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Patient education in allogeneic hematopoietic cell transplant: What patients wish they had known about quality of life

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Abstract

Quality of life (QOL) is increasingly recognized as an important clinical outcome of hematopoietic cell transplantation (HCT), but patient education is often overlooked. The goal of the current qualitative study was to examine education regarding post-HCT QOL from the patient's perspective. Allogeneic HCT recipients participated in one of four focus groups. Participants were asked to recall what they had been told about post-HCT QOL as they were preparing for transplant, how their QOL differed from what they expected, and how to educate future patients about post-HCT QOL. Verbatim transcripts were coded for both *a priori* and emergent themes using content analysis. A total of 24 patients participated (54% female, mean age 51, range 23-73). Participants frequently expressed the desire for additional education regarding post-HCT QOL, particularly late complications. They noted that late complications were often unexpected, had a profound impact on their QOL, and threatened their ongoing sense of recovery. They emphasized that the timing, content, and format of education regarding QOL should be flexible to meet their diverse needs. Findings from the current study draw attention to the importance of patient education regarding post-HCT QOL as well as additional QOL research designed with patient education in mind.

Keywords

Bone Marrow Transplantation; Hematopoietic Stem Cell Transplantation; Quality of Life; Patient Education as Topic

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There is growing recognition of the importance of quality of life (QOL) following hematopoietic cell transplant (HCT). Patients commonly cite QOL as one of their primary concerns (1, 2). QOL is increasingly assessed as a secondary endpoint in clinical trials as well as a main focus of observational research. Consequently, there is now a sizable body of research that is published or underway comparing QOL in various treatment regimens and describing changes in QOL during the transplant process (3-8).

Advances in knowledge regarding post-HCT QOL have the potential to facilitate better patient education about the potential risks and benefits of transplant. Nevertheless, the extent to which QOL research has been incorporated into routine patient education is not clear. A major barrier is that studies often report on means and standard deviations of commonly-used QOL measures such as the Medical Outcomes Study Short Form 36 (SF-36), the Functional Assessment of Cancer Therapy – Bone Marrow Transplant scale (FACT-BMT), and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire 30 (EORTC QLQ-C30). The information provided by these measures is valuable to researchers but often non-intuitive to patients (3). A few studies have presented QOL results in a format that is easier to understand, such as percent of participants who return to work or school, are able to climb a flight of stairs, or rate their QOL as “very good” or “excellent” (9-12). Nevertheless, studies which report these types of results are subject to bias due to high rates of attrition caused by morbidity and mortality. To our knowledge, only one study has quantified QOL in a way that is easy to understand and also accounted for attrition bias (10). That study reported the percentage of HCT participants who survived with good outcome, survived with poor outcome, died, or had missing data on a variety of QOL descriptors such as “Life has returned to normal” and “I have fully recovered from my transplant.” Additional innovative research efforts such as these are needed to improve patient education regarding post-HCT QOL.

In an effort to foster innovations in QOL research and patient education, we conducted a single-site, qualitative study of patients’ perspectives on education regarding QOL after allogeneic HCT. Patients at this institution standardly receive pre-HCT education on the anticipated post-HCT course through counseling (provided by HCT physicians, nurses, and social workers), printed educational materials, and by targeted education of patients’ caregivers. Allogeneic HCT recipients were recruited to participate in one of several face-to-face focus groups. We were interested in how patients recalled the pre-transplant education they received regarding post-HCT QOL, how they described their QOL at various points in the transplant process, and how their QOL differed from what they expected it to be. We also solicited recommendations from study participants regarding the optimal ways to educate future patients regarding post-HCT QOL. Thus, the goal of the study was not learning about post-HCT QOL per se but rather patient’s perceptions of education regarding QOL. While a variety of themes emerged from the groups, the current report focuses on content related to patient education. As the study was exploratory in nature, there were no *a priori* hypotheses.

Methods

Participants

Following University of South Florida Institutional Review Board approval, potential participants were identified through a database maintained by the Department of Blood and Marrow Transplantation (BMT) at Moffitt Cancer Center. Eligible patients were allogeneic HCT recipients who had been transplanted one to four years previously, were without evidence of primary disease relapse, were able to speak and read English, and were able to provide informed consent. Because participants were asked to travel to the Cancer Center to take part in an in-person focus group, recruitment focused on patients who lived in the greater Tampa Bay area. Participants were provided with a meal as compensation for their time.

