

# Quality of Life, Quality of Care, and Patient Satisfaction: Perceptions of Patients Undergoing Outpatient Autologous Stem Cell Transplantation

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**Purpose/Objectives:** To further expand the limited body of knowledge of the perceptions of quality of life (QOL), quality of care, and patient satisfaction among patients who receive high-dose chemotherapy with an autologous stem cell transplant (ASCT) on an outpatient basis.

**Design:** Descriptive longitudinal.

**Setting:** Nine clinical sites associated with a national oncology practice management network in locations across the United States.

**Sample:** 36 patients scheduled to receive high-dose chemotherapy with ASCT selected by nonprobability consecutive sampling.

**Methods:** Subjects completed the Functional Assessment of Cancer Therapy–Bone Marrow Transplant (FACT-BMT) before high-dose chemotherapy, four to six weeks postchemotherapy, and six months postchemotherapy. An independent nurse researcher conducted telephone interviews about the treatment experience, perceptions of quality of care, and satisfaction with care. FACT-BMT data were analyzed using descriptive statistics and multivariate analysis of variance, and qualitative data about perceptions of care were analyzed using Giorgi's methodologic reduction. Bivariate associations were made between overall degree of satisfaction with care and QOL as measured by the FACT-BMT.

**Main Research Variables:** Clinical outcome, QOL, patient satisfaction, and patient perceptions of care quality.

**Findings:** Mean FACT-BMT scores were lower one month post-treatment than at baseline and highest six months post-treatment. Subjects with progressive disease reported lower QOL at one and six months post-treatment, noted more complaints, and ranked their satisfaction with care lower than subjects with no evidence of disease. Subjects offered ASCT program improvement recommendations in the areas of communication, information, nursing care, ancillary needs assistance, ancillary agencies, and survivor support.

**Conclusions:** In this study, the QOL of patients undergoing outpatient high-dose chemotherapy with ASCT decreased post-treatment but increased to levels higher than those found at pretreatment by six months. A good clinical outcome following high-dose chemotherapy and ASCT was associated with higher QOL and greater satisfaction with care.

**Implications for Nursing:** Knowledge of the outpatient ASCT experience and its effect on QOL can be used to further refine the content and timing of educational and supportive interventions for patients undergoing ASCT. Information about patients' satisfaction with treatment and perceptions of quality of care provides insight about their expectations and perceived needs and can be used to redesign outpatient ASCT programs.

The combination of outpatient high-dose chemotherapy and autologous stem cell transplantation (ASCT) is a feasible treatment approach for motivated patients and their caregivers. Treatment-related toxicity and clinical

## Key Points . . .

- ▶ Patient satisfaction is an indicator of quality of care and includes the elements of subjectivity, expectations, perceptions, previous experiences, personal norms for making judgments, and reports about care obtained from others.
- ▶ Researchers debate whether patients can assess the technical quality of their care. Some researchers assert that patients are able to assess only the appearance of competency and not true clinical competency.
- ▶ Cultural beliefs influence a patient's definition of health and illness as well as the perception of effective and ineffective care.
- ▶ Concurrently measuring patients' perceptions of care quality, satisfaction with care, and quality of life (QOL) provides rich information about their treatment experiences as well as the effect of treatment on QOL.

outcome data for outpatient ASCT of patients with non-Hodgkin lymphoma, Hodgkin disease, breast cancer, and multiple myeloma are similar to inpatient data (Dix & Geller, 2000; Kyle, 2001; Schwartzberg et al., 1998; Seropian et al., 1999; Summers, Dawe, & Stewart, 2000). Although several researchers have purported that outpatient ASCT has psychosocial and economic advantages when compared to referral to a transplant center for inpatient treatment (Meisenberg et al., 1998; Weaver, West, Schwartzberg, Birch, & Buckner, 1998), scant research has been conducted in this area. In addition, little is known about patients' perceptions about the quality

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of outpatient ASCT care or their satisfaction with having an ASCT on an outpatient basis. The purpose of this study was to explore patients' perceptions of quality of life (QOL), quality of care, and satisfaction with care while undergoing outpatient ASCT.

## Measuring Care Quality and Patient Satisfaction

Since the 1990s, measuring patient satisfaction has come to be regarded as the method of choice for obtaining patients' views about their care and has been adopted widely as an outcome indicator of quality of care (Huston, 1999; Jennings, Stagers, & Brosch, 1999; Wiechers & Wiechers, 1996). Most healthcare facilities today use some type of patient satisfaction measure to obtain patients' opinions about their care. However, the concept of satisfaction has many dimensions and is influenced by a variety of factors. For instance, patients are inclined to view their care favorably when a treatment has a positive effect and, conversely, tend to report that their care was poor when they experienced an inadequate or adverse response to treatment (Lin, 1996). In addition, the high levels of patient satisfaction recorded in standardized surveys, with 75%–90% of patients satisfied with their care (Acorn & Barnett, 1999; Avis, Bond, & Arthur, 1995), suggest that patient satisfaction has not yet been operationalized as a discriminating measure. These high levels of satisfaction may be attributed to methodologic weaknesses in the satisfaction survey, the timing of the survey, social desirability bias (e.g., the desire to please the staff), reluctance to express a negative opinion, the wording of questions, and response set bias (e.g., forced choice when selecting an answer to questions) (Avis et al., 1995; Bredart et al., 2002; Campbell, Roland, & Buetow, 2000).

Most researchers agree that patient satisfaction is a multi-dimensional concept; however, no consensus exists regarding which dimensions of care should be evaluated to measure patient satisfaction (Acorn & Barnett, 1999). Numerous studies measure patient satisfaction without explaining the concept. Mahon (1996) noted that "this uncertainty makes it imperative for investigators attempting to measure patient satisfaction to first answer the question, 'what are we truly trying to measure?'" (p. 1243).

