

ORIGINAL ARTICLE

Patients' understanding of disease status and treatment plan at initial hematopoietic stem cell transplantation consultation

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Patients referred for hematopoietic stem cell transplantation (HSCT) often have knowledge deficits about their disease and overestimate their prognosis making it difficult initially to discuss potentially life-threatening transplant options. To determine patients' understanding of their disease and the adequacy of a 3-h consultation at our center, we developed a survey that measured perceived knowledge deficits of disease, prognosis, and emotional status before and after their initial consultation. Ninety nine consecutive eligible patients completed the survey. Although 76.7% claimed adequate information about their disease pre-HSCT visit, 51.5 and 41.4% respectively lacked knowledge about their 1-year prognosis with and without any therapy. After the visit, 66.7% of the patients had obtained enough information to make an informed decision regarding HSCT versus 23.2% pre-visit, and a significant reduction in the need for further information was reported by 53.5% of patients ($P < 0.001$). Patients were not overwhelmed or confused by the visit and there was a small but significant decrease in negative affect. Measures to increase patients understanding of their disease and its prognosis pre-HSCT consultation visit are warranted; however, a 3-h consultation visit provides the majority of patients with sufficient information to make an informed decision about the risk/benefit ratio of HSCT.

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Introduction

Obtaining informed consent for hematopoietic stem cell transplantation (HSCT), a complicated life-threatening procedure, is often a difficult task involving many individuals, and occurs slowly over many days or weeks. The initial visit with the transplant team is the critical first step in the process. It appears to be an overwhelming experience for many, and is complicated by the fact that patients often come to this meeting with an incomplete understanding of their disease or its prognosis. Because HSCT has potentially serious, life-threatening and lingering side effects that they need to understand, the first visit is critical in informing the patient and their family what their prognosis is in the context of the benefits and risks of the proposed transplant. Learning about their disease and its prognosis, often for the first time, can be emotionally challenging and diverts attention from the reason for their consultation. This impacts the ability of the patient to give informed consent.

Other factors seen in all cancer patients considering a change in therapy also impact the ability to provide consent. Consent may be adversely impacted by patients' diminished performance status (i.e., being too ill) or emotional state¹ (i.e., too overwhelmed), and the process itself may produce significant emotional distress for the patient.² In addition, patients' overestimation of the benefits from transplantation or denial of their disease severity may result in patients choosing a type of treatment that is incongruent with their desires.^{1,3,4} For example, some patients may place greater emphasis on the potential for cure of their disease and less importance on possible treatment-related side effects (e.g., acute and chronic graft-versus-host disease) that can develop. In such cases, a patient's hope for a longer life may contrast with their wish for a reasonable quality of life.

That patients overestimate the benefit of transplant is evidenced by the fact that patients rate perceived success of a cure after HSCT 78% higher than their physicians.⁵ Therefore, it is essential that patients and physicians communicate clearly and openly regarding patients' disease status, alternative treatment options, and post-treatment

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outcome. There are benefits to both the patient and physician for performing this correctly. When studied, greater than 90% of physicians feel that a fully informed patient is more likely to adhere to their treatment plan.⁶ However, other studies have shown that patients use the informed consent discussion to ascertain trust in the physician versus consideration of HSCT data.^{7,8}

In our clinical experience at the Bone Marrow Transplant Clinic of the Cardinal Bernardin Cancer Center at Loyola University Medical Center, many patients referred for HSCT consultation appear to have limited knowledge of their disease status and treatment options. In fact, it is not uncommon for patients to be shocked at how poor their prognosis is and they focus on this rather than taking the time to understand their options. This obviously can significantly impact a patient's ability to make an informed decision regarding transplant options. In addition, rather than taking the time needed to discuss these options, the HSCT team has to first educate the patient about their underlying disease and its prognosis before any discussion of the potential lethal complications of HSCT can be discussed. This makes an in-depth discussion of transplantation and its associated lethal risks difficult for the transplant physician and team.

