Beyond Depression, Anxiety and Posttraumatic Stress Disorder Symptoms: Qualitative Study of Negative Emotional Experiences in Hematopoietic Stem Cell Transplant Patients

Running Title: Negative Emotional Experiences in HSCT

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Abstract

Objective: Psychological distress impacts a variety of health outcomes in hematopoietic stem cell transplantation (HSCT). Focused qualitative studies on a wider range of psychological distress in HSCT patients are lacking. However, understanding the subtleties of psychological distress (e.g., fear, guilt, loss of control) in HSCT patients is imperative to optimizing the psychological well-being of this vulnerable population. To explore psychological distress after transplantation, we conducted semi-structured interviews with 25 HSCT patients.

Methods: Interviews were completed in the first 100 days after transplantation. Interview modules explored psychological distress symptoms in the hospital and during the first 100 days after HSCT, along with the perceived impact of these symptoms on their recovery.

Results: Of the negative emotional experiences reported, feeling trapped, fear, guilt, discouragement, and powerlessness were frequently expressed. Patients reported that negative emotional states interfered with their motivation to participate in health behaviors important to the transplant recovery.

Conclusion: As one of the few qualitative studies broadly characterizing the nature of negative emotional experiences after HSCT, these findings add to our understanding of the specific psychological challenges in this growing patient population and can inform development of targeted interventions and overall management of psychological distress during HSCT recovery.

Keywords. Cancer, psychological, psychosocial oncology, negative emotional states, hematopoietic stem cell transplant, quality of life

Introduction

Hematopoietic stem cell transplantation (HSCT) is a life-saving treatment for many patients with hematologic malignancies (Singh & McGuirk, 2016). Currently, approximately 20,000 HSCTs are performed in the United States annually and the number of transplants is projected to increase (Majhail et al., 2013). Survival following HSCT continues to improve with a decreased burden of physical symptoms and complications that follow the transplant. Psychological well-being is critical to successful recovery from HSCT due to the intense nature of the treatment during hospitalization and the demands of quarantine and frequent follow-up visits (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009).

Psychological well-being during HSCT recovery is usually threatened by multiple factors including rehospitalization, graft vs. host disease (GVHD), infections, and mandatory isolation while the immune system reconstitutes (Amonoo, Barclay, et al., 2019; Costanzo, Juckett, & Coe, 2013). Low levels of psychological well-being characterized by symptoms of depression, anxiety, posttraumatic stress disorder (PTSD) is prevalent (e.g., depression [35%], PTSD symptoms [20%]) (Amonoo, Massey, et al., 2019). These well-studied psychiatric symptoms significantly and negatively impact a variety of health outcomes in this population. For example, depression is associated with decreased health-related quality of life (QOL), poorer functioning and increased mortality (Loberiza et al., 2002; Mosher et al., 2011); and PTSD is associated with QOL deficits, and increased depression. (Mosher et al., 2009)

Despite the high prevalence of the negative psychological symptoms in the HSCT population, most HSCT patients do not meet criteria for a psychiatric diagnosis (Amonoo, Barclay, et al., 2019). The deep understanding of the impact of depression, anxiety and PTSD has resulted in targeted interventions for HSCT patients that improve health outcomes (El-Jawahri et al., 2016). However, we know that a variety of negative emotional experiences (e.g., shame(Dolezal & Lyons, 2017), guilt(Day & Bobocel, 2013), external locus of control(Nazareth et al., 2016), and fear(Page-Reeves et al., 2013)) which are not frequently assessed in medical populations as compared to depression and anxiety, negatively impacts health-related outcomes. As in a diverse group of medical populations, many HSCT patients continue to suffer with various psychological distress symptoms, and not all psychological distress is the same and the nature of the distress should inform management. Our understanding of psychological distress in HSCT patients must go beyond commonly studied symptoms that are typically measured quantitatively with self-assessment measures. Qualitative studies that explore the breadth of psychological distress beyond depression, anxiety, and PTSD symptoms in HSCT patients are lacking. Hence, we used semi-

structured qualitative interviews to explore the negative psychological experiences during their acute recovery from HSCT.

