

# Understanding Health Literacy in Patients Receiving Hematopoietic Stem Cell Transplantation

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**H**ematopoietic stem cell transplantation (HSCT) has become the standard of care for many patients with disorders of the hematopoietic system, such as hematologic malignancies (Gratwohl et al., 2010). Because this treatment has significant morbidity and mortality, understanding what it means for patients is important in shaping interventions to help them.

Patients with cancer typically report that they want to know all the available information about their type of cancer and its treatment, but they often are overwhelmed by the amount of information provided by clinicians, the mass media, and the Internet (Epstein & Street, 2007). Strategies to ensure that patients are informed are important. A systematic review by Husson, Mols, and van de Poll-Franse (2011) found that cancer survivors who had fulfilled information needs were satisfied, experienced fewer information barriers, and had less anxiety, depression, and better health-related quality of life. Another review found that low health literacy was associated with worse health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

The Institute of Medicine (IOM, 2004) defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services they need to make appropriate health decisions” (p. 32). This report also stated that health literacy includes the individual and depends on the skills, preferences, and expectations of health information from care providers, the media, and many other sources. Effective communication requires many skills, including both the patient and clinician understanding each other’s perspectives, the health condition, and the purpose of the interaction (Epstein & Street, 2007). Lack of health literacy in patients can be a major barrier to communication.

Low health literacy has been associated with several adverse health outcomes (Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004) and also may be important in explaining health disparities (Sentell & Halpin, 2006).

**Purpose/Objectives:** To describe the meaning of patients’ experiences with hematopoietic stem cell transplantation (HSCT), with a focus on health literacy.

**Research Approach:** A hermeneutic phenomenologic approach that combines descriptive and interpretive methods.

**Setting:** A National Cancer Institute-designated comprehensive cancer center in the southern United States.

**Sample:** 60 individuals who underwent HSCT; 20 Latino, 20 African American, and 20 Caucasian.

**Methodologic Approach:** In-depth interviews were conducted on five separate occasions. Interviews and analysis of verbatim transcripts used phenomenologic techniques.

**Findings:** The themes were as follows: they did not tell me, decision dilemmas, fears of dying, tough symptoms and side effects, and relying on others. These themes were found in all ethnic groups, both genders, and at all time points.

**Conclusions:** The themes from this study demonstrate that health literacy concerns are vital to patients’ understanding, decision making, and having active roles in their health care. Assessing patients’ understanding is important and requires a comprehensive approach because patients may not know what they need to ask and may not feel comfortable asking or raising objections because their fears, particularly that of dying, are barriers.

**Interpretation:** This article provides evidence that health literacy is not a simple function of age, ethnicity, race, or education. Health literacy and communication concerns require a more nuanced approach to provide optimal patient-centered outcomes.

**Knowledge Translation:** Understanding patients’ perspectives is vital to knowing what to communicate, how to communicate, and when to provide information. Providing information in a way patients can understand reduces risks for negative outcomes. A comprehensive assessment of patients’ understanding using improved education materials, clearer forms and communication techniques, teach-back methods, and reinforcement is needed to improve communication, particularly when illness and treatment evoke fears.

The purpose of the current study was to describe the meaning of patients’ experiences with HSCT over time. The authors selected participants from three ethnic

groups (Latino, African American, and Caucasian) to understand any differences that might exist between them. The role of health literacy emerged as an important aspect and is described in this article. Understanding the meaning of health literacy in patients' experiences with HSCT is important because most cancer communication research has involved patients with breast cancer; few studies have involved patients with other forms of cancer (Epstein & Street, 2007).

## Methods

This study was guided by hermeneutic phenomenologic, descriptive, and interpretive research methods (Cohen, Kahn, & Steeves, 2000). These methods, based on phenomenologic philosophy, are used to determine the meaning people make as they interpret their experiences with HSCT.

### Sample and Setting

Sixty participants were interviewed aged 22–71 years, with a mean age of 47 (see Table 1). Education varied from people with little formal education (e.g., third grade education) to people with graduate and professional degrees. Occupations included migrant workers and professionals. Participants were recruited from an outpatient transplantation clinic at a comprehensive cancer center in Houston prior to their admission to the hospital for HSCT. Interviews were conducted in a private setting at the hospital. Interviews were conducted in Spanish with 13 of the 20 Latino participants (65%); this group was culturally diverse and included people from Mexico, Puerto Rico, and various U.S. locations.

