = 3.38), with eigenvalues of 20.81, 8.43, 3.36, and 2.25, respectively. Kaiser's measure of sampling adequacy was 0.828, suggesting that the data were appropriate for the common factor model. The proportion of variance accounted for by each factor was 54%, 21.9%, 8.7%, and 5.8%, for a total of 90.4%. The internal consistency of the Activities of Daily Living Scale was estimated using the Cronbach alpha coefficient. Cronbach alpha for the first (0.89) and second factors (0.83) suggests a high degree of internal consistency and very good internal consistency for the third (0.71) and fourth factors (0.68). The items in each factor are reported in Figure 1.

Learning Needs

As seen in Table 2, family caregivers of patients with leukemia receiving chemotherapy identified as very

Caregiver Quality-of-Life–Cancer Scale

Factor 1: Burden
2. My sleep is less restful.
9. I fear my loved one will die.
11. My level of stress and worries have increased.
13. It bothers me, limiting my focus day to day.
14. I feel sad.
15. I feel under increased mental strain.
17. I feel guilty.
18. I feel frustrated.
19. I feel nervous.
21. I have difficulty dealing with my loved one's changing eating habits.
25. I fear the adverse effects of treatment on my loved one.
31. It upsets me to see my loved one deteriorate.
33. I am discouraged about the future.

Factor 2: Disruptiveness
1. It bothers me that my daily routine is altered.
3. My daily life is imposed upon.
8. My economic future is uncertain.
24. It bothers me that I need to be available to chauffeur my loved one to appointments.
26. The responsibility I have for my loved one's care at home is overwhelming.
29. It bothers me that my priorities have changed.
30. The need to protect my loved one bothers me.

Factor 3: Positive Adaptation and Financial Concerns
6. I am under financial strain.
7. I am concerned about our insurance coverage.
10. I have more of a positive outlook on life since my loved one's illness.
12. My sense of spirituality has increased.
22. I have developed a closer relationship with my loved one.

Factor 4: Support
16. I get support from my friends and neighbors.
34. I am satisfied with the support I get from my family.

Caregiver Well-Being Scale (Basic Needs)

Factor 1: Expression of Feelings and Self-Esteem
6. Feeling loved
7. Expressing love
9. Expressing laughter and joy
13. Feeling worthwhile
14. Feeling appreciated by others
15. Feeling good about family
16. Feeling good about yourself
21. Having people who think highly of you
22. Having meaning in life

Factor 2: Attendance to Physical Need
1. Having enough money
2. Eating a well-balanced diet
3. Getting enough sleep
4. Attending to your medical and dental needs
5. Having time for recreation

Factor 3: Security
17. Feeling secure about the future
18. Having close friendships
20. Making plans about the future

Factor 4: Confidence
11. Enjoying sexual intimacy
12. Learning new skills

Caregiver Well-Being Scale (Activities of Daily Living)

Factor 1: Household Maintenance
1. Buying food
2. Preparing meals
3. Getting the house clean
6. Having adequate transportation
7. Purchasing clothing
8. Washing and caring for clothing

Factor 2: Family Support and Self-Care
14. Taking time for reflective thinking
15. Having time for inspirational or spiritual interests
16. Noticing the wonderment of things around you
17. Asking for support from your friends or family
18. Getting support from your friends or family
19. Laughing

Factor 3: Leisure Activity
11. Enjoying a hobby
12. Starting a new interest or hobby

Factor 4: Personal Maintenance
21. Maintaining employment or career
22. Taking time for personal hygiene and appearance
23. Taking time to have fun with family or friends

Figure 1. Caregiver Quality-of-Life–Cancer Scale and Caregiver Well-Being Scale (Basic Needs and Activities of Daily Living)

Note. Numbers correlate with the questions on each instrument.