Methods

Study Criteria and Recruitment

We have previously reported full details about study design, procedures and analysis (Amonoo, Brown et al., 2019), and include brief details below. We used a qualitative research design and hour-long, semi-structured qualitative interviews to explore the negative emotional experiences of HSCT patients in the first 100 days of transplantation. Adult patients with hematologic malignancies hospitalized for allogeneic HSCT at an academic cancer center were eligible to participate in the study. Between September 2017 and December 2017, we approached eligible patients during their inpatient transplant hospitalization, recruited and enrolled participants into the study after written informed consent. We excluded patients who could not speak English, had an active psychiatric diagnosis (e.g., schizophrenia, substance use disorder) as diagnosed by the Mini International Neuropsychiatric Interview (MINI(Pinninti, Madison, Musser, & Rissmiller, 2003)) or had cognitive deficits (assessed with a six-item cognitive screen(Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002)) that would interfere with their ability to provide informed consent or engage in study procedures. We followed the consolidated criteria for conducting and reporting qualitative research (COREQ) guidelines (Tong, Sainsbury, & Craig, 2007). This research was conducted following all guidelines of the Declaration of Helsinki. The study was approved by our center's Institutional Review Board.

Patient Characteristics and Baseline Assessment

While participants' inpatient transplantation hospitalization lasted approximately 20-30 days, demographic information was obtained via self-report at enrollment and baseline (mean of 12 days after transplantation). The Hospital Anxiety and Depression Scale (HADS) (Bjelland, Dahl, Haug, & Neckelmann, 2002), a 14-item validated questionnaire, was used to measure symptoms of anxiety and depression at baseline and follow-up (mean of 100 days after transplantation). The cutoff score for the depression subscale (HADS-D) was ≥ 8 and that of the anxiety subscale (HADS-A) was ≥ 8 . (Zigmond & Snaith, 1983) Prior to the follow-up assessment at approximately a 100 days post transplantation, participants were required to follow-up twice weekly and then weekly as outpatients.

Qualitative Interviews

A trained psychiatrist (HA), with no prior relationship with participants, conducted semi-structured interviews at the end of their hospitalization and approximately 100 days after transplantation. Interviews explored patients' negative emotional experiences associated with their illness and HSCT

recovery. Baseline interviews (between September 2017 and February 2018) were conducted in person prior to patient discharge from the transplant hospitalization while the majority of follow-up interviews (between December 2017 and May 2018) conducted via phone. Interviews were recorded, transcribed verbatim and uploaded to QSR NVivo 12 software (QSR International, Melbourne, Australia) for analysis. Specific topics explored by interviews included the range, intensity, and timing of negative psychological experiences in the context of illness and HSCT recovery, and the impact of negative experiences on daily life.

Data Analysis

Qualitative Analysis

Directed content analysis, a descriptive approach to qualitative data analysis (Vaismoradi, Turunen, & Bondas, 2013) was used to analyze the data. In consultation with qualitative research experts and the senior author (JH), two a psychiatrist (HA) and a clinical psychologist (LB)] developed the codebook, prior to independently coding all interviews between July 2018 and October 2018. Our interview guide and qualitative data informed the development of the codebook. We modified the codebook after reading a small proportion of the transcripts to test the codes. The unit of coding was a complete sentence. Emerging themes from the codes were discussed during weekly team meetings, during which discrepancies were adjudicated to ensure that the themes reflected the original data. Inter-rater reliability of coding ($\kappa = 0.92$) was high. We reached thematic saturation with a sample size of 25 patients (consistent with similar studies (El-Jawahri et al., 2017; Saunders et al., 2018) at baseline and 21 patients follow-up.

Descriptive statistics analysis

The population's demographics and HADS were described using descriptive statistics (mean, standard deviation).

Results

Demographics

Of 36 approached patients, two were ineligible due to limited English proficiency and severity of illness, nine declined and 25 (71% of potentially eligible participants) ultimately enrolled. Figure 1 provides further details about patient enrollment. At follow-up, 21 participants (84%) completed the interviews. Table 1 shows baseline participant characteristics. Participants had a mean age of 50.4 (SD 14.2), 44% were women, 60% were married, and 80% were White. Acute myeloid leukemia (44%) was the most common hematologic malignancy, unrelated and matched unrelated donors were the most common transplants and most (84%) participants did not have acute GVHD. Participants did not meet criteria for clinically significant depression or anxiety symptoms based on the HADS scores as showed in Table 2.