A review of the literature failed to identify a measure to assess patients' level of knowledge regarding HSCT and their emotional state at the time of their initial consultation with the transplant team. Thus, a survey was undertaken to ascertain whether the initial consultation provided sufficient information for an informed decision regarding HSCT and to assess patients' emotional reactions before and after the consultation.

Materials and methods

The main objective of the present study was to develop and utilize a New Patient Questionnaire (NPQ) in order to identify differences in knowledge of disease and treatment options pre- and post-initial consultation for HSCT, to describe patients' emotional state pre- and post-consultation, and to determine whether patients felt the consultation provided enough information for them to make an informed decision regarding HSCT.

Patients

From October 2002 to August 2003, all consecutive new patients to the Hematopoietic Stem Cell Transplantation Clinic at the Cardinal Bernardin Cancer Center at Loyola University Medical Center were asked to complete the NPQ (data collection took place over 11 months due to staffing and scheduling constraints). The study was approved by the institutional review board and written consent was waived. To be eligible for participation, patients needed to be attending the HSCT clinic for an initial consultation visit where transplant was to be one of the options discussed, be able to read and understand English, and be 18 years of age or older. In advance of their first meeting, they are sent a booklet that describes the visit (who they will see, and what will occur), a description of

HSCT in broad terms, and they are reminded to bring along their family and a list of questions that they want answered.

Description of initial HSCT consultation

The initial consultation visit consists of a complete history and physical exam and review of records and X-rays as well as review of pathology reports. Before the appointment being scheduled, the patient is instructed to bring all records, X-rays, and pathology slides, which are reviewed at the time of the visit. The patient initially meets with a Hematology–Oncology fellow physician or a transplant advanced practice nurse for the initial exam. This is followed by a psychosocial evaluation by either a clinical psychologist assigned to the HSCT team or the HSCT social worker. After a team review with the attending, one of three attending physicians does a follow-up exam and then discusses for about 40 min, both conventional and high-dose options as well as the side effects and risks with the patient and assembled family. During this discussion, the attending physician ascertains any knowledge deficit the patient may have about their underlying disease including its prognosis and if any is noted, a thorough discussion of the disease and its prognosis with conventional therapy precedes a discussion about transplant options. A handwritten description of prognosis, risks, and complications as well as all treatment options is provided to the patients. After all questions are answered, the patient meets with one of the HSCT coordinators to discuss logistics and takes a tour of the transplant center. The entire process takes approximately 3 h.

Survey instrument

An HSCT team that consisted of a multidisciplinary group of three HSCT-dedicated physicians, HSCT nurse practitioners, coordinators, nurses, a clinical psychologist, a psychology fellow, and a social worker developed the NPQ. This face-valid questionnaire contains items related to patient demographics (i.e., gender, age, educational level, marital status, and employment), and 13 non-demographic items address patients' emotions, knowledge and information needs about their disease, and treatment options and medical decision-making. Items for the NPQ were developed based upon an apparent knowledge deficit that patients often have about their disease, and the typical concerns and questions they present with at the initial HSCT visit. Our intent was to develop a survey to obtain descriptive data because there was no measure in the literature to capture this information.

Table 1 contains representative questions from the NPQ, and a copy of the entire questionnaire can be obtained from the Principal Investigator. Items on the NPQ utilized a personal outcome format and patients could circle more than one response to an item when appropriate. The NPQ was piloted on 12 prospective patients and a similar number of active patients, and based on their feedback, modifications to the survey were made that led to the inclusion of questions to distinguish information patients receive about their disease status and treatment options and clarification of the wording on demographic items. Data