### Data Collection and Procedures

Permission to conduct this study was obtained from the institutional review boards of the University of Texas MD Anderson Cancer Center and the University of Texas Health Science Center at Houston. After patients signed informed consent, interviews were conducted at five time points: pretransplantation, engraftment, and days 30, 60, and 100 post-transplantation. Forty-seven participants (78%) completed all five interviews. Those completing fewer interviews were either too sick (i.e., were in an intensive care unit) or died before the end of the study.

Patients were asked at each time point to describe their experiences and, after the first interview, were asked how things changed for them. The interviewer used open-ended questions to ensure that the person being interviewed, rather than the interviewer, determined the content discussed. The goal was to help them verbalize, that is, to clarify their own meaning and to ensure the meaning of their experiences was clearly understood. Interviews, which lasted about an hour, were conducted by a team ethnically matched with

**Table 1. Sample Characteristics (N = 60)**

Characteristic	$\bar{X}$	Range
Age (years)	47	22–71

Characteristic	n
<b>Gender</b>	
Male	30
Female	30
<b>Marital status</b>	
Married	36
Single, widowed, or divorced	24
<b>Ethnicity</b>	
African American	20
Caucasian	20
Latino	20
<b>Education</b>	
Some high school or less	6
High school graduate	19
Some college or college graduate	22
Post-doctoral	13
<b>Type of transplantation</b>	
Autologous	34
Allogeneic	26
<b>Number of interviews completed</b>	
5	47
4	6
3	2
2	3
1	2

participants (i.e., a Latino team member interviewed Latino participants). The principal investigator reviewed interviewing techniques and transcripts with the research team members at least weekly to ensure the interviewers used equivalent techniques.

### Data Analysis

Interviews were audio recorded and transcribed verbatim. The interviewer verified the accuracy of the transcription by comparing the written transcript with the recorded interview. Spanish interviews were transcribed verbatim, translated into English, and verified by a second bilingual research coordinator. Differences were resolved by consensus between these coordinators.

Analysis of interviews, done by a team of researchers, revealed that issues related to health literacy were important. Additional analyses were conducted by a team that included a researcher with extensive experience in analysis of phenomenologic studies. Each nurse reviewed the interviews separately, and the team discussed the analysis until they reached a consensus.

The investigators began analysis by reading each transcript several times to get a sense of each interview as a whole. In the hermeneutic circle, researchers started to uncover a tentative notion of the meaning of an experience using reflective awareness. This awareness

led to dialectic examination of parts of the data to better understand the whole. When the whole was understood, different data or the same parts of the data were examined at a deeper level, and the analysis was repeated. The process helped researchers to understand statements in relation to the larger context of the individual experience. The authors identified themes in each transcript by examining it line by line and underlining and labelling passages with tentative theme labels. Passages from interview text and theme labels for each interview were compared with passages and themes among all other interviews (Cohen et al., 2000).

Procedures to ensure scientific rigor included having the analysis conducted by a research team. Verification of theme labels with patients would have been ideal, but most patients were not available (i.e., no longer alive or had left the area) by the time analysis was completed. Interviews were conducted until data saturation was reached, meeting the standard criterion used in qualitative research (Cohen et al., 2000). In addition to considering overall saturation, interviews were still conducted to obtain saturation in each ethnic group regarding any differences that might be linked to ethnicity. Saturation was reached after 20 interviews total, but interviews were conducted until they included 20 people from each ethnic group to discern whether important ethnic differences existed. No ethnic differences were found from the data.

## Findings

The authors' analysis revealed supports as well as barriers to understanding. The themes included: they did not tell me, decision dilemmas, fears of dying, tough symptoms and side effects, and relying on others. These themes were found in all ethnic groups, both genders, and all time points.

### They Did Not Tell Me

Participants did not understand many aspects of what they would experience with HSCT. A 42-year-old Latina who had 20 years of experience as an RN noted,

I got a big fat booklet at the very beginning, but I didn't think it gave me much information of what to expect. Like, just about two days before I came in, I found out that I have to be on a no-fresh-fruits, no-vegetables [diet], even throughout the three months that I am going to be out. . . . I had to learn [that] by eavesdropping.

