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HRQOL and Personal Life Goals of Adults with SCD after HSCT

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Abstract

Sickle cell disease (SCD) has devastating short and long-term effects on adults. Allogeneic hematopoietic stem cell transplantation (HSCT) from an HLA-matched sibling donor offers a unique therapy to reverse SCD. This mixed methods study explores recipients' perception of HSCT success, personal life goals, and associated health-related quality of life (HRQOL) more than one year after HSCT. Recipients completed a 5–10 minute HRQOL survey (SF-36v1), a 5-minute questionnaire about themselves, followed by a 60 to 90-minute face-to-face or telephone audio-recorded interview. Eleven of 15 (75%) eligible recipients participated in the study. Although the eight HRQOL subscale scores varied, the three recipients with a successful HSCT and the highest scores were pursuing their personal life goals. The four with avascular necrosis (AVN) had low physical role limitations scores and were pursuing their goals. The two reporting a failed HSCT had reverted back to having SCD and most of their scores were among the lowest. Our results show that HSCT success, ability to pursue personal life goals, and HRQOL align in predictable ways and the recipients' narratives help to disentangle the complex relationships among physical, emotional and mental health and the intervention to cure this chronic condition.

Keywords

sickle cell disease; personal life goals; health-related quality of life; stem cell transplantation; mixed methods

Sickle cell disease (SCD) is the most common inherited single gene condition (Rees, Williams, & Gladwin, 2010) affecting about 100,000 people in the United States (U.S.; Hassell, 2010; Piel, Steinberg, & Rees, 2017). Collectively, early diagnoses through infant screening, immunizations, penicillin prophylaxis, blood transfusions for stroke prevention and hydroxyurea to minimize pain episodes have improved health outcomes for those with SCD. However, SCD is a chronic and systemic condition affecting most body organs and impacting a person's physical and psychosocial capabilities (Azar & Wong, 2017); it leads

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to early death (Platt, Brambilla, Rosse, Milner, Castro, Steinbert, & Klug, 1994). All of these treatment advances have shifted the mortality curve from childhood and adolescence to adulthood. The life expectancy of adults with SCD, however, has remained unchanged over the last 40 years with a median survival age estimated at about 42 years for males and 48 for females (Chaturvedi & DeBaun, 2016; Platt, Brambilla, Rosse, Milner, Castro, Steinbert, & Klug, 1994).

At present, allogeneic hematopoietic stem cell transplantation (HSCT) from a HLA-matched full sibling donor is the best studied treatment with the highest cure rates for adults with SCD that abates progressive organ damage associated with early death (Bauer, Brendel, & Fitzhugh, 2017; Fitzhugh, Abraham, Tisdale, & Hsieh, 2014; Hsieh, 2016; Ozdogu & Boga, 2015; Talano &Cairo, 2014). The major aim of HSCT is to eradicate sickle erythropoiesis that produces abnormal red blood cells, and contributes to the sickling process and the complex serious acute and chronic complications (Walters et al., 2016).

Nonmyeloablative allogeneic HSCT (Hsieh et al., 2014; Saraf et al., 2016) in SCD begins with a full consultation and follow-up clinic visits with the transplant center team members. Reproductive risks and possibility of infertility are discussed and all patients accept this potential risk. This consultation also includes a visit with a social worker to discuss the person's psychosocial needs. The next step is conditioning by immunotherapy and total body irradiation before HSCT. After 7 days the donor peripheral blood stem cells, mobilized by granulocyte colony-stimulating factor (G-CSF), are infused into the bloodstream through a central venous catheter. The recipient is given an immunosuppressant medication, sirolimus, and is hospitalized for approximately one month as the marrow begins to restore the immune system and produce normal red blood cells. After HSCT some recipients have > 90% of blood cells derived from donor stem cells, and some have a mix of blood cells from their own and the donor's stem cells, called stable mixed chimerism (Bauer, Brendel, & Fitzhugh, 2017). Researchers reported that SCD is reversed when at least 20% of the peripheral blood cells are of donor stem cell origin (Abraham et al., 2017; Fitzhugh, Cordes, Taylor, Coles, Roskom, Hsieh, & Tisdale, 2017).

Only a small minority of the 25 million people with SCD worldwide have had a HSCT and in the United States fewer than 1% of people with SCD have had a HSCT (Walters et al., 2016). In part, this is because HSCT requires an HLA-matched full sibling donor and each sibling only has a 25% chance of being an HLA-identical match (Gluckman et al., 2017). Of course, there are concerns about HSCT-related complications and mortality and structural issues that include social and economic barriers (e.g., insurance denial, and additional treatment costs) (Gluckman et al., 2017.).