Table 1 Sample of items from the new patient questionnaire

Item	Response options
• How do you feel about your disease? (Please circle all that apply)	a. Scared or nervous b. Depressed or sad c. Angry d. Unhappy e. Overwhelmed f. Optimistic/hopeful
• Where do you get your information about treatments? (Please circle all that apply)	a. My oncologist b. Friends and family c. Support group d. Media e. Internet f. Library
• What are your information needs about your disease? (Please circle all that apply)	a. I have enough information about my diagnosis b. I have enough information about my treatment options c. I would like more information about my diagnosis d. I would like more information about my treatment options e. I am confused by the information about my diagnosis f. I am confused by the information about my treatment options
• I believe that my chances for 1-year survival with continued conventional chemotherapy or other treatment are (not transplant)	a. 0–10% (very poor) b. 11–20% (poor) c. 21–40% (fair) d. >40% (good) e. I do not have enough information
• I believe that my chances for 1-year survival without any treatment are	

from the pilot subjects were not included in the final statistical analyses. The NPQ was completed on site before patients' initial consultation with the HSCT team and the non-demographic questions were re-administered after the consultation. Patients unable or unwilling to complete the post-consultation items of the NPQ were contacted by a psychology fellow within 1 week to complete the questionnaire by telephone. Members of the HSCT team were available to answer any patient questions related to the questionnaire. A statistical consultation determined that 100 patients provided sufficient power for our own statistical analyses.

Statistics

All *P*-values reported are two-tailed, and statistical analyses were performed using the Statistical Package for Social Sciences, version 10 (SPSS-10.0). Descriptive data are presented using means for continuous variables and frequencies and percentages for categorical variables. Comparisons among patients on demographics and medical variables used χ^2 tests. Comparisons between patients' responses on the baseline NPQ and follow-up NPQ were made using the McNemar test, which insures that answers pre- and post-visit are analyzed as a pair.

Results

Patients

During the time period of the survey, 114 consecutive patients agreed to participate. Patients who did not complete the post-consultation questions or failed to

respond to >20% of the total questionnaire items were excluded from statistical analysis. Of the original 114 patients who were given the NPQ, 99 patients met inclusion criteria. Patients who failed to answer the NPQ adequately were more likely to be male ($\chi^2=4.87$, $P=0.027$), but otherwise no significant differences were found between patients completing and not completing the NPQ on demographics or medical variables. Similarly, there were no significant differences found between patients who completed the post-consultation items of the NPQ at the clinic (90 patients) or by phone (nine patients) on demographics or medical variables. Of the 15 patients who did not complete the survey, (1) one patient did not complete questions owing to a language barrier, (2) four patients completed baseline questions but declined the follow-up NPQ because they were not candidates for HSCT, and (3) 10 patients indicated that they were not interested in completing the NPQ (seven patients completed only the baseline NPQ, three patients did not complete baseline or follow-up NPQ).

The average age of participants was 51 years (range=18–77) and the gender ratio was nearly equal, with women comprising 50.5% of the study. Participants were predominantly Caucasian (84.8%), married (74.7%), employed in full-time or part-time jobs (57.7%), well-educated (college or above, 66.7%), and had an annual household income exceeding \$50 000 (43.4%). Patients' diagnoses included lymphoma/myeloma (59.6%), acute hematologic malignancies (18.2%), chronic hematologic malignancies (15.2%), and solid tumors (7.1%). The majority of patients (77.8%) were new to the Loyola University Health Care system. The referring oncologist was reported as the main source of treatment information

by the majority of patients (90.9%). Other sources of information for patients included the Internet (58.1%) and friends/family (33.3%). Patients with a college education were more likely to obtain information from the Internet ($\chi^2 = 30.58$, $P < 0.0001$).

Questionnaire results

Before the visit, the majority of patients (76.7%) reported that they had received 'enough' to 'a lot' of information about their disease and treatment plan by their referring oncologist. Although most patients felt well-informed by their referring oncologist, 41.8% of patients reported a significant increase in information about their diagnosis ($P < 0.0001$) after the consultation visit and 53.1% of patients reported a significant increase in information about their treatment options ($P < 0.0001$). Few patients reported being confused by information about their diagnosis (3.1% pre- versus 6.1% post-consultation, NS) and patients were significantly less confused about their treatment options after the visit (13.3% pre- versus 4.1% post-consultation, $P = 0.035$).