Negative Psychological Experiences

Participants reported a breadth of negative emotional experiences at both time points. At baseline, common themes of negative emotional experiences included that of feeling a lack of control over their illness and treatment, guilt about burdening family to care for them during the HSCT recovery, fear of death, and feeling overwhelmed by the transition from hospital to home. At follow-up, common themes of negative emotional experiences included frustration with limited physical function and fear of cancer recurrence. A report of feeling trapped by the required isolation either in the hospital or at home was common at both time points. We highlight the negative emotional experiences reported by patients below. Table 3 provides a detailed summary of themes of negative emotional experiences described by participants.

Guilt

Participants reported guilt about their response to treatment or the impact of their illness and treatment on their family. Guilt was also reported about good recovery when none of the complications anticipated by the clinical team were experienced:

"I'm almost feeling guilty that I don't feel the way they said." (ID 5)

Guilt was also expressed about the perceived burden imposed on family and loved ones by the level of support that recovery from the transplant and the routine follow-up entailed:

"So I have a little bit of guilt as far as the burden, the burden that I was going to put on my family so quickly." (ID 19)

Feeling Trapped

Participants consistently reported they felt trapped by various aspects of the transplantation process and the recovery. During hospitalization, allogeneic recipients are quarantined in their rooms for most of the admission, leading to substantial impingement on their activities. One patient articulates:

"Either way, you do feel like you're trapped and there's nowhere to go and the rooms are small." (ID 10)

Some participants at follow-up reported that the isolative aspects of recovery outside the hospital, such as restrictions from visiting crowded places, limitations on travel especially travel by plane, and having to wear masks was distressing:

"I just wanna be able to go outside without masks on and just be normal. I want to be able to travel, we travel a lot usually. And just the limitations of feeling trapped in my local area I don't like." (ID 7)

Fear

Fear was explicitly reported, especially at baseline, about cancer recurrence, complications, and inability to return to baseline level of functioning. One participant reported that the transplantation and being in the hospital caused more heightened fear of cancer recurrence than he has experienced in the past:

“Tremendous fear that the cancer would come back.” (ID 16)

Several participants at both baseline and at follow-up also reported increased fear of dying than they had experienced prior to the transplant:

“Yeah, because I feel afraid of dying a lot more” (ID 8)

Discouragement

Despite the promise of cure offered by HSCT, participants reported feeling discouraged about the uncertainty of their treatment response or their chances of remission after the transplant at baseline and especially at follow-up in the setting of some complications and worsening physical symptoms. One participant articulates:

“And I don't know what those chances [of remission] are, so that's pretty discouraging to me right now” (ID 1)

Although most HSCT recipients go into the transplant with awareness of the potential physical limitations that the recovery entails due to fatigue, the quarantine status, and isolation, several participants reported discouragement about their physical limitations that negatively impacted their psychological well-being. One participant at follow-up reported:

“Yeah... I have the energy to do certain things up to a point. So that's discouraging too sometimes, ... getting too tired quick.” (ID 3)

Powerlessness and Lack of Control

Some patients reported that the transplant process and recovery is overwhelming in ways they did not anticipate prior to their transplant. The feeling of powerlessness and lack of control was consistently reported more at follow-up than baseline. One participant describes:

“This is much harder than I thought it was going to be. I did not expect it to be so difficult to feel so powerless” (ID 16)

Closely related to feeling powerless is the sense of feeling out of control over the treatment outcome, and physical functioning in a way that some participants felt was underestimated prior to the transplant. One participant states:

“...Feel like you have no control over your bodily functions and you're being potty trained again, and that's kind of disturbing.” (ID 25)

Relationships between Negative Emotional Experiences and Health Behaviors

A relationship between negative emotional experiences and health behaviors was reported by several participants at both time points. Negativity in general, was associated with decreased motivation for meaningful activities and reduced physical activity. Several participants reported noting a connection between a negative emotional state and willingness to engage in health behaviors, including self-care and physical activity:

"I think when you focus on the negative, you tend to feel drained. So it's easier to take a nap than it is to unroll your yoga mat." (ID 2)

"If you're feeling negative, you kind of just want to sleep all day and not really do much." (ID 17)

Participants also reported that negativity fueled hopelessness, apathy and disengagement with healthy behaviors and care:

"Yeah. If you feel sad you're kind of, not quitting on yourself, but kind of giving up, I think." (ID 5)

"Yes, when you are not feeling great, you just disengage." (ID 14)