Historically, children have been the primary recipients of HSCT (Walters et al., 2016) because increasing age is associated with greater risk of toxicity, graft-versus-host disease (GVHD), and HSCT-related mortality. A consensus panel recommended that young children with symptomatic SCD be transplanted as early as preschool age because survival has greatly improved (Angelucci et al., 2014). Of all the HSCT performed world-wide for SCD, 85% are among children and just 15% are adults (Gluckman et al., 2017). However, over the last 30 years, innovative approaches and an increase in eligible donors have made HSCT

safer and enabled more adults who suffer the burden of SCD symptoms and complications to receive HSCT (Talano & Cairo 2014).

Clinical trials using reduced intensity conditioning show positive clinical results, including 87% long-term engraftment without acute or chronic GVHD measured at median follow up of 3.6 years after HSCT, and an overall survival rate of 97% (Hsieh et al., 2014).The stable mixed recipient-donor chimerism from these reduced intensity conditioning regimens results in normalized hemoglobin concentrations and is associated with improved health-related quality of life (HRQOL) at one year after HSCT (Saraf et al., 2016).

In addition to survival and care management outcomes, HRQOL with SCD and after HSCT has been identified as a significant patient outcome (Caird, Camic, & Thomas, 2011; Panepinto, 2012; Panepinto & Bonner, 2012). This interest in HRQOL is especially relevant as the number of people who survive after HSCT continues to increase and a nuanced understanding of long-term effects is necessary (Battiwalla, Tichelli, & Majhail, 2017). HRQOL refers to a person's assessment of their level of functioning and well-being that includes physical, cognitive, social and emotional functioning affected by a health condition or its treatment (Panepinto, 2012). The focus on HRQOL in SCD and after HSCT helps to document the recipient's perspective of the experience and can assist health providers to better communicate with patients and families, tailor care, and assess the impact of the clinical care (Dobrozsi & Panepinto, 2015; Panepinto & Bonner, 2012).

Multiple publications on HRQOL among children, adolescent and young adults with SCD and after HSCT have been reported (Bhatia & Sheth, 2015). Regardless of age, HRQOL is associated with clinical manifestations such as frequent pain episodes, disease-related complications (i.e., stroke, acute chest syndrome, avascular necrosis), and the use of hydroxyurea (Panepinto & Bonner, 2012). Pain from vaso-occlusion negatively affects physical functioning. The psychosocial functioning dimension reflects the severity of SCD, neurobehavioral co-morbidities and other determinants of health (e.g., age, sex, income, education) (Panepinto & Bonner). Furthermore, style of coping, high symptom burden, rural versus urban living, employment, fetal hemoglobin, opioid use and genotype are associated with HRQOL in adults (Panepinto & Bonner). With the exception of mental health, increasing age was associated with poorer HRQOL scores as measured by the SF-36. Women showed greater risk for lower physical functioning and vitality (Dampier et al., 2011).

Recent studies of HRQOL in children, adolescent and young adults with SCD showed that perceptions of SCD and the use of hydroxyurea (Badawy, Thompson, Lai, Penedo, Rychlik, & Liem, 2017), hip dysfunction (Malheiros, Lisle, Castelar, Sa, & f, 2015), and fatigue (Anderson, Allen, Thornburg, & Bonner, 2015) were reflected in HRQOL measures. A study on adults using Patient-Reported Outcome (PRO) measures that included physical, mental health and sickle cell-related domains indicated that a sizable number of patients were at least 1 SD below the population norms on physical and mental health at admission to the hospital and at discharge one week later (Esham, Rodday, Weidner, Buchsbaum, Smith, & Parson, 2016).

Three studies have reported HRQOL among children and adolescents with SCD after HSCT (Arnold, Sands, Bhatia, Kung, & Satwani, 2015; Bhatia et al., 2015; Kelly, Pennarola, Rodday, & Parsons, 2012). Children and adolescents significantly improved in most components of HRQOL over the first year after HSCT (Arnold, Sands, Bhatia, Kung, & Satwani; Bhatia et al.). However, in children the physical and emotional functioning scores returned to baseline functioning by 3 months after HSCT (Kelly et al.). As of this writing, only our group (Saraf et al., 2016) has published HRQOL data among adults with SCD after HSCT using the SF-36v1, short form (Ware, Snow, Kosinski & Gandek, 1993) at 4 time-points: before HSCT and at days +30, +90, and +365 after HSCT. HRQOL results showed improvements as early as day +30 after HSCT with significantly greater improvements in general health, bodily pain, and energy at 1 year after HSCT.