Table 2. Learning Needs Identified by Family Caregivers

Variable	Not Important n	Not Important %	Somewhat Important n	Somewhat Important %	Very Important n	Very Important %	N
Giving medications	27	15	25	13	133	72	185
Managing side effects of medications	15	8	15	8	157	84	187
Learning about managing symptoms[a]							
Pain	18	10	20	12	137	78	175
Nausea and vomiting	15	9	20	11	139	80	174
Fatigue	13	8	18	10	142	82	173

[a] Includes one mention each of appetite, dehydration, exercise, fever, fullness, high temperature, and psychological factors, and two mentions each of depression; however, no ranking was assigned to these categories.

important the need to learn about managing side effects (84%), giving medications (72%), and managing symptoms such as fatigue (82%), nausea and vomiting (80%), and pain (78%). Family caregivers also mentioned the importance of learning more about managing other symptoms, including appetite, dehydration, exercise, fever, fullness, psychological factors, and depression.

Caregivers identified five important themes when asked to "write anything else you feel nurses could do for you that would improve your quality of life as a caregiver." The themes were communication, failure to coordinate schedules, getting support, providing education, and nurses' positive attitudes and caring approaches. The following quotations illustrate each theme.

Communication: "Good communication between patient, caregiver, and nurses on the smaller details! As a caregiver, I focus on the big issues: medications, blood counts, etc."

Failure to coordinate schedules: ". . . individual departments do not schedule the next appointments in a timely manner and do not try to work with you to coordinate with your personal schedule. . . ."

Getting support: "Help us plan as a family so one person does not end up doing all the work. I have a teenage daughter who does not help partly because I do not know what to tell her to do."

Providing education: "Are there any brochures available regarding the drugs being received (patient education) or brochures that discuss all the areas open to patients and caretakers at this institution?"

Nurses' positive attitudes and caring approaches: "I believe the positive attitude of all staff has been exceptional. The honesty, friendliness, and knowledge they exhibit give me reassurance and comfort. It has been a wonderful experience."

Discussion

This article described QOL and well-being of caregivers of patients with leukemia receiving chemotherapy. Similar to other caregiver studies in cancer, caregivers of patients with leukemia described burden, disruptiveness, positive adaptation or financial concerns, and support as factors influencing their QOL. Caregiver variables, such as increased burden, poor psychological adaptation, and worsening physical function also can affect QOL and management of the patient (Andrews, 2001; Nijboer et al., 2000; Pasacreta & McCorkle, 2000; Schumacher, 1996; Weitzner & McMillan, 1999).

The authors believe this was the first study to use the CWB in assessing the well-being of caregivers of patients with leukemia. Berg-Weger et al. (2000) used the CWB scale with a mixed population of caregivers of adults and children, and the Basic Needs Scale identified the following factors: expression of feelings, attendance to physical needs, and self-security. On the Activities of Daily Living Scale, the factors were time for self or leisure activities, maintenance of functions outside the home, family support, household maintenance, and household tasks. This study described expression of feelings and self-esteem, attendance to physical needs, security, and confidence under the Basic Needs Scale, as well as household maintenance, family support, and self-care, leisure activity, and personal maintenance under the Activities of Daily Living Scale, as important aspects to improve the strength of caregivers.

Recognition of the educational and psychosocial needs of caregivers is an important first step to enhancing their QOL and well-being. Oncology nurses provide chemotherapy education and manage symptoms for patients and their caregivers. Caregivers have identified giving medications, managing side effects, and managing symptoms such as pain, nausea and vomiting, and fatigue as very important learning needs.

As described in other studies, communication with patients and healthcare providers is important in promoting caregivers' QOL (Iconomou et al., 2001). Other aspects identified included improved coordination of care, education, support, positive attitude, and caring approach by the healthcare team.

Several limitations to the study exist. This was a cross-sectional study in which data were obtained at one time point when the patient was undergoing chemotherapy in the outpatient setting; therefore, full understanding of the effect of cancer on the caregiver is limited. The patient was approached without consideration for stage of cancer or the number of treatments received. Another limitation was incomplete data because some family caregivers did not respond to all items. Most participants were Caucasian with a middle-class income (a gross salary greater

than $50,000) so results may not be applicable to different socioeconomic or ethnic groups.

Implications for Research and Practice

This article highlights the need for better communication and caregiver education, particularly in the areas of symptom management and medication administration. Additional research should focus on factors that affect caregivers' QOL, their educational needs, and interventions to assist nurses in better delivering new information or reinforcing old information. Other themes described by the caregivers to promote QOL include coordination of care, help for getting support for the caregiver, and the positive attitudes and caring approach of the nurses. The authors understand that unidentified needs can lead to decreased QOL and, therefore, future research should address the deficits identified by this study.