Discussion

We used semi-structured interviews and qualitative analysis to explore psychological distress in 25 allogeneic HSCT recipients at an academic cancer institution during the first 100 days of the recovery from HSCT. Prior studies in this area have used primarily cross-sectional quantitative methods or self-report questionnaires and have focused on depression, anxiety and PTSD symptoms without exploring negative emotional experiences broadly. To our knowledge, this is one of few focused studies that are qualitative in nature and explored a broad range of negative psychological states in this population (Xuereb & Dunlop, 2003). Not all psychological distress is the same and interventions that target distress should be tailored to the specific type of distress. Hence, a comprehensive understanding of the psychological distress beyond those commonly assessed via self-report questionnaires (e.g., HADS) in hematologic cancer patients will help HSCT clinicians better identify and manage distress in this population. Patients readily reported a variety of negative emotional experiences (e.g., feelings of powerlessness or a challenged locus/sense of control regarding their illness and treatment, guilt about the burden placed on their caregivers due to intensive follow-up requirements and frequent hospital visits following the transplant, feeling trapped in the setting of the required quarantine status) although patients did not meet criteria for clinically significant depression or anxiety based on their HADS scores. This emphasizes the need for alternate ways of distress assessment in addition to validated measures of distress in the HSCT population.

Feelings of powerlessness and feeling trapped were prominent themes articulated by many patients in our cohort. Prior studies in cancer populations have highlighted patients' frustration with feeling powerless as they recover from their cancer and treatment (Baqutayan, 2012; Knapp, Marziliano, & Moyer, 2014). More so than other medical populations, for HSCT patients, a sense of powerlessness may be especially heightened due to the added restriction and needed isolation as patients reconstitute their immune system (Xuereb & Dunlop, 2003). While our cohort highlighted the distress that accompanies feelings of powerlessness over their health in the first 100 days, the feeling of powerlessness can persist longer in survivorship (Baker, Zabora, Polland, & Wingard, 1999).

Closely linked to powerlessness is guilt reported by a portion of our sample. Prior studies have highlighted a high prevalence of guilt in lung cancer patients compared to those with breast or prostate cancer due to lung cancer patients' attribution to smoking as the cause of their cancer (Dirkse et al., 2014; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). Guilt is also prevalent in solid organ transplant survivors, especially as it pertains to survivor's guilt where patients express guilt that they survived while their donor did not (Zimmermann, Pabst, Bertram, Schiffer, & de Zwaan, 2016). Compared to solid organ transplantations where donors mostly do not survive their donation, HSCT donation is not typically accompanied by the death of the donor (Perez-San-Gregorio et al., 2017). It was notable to observe that guilt expressed in our cohort was more focused on loss of independence and control, and feeling like a burden to family and caregivers. Guilt in our cohort like many cancer survivors has also been reported in the context of survivors comparing their lives to others with similar diseases and treatment trajectories who have died from the experience. (Glaser, Knowles, & Damaskos, 2019) For example, in a study aimed to understand survivor guilt in 108 lung cancer survivors by Perloff et al., 64% of participants scored above the mean on the survivor guilt scale and a report of the death of others was one of the five recurring themes underlying survivor guilt. (Perloff, King, Rigney, Ostroff, & Johnson Shen, 2019) Despite the limited evidence of effective interventions to address guilt, brief psychotherapeutic interventions that highlight cognitive restructuring of the sources of guilt could be emphasized by HSCT clinicians in the acute recovery (Perloff, King, Rigney, Ostroff, & Johnson Shen, 2019).

Fear, an acute and intense emotional reaction to a specific and present danger (Davis, 1998), has been increasingly studied in medical populations, including cancer patients (Reed et al., 2019; Sarkar, 2014). Similar to the findings of prior studies, our cohort expressed a fear of relapse or transplant failure (Baker et al., 1999). Among medical populations, fear is more prevalent in cancer populations partly due to the uncertainty regarding treatment efficacy and relapse (Sharpe, Curran, Butow, & Thewes, 2018). Although the risk of relapse in the HSCT population is less than those in patients who fail conventional treatment but do not receive HSCT, the risk of relapse or secondary malignancies remains significant (Barrett & Battiwalla, 2010; Bomken & Skinner, 2015). Fear can be debilitating and undermine patients'

ability to cope and function (Bevans, Mitchell, & Marden, 2008), and most concerningly interfere with adherence to recommendations for optimal recovery. Hence, fear should be explored explicitly especially during the first 100 days of the transplant when the risk of complications is highest.