Moderators' Guide

A focus group guide was developed by the study investigators based on clinical experience and relevant literature. The guide consisted of sixteen questions regarding patients' expectations and experiences of post-HCT QOL, which was defined for participants as encompassing physical, social, emotional, and role functioning (see Table 1) (3, 4). Questions and prompts were reviewed for accuracy by a transplant physician and pre-tested with HCT recipients.

Procedure

Participants attended one of four focus groups held in November 2011 and March 2012. Separate focus groups were held for male and female HCT recipients to facilitate open discussion of topics such as changes in sexuality and appearance. Groups ranged in size from four to six patients. Prior to the focus group, participants signed informed consent and completed a brief demographic questionnaire. Questionnaire items included date of birth, ethnicity, race, marital status, education, and annual household income. Clinical information (i.e., cancer diagnosis, disease status, donor type, and time since transplant) was obtained later from the BMT Department registry. Each focus group lasted approximately 90 minutes and was audio-recorded. A moderator, co-moderator, and research assistant were present for all focus groups. All moderators and assistants were gender-concordant with the group and none had prior relationships or contact with the participants. Each moderator had previously received training from an experienced qualitative health researcher. Moderators were not affiliated with the transplant team and no members of the transplant team were present, although a transplant physician was available at the completion of each group to answer medical questions.

Focus group audio files were professionally transcribed verbatim by a local professional transcriptionist with experience in qualitative health research. The transcripts were analyzed using a combination of content analysis via hand coding and crystallized immersion method whereby the researchers reviewed all the data and culled out those aspects most relevant to the objectives (13). Content analysis of the transcripts provided common themes illustrating the informational needs and concerns about QOL. Eight investigators participated in the coding process. Codes were generated and refined using an iterative process that included

the whole group. One pair of raters was then assigned to code each transcript. Members of the pair conducted coding independently, compared codes, and resolved disagreements by consensus. The research team concluded that saturation had been reached (i.e., no new themes emerged) after the fourth focus group. After consensus was reached and a definition was created for each code, a member of the research team re-read the transcripts and, using the final code categories, entered the data into ATLAS.ti (14). Validity was determined by peer debriefing in which the entire research team reviewed, validated, and verified all interpretations and conclusions of the data (consensual validity).

Results

Participants

A total of 24 HCT recipients participated in the focus groups. As shown in Table 2, participants had a median age of 53 (range 23-73). The majority was Caucasian, non-Hispanic, married, had not completed college, and reported a current annual household income of \$40,000 a year or less.

Sources of Information Regarding Post-HCT QOL

Focus group participants were first asked to recall how they obtained information regarding post-HCT QOL. Representative participant quotes are presented in Table 3. Nearly all participants reported receiving information from the transplant team in the form of a book and/or orientation class, attendance at which was required. Most of these participants recalled receiving specific information on side effects of the conditioning regimen, graft-versus-host disease (GVHD), and dietary and other behavioral restrictions to prevent infection. Participants were divided on their responses to the information. Many indicated that they tried to avoid information about the transplant; many of these same participants also reported avoiding information from other sources. Other patients sought additional information about transplant outcomes from books, scientific articles, Internet searches, and advice from patients who were farther along in the transplant process. Participants also mentioned the role of family and friends in locating and sharing information with them regarding transplant. This was helpful for some, as trust in a knowledgeable caregiver allowed them to focus on the transplant itself. For others, information from friends and family was intrusive and unwelcome.

Expectations Regarding Post-HCT QOL

Participants were asked to describe how their actual experience of post-HCT QOL differed from what they had expected prior to the transplant. Several patients reported that they were well-informed by the treatment team. Others did not recall any expectations regarding QOL after transplant. Still other participants indicated that their post-transplant experiences differed from what they had expected prior to transplant. A few participants reported relief that the transplant was not as bad as they expected. In contrast, others emphasized that they had expected gradual improvement after transplant and were surprised by late-onset or persistent side effects that compromised their daily functioning. Participants also reported that they felt unprepared for the “ups and downs” of recovery. The late or persistent side effects most often described as distressing were avascular necrosis and joint replacement,

peripheral neuropathy, edema, diabetes, fatigue, dry mouth, dry eyes, cataracts, weight gain, and hair loss. Many patients reported being unaware that these side effects could occur, or if aware, surprised by their severity and duration. Participants reported that side effects such as these were distressing because they prevented return to activities of daily life, such as walking unaided, standing for extended periods of time, reading, watching television, participating in hobbies, driving a car, and returning to work or school.