A 63-year-old African American man illustrated confusion about the types of HSCT.

The only thing that struck me later [after the transplantation] that they didn't tell me, or it didn't sink in, was the platelets, I mean, the stem cells.

They used my stem cells. . . . If I had a donor, I might have had a better chance of having a successful transplant.

The patient did not understand that the type of transplantation he received (autologous) reduced many risks, but he felt he was not getting the best chance for a successful transplantation, when, in fact, he was.

Many participants thought their transplantation would be an invasive surgery, such as a heart or kidney transplantation. A 39-year-old Caucasian man who worked as an Internet marketing businessman expressed surprise. "When you think of a transplant, you think of heavy trauma and lots of surgery, but really this is just a simple IV infusion."

Lack of understanding of medical vocabulary was part of why participants felt they lacked important information. A 35-year-old Caucasian man who worked as a postal carrier stated, "They used too many big words. . . . It is a complicated procedure. They explained everything, but you still don't get it." Similarly, a 67-year-old retired African American woman said, "My doctor told me my IgA [immunoglobulin-A] count was high. I didn't know what that meant, and I didn't understand what he was explaining."

### Decision Dilemmas

The lack of agreement from professionals made it hard for some participants to decide to undergo an HSCT. A 42-year-old Caucasian woman who worked as a pharmacy technician said, "It was really hard to make the decision to have a transplant because one doctor wants to do chemotherapy, and another doctor wants to do the transplant." A 57-year-old Caucasian man who worked as a computer technician was frustrated by his limited comprehension of the procedure, but he was willing to sign the consent for treatment form. He said, "I'll sign anything; let's just get this done." A 39-year-old African American man who worked as an auto mechanic illustrated his dilemma with refusal. He said, "It was a situation where the only say-so I could have was just to refuse, but, by that time, they had so scared me at that point, I am like, 'okay.'"

### Fears of Dying

Fears were linked with lack of understanding, which may be because fear limited what patients understood by interfering with their ability to think clearly. Participants expressed fears of death, which were linked with fears of the unknown and fears for their family. Expressing his fear of the unknown, a 42-year-old Latino who worked as an industrial worker said, "Many of the things you fear are those you don't understand." A 63-year-old Latino who worked as an agricultural worker expressed his fear of death when he said, "You

are scared of dying before your time, and that the transplant might not work and I would die during the procedure.” A 39-year-old Caucasian who worked as an Internet marketer talked about his fear of death in a more indirect way.

I am nervous just because it involves basically killing your entire immune system and killing your bone marrow and then bringing it back, so that’s disconcerting . . . even though it didn’t seem like it would be that emotional of a deal for me. It was kind of emotional, and it was even kind of traumatic. . . . Part of me was dead, and that was my immune system . . . my bone marrow . . . that [had] been allowing me to live all these years . . . and then to realize the chemo has killed your bone marrow.

Concerns about family also were related to fears of death. A 33-year-old Caucasian mother undergoing a second transplantation said,

I was supposed to be well. . . . I told the kids I would never leave them again. . . . I hold the house together. . . . How would I plan for someone else to take my place? . . . I pray to God that He lets me stay here and raise my kids—raise them the way they are supposed to be raised. I don’t want them to have to talk to a grave. . . . I’m a good person. . . . I did what I was supposed to, and I still didn’t win. . . . They say everything you do, there will be a payback. . . . You reap what you sow. . . . Last time, I put too much focus on the doctors. . . . This time, I’m going to focus on God.

## Tough Symptoms and Side Effects

The HSCT created symptoms and side effects that participants did not expect. A 56-year-old Latina who worked as a university professor described her recovery.

The process is long, and I didn’t realize when I first came that it was going to be this hard. Fever, diarrhea, throwing up, low energy, rushing around for appointments: You don’t have time to rest.

Similarly, a 57-year-old Caucasian woman who worked as an RN explained about her ignorance of the side effects HSCT would cause.

The mouth sores. . . . [you] hear about them peripherally. . . . When they came, I started sucking on popsicles and ice, and I thought, “What is going on here?” So a little more education on my part would have been better.