Meeting personal life goals after HSCT such as employment, returning to school, or participating in other activities is understudied, important, and highly desirable as indicated by those recipients recovering from hematological cancers (Morrison et al., 2016; Winterling, Johansson, Wennman-Larsen, Petersson, Ljungman, & Alexanderson, 2014). Meeting life goals helps recipients regain a personal identity, promotes a feeling of well-being after recovery, and provides a sense of normality in life; these are important indicators to track as part of overall and long-term adjustment (Morrison et al.). Unemployment not only adds to financial strain, but also has negative psychological effects. Between 54%−74% of recipients of HSCT for hematological cancers are unable to return to work; those who did not return to work reported multiple health problems including fatigue and pain, and poorer quality of life and perceived health and some needed disability support to alleviate some of the financial burden (Battiwalla, Tichelli, & Majhail, 2017; Winterling, Johansson, Wennman-Larsen, Petersson, Ljungman, & Alexanderson).

Even with current advanced treatments, adults with SCD have challenges in finding and keeping employment, continuing their education, and advancing their careers due to physical constraints and the unpredictability and uncertainty of living with this chronic disease (Thomas & Lipps, 2011). Adults with SCD have indicated that lengthy absences due to the unpredictability of pain episodes, hospitalizations and complications, and struggling to keep up with work or school or not being able to work or attend school represent significant and debilitating effects that SCD has on everyday life (US, FDA, 2014). These related consequences are supported by qualitative data showing that adults felt that SCD limited their career and educational goals and that a successful HSCT would allow them to pursue these goals (Van Speybroeck, Adeniyi, & Hsu, 2016).

Purpose

We build on the work of the Saraf et al. (2016) and are responding to calls by others to track the unique and significant challenges faced after surviving a HSCT (Battiwala et al. 2017). We extended the timeframe beyond the first year (1–4 years) and evaluated recipients' HRQOL subscale scores as they related to narratives about their HSCT outcome (i.e., success or failure) and related experiences and, more specifically, their personal life goals (e.g., employment, school attendance and/or completion, pursuit of a career).

Materials and Methods

Design

A mixed methods approach guided the exploratory qualitative and survey components of this analysis (Creswell, 2013). Each participant completed a standardized measure of HRQOL and a short demographic questionnaire before participating in a face-to-face or telephone semi-structured interview (Leech & Onwuegbuzie, 2009). The analyses comprised conventional content analysis (Hsieh & Shannon, 2005), a series of data matrices and summaries, and descriptive statistics. Here we focus on reporting recipients' perspectives on their HSCT outcomes, personal life goals, and HRQOL.

Sample and Setting

Based on a list received from a member of the transplant team, there were 15 eligible adults. Each received a novel, nonmyeloablative conditioning regimen and were more than one year post-HSCT from a healthy, HLA-matched sibling at the Stem Cell Transplant Center in University of Illinois Hospital and Health Science System (Saraf et al., 2016).

Measures

Interview guide.—A semi-structured interview guide that included a series of open-ended questions and accompanying probes was developed by our team. Our goals were to learn how recipients made the decision to undergo HSCT, about their recovery process, and document the impact of HSCT on them, their families and relationships and relate this to their HRQOL. Included in the guide were questions specifically related to perceptions of HSCT success, health prior to and after HSCT, and personal life goals. For example, we asked, "How would you describe your health since your transplant? Do you have any new or returning symptoms and/or concerns? Do you expect any changes in your condition or treatment in the near or distant future? If yes, what do you expect? What were your wishes and hopes about having the transplant? In what ways do you think your life has changed since the transplant (e.g., daily routine, impact on employment, job situation, career, school, new areas of ability, long-term plans)?" The design of the interview questions and format was to encourage open expression of ideas and experiences by recipients.