What Patients Wished They Had Known

In general, participants reported being well-prepared for the acute transplant process. Although most patients described the first 100 days post-transplant as “rough” and “horrible,” many noted that the acute transplant unfolded as they had been told it would. There were very few suggestions for how to improve education regarding the acute transplant process. An exception noted by three participants was a better description of the transplant itself (i.e., the infusion of the blood product). Another participant suggested that education should include practical tips from nurses and other patients. The majority of suggestions for patient education focused on late complications. Although participants acknowledged that there was a great deal of variability in patients’ experiences of QOL after the acute transplant period, they wanted more information regarding what long-term side effects could happen, how severe they might be, how long they could persist, and how they might affect their lives.

When and How to Communicate QOL Information

Nearly all participants agreed that talking to patients further along in the transplant process was an important adjunct to education by the transplant team. Some participants wanted to talk to patients one-on-one while others preferred a support group and still others wanted to attend a question-and-answer session moderated by a physician. In fact, many participants reported that they independently sought out HCT survivors before their transplant, which was helpful in dispelling some of their fears.

Although many participants focused on the importance of interacting with HCT survivors before the transplant, some indicated that they wanted regular contact with other survivors after the transplant. One suggestion was to match newly transplanted patients with a mentor or buddy who had been transplanted several months or years previously. Another popular suggestion was support groups that focused on specific side effects.

There was also enthusiasm about educating patients via the Internet. Some participants pointed out that a website would be easy to update, while others liked the flexibility of navigating only to areas of the website that were of interest to them. In contrast, there were mixed responses to the suggestion of print or audiovisual material. Some patients wanted a hard copy of information such as a book, while others worried that it would be similar to the education book they received prior to transplant. Regardless of the format of patient education, participants emphasized that it was important to present a range of different possible outcomes. Equally important to participants was the ability to control the amount and timing of information they received, because many were afraid of feeling overwhelmed or discouraged by too much negative information.

QOL Information and Transplant Decisions

Participants were asked whether more QOL information would have changed their decision to have a transplant or plan differently for life after transplant. A large majority of patients indicated that additional information would not have changed their decision. A few participants reported they would not have had the transplant or were uncertain. These participants reported the experience had been too arduous for themselves or their caregivers. Some patients dreaded or planned to refuse a second transplant if it became necessary. Thus, patients reported that greater information about post-HCT QOL would not only be helpful in coping with long-term side effects, but may also help with transplant decision-making as well.

Discussion

The goal of the current study was to collect qualitative information from allogeneic HCT recipients regarding education about post-HCT QOL. As such, we conducted face-to-face focus groups of patients who responded to questions regarding their recollection of patient education regarding post-HCT QOL, their experience with post-HCT QOL, how their experience differed from what they expected, and how we could better educate future patients. In general, we found that study participants were eager to share their experiences and suggestions for how to improve patient education.

A primary theme that emerged in all four focus groups was the importance of controlling information to manage anxiety regarding transplant. Study participants generally fell into two categories regarding their preference for information: monitors and blunterners (15, 16). Monitors cope with anxiety by scanning for threatening information. They actively seek out detailed information regarding health risks as well as strategies for preventing or managing risks (15). In the current study, patients who were monitors took an active role in seeking out information from multiple sources, primarily the transplant team, the Internet, and other patients. In contrast, blunterners cope with anxiety by actively avoiding potentially threatening information. They tend to find large amounts of detailed information to be stressful and try to block it out (15). In the current study, blunterners reported avoiding information provided by the transplant team, such as making the decision not to read educational materials. These comments suggest that, beyond information required for informed consent, educational material should be presented in a format that allows patients to select as much or as little information as they wish. For example, a website with a menu of topics could accommodate both monitors and blunterners. It could also be a useful reference throughout the transplant process, as patients and caregivers could select topics most relevant to their current situation. Further, tailored health information often enhances the relevance of health messages and may improve patient engagement (17-19).