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References

Andrews, S.C. (2001). Caregiver burden and symptom distress. *Oncology Nursing Forum, 28,* 1469–1474.

Baider, L., & Bengel, J. (2001). Cancer and the spouse: Gender-related differences in dealing with healthcare and illness. *Critical Reviews in Oncology and Hematology, 40,* 115–123. doi: 10.1016/S1040-8428(01)00137-8

Berg-Weger, M., Rubio, D.M., & Tebb, S.S. (2000). The Caregiver Well-Being scale revisited. *Health and Social Work, 25,* 255–263.

Boyle, D., Blodgett, L., Gnesdiloff, S., White, J., Bamford, A.M., Sheridan, M., & Beveridge, R. (2000). Caregiver quality of life after autologous bone marrow transplantation. *Cancer Nursing, 23,* 193–203. doi: 10.1097/00002820-200006000-00006

Cameron, J.I., Franche, R.L., Cheung, A.M., & Stewart, D.E. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. *Cancer, 94,* 521–527. doi: 10.1002/cncr.10212

Cattell, R.B. (1966). The screen test for the number of factors. *Multivariate Behavioral Research, 1,* 245–276. doi: 10.1207/s15327906mbr0102_10

Crowe, H., & Costello, A.J. (2003). Prostate cancer: Perspectives on quality of life and impact of treatment on patients and their partners. *Urologic Nursing, 23,* 279–285.

Ferrans, C.E. (2005). Quality of life as an outcome of cancer care. In C.H. Yarbro, M.H. Frogge, M. Goodman, & S.L. Groenwald (Eds.), *Cancer nursing: Principles and practice* (6th ed., pp. 184–197). Sudbury, MA: Jones and Bartlett.

Gaston-Johansson, F., Lachica, E.M., Fall-Dickson, J.M., & Kennedy, M.J. (2004). Psychological distress, fatigue, burden of care, and quality of life in primary caregivers of patients with breast cancer undergoing autologous bone marrow transplantation. *Oncology Nursing Forum, 31,* 1161–1169. doi: 10.1188/04.ONF.1161-1169

Gaugler, J.E., Given, W.C., Linder, J., Kataria, R., Tucker, G., & Regine, W.F. (2008). Work, gender, and stress in family care giving. *Supportive Care in Cancer, 16,* 347–357. doi: 10.1007/s00520-007-0331-y

Giarelli, E., Pisano, R., & McCorkle, R. (2000). Stable and able. A standardized nursing intervention protocol for patients with cancer redefines the relationship among patients, caretakers, and nurses. *American Journal of Nursing, 100,* 26–31. doi: 10.2307/3522186

Glozman, J.M. (2004). Quality of life of caregivers. *Neuropsychology Review, 14,* 183–196. doi: 10.1007/s11065-004-8158-5

Goldstein, H. (1990). Strength or pathology: Ethical and rhetorical contrasts in approaches to practice. *Families in Society, 71,* 267–275.

Gozum, S., & Ackay, D. (2005). Response to the needs of Turkish chemotherapy patients and their families. *Cancer Nursing, 28,* 469–475. doi: 10.1097/00002820-200511000-00010

Hagedoorn, M., Buunk, B.P., Kuijer, R.G., Wobbes, T., & Sanderman, R. (2000). Couples dealing with cancer: Role and gender differences regarding psychological distress and quality of life. *Psycho-Oncology, 9,* 232–242. doi: 10.1002/1099-1611(200005/06)9:3<232::AID-PON458>3.0.CO;2-J

Iconomou, G., Vagenakis, A.G., & Kalofonos, H.P. (2001). The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. *Supportive Care in Cancer, 9,* 591–596. doi: 10.1007/s005200100259

Kaiser, H.F. (1970). A second generation little jiffy. *Psychometrika, 35,* 401–415. doi: 10.1007/BF02291817

Kitrungote, L., & Cohen, M.Z. (2006). Quality of life of family caregivers of patients with cancer: A literature review. *Oncology Nursing Forum, 33,* 625–632. doi: 10.1188/06.ONF.625-632