Most definitions of patient satisfaction include the elements of subjectivity, expectations, and perceptions. Patients' satisfaction has been linked to their expectations; patients who expect to be satisfied tend to express satisfaction when surveyed (Fielding, Hedley, Cheang, & Lee, 1997; Hogan, 2000). Previous experience is believed to influence patient satisfaction, and patients' evaluation of care also is influenced by their experience of power, control, and autonomy in the professional-patient relationship and the ease with which they can adopt what they consider to be an appropriate "patient role" (Avis et al., 1997). Other influences include each patient's unique frame of reference and set of personal norms for making judgments about care (e.g., not feeling rushed, being treated with respect), patients' attitudes about receiving care, patients' knowledge of the services available, and reports about care that patients have obtained from others (Acorn & Barnett, 1999; Avis et al., 1995; Bredart et al., 2001; Oermann, Dillon, & Templin, 2000). Historically, researchers have suggested that patients who have good clinical outcomes

are more satisfied with their care; however, this positive association more likely represents a tendency of healthier people to report greater satisfaction with care than a tendency of patients who clinically improve to report greater satisfaction (Covinsky et al., 1998; Kaldenberg, 2001; Kane, Maciejewski, & Finch, 1997; Thi, Briancon, Empereur, & Guillemin, 2002; Welton & Parker, 1999).

Researchers debate whether patients make any distinction between the technical and interpersonal aspects of care (Bond & Thomas, 1992). One argument maintains that patients are not in a position to assess the technical quality of their care (Hart, 1996). Some assert that patients can assess only the "appearance of competency" and not true clinical competency (Carson, Carson, & Roe, 1998). In satisfaction measures that include patients' perceptions of their healthcare providers' competence and technical skills, patients consistently tend to rank competence and skills high (Bredart et al., 1999; Lin, 1996). However, Ward and Gordon (1994) found that patients in a pain management program indicated satisfaction with their care and rated their healthcare providers high in competency and skills, but they concurrently were experiencing moderate to severe pain. Therefore, patients' ability to judge the quality of the technical aspects of care is debatable.

Some researchers also disagree about whether patients consider "observed quality" and "perceived quality" as synonymous. As Hart (1996) aptly noted,

Patient perception that quality of service may be diminishing could be due to a revolution of rising expectations in which 'real' improvements in clinic quality (particularly if unseen) are not sufficiently appreciated. Conversely, a perception that quality is increasing could be a function of the 'hotel services' aspects of patient care (comfortable waiting areas, availability of refreshments, and so on) rather than a reflection on the technical aspects of clinic efficiency (p. 1239).

A great deal of variability can be found in the response formats used in eliciting patient ratings of quality care and satisfaction. Scales vary from "agree or disagree" to seven options ranging from "very satisfied" to "not at all satisfied." To date, little research has addressed whether differences exist between respondents and nonrespondents. A review of 210 published patient satisfaction and quality-of-care studies revealed a response rate of 77% for surveys distributed in person and 67% for mailed surveys (Sitzia & Wood, 1998). Nonrespondents may be less satisfied with care than respondents; however, some researchers found that patients who were more satisfied with their care were less likely to return questionnaires (Howland-Gradman & Broderick, 2002; Lin, 1996).

Demographic characteristics such as age, gender, and education appear to affect patients' ratings of satisfaction. Older patients are more likely to rate higher satisfaction (Lin, 1996; Rahmqvist, 2001; Thi et al., 2002), men are more likely to be satisfied with care than women, and less-educated patients are more satisfied with the care they receive (Foss, 2002; Rahmqvist; Thi et al.).

Cultural beliefs influence a patient's definition of health and illness as well as the perception of effective and ineffective care. Many patient satisfaction models have a dominant Anglo-European cultural influence; therefore, meaningful ethnocultural data that focus on the perceptions, attitudes, values, and expectations of diverse patient populations are

needed to accurately assess patient satisfaction (Bushy, 1995). With all of the variables involved in assessing patient satisfaction, as well as the multitude of methods and questionnaires, Kravitz's (1998) question about whether assessing patient satisfaction with health care is "a critical outcome or simply 'trivial pursuit'" (p. 280) is not surprising.

Developers of patient satisfaction tools often have failed to provide adequate evidence for the reliability and validity of their patient satisfaction measures. Only 11 of 181 (6%) published articles describing patient satisfaction instruments reported content validity and criteria or construct validity and reliability (Sitzia, 1999). Most existing patient satisfaction tools have been found to be insensitive to discriminating patient satisfaction; they generate highly positive skewed scores. No matter how good or bad the care is, patients generally are highly satisfied (Lin, 1996; Scardina, 1994).

Most patient satisfaction surveys have been designed to assess satisfaction with inpatient care at a particular facility, care rendered in emergency departments and physicians' offices, and care provided during specific procedures, such as laser eye surgery and laparoscopic procedures. Few studies specifically have addressed patient satisfaction with blood or marrow transplant procedures in outpatient settings. Lawrence, Gilbert, and Peters (1996) assessed patient satisfaction with outpatient autologous bone marrow transplantation (BMT) by asking six open-ended questions during a personal interview conducted before discharge. The researchers asked patients what they liked and did not like about the outpatient BMT program, how the program could be improved, what problems were encountered during the outpatient BMT process and in the hospital, and what levels of anxiety were experienced. Lawrence et al. found that patients preferred being out of the hospital and reported that their anxiety was controlled, although most had some difficulty with the outpatient clinic or medications required. This study provides some preliminary information about patient satisfaction with a specific outpatient BMT program, but the findings cannot be generalized to other settings. In addition, the reliability and validity of the questionnaire were not assessed, and the study's design did not address the many factors noted previously (e.g., timing of the survey, reluctance to express a negative opinion) that are believed to influence perceptions of patient satisfaction.

The most significant criticism about patient surveys is that they are producer-led; in other words, questions are developed solely by the researcher. The voice of the ultimate consumer—the patient—is not heard. The providers of the service frame the questions, and patients circle or check off their answers (Hart, 1996). As Carr-Hill (1992) noted, "The questionnaire method only obtains answers to a series of preset questions, not the patient's considered or spontaneous views on the issues that concern them. Thus, it is common place to observe that health policy has been steered by the providers' perceptions and definitions of good practice" (p. 245). Therefore, researchers need to know which factors truly affect perceptions of quality care and patient satisfaction from the patients' perspectives. Emphasis needs to shift from what healthcare providers believe is quality and what they perceive that patients desire in terms of quality to what patients themselves perceive to be quality (Kirsner & Federman, 1997; Lynn & McMillen, 1999; Lynn & Moore, 1997). Avis et al. (1995) noted that "a qualitative approach to obtaining patients'

views about their care is essential in order to maintain a critical perspective, utilizing the full range of patients' values and experiences" (p. 319).