Patients were also asked specific questions about their perceived prognosis and probability of survival with and without conventional chemotherapy. Despite the fact that nearly 77% reported having 'enough' or 'a lot' of information pre-visit about their disease, 53.1% of patients reported not having enough information to ascertain their chances of a 1-year survival with conventional therapy, and 41.7% were uncertain what their 1-year survival was without any therapy. Following the consultation, levels of uncertainty dropped significantly, with only 16.7% ($P < 0.0001$) of patients not having enough information to specify their 1-year survival with conventional therapy and 12.5% ($P < 0.0001$) of patients uncertain of their 1-year survival without any therapy.

Patients' perceived degree of knowledge specific to bone marrow/stem cell transplantation before and after their HSCT consultation is presented in Figures 1–3. Before the consultation, 69.7% of patients reported needing more information about HSCT before being able to make an informed decision regarding this treatment (Figure 1). Following the consultation, significantly fewer patients needed more information to make a decision for treatment (16.2%, $P < 0.001$), and the majority of patients (66.7%) felt informed enough to make a decision regarding HSCT. Before the consultation, 52.5% of patients needed more information about transplant to rate the risks of HSCT (Figure 2); after consultation, significantly fewer patients needed more information (14.1%, $P < 0.001$). With regard to patients' perceived outcome of an HSCT, 40.4% of patients entering into the initial consultation reported that they needed more information about HSCT to determine probable outcomes (Figure 3), and following the visit, this percentage dropped significantly to 12.1% ($P < 0.001$). Nearly all the patients reported a significant increase in overall knowledge after the consultation visit (94.7%, $P < 0.001$).

When making decisions about the type of therapy received for cancer care, 86.9% of patients stated that they participated in making the decision, and 59.6, 31.3, and

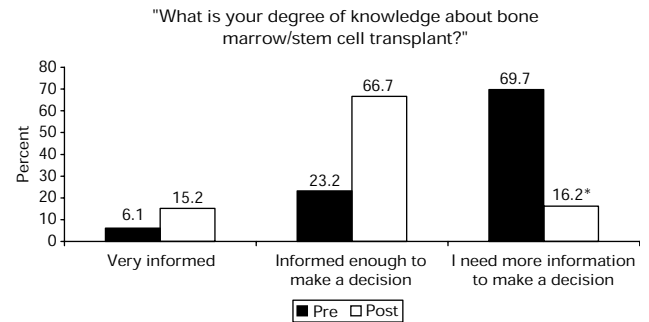


Figure 1 Patients' perceived degree of knowledge about HSCT pre- and post-consultation. * $P < 0.001$.

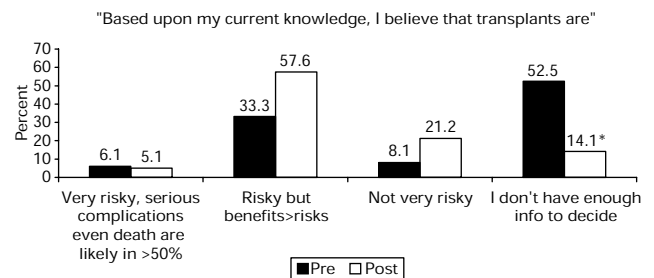


Figure 2 Patients' assessment of risk associated with HSCT pre- and post-consultation. * $P < 0.001$.

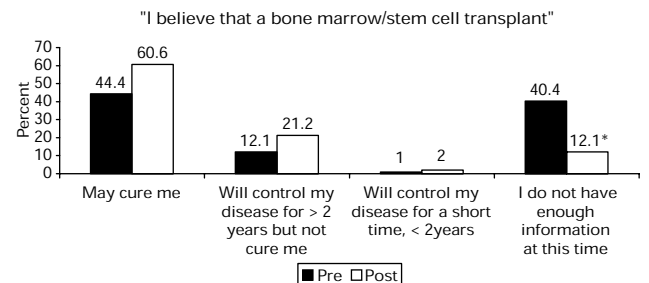


Figure 3 Patients' beliefs regarding HSCT outcome pre- and post-consultation. * $P < 0.001$.

15.2% respectively noted that their doctor, family, or significant other participated as well. No significant changes in participation in treatment decision-making were found after the HSCT consultation visit.