Langer, S., Abrams, J., & Syrjala, K. (2003). Caregiver and patient marital satisfaction and affect following hematopoietic stem cell transplantation: A prospective longitudinal investigation. *Psycho-Oncology, 12,* 239–253. doi: 10.1002/pon.633

Lloyd-Williams, M., Dennis, M., & Taylor, F. (2004). A prospective study to determine the association between physical symptoms and depression in patients with advanced cancer. *Palliative Medicine, 18,* 558–563. doi: 10.1191/0269216304pm923oa

McIlfatrick, S., Sullivan, K., & McKenna, H. (2005). What about the carers? Exploring the experience of caregivers in a chemotherapy day hospital setting. *European Journal of Oncology Nursing, 10,* 294–303. doi: 10.1016/j.ejon.2005.12.003

Mellon, S. (2002). Comparisons between cancer survivors and family members on meaning of the illness and family quality of life. *Oncology Nursing Forum, 29,* 1117–1125. doi: 10.1188/02.ONF.1117-1125

Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & van den Bos, G.A. (2000). Patterns of caregiver experiences among partners of cancer patients. *Gerontologist, 40,* 738–746.

Northouse, L.L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social Science and Medicine, 50,* 271–284. doi: 10.1016/S0277-9536(99)00281-6

Northouse, L.L., Mood, D.W., Montie, J.E., Sandler, H.M., Forman, J.D., Hussain, M., . . . Kershaw, T. (2007). Living with prostate

cancer: Patients' and spouses' psychosocial status and quality of life. *Journal of Clinical Oncology, 25,* 4171–4177. doi: 10.1200/JCO.2006.09.6503

Pasacreta, J.V., & McCorkle, R. (2000). Cancer care: Impact of interventions on caregiver outcomes. *Annual Review of Nursing Research, 18,* 127–148.

Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family care giving: A meta-analysis. *Gerontologist, 45,* 90–106.

Savoie, M.L., Nevil, T.J., Song, K.W., Forrest, D.L., Hogge, D.E., Nantel, S.H., . . . Lavoie, T.C. (2006). Shifting to outpatient management of acute myeloid leukemia. *Annals of Oncology, 17,* 763–768. doi: 10.1093/annonc/mdl011

Schumacher, K.L. (1996). Reconceptualizing family care giving: Family-based illness care during chemotherapy. *Research in Nursing and Health, 19,* 261–271. doi: 10.1002/(SICI)1098-240X(199608)19:4<261::AID-NUR1>3.0.CO;2-G

Stevens, J.P. (1996). *Applied multivariate statistics for the social sciences* (3rd ed.). Mahwah, NJ: Lawrence Erlbaum Associates.

Vedhara, K., Shanks, N., Anderson, S., & Lightman, S. (2000). The role of stressors and psychosocial variables in the stress process: A study of chronic caregiver stress. *Psychosomatic Medicine, 62,* 374–385.

Weitzner, M.A., & McMillan, S.C. (1999). The Caregiver Quality of Life Index-Cancer (CQOLC) scale: Revalidation in a home hospice setting. *Journal of Palliative Care, 15,* 13–20.

Weitzner, M.A., McMillan, S.C., & Jacobsen, P.B. (1999). Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *Journal of Pain and Symptom Management, 17,* 418–428. doi: 10.1016/S0885-3924(99)00014-7

Journal Club Questions

This article has been chosen as particularly suitable for reading and discussion in a Journal Club format. The following questions are posed to stimulate thoughtful critique and exchange of opinions, possibly leading to changes on your unit. Formulate your answers as you read the article. Photocopying of this article for group discussion purposes is permitted.

1. Which stressors may cause caregiver strain when a family member is undergoing cancer treatment?
2. How would you define or describe quality of life?
3. In your facility or practice, how do (or could) you assess caregiver strain and quality of life?
4. How can you assess whether caregiver strain is affecting the patient's adaptation to the disease and treatment?
5. Identify some important demographic characteristics of the caregivers in this study. Could the findings from this study be generalized to caregivers of patients undergoing adjuvant breast cancer treatment? Why or why not?
6. Which nursing interventions could increase caregiver quality of life over the continuum of the cancer experience?

At the end of the session, take time to recap the discussion and make plans to follow through with suggested strategies.