## Measuring Quality of Life

A majority of clinical trials and cancer research studies include some form of QOL assessment. Many definitions of QOL exist, and dozens of instruments to measure QOL have been developed (Dean, 1997; Padilla & Frank-Stromborg, 1997; Stenstrup, 1996). King et al. (1997) noted that more than 4,000 QOL health-related articles were published from 1993–1997 and that 1,022 of those articles referred to QOL in patients with cancer.

The general Functional Assessment of Cancer Therapy–BMT (FACT-BMT) (McQuellon et al., 1997) is a 47-item measure of five dimensions of QOL in BMT recipients. A three-step validation process of the instrument involved the generation of BMT-specific items and the testing of overall measures. Items were selected from a list produced by 7 oncology experts and 15 patients and were designed to assess QOL content specific to the BMT process. A total of 182 patients completed the FACT-BMT at baseline, prior to BMT. An analysis measuring sensitivity to change was performed with 74 patients after transplantation and 60 patients at baseline, hospital discharge, and 100 days following transplant. The FACT-BMT subscales were correlated, sensitivity to change was measured, and the internal consistency for each scale was calculated. Coefficients of reliability and validity ranged from 0.86–0.89 for the entire FACT-BMT and 0.54–0.63 for the BMT subscale. The BMT subscale was used to discriminate patients on the basis of performance status rating and demonstrated sensitivity to change over time.

In October 1997, version 4 of the FACT-BMT was introduced. Version 4 is identical to the prior version with the exception that the BMT subscale was expanded from 12 items to 23 to more specifically measure the unique effects of BMT on QOL. Items that were added to the subscale included ability to remember things, ability to concentrate, experiencing frequent colds or infections, experiencing blurry eyesight, noting food taste changes, having tremors, experiencing shortness of breath, having skin problems, experiencing bowel trouble, whether illness is a hardship on family members, and the cost of treatment (McQuellon et al., 1997).

## Methods

A qualitative phenomenologic approach consisting of three patient interviews via telephone over a six-month period of time was used to explore the experience of outpatient ASCT, perceptions of care quality, and satisfaction with the outpatient treatment. The FACT-BMT version 4 instrument (McQuellon et al., 1997) was used to measure QOL prior to, during, and following the outpatient treatment experience. Clinical outcome, or treatment response, was determined by the patients' treating physicians and categorized as successful or unsuccessful.

## Sample and Settings

English-speaking adults, who were 18 years of age and older and scheduled for outpatient ASCT following high-dose chemotherapy in nine clinical sites affiliated with US Oncology,

were eligible to participate in this study. Patient exclusion criteria included lack of access to a telephone and cognitive dysfunction impairing the patient's ability to provide informed consent or respond to questions.

Sample sizes in qualitative research are determined by the particular type of qualitative method used and the purpose of the research. When phenomenologic methods are used to discern the essence of experiences and generate items for an instrument, at least 25 descriptions of an experience are required (Sandelowski, 1995). Therefore, 25 or more participants were needed to provide data for the qualitative component of this study that explores the treatment experience and patients' perceptions of that experience (patient satisfaction). The researchers needed to obtain enough data to develop domain descriptions so that a tool measuring patient satisfaction could be created in the future.

For the quantitative component of this study, which involved repeated measures of QOL, a sample size of 35 was required to have a power of 0.80 when the effect size is 0.60 and  $\alpha_2$  equals 0.10 (Portney & Watkins, 1993). Using nonprobability consecutive sampling, 40 patients were enrolled in this study to allow for potential participant attrition because data were collected on each patient over a six-month period.

## Instruments

FACT-BMT version 4 (McQuellon et al., 1997) is a self-completed measure of five dimensions of QOL (i.e., physical [7 items], social/family [7 items], emotional [6 items], and functional well-being [7 items]; and BMT effects [23 items]). A Likert-type scale is used to rate each item, such as "I have a lack of energy," from 0 (not at all) to 4 (very much). Higher scores are associated with higher levels of satisfaction with QOL, and total scores for the FACT-BMT can range from 0–200. Although BMT differs in some ways from ASCT, potential complications and toxicities are similar. Furthermore, a tool with specific subscales addressing transplantation effects on QOL was believed to be superior to generic measures of QOL that do not incorporate treatment-specific subscales.

Telephone interviews guided by open-ended questions were used to explore patients' ASCT experiences and satisfaction with the outpatient ASCT process. Phenomenology seeks to find personal meanings in experiences, such as undergoing ASCT, and ultimately strives to understand the experience from the patient's point of view. Meaningful narrative data are obtainable because patients are able to freely express their perceptions, attitudes, values, and expectations. Pretreatment telephone interviews began with the question, "What do you think your treatment will be like for you?" Post-treatment interviews began with the question, "What has your treatment experience been like for you?" Other questions asked during the pre- and post-treatment interviews are listed in Figure 1. Additional question probes were used when applicable to clarify or expand patients' responses.

Calnan's (1988) conceptual framework of lay evaluation of health care and the Linder-Pelz (1982) theory of patient satisfaction further guided the telephone interview format. Calnan's framework incorporates the following elements: the goals of those seeking care, the level of experience of use of health care, the values placed on health and health care, and the images of health held by the lay population. Linder-Pelz asserted that probable determinants of a patient's satisfaction with health care are

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### Pretreatment

- What do you think your treatment will be like for you?
- How do you define the words "health" and "illness"?
- How important is it to you to be healthy?
- What do you hope your treatment will accomplish?
- Have you received health care in the past? Please describe your experiences and your feelings about your care.
- What are your expectations for the care you will receive at [name of treatment facility]?
- Have you received information or suggestions from others (e.g., other patients who underwent autologous stem cell transplantation, family members, friends) about your treatment, and if so, what are your thoughts about the information you received?