A second major theme was concern about late complications of HCT and immunosuppressive therapy. Although patients reported that they had been educated regarding side effects such as GVHD, they described feeling unprepared for many of the other side effects such as neuropathy, diabetes, weight gain, and avascular necrosis. Patients also reported feeling unprepared for the extent to which these side effects and GVHD could affect their lives. Many expressed feeling a loss of identity as they could no longer engage in

many of the normal activities of daily living, such as driving, reading, walking, and other hobbies. One of the most difficult aspects of chronic side effects was uncertainty regarding when and if their health would improve. For patients who expected a gradual return to normal life, the unpredictability of GVHD flares and other late complications was particularly upsetting. These findings are consistent with previous research suggesting that active chronic GVHD is associated with a twofold risk of distress (20). Some would have decided against a transplant if they had known of its negative impact on their caregivers or their own QOL. Thus, patient education materials should provide extensive information describing chronic side effects. Information should describe the side effects, why they occur, the extent to which they could interfere with daily functioning and QOL, their chronicity, and common treatment options. This information should be available to interested patients as they make decisions about transplant and also as part of long-term follow-up care (21, 22).

A third major theme that emerged in all of the focus groups was the desire to hear about QOL from other patients. Many participants expressed appreciation for the focus groups, which helped to normalize some of their experiences. Participants reported seeking out other HCT patients in the clinic waiting room, local HCT patient housing, or online via Facebook. While many expressed the desire to attend support groups, some described ambivalence about hearing overly negative or upsetting information. Nevertheless, the frequency with which other patients were mentioned as a desired source of information underscores the importance of including them in patient educational materials. A primary concern to educators is the accuracy of information patients provide to one another. Lay health educators trained by the transplant team are one option to address this issue. Another option is to incorporate patients' perspectives into print or audiovisual materials through quotations or video interviews. It was clear that participants wanted detailed, practical, and genuine information from patients regarding their own experiences. Thus, information from other patients should be an integral and informative part of educational materials.

To our knowledge, this is the first study of patient education regarding post-HCT QOL. Strengths of the study include a sample of allogeneic recipients interviewed one to four years after HCT as well as use of rigorous qualitative research methodology. Study limitations should also be noted. The sample was relatively small and composed primarily of Caucasian and non-Hispanic participants. Thus, although saturation was reached with this sample, a more diverse sample of allogeneic HCT recipients may have yielded additional themes. The current study was conducted at one institution and findings may not generalize to other transplant centers with different educational practices. In addition, participants' responses were often based on retrospective recall, which may be inaccurate. These data are nonetheless valuable since the goal of the current study was to better understand patients' perceptions of their transplant rather than to garner accurate information regarding patient education practices.

In summary, the current study provides a great deal of information regarding post-HCT QOL that has not been captured to date by standardized instruments such as the SF-36, FACT-BMT, or EORTC QLQ-C30. This information can be used clinically to develop better educational materials regarding post-HCT QOL. It also points to gaps in existing

research. For example, literature is sparse regarding how long-term side effects such as avascular necrosis, joint replacement, and peripheral neuropathy affect QOL in allogeneic HCT recipients. It underscores the importance of conducting QOL research that yields findings which are easily understandable to patients. Research on topics such as these may inform future interventions to educate patients and improve their QOL.