A 44-year-old Latino college professor described issues with cognition.

The physical side went easy. What hit me the most was the brain. It was the capacity to reason, and

sometimes I do not know what I was saying or talking or what I said.

Participants felt unprepared for the severity of the symptoms they experienced. A 32-year-old African American man who worked as a hospital worker summed up his experience by stating, “I don’t know how you can prepare for something like this. You really can’t. You have to take one day at a time.” However, others did help patients understand what they were experiencing, as described in the theme of relying on others.

## Relying on Others

Participants relied on many sources (e.g., patients who had HSCT previously, family, religion, nurses) to fill gaps in understanding. Several noted that they received great comfort from listening to others who had a transplantation. A 41-year-old African American woman said,

I have done research through the Internet. The Leukemia Society, I called them, and they got me, they hooked me up with another patient that had gone through all of this, and she and I talked back and forth on the phone. She told me about talking to other patients at the hospital. I am a member of a support group on the Internet that we counsel leukemia and everything, and every kind of research that you can think of, I have read about it. So, when the doctors come in and talk to me, it is nothing unknown or shocking to me because I have read about it.

The Internet was a resource for many. A 64-year-old Latino who worked as a crane operator stated,

I just know what the doctor told me. My wife went on the Internet and found all of this different stuff out, and she passed it on to me. I didn’t do it. She did it for me, and that is how I got my information. . . . She does a lot for me.

Although most relied on families, a few did not have that option. A 32-year-old Latino who worked as a salesman felt the distance and time away from his family were too great, and it resulted in divorce. His wife felt she could not leave their small child to be with him. The lengthy recovery and the necessity to stay in the local area for follow-up after an HSCT can be barriers to receiving support.

Participants often mentioned support from religion. A 46-year-old Caucasian man who worked as an entrepreneur talked about his need to “stay in neutral.” When asked what he meant by this, he said,

It is just happy, not sad, relaxed, not thinking about anything because I took care of everything, everything was taken care of. . . . I turned it all over to



God, and that is all you have got to do. It is that simple. So, I was going through neutral. I don't worry about nothing. I don't sit around fretting.

A 62-year-old African American woman described the role of family, friends, prayers, and those providing care.

I think calm is very, very important. The attitude makes a big difference in how the family handles it and how a person handles it. I think it is really important to have very close support groups of the family, close friends, or what. . . . And know that the prayers are out there so that gives you a certain sense of strength in going through it. But you need to make up your mind that you are going to get through it. And then have the confidence in the people who are going to do it.

Many described how important nurses were to them. A 50-year-old Caucasian woman provided particularly good examples of how to improve the care to patients undergoing this treatment. She talked about the time nurses spent with patients and the reassurance they provided.

Take that extra minute or two . . . instead of waiting for you to hit the call button. This is necessary because you feel like a car having the tires serviced, where you would just come in, and they take the tires off and leave. They don't bother wiping the car off or washing it or doing any of the little extra things. And even though you have company, and even though there are other people to fulfill your social needs, it is really nice for your nurse to stop and say, "You know you are doing okay, don't you?" Or, "You know that it is normal for you to be this tired," or, "It is normal for you to have this terrible diarrhea," or, "It is normal for you," or, "You have a tin taste in your mouth." . . . Because you don't really know what to expect.

She also noted the importance of explanations from the healthcare team.

Healthcare professionals . . . need to talk to the patient and not at the patient. And they need to explain to the patient what they are doing, why they are doing it, and what the results are of what they did. Even if it is a simple little thing about what your blood pressure was, or whatever. Some people are so secretive, and they don't realize that this is your life, and the fear that you have is often greater than the knowledge, so understanding your condition and being able to accept it is far more important than the fears that you have because no one has really discussed with you what they do behind the little drape and talk about or what they talk about in the hall . . . I know the good, the

bad, and the ugly, and the bad and ugly upset me, but it is a lot easier to deal with than the fear that I am going to die in the next two months. Having somebody explain to me, "Well this is happening here because of this," and "I think we can clear this up with this." . . . You know your body better than anybody else and . . . you know that there is a problem. So, I absolutely require for me, emotionally, physically, mentally everything, I have to have people that talk with me honestly and openly. . . . I know the process I am going through now is, can result in a fatality.