### Post-treatment telephone interview

- What has your treatment experience been like for you?
- In the pretreatment telephone interview, you said your goal of undergoing treatment was \_\_\_\_\_. To what degree has the chemotherapy and stem cell rescue met this goal?
- How would you compare your previous experiences with health care to your current experiences?
- How would you compare the information you received prior to treatment with your actual experiences so far?
- Did you talk with other patients who have undergone this treatment before you had your transplant? Was talking with other patients helpful or not helpful to you?
- What could be done differently to make the treatment process easier or better?
- How satisfied are you with your care?
- When you hear the term "quality care," what kinds of things come to mind?
- Did you receive "quality care"? [Please explain.]

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## Figure 1. Pre- and Post-Treatment Questions Used to Guide the Telephone Interviews

his or her attitudes and perceptions prior to experiencing care; in addition, expectations, values, entitlement, occurrences, and interpersonal comparisons influence satisfaction with care.

### Data Collection

After approval of the study by the institutional review board, local nurse coordinators informed patients scheduled to undergo high-dose chemotherapy with ASCT of their eligibility to participate in the study. Following an explanation of the study and agreement to participate, written informed consent was obtained from the patients and demographic patient information was sent via facsimile to an independent nurse researcher located in another city. The coordinators gave a copy of the FACT-BMT instrument to each patient to complete prior to receiving high-dose chemotherapy with instructions to place initials on the form and omit a return address on the postage-paid envelope. When patients were contacted by the nurse researcher via telephone for the initial interview, the study was described again and participants were informed that the nurse researcher was not an employee of the clinical site where they obtained treatment, telephone interviews would be recorded, study participation could be terminated at any time, and confidentiality would be maintained strictly.

During the two subsequent telephone interviews, during the four to six weeks following high-dose chemotherapy, and at six months postchemotherapy, patients were asked to complete the FACT-BMT forms and describe their treatment experiences. Additional question probes explored how

their experiences met or did not meet their expectations, perceptions of healthcare providers' competence and caring, problems encountered during ASCT, and their perception of overall satisfaction, which they were asked to describe and rate on a scale of 0 (not at all satisfied) to 10 (highest level of satisfaction imaginable).

## Data Analysis

Qualitative data obtained during the telephone interviews were recorded, and the audiotapes were transcribed professionally. The typed interview transcripts were analyzed using Giorgi's methodologic reduction (Beck, 1994). The qualitative data reflecting patients' responses about their treatment experiences and satisfaction with their treatment were categorized; for instance, responses to questions about goals of seeking care, previous experiences with health care, and expectations of treatment were examined for common themes and categorized accordingly.

A decision trail was maintained to allow for audit ability, and data reduction was performed independently by the nurse researcher and a research assistant (a doctoral nursing student) to ensure that patient responses were categorized properly. Because the interview was conducted by a person outside of the organization that treated the patients, neutrality was enhanced, thereby reducing bias, motivations, interests, or perspectives in patient responses (Beck, 1994; Sandelowski, 1986).

Quantitative data were coded for statistical analysis, and the research assistant checked ongoing data entry for reliability. The SPSS® (SPSS Inc., Chicago, IL) computer statistical software system was used for data analysis. Statistical methods included simple descriptive techniques of demographic data, and a one-group repeated measures design using multivariate analysis of variance was used to evaluate scores on the FACT-BMT. Bivariate associations were made between patients' overall degree of satisfaction as expressed during the telephone interviews and their QOL as measured by the FACT-BMT.

## Results

### Sample Demographics

Forty patients met the study criteria and consented to be enrolled. A 45-year-old man with multiple myeloma withdrew from the study after consenting to participate but before the initial interview was conducted and FACT-BMT was completed because he developed an increased temperature, had his stem cell harvest delayed, and ultimately decided not to participate in the study. Three additional patients were withdrawn from the study: (a) A 37-year-old man with lymphoma completed the initial interview and FACT-BMT but was unable to mobilize a sufficient number of stem cells and therefore could not undergo ASCT, (b) a 50-year-old woman with breast cancer completed the initial interview and FACT-BMT but decided to undergo her transplant in the hospital because she did not have adequate support at home, and (c) a 36-year-old woman with non-Hodgkin lymphoma reported having personal problems and declined to complete the second and third interviews and FACT-BMT forms.

Table 1 shows the demographic information for the 36 participants who completed three telephone interviews and three FACT-BMT forms (at baseline, four to six weeks postchemotherapy, and six months postchemotherapy). When asked what

they expected the high-dose chemotherapy and ASCT to accomplish, 20 (56%) wanted the therapy "to cure my cancer" and 16 (44%) said that they expected to get "control of the cancer." A significant difference was found in age groups and goal of therapy; the goal for patients younger than age 50 was cure, whereas the goal for those older than age 50 was control ( $p = 0.045$ ). No significant differences were found in goals of treatment when patients were grouped by diagnosis.

Thirty (83%) participants reported that their previous experiences with health care were positive, whereas six (17%) reported negative previous experiences, including accounts of delayed diagnosis, interpersonal communication problems, and surgical complications. No significant differences existed in perceptions of previous experiences when patients were grouped by diagnosis or education.

When asked to rate the overall treatment experience at four to six weeks post-treatment, 30 (83%) participants reported having a positive experience and 5 (14%) reported having a negative treatment experience (one patient had a neutral experience). No significant differences were found in perceptions of the overall ASCT experience when patients were grouped by diagnosis or education. A negative treatment experience was associated with experiencing severe or life-threatening side effects during high-dose chemotherapy and ASCT ( $p = 0.002$ ). Perceptions of side effects were ranked as mild by 12 patients (33%), moderate by 15 patients (42%), severe by 7 patients (19%), and life threatening by 2 patients (6%). Various complications that required hospitalizations of 1–22 days in duration occurred in 25 patients (69%). Eleven patients did not require hospitalization at any point.