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References

1. Baker F, Denniston M, Smith T, West MM. Adult cancer survivors: how are they faring? *Cancer*. 2005; 104(11 Suppl):2565–76. [PubMed: 16258929]
2. Heinonen H, Volin L, Zevon MA, Uutela A, Barrick C, Ruutu T. Stress among allogeneic bone marrow transplantation patients. *Patient Educ Couns*. 2005; 56(1):62–71. [PubMed: 15590224]
3. Pidala J, Anasetti C, Jim H. Health-related quality of life following haematopoietic cell transplantation: patient education, evaluation and intervention. *Br J Haematol*. 2010; 148(3):373–85. [PubMed: 19919651]
4. Pidala J, Anasetti C, Jim H. Quality of life after allogeneic hematopoietic cell transplantation. *Blood*. 2009; 114(1):7–19. [PubMed: 19336756]
5. Braamse AM, Gerrits MM, van Meijel B, Visser O, van Oppen P, Boenink AD, et al. Predictors of health-related quality of life in patients treated with auto- and allo-SCT for hematological malignancies. *Bone Marrow Transplant*. 2012; 47(6):757–69. [PubMed: 21725373]
6. Garcia CM, Mumby PB, Thilges S, Stiff PJ. Comparison of early quality of life outcomes in autologous and allogeneic transplant patients. *Bone Marrow Transplant*. 2012; 47(12):1577–82. [PubMed: 22562082]
7. Grulke N, Albani C, Bailer H. Quality of life in patients before and after haematopoietic stem cell transplantation measured with the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Core Questionnaire QLQ-C30. *Bone Marrow Transplant*. 2012; 47(4):473–82. [PubMed: 21602898]
8. Frodin U, Borjeson S, Lyth J, Lotfi K. A prospective evaluation of patients' health-related quality of life during auto-SCT: a 3-year follow-up. *Bone Marrow Transplant*. 2011; 46(10):1345–52. [PubMed: 21113189]
9. Bush NE, Donaldson GW, Haberman MH, Dacanay R, Sullivan KM. Conditional and unconditional estimation of multidimensional quality of life after hematopoietic stem cell transplantation: a longitudinal follow-up of 415 patients. *Biol Blood Marrow Transplant*. 2000; 6(5A):576–91. [PubMed: 11071263]
10. Lee SJ, Fairclough D, Parsons SK, Soiffer RJ, Fisher DC, Schlossman RL, et al. Recovery after stem-cell transplantation for hematologic diseases. *J Clin Oncol*. 2001; 19(1):242–52. [PubMed: 11134219]
11. Syrjala KL, Langer SL, Abrams JR, Storer B, Sanders JE, Flowers ME, et al. Recovery and long-term function after hematopoietic cell transplantation for leukemia or lymphoma. *Jama*. 2004; 291(19):2335–43. [PubMed: 15150205]
12. Syrjala KL, Langer SL, Abrams JR, Storer BE, Martin PJ. Late effects of hematopoietic cell transplantation among 10-year adult survivors compared with case-matched controls. *J Clin Oncol*. 2005; 23(27):6596–606. [PubMed: 16170167]
13. Borkan, J. Immersion/Crystallization. In: Crabtree, BF.; Miller, WL., editors. *Doing Qualitative Research*. Sage Publications; Thousand Oaks, CA: 1999. p. 179-194.
14. Berlin Scientific Software Development. *ATLAS/ti*. 2008.

15. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer*. 1995; 76(2):167–77. [PubMed: 8625088]
16. Ong LM, Visser MR, van Zuuren FJ, Rietbroek RC, Lammes FB, de Haes JC. Cancer patients' coping styles and doctor-patient communication. *Psychooncology*. 1999; 8(2):155–66. [PubMed: 10335559]
17. Gruman J, Rovner MH, French ME, Jeffress D, Sofaer S, Shaller D, et al. From patient education to patient engagement: implications for the field of patient education. *Patient Educ Couns*. 2010; 78(3):350–6. [PubMed: 20202780]
18. Kreuter MW, Wray RJ. Tailored and targeted health communication: strategies for enhancing information relevance. *Am J Health Behav*. 2003; 27(Suppl 3):S227–32. [PubMed: 14672383]
19. Rimer BK, Kreuter MW. Advancing tailored health communication: A persuasion and message effects perspective. *Journal of Communication*. 2006; 56(S1):S184–S201.
20. Sun CL, Francisco L, Baker KS, Weisdorf DJ, Forman SJ, Bhatia S. Adverse psychological outcomes in long-term survivors of hematopoietic cell transplantation: a report from the Bone Marrow Transplant Survivor Study (BMTSS). *Blood*. 2011; 118(17):4723–31. [PubMed: 21821714]
21. Majhail NS, Douglas Rizzo J. Surviving the cure: long term followup of hematopoietic cell transplant recipients. *Bone Marrow Transplant*. 2013
22. Majhail NS, Rizzo JD, Lee SJ, Aljurf M, Atsuta Y, Bonfim C, et al. Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation. *Bone Marrow Transplant*. 2012; 47(3):337–41. [PubMed: 22395764]

Table 1

Interview Guide Questions.

<p>Before transplant, what did the BMT team tell you to expect regarding your post-transplant quality of life?</p> <p>Did you go to other sources to learn about quality of life after transplant?</p> <p>What was your quality of life like during the first 100 days following transplant?</p> <p>How did your quality of life in the first 100 days differ from what you expected going into transplant?</p> <p>What is your quality of life like now?</p> <p>How is your quality of life now differ from what you expected going into transplant?</p> <p>When was the last time you felt like yourself?</p> <p>At this point in your recovery, is this how you expected to feel? Did you expect to recover faster? Slower? Was your recovery about what you expected?</p> <p>Are there things that you understand about your quality of life now that you wish your doctor would have told you prior to the transplant?</p> <p>Would having this information have changed your decision to have a transplant?</p> <p>If you had that information, would you have prepared for life after transplant differently? How?</p> <p>When is the best time to discuss quality of life information?</p> <p>What is the best way to share quality of life information?</p> <p>What is the most important thing you have done to improve your quality of life after transplant?</p> <p>If you met someone who was planning to have a transplant, what would you tell them to expect about post-transplant quality of life?</p> <p>If you met someone who was planning to have a transplant, what advice would you give them about how to improve their quality of life after transplant?</p>

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Table 2

Sociodemographic and Clinical Characteristics of the Sample.