She provided an example of a particularly good nurse.

She made a list of all the medications . . . so I could understand what I was going to be taking and when I was going to take them and the dosage and I like to always check to make sure I have got the right medication so that made me very comfortable.

A 57-year-old Caucasian nurse described what helped her.

They [nurses] explained everything to me. They didn't just assume I knew what was going on, because, believe me, I didn't, I still don't. All I know is I got my cells. . . . And then after I started to feel better, then [the nurses used] wonderful teaching skills, every nurse was willing to teach me. . . . Anybody was willing to answer questions, and if they didn't know them, they would find out. They didn't just fluff it. And being a nurse for 35 years, I mean, this doesn't always happen. You get fluffed a lot.

## Discussion

The participants described barriers to understanding HSCT. They often felt they were not told what they needed to know. Although information was provided, it was not in a way that led to understanding. Details were missing, or the words professionals used were too complicated. In addition, many decisions posed dilemmas. It was hard to decide and also hard to say no to a transplantation. Through all of this, fear of death was present and linked to fears of the unknown and concerns about families. Difficult symptoms and side effects were unexpected and hard to deal with. Family, others who had been there, religion, and nurses provided support to understanding.

Several factors believed to alter health literacy that have been studied in other research were not related to understanding in this study. Understanding did not differ for participants of different ages, ethnicity, occupation, or education. This study underscores that gender, age, ethnicity, and education do not fully explain what patients comprehend (IOM, 2004). Although the IOM (2004) report noted that culture may provide a context

through which meaning is gained, in the case of HSCT, it may be that the concerns are so fundamental to human existence that they were not altered by culture.

Although research substantiates the need for open communication among healthcare providers and patients, studies indicate that this is difficult to accomplish, particularly with patients who have low health literacy. In a study by Wynia and Osborn (2010), surveys that included health literacy items were distributed to patients from 13 participating healthcare organizations and completed by 2,116 patients. Patient diagnoses were not reported. Patients with low health literacy reported having problems learning about their medical condition and were less likely to report being provided with patient-centered communication, that nurses and doctors listened to them, that nurses and doctors made sure they understood their instructions, or that it was easy to ask questions at the hospital or clinic. The ethnicity of the sample in Wynia and Osborn's (2010) study was comparable to the current study.

The risk for negative outcomes increases when healthcare providers do not provide information in a manner that patients can understand. All patients in this study received a booklet about the type of HSCT (autologous or allogeneic) they were to receive. This booklet was more than 30 pages of text with no diagrams or pictures. Although all patients received this, few discussed it in the interviews, which may indicate it was not of central importance to them. Those who did discuss the booklet found that it lacked important information on what to expect. In addition, the need to prepare patients undergoing HSCT as well as their families is suggested by the important role family members played in participants' comprehension.

Patient expectations also can alter understanding. A survey by Weeks et al. (2012) of about 1,200 patients with metastatic lung or colorectal cancer found that many may not understand that chemotherapy is unlikely to be curative. Smith and Longo (2012) noted, "If patients actually have unrealistic expectations of a cure from a therapy that is administered with palliative intent, we have a serious problem of miscommunication that we need to address" (p. 1651). They noted that patients may not be told information, may choose not to believe what they are told, or that it is possible to give patients information more effectively.

Patients often experience significant emotional distress when dealing with cancer, which may limit the capacity to understand what is said (Epstein & Street, 2007). Because medical information is complex, even the most educated patients may not understand. Fear of dying was central to the fears of the participants and is not an unrealistic concern. Survival rates vary with the disease and specific type of HSCT; Serna et al. (2003) reported overall survival rates of 51% at three years.

Support received from family or others who had undergone HSCT aided in individual comprehension. Some obtained the needed information from their family or from someone who underwent HSCT previously. Many reported they were caught off guard regarding the impact of symptoms and follow-up care. Participants varied when reporting the amount of information they could process.

The importance of religion in health is well documented. Many disparate studies found that religion positively affects many aspects of well-being and physical and mental health despite limited measures of religion and other methodologic weaknesses in the research (Cohen, Holley, Wengel, & Katzman, 2012). These patients underscored the value religion had during this experience. It often was a resource that replaced the desire for information.