### Quality-of-Life Scores

QOL scores are reported in Table 2. Mean group scores for the FACT-BMT were 141.37 at baseline, 136.03 one month post-treatment, and 156.20 six months post-treatment (a maximum total score is 200). No significant differences were found in any of the FACT-BMT subscales or total scores at baseline, four to six weeks post-treatment, or six months post-treatment between men and women; among patients who lived at home, in an apartment, or in a residence facility during treatment; by cancer diagnosis; or by length of time since diagnosis.

One way analysis of variance revealed that no significant differences existed among three age groups (i.e., 18–41, 42–49, and 50–65 years) and any of the FACT-BMT subscales or total scores at baseline, four to six weeks post-treatment, and six months post-treatment. A significant difference was found in scores for the emotional well-being subscale at four to six weeks post-treatment when patients were grouped by marital status; patients who had never married had significantly higher scores indicating higher levels of emotional well-being ( $\bar{X} = 19.4$ ) than married patients ( $\bar{X} = 14.63$ ,  $p = 0.017$ ).

College-educated patients had significantly higher physical well-being subscale scores ( $\bar{X} = 22.11$ ) at four to six weeks post-treatment than those with some college ( $\bar{X} = 17.35$ ) and those with a high school education ( $\bar{X} = 15.7$ ,  $p = 0.014$ ), and significantly higher FACT scores ( $\bar{X} = 82.11$ ) at four to six weeks post-treatment than those with some college ( $\bar{X} = 68.11$ ) or a high school education ( $\bar{X} = 64.5$ ,  $p = 0.007$ ). Total FACT-BMT scores at four to six weeks postchemotherapy were significantly higher for college graduates ( $\bar{X} = 152.0$ ) than high school graduates ( $\bar{X} = 125$ ,  $p = 0.016$ ).

**Table 1. Demographic Sample Summary**

| Variable  | n  | %  |
|---|----|----|
| <b>Location of residence</b>                            |    |    |
| Colorado  | 12 | 33 |
| Kansas  | 10 | 28 |
| Texas   | 3  | 8  |
| Indiana   | 3  | 8  |
| North Carolina  | 3  | 8  |
| South Carolina  | 2  | 6  |
| Arizona   | 1  | 3  |
| Virginia  | 1  | 3  |
| Nevada  | 1  | 3  |
| <b>Gender</b>   |    |    |
| Female  | 27 | 75 |
| Male  | 9  | 25 |
| <b>Location during chemotherapy or stem cell rescue</b> |    |    |
| Home  | 23 | 64 |
| Apartment   | 12 | 33 |
| Residence facility                                      | 1  | 3  |
| <b>Age (years)</b>                                      |    |    |
| 18–25   | 1  | 3  |
| 26–33   | 4  | 11 |
| 34–41   | 4  | 11 |
| 42–49   | 11 | 31 |
| 50–57   | 14 | 39 |
| 58–65   | 2  | 6  |
| <b>Race</b>   |    |    |
| Caucasian   | 34 | 94 |
| African American  | 1  | 3  |
| Hispanic  | 1  | 3  |
| <b>Diagnosis</b>  |    |    |
| Breast cancer, stage IV                                 | 11 | 31 |
| Breast cancer, stage II–III                             | 10 | 28 |
| Lymphoma  | 7  | 19 |
| Multiple myeloma  | 5  | 14 |
| Germ cell   | 1  | 3  |
| Hodgkin disease   | 1  | 3  |
| Ovarian cancer  | 1  | 3  |
| <b>Previous stem cell transplant</b>                    |    |    |
| No  | 35 | 97 |
| Yes   | 1  | 3  |
| <b>Relationship status</b>                              |    |    |
| Married   | 24 | 67 |
| Married-like relationship                               | 1  | 3  |
| Never married   | 5  | 14 |
| Separated or divorced                                   | 6  | 17 |
| <b>Education</b>  |    |    |
| High school graduate                                    | 10 | 28 |
| Some college  | 17 | 47 |
| College graduate  | 5  | 14 |
| Postgraduate  | 4  | 11 |
| <b>Employment status</b>                                |    |    |
| Employed outside the home                               | 29 | 81 |
| Not employed outside the home                           | 5  | 14 |
| Retired   | 2  | 5  |
| <b>Length of time since cancer diagnosis</b>            |    |    |
| Less than three months                                  | 2  | 6  |
| Three months to one year                                | 15 | 42 |
| One to two years  | 6  | 17 |
| More than two years                                     | 13 | 36 |

*(Continued in next column)*

Note. Because of rounding, not all percentages total 100.

N = 36

Patients who had progressive disease had significantly lower physical well-being subscale scores ( $\bar{X} = 13$ ) six months post-treatment than patients on adjuvant therapy ( $\bar{X} = 22$ ) or those with no evidence of disease ( $\bar{X} = 22.07$ ) and had significantly lower overall FACT-BMT scores at six months post-treatment ( $\bar{X} = 123$ ,  $p = 0.045$ ).

Patients who reported negative previous healthcare experiences had significantly lower emotional well-being subscale scores ( $\bar{X} = 12.2$ ) at one month post-treatment than did those who reported having positive previous experiences ( $\bar{X} = 16.73$ ,  $p = 0.025$ ). Scores at six months for additional concerns (i.e., the BMT component of the FACT-BMT that contains 23 transplant-specific items) were significantly higher for patients who had positive previous healthcare experiences ( $\bar{X} = 73.8$ ) than for those who had negative previous experiences ( $\bar{X} = 63.6$ ,  $p = 0.017$ ). Total FACT-BMT scores at six months also were significantly higher for patients with positive previous experiences ( $\bar{X} = 159.1$ ) than for those with prior negative experiences ( $\bar{X} = 138.8$ ,  $p = 0.035$ ).

“Satisfaction with sex life” was rated as 1.93 at baseline, 1.77 at four to six weeks post-treatment, and 2.31 at six months post-treatment (group means). Patients older than 50 years rated their baseline satisfaction with their sex life significantly lower than did patients younger than 50 years ( $p = 0.003$ ). Older patients also had significantly lower mean sex life satisfaction scores at six months post-treatment ( $p = 0.026$ ).