	(n=24)
Age: median (range)	53 (23-73)
Gender: n (%) male	12 (50%)
Ethnicity: n (%) non-Hispanic	23 (95.8%)
Race: n (%) Caucasian	23 (95.8%)
Marital status: n (%) married	17 (70.8%)
Education: n (%) college grad	8 (33.3%)
Annual household income: n (%) \$40,000 or more	9 (37.5%)
Diagnosis	
Acute myelogenous leukemia	11 (46%)
Acute lymphoblastic leukemia	4 (17%)
Non-Hodgkin's lymphoma	3 (13%)
Myelodysplastic syndrome	2 (8%)
Aplastic anemia	2 (8%)
Chronic lymphocytic leukemia	1 (4%)
Chronic myelomonocytic leukemia	1 (4%)
Disease Status	
Complete remission 1	10 (41.7%)
Complete remission 2	4 (16.7%)
Complete remission 3	1 (4.2%)
Partial remission	3 (12.5%)
Hematologic improvement	1 (4.2%)
No response/stable	3 (12.5%)
Untreated	2 (8.3%)
Donor: n (%)	
Unrelated	13 (54.1%)
Related	10 (41.7%)
Umbilical cord blood	1 (4.2%)
Time since transplant in months: mean (range)	29.7 (12-71.2)

Table 3

Representative Participant Responses to Focus Group Questions.

Sources of Information Regarding Post-HCT QOL
"I did not want to read that book, I did not want to know, I just wanted to go into what I had to do and deal with the rest later."
"Someone said, 'Don't look up bone marrow transplants on the computer... it's only going to scare you to death'... So I just do what I am told [by my physician] and stay off the computer."
"I still read everything."
"On the computer, my wife did most of [the research]. I mean, I did some of it but she really took care of everything."
"My family had a lot of talk. It's like everybody became an instant doctor in their own minds... you know, start doing this, stop doing that... but I had to leave it up to my doctor and myself."
Expectations Regarding Post-HCT Quality of Life
"I have to admit that [the transplant team] explained it pretty well, I knew it, I knew going in where it was, what might happen."
"Well, I know [the transplant team] said some things about it to me, but I was more focused on what was going to happen during the transplant, because I wanted to get through the transplant, and I'd worry about what happens afterwards [later]."
"It's better than what I expected... I had a few bad days, I had the mouth sores and that was pretty much it."
"It's like devastating things that aren't in the manual, you know, the chronic side effects are in the manual but the degree that they limit the things that you can do."
What Patients Wished They Had Known
"I would like to see some practical tips added to the manual"
"Let me know in my situation [how long it will be until I feel better]. Is it going to be five years? Is it going to be three years?... [First] it was six months, then it was one year, then it was after two years... they didn't tell me when I am going to actually be me, me again, because I am not me, and I know I am never going to be me, but I'd like to be close to me."
"They tell you about graft versus host disease, but they don't really go into that much detail of what exactly that means and, you know, what it entails."
When and How to Communicate QOL Information
"If you are going to have a transplant it would be nice to sit with a group of people who have been through it, so that you can hear the stories of what they have done, as long as they are wise enough to know you don't want to scare the bejesus out of somebody."
"...that's what I am hoping will come out of this [study], is that you have support groups that would focus on key areas: neurological side effects, orthopedic side effects, you know, mental emotional side effects."
"I don't like to go to groups like that because I may hear something that may happen to me and I am going to worry and I am thinking 'oh my God! What if that happens to me? Oh my God.' You know, I don't want to know that kind of stuff."
QOL Information and Transplant Decisions
"I still would have gone through with it; I don't think I had much of a choice."
"I don't think I could have prepared any differently"
"I am not sure I would have gone through [with it] if I knew [all of the side effects]."
"No, there is no way [I would have another transplant]... it is just brutal on your caregivers."