Patients' emotional status with respect to their disease was queried before and after the initial consultation visit. Before the consultation, patients endorsed being scared or nervous (45.9%), depressed or sad (22.4%), angry (15.3%), unhappy (20.4%), overwhelmed (21.4%), and optimistic/hopeful (79.6%). Following the consultation, fewer patients reported being scared or nervous (38.8%), depressed or sad (15.3%), angry (9.2%), and unhappy (11.2%). Reductions in negative affect were statistically significant for depressed/sad ($P = 0.039$) and unhappy ($P = 0.035$) mood states. Reported optimism/hopeful outlook increased slightly after the consultation (81.6%, NS). Notably, despite the 3-h consultation experience and a large amount of information being presented, only a slightly higher percentage of patients (28.6%, NS) reported feeling overwhelmed after the initial consultation.

Discussion

This study is the first to examine patients' understanding of disease and treatment plan and emotional status before and after initial consultation for HSCT. Although it is appropriate to conclude that referral for a transplant is made because of a presumed survival advantage as compared to conventional therapy options, in our experience, many patients referred to our clinic possess limited knowledge of their disease, their treatment options, and most importantly considering the morbidity and mortality of a transplant, their survival rate without a transplant. These data indicate that our perceptions were largely correct.

Although the majority of patients in this survey claimed that they knew enough about their disease before their initial consultation visit with the HSCT team (76.7%), only approximately one-half reported sufficient knowledge to determine what their survival rate was over the next year, with either conventional or no therapy at all. As patients typically overestimate their survival even with conventional therapy options, this knowledge deficit makes it more difficult to defend the mortality rate of a transplant procedure without a thorough discussion first of the patient's prognosis without transplant. Therefore, these data indicate that before a discussion of transplant, the first goal of the initial visit is to ascertain this knowledge level and if missing, the team needs to provide a discussion about the underlying disease process and its prognosis, that is, the rationale for the referral in the first place. Ideally, this should be performed before the initial HSCT consultation to enable the consultation to focus on transplant-specific questions and improve patients' capacity to make informed treatment decisions.

Nevertheless, the findings of this study indicate that although most patients (69.7%) do not believe they have an adequate knowledge base to make decisions regarding HSCT before their initial transplant consultation, after a single 3-h evaluation/education session, the number of patients needing additional information dropped significantly. While 29% reported being overwhelmed after their consultation, this was essentially the same percentage as pre-visit at 21%, and few patients reported being confused by the information presented, suggesting that despite the long initial visit with the entire team, the experience was not too lengthy or daunting for the majority of patients. In fact, pre-consultation, 90% of patients wanted 'as much information as possible' about the transplant option. At the end of the visit, 94.7% reported a significant increase in knowledge and two-thirds felt informed enough to make a treatment decision.

It is however important to differentiate between perceived knowledge and objective data, even after the 3-h consultation. To minimize this difference, we use several different modalities to provide accurate information. First, we send out a brochure in advance of the consultation, inviting patients to bring their family along to help understand the information presented, and to prepare any questions they have in advance of their visit. Second, we write out for them the anticipated complication and survival rates for each option, and spend a considerable

amount of time to insure that they understand these data. Finally, we recently initiated a 4-h education class for all prospective patients, where we review in presentations and in written material the rationale for transplant and its complications. There is often a first-hand presentation by a former patient as well, who is available for questions. Thus, although we do not directly test patients' knowledge, we make every effort to insure that they are making an informed decision for transplant therapy.

Considering that the vast majority of patients look to the physician as a primary source of information regarding treatment and want as much information as possible, our results point to the need to better educate patients about their disease and treatment options before their initial transplant consultation. Ideally, this should come from the transplant centers themselves. We found that the Internet is another source of information used widely by the majority of patients. Although caution should be taken when assessing patient's knowledge about their disease and treatment options based on unfiltered information gathered from the Internet, which may or may not be completely accurate,^{9,10} there are numerous sites that can be recommended. Discussion of which websites patients obtained information from and assessment of the credibility of these sources of information by the transplant team should be conducted. Based on the results of this survey, additional information regarding transplant is being sent out to patients before their initial consultation, including a list of websites to select for additional information.