Concern about a job, including work at home, declined over time and was rated as 1.39 at baseline, 1.09 at four to six weeks post-treatment, and 0.727 at six months post-treatment. No significant differences were identified in job concern among patients in three age groups (i.e., 18–41, 42–49, and 50–65 years). The greatest amount of concern about employment was expressed pretreatment, which is expected because of the uncertainty about the transplant’s effectiveness and the unknown complications that might occur. At six months post-treatment, most of the patients who had been employed had returned to work.

Memory loss and concentration impairment were experienced by 22 patients (61%). Significantly more patients with

**Table 1. Demographic Sample Summary (Continued)**

| Variable   | n  | %  |
|--|----|----|
| <b>Number of days hospitalized following outpatient chemotherapy and stem cell rescue (N = 36)</b> |    |    |
| Not hospitalized   | 11 | 31 |
| 1–3  | 9  | 25 |
| 4–7  | 9  | 25 |
| 8–12   | 1  | 3  |
| 13–17  | 4  | 11 |
| 18–22  | 2  | 6  |
| <b>Reason for hospitalization (N = 25)</b>   |    |    |
| Neutropenic fever  | 12 | 48 |
| Gastrointestinal complications   | 6  | 24 |
| Infected IV catheter   | 2  | 8  |
| Caregiver issues   | 2  | 8  |
| Hemorrhagic cystitis   | 1  | 4  |
| Platelet transfusion reaction  | 1  | 4  |
| Bartholin gland abscess  | 1  | 4  |

Note. Because of rounding, not all percentages total 100.

**Table 2. Mean Quality-of-Life Scores**

| Quality-of-Life Dimensions (Range)         | Baseline | One Month Postchemotherapy | Six Months Postchemotherapy |
|--|----------|----------------------------|-----------------------------|
| Physical well-being (0–28)                 | 19.74    | 18.08                      | 21.54                       |
| Social and family well-being (0–28)        | 23.20    | 20.56                      | 22.29                       |
| Emotional well-being (0–24)                | 16.43    | 16.06                      | 19.66                       |
| Functional well-being (0–28)               | 16.83    | 15.92                      | 20.37                       |
| Total FACT score (total of above) (0–108)  | 76.20    | 70.61                      | 83.86                       |
| Additional concerns specific to BMT (0–92) | 65.17    | 65.42                      | 72.34                       |
| Total score, FACT-BMT (0–200)              | 141.37   | 136.03                     | 156.20                      |

BMT—bone marrow transplant; FACT—Functional Assessment of Cancer Therapy; FACT-BMT—Functional Assessment of Cancer Therapy–Bone Marrow Transplant

N = 36

stage IV breast cancer (none had known brain metastasis) experienced memory loss compared to patients with other diagnoses ( $p = 0.036$ ). Concentration and memory problems were described as affecting work, household responsibilities, leisure activities, and interpersonal relationships. As one woman noted during the four-week postchemotherapy interview, “I don’t know what’s worse. I either forget to tell my husband something or I tell him twice.”

Satisfaction with care (0 = very dissatisfied to 10 = extremely satisfied) was rated as 9.11 at four to six weeks post-treatment and 9.14 at six months post-treatment. At six months, 29 patients (80%) were without evidence of disease, 5 (14%) had received or were receiving adjuvant treatment with radiation therapy, and 2 (6%) had progressive disease. Patients with progressive disease had significantly more complaints about the treatment experience than did patients who had no evidence of disease or were receiving adjuvant therapy at six months post-treatment ( $p = 0.024$ ).

Patients who had progressive disease had significantly more regret for having had the transplant four to six weeks post-treatment than did patients who had no evidence of disease ( $p = 0.003$ ) and had significantly more regret than patients receiving adjuvant therapy and disease-free patients at six months post-treatment ( $p = 0.0001$ ). A man with lymphoma whose disease recurred six weeks after his stem cell transplant said, “I never would have gone through [the transplant], if I’d known that this cancer would have come back so soon.”

Relationships among variables were examined. No relationships were found between gender and goal of treatment, previous experiences, length of time since diagnosis, perceptions of treatment experience (positive or negative), perceptions of severity of side effects, or clinical status at six months. Additionally, no relationships were found between where the patient lived while receiving the treatment (home, apartment, or residence facility) and length of time since diagnosis, perceptions of treatment experience (positive or negative), or perceptions of side effects. No significant differences existed between age and length of time since diagnosis, perceptions of treatment experience, or perceptions of side effect severity.

### Interview Data

Telephone interviews, 20–30 minutes each in duration, were conducted at times identified as convenient for the participants in this study. Participants were asked to define the word “health” during the pretreatment interview; 30 (83%) people defined health as the absence of illness or functional impair-

ment, and 6 (17%) defined health holistically. For example, one woman said, “Health has more than one dimension. There’s the physical component for sure, but there’s also the emotional side and the spiritual side.” Participants rated being healthy as very important. Expectations of the treatment experience varied widely and included responses such as “I have no idea what it will be like. I try not to think about it,” “I expect the worst and hope for the best,” and “It’s gonna be a piece of cake.”

Several information sources were identified in the initial interviews. Forty-eight percent of the patients talked about independently researching treatment options or obtaining information from their referring oncologists prior to being seen at the transplant center, but all 36 patients stated that the bulk of information they received about high-dose chemotherapy and ASCT came from personnel at the treatment sites. Three patients contacted national information sources such as the National Cancer Institute and the International Multiple Myeloma Society. Two searched medical libraries for information, although they added that the journal articles were difficult to read and understand. Seventeen patients or their friends and families searched for information on the Internet and reported that they were overwhelmed by the sheer volume of data and disappointed by the quality of some of the information they had to sift through to locate what they perceived to be reliable content.

The participants in this study had various responses after talking with other patients who had undergone ASCT. For 16 of the 20 study participants who spoke with other patients, the experience offered an opportunity to obtain information from those with firsthand experience with the treatment; however, for the four others, the subjective nature of the information provided was not believed to be relevant or was perceived as unhelpful or frightening.