There is a robust literature on the negative association between negative psychological states and health behaviors in many medical populations (Hardcastle et al., 2015). However, our understanding of the impact of negative psychological states beyond depression, anxiety and PTSD in HSCT patients is limited. Most participants reported that feeling negative hindered their ability to stay motivated and engage with their treatment, consistent with other findings about negative states and engagement in care in other populations (Bogner & McClintock, 2016; Fiske, Wetherell, & Gatz, 2009; Unutzer & Park, 2012). This further underscores the need for HSCT clinicians to understand the wide range of psychological distress symptoms in this population in order to effectively determine the best targeted interventions to address distress.

This study was limited by several factors. The sample was mostly non-Latino White, married, educated and were recruited from a tertiary academic medical center, limiting the generalizability of our findings. Our sample size was small (N=25) but allowed for thematic saturation. Different types of HSCTs are accompanied with varying amount of psychological distress due to the differences in symptom burden, complications and recovery needs. Hence, with our sample including only allogeneic recipients, other HSCT recipients, including autologous recipients, may report different negative experiences. With 70% of potentially eligible patients enrolling in the study, selection bias was likely not a prominent factor, although patients who elected to participate in the study may have been more psychologically-minded than those who declined to participate. Finally, as majority of participants did not meet criteria for clinically significant depressive symptoms or anxiety based on their HADS score, we did not categorize qualitative data based on HADS scores although patients with clinically significant depressive or anxiety symptoms could likely have more intense negative emotional experiences than those who did not.

In conclusion, assessing for psychological distress beyond depression, anxiety and PTSD is warranted in the HSCT population, especially since most of these patients do not meet diagnostic criteria for psychiatric disorders. HSCT clinicians should partner with mental health clinicians, especially consultation-liaison psychiatrists to comprehensively assess, explore and manage the psychological distress in acute transplant recovery. Our study highlights that HSCT patients (even those who do not meet criteria for a mood disorder on a self-report measure such as the HADS) experience a variety of distress symptoms (e.g., guilt, powerlessness and fear) which have varying impact on the recovery, function and quality of life throughout HSCT recovery. One size does not fit all, hence, a comprehensive understanding of the nature of distress in HSCT patients will inform the development of targeted interventions that effectively address psychological distress in this population.

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Table 1. Participant Characteristics

Age and Sex

Age (years; mean $\pm$ standard deviation)	50.4 $\pm$ 14.2
Women	11 (44)

Race & Ethnicity	
White	20 (80)
Asian	1(4)
American Indian/Alaska Native	1(4)
Native Hawaiian or Other Pacific Islander	1(4)
More than one race	1(4)
Unknown	1(4)
Hispanic or Latino	2 (8)
Education	
Associate degree or higher	16 (64)
Marital Status	
Married	15 (60)
Type of Cancer	
Acute myeloid leukemia (AML)	11 (44)
Chronic myeloid leukemia (CML)	1 (4)
Acute lymphocytic leukemia (ALL)	5 (20)
Acute undifferentiated leukemia (AUL)	1 (4)
Chronic myelomonocytic leukemia (CMML)	1 (4)
Myelodysplastic syndrome (MDS)	3 (12)
Other	3 (12)
Type of Transplant	
Unrelated donor	8 (32)
Matched unrelated donor	8 (32)
Matched related donor	5 (20)
Haplo-identical/mismatched related donor	1 (4)
Mismatched unrelated donor	3 (12)
Conditioning Regimen	
Reduced-intensity conditioning	5 (20)
Acute GVHD [†] in 100-days	4 (16)
Stem Cell Source	
Bone marrow transplant	10 (40)
Peripheral blood stem cell transplant	14 (56)

Cord blood transplant

1 (4)

	Baseline (N=25)	Follow-up (N=19)	t	p-value
HADS Total (range: 0-42)	10.4 ± 4.8	10.4 ± 4.7	.25	.81
HADS Anxiety (range: 0-21)	5.6 ± 2.9	6.1 ± 3.3	1.42	.17
HADS Depression (range: 0-21)	4.8 ± 3.0	4.3 ± 2.3	-.84	.41
GVHD Severity				
0 (none)		21 (84)		
1 (mild)		3 (12)		
2 (moderate)		1 (4)		
Other		1 (4)		

[†]GVHD: Graft-vs-host disease.

