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# **Caring for the Caregiver**

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s 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 **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.

(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

| Table 1. Demographic Characteristics of Caregivers |         |          |          |          |          |     |  |  |  |  |  |
|--|---------|----------|----------|----------|----------|-----|--|--|--|--|--|
|  | Men     |          | Won      | nen      | Total    |     |  |  |  |  |  |
| Variable   | n       | %        | n        | %        | n        | %   |  |  |  |  |  |
| 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 (\$)                              | 2.4     | 6.2      | 05       | 6.4      | 100      | 6.4 |  |  |  |  |  |
| 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                                  | 17      | 47       | 26       | 20       | 50       | 2.4 |  |  |  |  |  |
| Full-time  | 17      | 47       | 36       | 29       | 53       | 34  |  |  |  |  |  |
| Part-time  | -       | - 17     | 15       | 12       | 15       | 9   |  |  |  |  |  |
| Unemployed<br>Other                                | 6<br>13 | 17<br>36 | 52<br>19 | 43<br>16 | 58<br>32 | 37  |  |  |  |  |  |
| Education  | 15      | 50       | 19       | 10       | 32       | 20  |  |  |  |  |  |
| 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  |         | 20       | 51       | 23       | 15       | 23  |  |  |  |  |  |
| Coresident   | 31      | 94       | 100      | 86       | 131      | 88  |  |  |  |  |  |
| Not a coresident                                   | 2       | 6        | 16       | 14       | 18       | 12  |  |  |  |  |  |
| Relation to care recipient                         | -       | Ū        |          |          |          | • = |  |  |  |  |  |
| 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.

# 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 ( $\overline{X} = 28.55$ ) was the highest concern, followed by disruptiveness ( $\overline{X} = 21.60$ ), positive adaptation or financial concerns ( $\overline{X} = 12.67$ ), and support ( $\overline{X} = 6.05$ ), 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 ( $\overline{X} = 3.9$ ), attendance to physical needs ( $\overline{X} = 3.38$ ), security ( $\overline{X} = 3.41$ ), and confidence ( $\overline{X} = 2.39$ ), 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 ( $\overline{X}$  = 3.88), family support and self-care  $(\overline{X} = 3.21)$ , leisure activity ( $\overline{X} = 1.99$ ), and personal maintenance ( $\overline{X} = 3.38$ ), with eigenvalues of 20.81, 8.43,

#### 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

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

- 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
- Having time for inspirational or spiritual interests
- 16. Noticing the wonderment of things around you
- 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

|  | Not<br>Important |         | Somewhat<br>Important |         | Very<br>Important |          |            |  |  |  |
|--|------------------|---------|-----------------------|---------|-------------------|----------|------------|--|--|--|
| Variable   | n                | %       | n                     | %       | n                 | %        | Ν          |  |  |  |
| Giving medications<br>Managing side effects of medications | 27<br>15         | 15<br>8 | 25<br>15              | 13<br>8 | 133<br>157        | 72<br>84 | 185<br>187 |  |  |  |
| Learning about managing symptoms <sup>a</sup>              |                  |         |                       |         |                   |          |            |  |  |  |
| 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        |  |  |  |

<sup>a</sup> 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. Simi-

lar 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 & Mc-Corkle, 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 selfcare, 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 crosssectional 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

# 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. The authors gratefully acknowledge the nurses in the ambulatory treatment center for all their assistance with identifying participants and gathering data.

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# **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.