Although the majority of patients are optimistic about HSCT, we found a subset of patients who experienced negative affect and felt overwhelmed. Following the consultation, there were small, but in some cases, significant reductions in negative affect, which suggests that providing information helped to alleviate emotional distress for some patients.

Several limitations of the present study should be noted. First, only descriptive data were collected. In particular, we did not do a lengthy emotional analysis using a validated scale. Emotional distress among this population is noteworthy and our previous reports indicate a 22% incidence of significant depressive symptoms in this population.^{11,12} However, because evaluation of the patient's psychological state was not the focus of this study, we chose to ask only a single question regarding negative affect specific to the patient's disease, as opposed to using one of the lengthier surveys, which have 20 or more questions. Second, the study was conducted at one site with a limited socio-demographic sample of patients (i.e., Caucasian, well-educated); additional research utilizing multisite data would expand our ability to generalize the findings. Third, it is possible that administration of the pre-consultation NPQ may have prompted subject reactivity, resulting in patients asking questions during the consultation that they might otherwise have not asked. Further research is needed to control for these limitations, and study of patients of diverse backgrounds is needed. Future research may also benefit from a short debriefing after patients complete the consultation visit to allow for clarification of the information obtained and to address patients' questions. Nonetheless, we found the NPQ to be a useful tool for assessing

patients' understanding of their disease and treatment plan, the majority of patients completed the questionnaire without difficulty, and the results of the survey have led to improvements in patient education at our center. Importantly, the findings add to the scant literature regarding the information needs of patients considering HSCT.

References

- 1 Weeks JC, Cook EF, O'Day SJ, Peterson LM, Wenger N, Reding D *et al*. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998; **279**: 1709–1714.
- 2 Dermatis H, Lesko LM. Psychosocial correlates of physician–patient communication at time of informed consent for bone marrow transplantation. *Cancer Invest* 1991; **9**: 621–628.
- 3 Andrykowski MA, Brady MJ, Greiner CB, Altmaier EM, Burish TG, Antin JH *et al*. Returning to normal following bone marrow transplantation: outcomes, expectations, and informed consent. *Bone Marrow Transplant* 1995; **15**: 573–581.
- 4 Eidinger RN, Schapira DV. Cancer patients' insight into their treatment, prognosis, and unconventional therapies. *Cancer* 1984; **53**: 2736–2740.
- 5 Lee SJ, Fairclough D, Antin JH, Weeks JC. Discrepancies between patient and physician estimates for the success of stem cell transplantation. *JAMA* 2001; **285**: 1034–1038.
- 6 Singer DA, Donnelly MB, Messerschmidt GL. Informed consent for bone marrow transplantation: identification of relevant information by referring physicians. *Bone Marrow Transplant* 1990; **6**: 431–437.
- 7 Jacoby LH, Maloy B, Cirenza E, Shelton W, Goggins T, Balint J. The basis of informed consent for BMT patients. *Bone Marrow Transplant* 1999; **23**: 711–717.
- 8 Patenaude AF, Rapoport JM, Smith BR. The physician's influence on informed consent for bone marrow transplantation. *Theor Med* 1986; **7**: 165–179.
- 9 Bichakjian C, Schwartz J, Wang T, Hall J, Johnson T, Biermann J. Melanoma information on the internet: often incomplete – a public health opportunity? *J Clin Oncol* 2002; **20**: 134–141.
- 10 Berland G, Elliott M, Morales L, Algazy J, Kravitz R, Broder M *et al*. Health information on the internet: accessibility, quality, and readability in English and Spanish. *JAMA* 2001; **20**: 2612–2621.
- 11 Hurley CL, Mumby PB, Di Iorio S, Stiff P. Gender and marital status predict depression and social support in bone marrow transplant patients. *Ann Behav Med* 2004; **27** (Suppl): S020.
- 12 Hurley CL, Mumby PB, Stiff PJ. Predictors of noncompliance autologous bone marrow transplant patients. *J Psycho-Oncol* 2005; **14** (Suppl 1): 45.