One patient (3%) stayed at a residence facility during treatment, 23 (64%) lived at home, and 12 (33%) stayed in an apartment during the outpatient ASCT treatment. Apartment and residential facility stays (usually four to six weeks in length) were required for those patients who resided too far away from the stem cell transplant program sites. Five of the 35 (14%) patients expressed apprehension about staying at home, whereas the remainder expressed relief that the ASCT could be performed on an outpatient basis. One patient who originally was scheduled for an outpatient transplant ultimately decided to have the ASCT in the hospital and said the following.

I’m going in the hospital for three to four weeks to do the transplant there. Outpatient would have been too

much of a hardship on my family. My husband can't take three weeks off in a row, my son lives out of town, and my daughter has three little kids. Besides, isn't that why hospitals are there in the first place? Nobody expects your husband to take out your appendix, so why all of a sudden are family members expected to do all kinds of medical things when you need chemo and a stem cell transplant?

## Quality Care From the Patient's Perspective

Participants were asked to describe what they thought comprised quality care prior to high-dose chemotherapy, one month postchemotherapy, and six months postchemotherapy. Two patients described quality care in the following way: "Care is good when you don't have any complaints; it's as simple as that" and "Most people don't know what good care is until they don't get it."

Data on the components of quality care were collected until data saturation occurred. Common themes among the many responses were identified. The perceived indicators of quality were categorized into one of the following areas.

- **Healthcare provider attributes:** professional appearance, caring attitude, interpersonal skills, clinically competent, attentive, views patients as individuals, provides holistic care, responsive
- **Characteristics of the treatment facility:** efficient and safe environment, inviting atmosphere, well-maintained furniture and equipment, promotes patient comfort
- **Stem cell program attributes:** collaborative approach, continuity of care, family-centered care and support

Participants in this study were able to articulate what they believed to be very specific indicators of quality. Many (72%) of the patients phrased quality indicators in the negative (e.g., "I wasn't sure who was taking care of me. Everybody looks the same now, and the names on the tags are so small"). The researcher positively rephrased all of the comments in the abridged list of three indicator categories for consistency. For example, if a participant indicated that a nurse appeared to be dressed unprofessionally, the researcher rephrased the comment to "professional appearance."

Several specific suggestions for ASCT program improvement were offered by the participants in this study. Thirty patients recommended personalizing the information about ASCT to a greater degree. One patient noted that "everybody gets the same drill, the same notebook. It would have been nice if they had asked me what I was concerned about or what I wanted to know first, before going on auto-pilot and rattling off the standard information." Three patients requested that healthcare providers consistently include rationales when teaching procedures or making symptom management recommendations. One patient commented, "They said I needed to be reimmunized, but it wasn't clear why."

Study participants also suggested that the healthcare providers initiate a conversation about topics that are not routinely discussed or are underemphasized, such as spirituality, sexuality, effects of treatment on fertility, long-term effects, and complementary and alternative therapies. Patients requested more explicit recommendations to maintain strength and activity tolerance. One patient noted, "I asked about exercise and they said 'use common sense.' I wanted more direction than

that." Patients expressed their need for expanded information about fatigue, skin changes, and how to dress or undress while connected to infusion pumps. Their suggestions were site specific or regionally influenced; for example, they reported that communication with certain homecare agencies could be improved, respite care services were needed to enable family caregivers to run errands or take a break, and psychosocial support services should be offered for patients and families post-transplant. Excerpts from the qualitative data appear in Figure 2.

## Discussion

Data from 36 patients who underwent high-dose chemotherapy and ASCT at nine outpatient treatment facilities in various regions of the United States revealed that the majority had a positive overall treatment experience. Patients reporting a negative experience also experienced severe or life-threatening side effects. Nearly a third of the patients in the present study were able to undergo intensive chemotherapy and ASCT completely on an outpatient basis. Few published studies clearly have documented how often and for how long hospitalization is needed during outpatient transplants. In a study of 49 patients with non-Hodgkin lymphoma or Hodgkin disease who received outpatient ASCT, only 14 (28%) were never admitted to the hospital (Seropian et al., 1999). The incidence of hospitalization in the present study is lower than that reported by Seropian et al.; however, data comparison is limited because of differences in cancer diagnoses and the number of treatment facilities used in the studies.

Febrile neutropenia requiring hospitalization occurred in nearly half of the patients, which is not unexpected because neutropenic fever occurs frequently among patients undergoing high-dose chemotherapy with ASCT (Dix & Geller, 2000). However, nearly two-thirds of the patients who required hospitalization in the present study were hospitalized for a week or less.

Mean QOL, as measured by the FACT-BMT, dropped from pretreatment levels four to six weeks post-treatment and was highest at six months post-treatment. This variation is similar to the trend in FACT-BMT scores observed by McQuellon et al. (1997) in an evaluation of the FACT-BMT version 3 scale, as well as the experiences of patients with non-small cell lung cancer who received radiation therapy in a study conducted by John (2001) where perceptions of QOL decreased during treatment and increased post-treatment at one and four months. No significant differences in FACT-BMT scores (subscale and total scores) were found when gender, age, outpatient residence location (home versus apartment), type of cancer diagnosis, or length of time since diagnosis was examined.

Patients who developed progressive disease had significantly lower total FACT-BMT scores at six months and had significantly more complaints about the treatment experience than patients without evidence of disease and those receiving adjuvant therapy. This finding is similar to previous research studies in which patients who experience a poor outcome of treatment reported lower QOL and less satisfaction with care than patients with good clinical outcomes (Lin, 1996).

Patients who had never married had significantly higher levels of emotional well-being than married patients. One explanation for this finding may be that many of the younger married patients had children younger than the age of 18 and



“They have so many patients coming through that everybody gets the same information, which is good for consistency, but there wasn’t much attention to what I was worried about or what I wanted to know. They basically went on auto-pilot and rattled off information.”

“They didn’t say I’d be sterile afterwards. I found that out from some reading that I did. They were pretty mum on sexuality activity too. Taboo topic. Of course, I didn’t bring it up either. So it’s partly my fault too.”