Health-related quality of life (HRQOL).—Health-related quality of life (HRQOL) was measured using the Short Form-36, version 1 (SF-36v1; Ware & Sherbourne, 1992), the same instrument used in the study by Saraf et al. (2016). The SF-36 is widely used for clinical research, health policy evaluations as well as general population surveys (McHorney, Ware, Racchel, & Sherbourne, 1994; Ware, Kosinski, Dewey, & Gandek, 2000). Reliability alphas range from 0.78 to 0.93 on all subscales (Ware & Sherbourne, 1992). The survey took about 5–10 minutes to complete. Ten item are used to assess physical functioning (PF), 4 items for role limitations due to physical health problems (RP), 2 items for the intensity of bodily pain or discomfort and the extent to which it interferes with normal activities (BP), 5 items about general health perceptions (GH), 4 items represent vitality and reflect energy levels and/or fatigue (VT), 2 social functioning items capture the impact of health or emotional problems on normal social activities (SF), 3 items indicate role limitations due to personal or emotional problems that apply to everyday responsibilities (RE), and 4 items are

used to assess mental health related to psychological distress or well-being (MH). Participants' Likert scale responses to the items were coded; 10 items were recoded so that higher scores would indicate a more favorable health state. Individual coded responses were summed across items in the same scale to produce raw scale scores. These were then transformed to a 0–100 scale for each of the eight subscales that reflect different dimensions of health and relationships to quality of life (Ware, Snow, Gandek & Kosinski, 1993).

Data Collection

After study approval by the University of Illinois at Chicago Institutional Review Board (IRB), we received a list of 15 eligible recipients from a member of the transplant team. A research team member not involved in SCD or HSCT care management contacted each recipient by telephone to explain the project and invite his or her participation. A team member kept in contact by email, text, or telephone until an interview could be scheduled. A copy of an IRB approved project information and consent form was provided either by post, email, or face-to-face. At the beginning of each private interview, the purpose of the study and study procedures were explained in detail and after informed consent, the participant signed the consent form. Over 2 hours, each participant completed: a 6-item demographic form, HRQOL survey (SF-36, v1), and 60–90-minute digitally audio-recorded face-to-face or telephone interview in that order. Interviews were completed over six months from August 2016 to February 2017.

Data Analysis

Interviews were digitally audio-recorded, transcribed verbatim by a professional transcriptionist, and checked for accuracy against the original interview by a research assistant. Initial analysis of the interview transcripts began with an iterative process by two authors (AT & AMG). First, they independently reviewed all interview transcripts to ensure immersion in the data. Then they identified each recipient's responses to the specific interview questions related to HSCT success or failure, health prior to and after HSCT, and personal life goals and placed these responses into computer-generated data matrix for each recipient, which was consistent with our data management and analysis approach (Creswell, 2013; Miles & Huberman, 2014). They condensed each recipient's responses related to the two preset themes (HSCT success; personal life goals) to phrases or sentences. Inductive codes were identified from the condensed data for the two preset themes and applied to all the recipients' phrases and sentences. Through a series of matrices, we categorized codes in the preset themes and this process led to the generation of sub-themes for reflecting their success or failure experience of the HSCT and personal life goals.

To facilitate and support our mixed methods approach, we included the HRQOL subscale scores, and selected demographic and condition characteristics (e.g., recipient age/sex; current avascular necrosis (AVN) pain; current use of anti-rejection medication) to the data matrix. We arranged the table to reflect higher and lower subscale scores based on success or failure and whether or not the recipient had AVN. We then worked to provide explanatory insights about HRQOL by linking patterning to narratives about HSCT success and personal life goals. AT and AMG consulted biweekly during data analysis for debriefing and to

compare and evaluate analytic processes and discuss and changed any differences through consensus. As the analysis progressed, all co-authors provided additional insights.

Results

Sample

Eleven of the 15 (75%) of eligible recipients participated in this study. The four females and seven males were between 19–52 years old (M = 31.2), their age at HSCT ranged from 16 to 51 years (M = 26.7), and they were 1.01 to 4.11 (M = 2.71, SD = .03) years post-HSCT at the time of the interview. All recipients were Black or African American with two of these reporting multiracial ethnicities. All participants had completed high school except for one who completed 11th grade, two completed some college, and four obtained an undergraduate or graduate degree. Income cut across all levels including 3 reporting < $10K, 2 >$10K and < $20K, 4 > $20K and <$60K, and 1> $60K with one missing income report. There was no acute or chronic GVHD in any of the recipients.

Descriptive Themes and Health-related Quality of Life

We report on two descriptive preset themes within the context of recipients who reported either a successful or failed HSCT. Theme 1, Success with Stipulations, revealed that recipients had refined definitions about the level of success or failure for the HSCT. In other words, it was not a binary (either/or) category to most of them. Theme 2, Shifting Expectations of Personal Life Goals, is about the way that a HSCT affected recipients' expectations for their personal life goals. HRQOL subscale scores are used commonly because these scales provide fairly comprehensive and diversified health status information. The recipients' subscale scores ranged widely and were able to identify from the recipients' narratives reasons for why some scores were higher and lower (see Table 1). Through this mixed methods approach, we provide explanatory insights about the HSCT outcome and concurrent health experiences as these related to the recipients' personal life goals.