A systematic review conducted for the Agency for Healthcare Research and Quality (2011) examined research related to health literacy. Low health literacy was consistently associated with greater use of healthcare resources, lower use of screening or preventive care measures, and poorer ability to take medications appropriately or to interpret labels and health messages. The Agency for Healthcare Research and Quality review (2011) also found that health disparities are more closely tied to levels of health literacy than ethnic differences. Although 27 intervention studies were reviewed, the strength of the evidence was low or insufficient. Features that did seem to improve comprehension included intensive self-management, disease-management interventions, and mixed interventions.

Professionals do not always communicate at a level that is understood by patients with low health literacy. In addition, patient education materials may be too complex, written at too high a level, or not organized from patients' perspectives. Over time, these factors could contribute to worse health among those with low health literacy. The current study included only patient experiences, and the authors know all patients received a booklet about their type of HSCT (autologous or allogeneic). The booklet was revised when healthcare staff became aware of the results of this study. However, this study did not evaluate the booklet, and no data were collected after it was revised. In addition, patients noted staff members spent considerable time discussing the HSCT, which they underscored as valuable in good nursing care. When nurses listened to patients and provided encouragement and information, the value was immeasurable.

Many patients feign understanding by nodding their head, signing forms, or simply not asking questions when they do not actually understand what is happening or what to expect. Skloot (2010) described the misunderstanding between scientists who were studying DNA from cells grown from Henrietta Lacks' cervical tumor,

known as HeLa cells. The Lacks family and the scientists decided it would be useful to have DNA samples from the immediate family to compare their DNA to HeLa cells. In 1973, a scientist, whose native language was not English, talked to the family. She said, "We come draw blood to get HLA antigen, we do genetic marker profile because we can deduce a lot of Henrietta Lacks genotype from the children and the husband" (p. 182–183). The scientist said she believed the husband understood, noting the family was receptive and intelligent. This was prior to the time informed consent forms were required, and the scientist believed this was not needed "because you just go to draw blood" (p. 183). However, the husband told his children to come because the doctors were "coming to test everybody's blood to see if you all got the cancer your mother had" (p. 184). The scientists involved told the author of the book that it was not possible to detect the cancer from the tests they were conducting, so they did not tell the family this. The children worried for a long time about the test results. This example underscores how important and complicated it can be to assess what patients understand. Although this example happened at a different time with different methods for informing patients, the Lacks family demonstrates that patients may convey understanding when they do not understand.

## Limitations

Although this study provides an opportunity to better understand health literacy, limitations exist. The sample offered a diverse cross-section of participants, but all participants were treated at one facility. Experiences may differ in other settings. In addition, the authors did not assess reading level. However, the findings were consistent across people who had little formal education and those with graduate and professional degrees.

## Clinical Implications

People with limited health literacy are less likely to report receiving patient-centered communication (Wynia & Osborn, 2010). Methods to address the needs of individuals include improved educational materials, clearer forms, clearer communication techniques, teach-back methods, and reinforcement. These strategies can enhance communication and verify patient under-

standing of important elements in his or her health care. The healthcare providers ensure that vitally important responsibilities are met. Adequate time to discuss and to determine patients' levels of understanding about their disease and treatment, gauging emotions and pacing when providing information to match patients' ability to comprehend, involving family and key people who provide support, and determining how much more the patients want to learn are important responsibilities for healthcare providers.

## Conclusions

The themes from this study clearly demonstrate that health literacy concerns are vital to patient understanding, decision making, and having active roles in their health care. Assessing patient understanding is important and requires a comprehensive assessment because patients may not know what they need to ask and may not feel comfortable asking or raising objections. The role nurses play in assisting patients also was important to these patients. The authors' research provides evidence that health literacy is not a simple function of age, ethnicity, race, or education. Rather, health literacy and communication concerns require a more nuanced approach to provide optimal patient-centered outcomes.

*The authors wish to acknowledge with great sadness that coauthor Elizabeth D. Carlson passed away last March after a long illness. The authors miss her and cherish her many contributions to their lives. This article, her last professional contribution, is dedicated to her memory.*

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