“No one ever said anything about the Lord. They don’t seem to realize that He is the one who is responsible for making me well and that He is the one who gave the nurses and doctors the gift of healing.”

“I asked about Chinese herbs. I’ve been taking them for a while, and I really think they helped me through previous chemo. My mouth sores weren’t as bad as other people’s. And my doctor flat out said no. I had to pin him down on why. He said they have the potential for mold. Well, I don’t think so. So now I’m trying to get a statement from the supplier saying they’re free of mold. . . . I really want to take them.”

“And when I started talking about my Indian healer—well, you could just see the eyes roll in that room! *Nobody* knew what to say about that. They just kept looking at each other, like they were waiting for someone else to start talking. I look at it like this: When you’re young and have multiple myeloma, you have to do anything and everything you can. It’s going to take more than just chemo and stem cells! So I look at it as holistic care, but they’re not looking at it like that.”

“They did a good job going over things in general fashion, but I always wanted to know more and, more importantly, know why.”

“This lady in the support group said everybody loses 10–20 pounds. Is that accurate? See, I’m not even sure if that’s accurate. I don’t have 10–20 pounds to lose and nobody’s told me what I should eat.”

“There should be more information about the whole nutrition thing. They said ‘eat a balanced diet.’ But shouldn’t I be eating more protein?”

“I thought, or at least they gave me the impression, that when your [blood] counts go up, you start feeling better. But it didn’t work that way for me. Maybe it was wishful thinking on my part.”

“I had lots of questions about exercise. I know that it boosts the immune system and reduces depression and all that. Last week when I asked about it, my doctor said, ‘Use common sense.’ What is that supposed to mean?”

“I could hardly climb the back steps to get in the house and I need to start doing something to get my strength back, but all they said was ‘do a little more each day.’”

“They said my skin would peel but it’s coming off in slabs. The bottoms of my feet are killing me. Even my panties, down there. After I had babies, I’d sit in the tub and soak, but they don’t want me to soak so I’m out of ideas.”

## Figure 2. Patients’ Comments Excerpted From Qualitative Data

expressed emotional distress during their first postchemotherapy interview, specifically citing concerns about their children, an inability to care for children in the same manner as pretreatment, family role changes, and, in some cases, separation from children during the treatment process. A woman with three young children said,

This time I had to depend on my mother more to take care of the kids. With the other chemo, I was down for just a couple of days. I’ve been down for four weeks now with the high-dose, and it’s discouraging, all the things you can’t do. So I’d have to say that this round of chemo has been rougher in the emotional sense than the ones before.

Patients with higher levels of education had significantly higher physical well-being scores four to six weeks post-treatment. An explanation for this finding may be that, in the telephone interviews, many college-educated patients reported aggressively researching symptom management techniques and reported that they often asked questions during their clinic visits. In contrast, less-educated patients verbalized that a more passive role in information seeking and symptom management was preferred or necessary. During a five-week postchemotherapy interview, a 30-year-old woman who had a high school education and two children aged 6 and 10 said, “I know I should be reading and doing more, but my kids need me to be their mom. So, I have left things up to [nurses] to tell me as we go along.” In contrast, during a four-week postchemotherapy interview, a college professor said,

I searched MEDLINE®, the NCI [National Cancer Institute] database, the Internet in general, and have read everything in sight. I have a BP [blood pressure] cuff,

and I’ve been charting how I’ve been doing—my weight, BP, temp, skin, and I’ve even done a fluid track. I write down everything I eat and then figure out the calories and protein. I’m trying to stay on top of things so if something comes up, I can let them know right away and get it taken care of. I’m doing positive thinking and relaxation, and I go to see a counselor once a week.

## Limitations

This study has several limitations, such as a nonrandomized sample selection and small sample size. Patients in the study were predominantly Caucasian and well educated (all had at least completed high school). Therefore, study findings cannot be generalized. However, the study design, in which QOL measurement was augmented by patients’ narrative accounts of their treatment experiences, produced rich data and insightful information about the ASCT experience. QOL data alone, obtained when patients circled numeric responses to reflect how they felt at one particular point in time, do not provide any information about why patients felt the way they did. By combining this quantitative data with patients’ accounts of their experiences, greater insight about each patient’s treatment experience can be obtained and appropriate individualized nursing interventions can be initiated. The QOL and experiences of several patients also can be examined in aggregate, and ASCT program changes can be implemented.

## Nursing Implications

ASCT program changes could include revising the timing and content of information about high-dose chemotherapy and ASCT provided to patients. These are changes that are

based on patient-generated evidence and patients' needs rather than changes that healthcare providers intuitively feel are indicated. For instance, patients undergoing ASCT may benefit from receiving personalized information rather than preprinted educational booklets. Computers can be used to print out customized patient education materials based on each patient's needs and preferences. Information provided in an educational booklet can be arranged by priority, with patient-identified areas of concerns addressed first. Nurses can identify and prioritize patients' concerns by simply asking the question, "What is of most concern to you right now?"

Nurses caring for patients undergoing ASCT need to initiate discussions about sensitive topics, such as sexuality, spirituality, and complementary and alternative therapy use. These discussions must be ongoing during treatment because patients' questions, needs, and concerns may change during and following treatment. In addition, specific symptom management recommendations need to be given to patients. Patients in this study stated that the information they received was well intended but often vague (e.g., "Eat what you can," "Exercise, but don't overdo it"). Providing specific dietary

suggestions and exercise prescriptions should be considered. Healthcare providers should not overlook additional needs for information not directly related to the ASCT process, such as providing smoking cessation recommendations and support.

Healthcare providers likely are dispensing general advice to patients undergoing ASCT because evidence-based information about managing many ASCT-related symptoms is lacking. Research is needed about optimal nutritional intake, exercise, skin care, the role of complementary therapies, and effectiveness of individual counseling and support groups. Further research also is needed regarding care delivery models (e.g., clinic versus home care), educational methods and outcomes for preparing patients to undergo outpatient ASCT, and long-term follow-up of patients who have undergone ASCT.

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