Table 2. Quantitative Assessment of Depression and Anxiety at Baseline and Follow-up

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Table 3. Negative Emotional Experiences

Theme	Sub-Theme	Quotes
Locus of Control	Lack of control over illness	“It's something you have no control over. Some people get a shitty hand. .. Just bad luck.” (ID 4). “I'm a guy who's always in control and this disease, you have no control.” (ID 5) “...Feel like you have no control over your bodily functions and you're being potty trained again, and that's kind of disturbing” (ID 25)
Guilt	Guilt about burden on family	“So I have a little bit of guilt as far as the burden, the burden that I was going to put on my family so quickly.” (ID 19)
	Guilt about no physical complications	“I'm almost feeling guilty that I don't feel the way they said.” (ID 5)
Feeling Overwhelmed	Overwhelmed by transition from hospital to home	“And I think going from the hospital to home, although it's been a positive change, I just kind of get overwhelmed.” (ID 2)
Frustration	Frustrated with limited physical function	“So it's frustrating on that part... I mean, I can go, not very far, but I can go a distance walking with them for a little while.” (ID 6). “It's frustrating to have to rethink what you do every second of the day and not to be able to go out, make things happen, do things. That's frustrating.” (ID 11)
Depression	Impact of depression on interaction with family	“I couldn't even Facetime with them [family] because I was so depressed” (ID 7)
	Depression due to less physical activity	“I've been a little bit kind of depressed. But I mean, a lot of it's kind of being more so kind of less active.” (ID 4)
Feeling trapped/Social	Feeling trapped by hospitalization	“Either way, you do feel like you're trapped and there's nowhere to go and the rooms are small” (ID 7)

isolation	Feeling trapped by the required isolation	“I just wanna be able to go outside without masks on and just be normal...I want to be able to travel, we travel a lot usually. And just the limitations of feeling trapped in my local area I don't like.” (ID 7)
Fear	Fear of death	“Yeah, because I feel afraid of death a lot more” (ID 8)
	Fear of cancer recurrence	“Tremendous fear that the cancer would come back” (ID 16)
Sadness	Sadness about decreased physical function	“And there were periods of time, weeks, when I just-- I can't move. I've no energy. I don't have enough energy to read, which makes me very sad.” (ID 16)
Anxiety	Anxiety about leaving the house in the setting of immune system recovery post-transplant	“Unless my numbers were okay. But even when they were okay, I would still get a little nervous going out.” (ID 17)
	Anxiety in the setting of transition to home	Because I think when you are in treatment, you're just so focused on getting your treatments and that day and what's happening that day, that when you're done and you're home and everything is done and basically that's it, you kind of just have nothing else to focus on except every little ache and pain and ruminate on things like that, and so it just gives you anxiety. (ID 17)
	Anxiety about reduced restrictions	“Well, I've just been anxious to getting back to being allowed to do things. I mean my body has been progressing so my mind is saying, "Okay, I feel great," but I don't want to jinx anything, but for the most part following the doctor's regulations and requests and restrictions.” (ID 22)
	Worry about family	“I felt more worried about them [family] than myself [inaudible] because like I said, I'm an only child so-- I definitely have a close relationship to both my parents.” (ID 4)
Disappointment	Disappointment about physical limitations	“Well, I'm disappointed I can't do the things that I'm used to doing, but I've kind of taken on projects or things that I should've done a long time ago.” (ID 1)
Discouragement	Discouragement about uncertainty of	“And I don't know what those chances [of treatment] are, so that's pretty discouraging to

	treatment efficacy	me right now.” (ID 1)
	Discouragement about physical limitations	“Yeah. Sometimes I get disappointed if I don't have the energy to do things... So that's discouraging too sometimes, not physically being or getting too tired quick.” (ID 3)
Doubt	Questioning decision for the transplant based on uncertainty about quality of life and complications	“Sometimes I wonder if going through transplant was worth it.” (ID 2)
Powerlessness	Feelings of powerlessness in the setting of required treatment	“This is much harder than I thought it was going to be. I did not expect it to be so difficult to feel so powerless.” (ID16)
Emotional Tenderness	Emotional tenderness and increased tearfulness	“I was so emotionally tender that if somebody was kind, or some music came on the radio, or there was an article in the newspaper, and I would just cry.” (ID 16)
PTSD (As direct quote from patient using diagnosis in a colloquial sense)	Reliving treatment experiences as in PTSD	“It's almost like PTSD. You hear something, or you smell something, or you see something, and then you think about what you went through when you were in treatment.” (ID 17)

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Figure 1: Participant Enrollment

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Title:

Beyond depression, anxiety and post-traumatic stress disorder symptoms: Qualitative study of negative emotional experiences in hematopoietic stem cell transplant patients

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