Theme 1: Success with Stipulations.—Before the transplant**,** all recipients expected success. Each thought the transplant would enable them to pursue desired life goals (e.g., return to school, work and/or participate more in activities). Nine of the eleven categorized their transplant as a success; however, the meaning of this success varied. Two recipients identified their transplant as failed, but also found ways to reframe some aspects of the transplant as successful. These two also were able to reason out why they thought the transplant failed and did not "cure" their SCD.

Successful transplants.: Nine recipients categorized their transplant as successful or nearly successful; all nine referred to the whole procedure as a "big commitment, "hard on the body," and the described the recovery process as lengthy. One man said that the procedure caused him to feel "… a lot of discomfort and it was just hard. I had this magical transition taking place in [me]---I didn't think it'd cause discomfort just to cure. It wasn't what I expected, but it was worth it." Six recipients, three still on anti-rejection medication, were thrilled that they no longer experienced pain episodes. Two women marveled about being pain free for more than 2 years. A 36-year-old woman with high subscale scores declared,

"The transplant changed my life, I can live my life. When I want to do something I just go and do it." She was among the three recipients who definitively labeled their transplant as a success and felt "cured" of SCD. A 34 year old woman, who was still taking anti rejection medication and believed she was still having pain episodes (as indicated in her lower BP, GH, VT, SF scores), also reported high PF, RP, RE, MH scores; she said "[the transplant] cured me of some things, but not all".

Six recipients modified the definition of success by referring to the successful transplant as a "cure with stipulations". Three stated that full success would come when they could stop taking anti-rejection medication. To illustrate, a 36 year old woman who reported high subscale scores described her transplant success as being "95% cured" and said she will only be "100% [cured]" when she no longer takes anti-rejection medication. The teen recipient with the highest overall scores also would not called his transplant a complete success. He stated that the lack of pain episodes certainly pushed his definition of transplant very close to the full success side of the continuum, but he held firm that his definition was linked to whether or not he had to take the anti-rejection medication. He said, "[When I stop the medications], I'll call myself officially cured … I feel like I am partially there …" Nevertheless, some recipients accepted that for their transplant to stay successful they might have to remain on anti-rejection medications for life. A 43 year old man with a high RE score and no longer experiencing SCD symptoms but experiencing AVN pain had expected to be off of anti-rejection medication within one year. He said, "That was three years ago; I am still on the medication. Every time they take me off of the medication sickle cells rapidly return. So basically, I'll be on this medication for the rest of my life. But it's cool, I've got used to it." One 28 year old man tempered his excitement about success with feelings of uncertainty. He was no longer taking anti-rejection medication and had some AVN pain and his PF and MH scores were high; nevertheless, he was apprehensive to call his transplant a success and a "cure". He talked about his worries and was anxious about whether or not his SCD would be "coming back" or if it was really "completely gone".

The failure/success continuum also related to current pain experiences. Four recipients with a successful transplant had avascular necrosis (AVN) pain in the hip, spine, shoulder and/or wrist or some continued pain from SCD. Most of these recipients had lower physically-related subscale scores yet had higher RE scores (see Table 1). The 23 year old man, no longer experiencing pain episodes, still on anti-rejection medication, and with AVN hip pain said, "Once we got rid of the [SCD], the hip pain started coming along with necrosis and my hip started to deteriorate. I just got to get hip surgery." His discussion of AVN pain was captured in both the low RP and RE scores; his AVN pain limited his ability to walk, bend, dance, and negatively affected his social functioning.

Nine of the eleven recipients talked about their or their parents' spirituality, religiosity or relationship to a higher being. Two recipients who no longer had SCD pain episodes as a result of a successful transplant did *not* consider themselves "spiritual" or having a relationship with a higher being (e.g., God) as a source of coping or healing. For example, the teen recipient with a successful transplant and with the highest subscale scores indicated that he did not pray and it was up to him to recover, "It's me, myself and I that carried me up and down the mountain" of the SCD and transplant experience. Seven recipients including

one with a failed transplant, clearly indicated that they were “spiritual” and had faith in God to “cure” them. A 28 year old man not experiencing pain episodes and having AVN explained, “I was born with sickle cell for a reason, to teach me certain things. I’m being tested. So that’s why after living with sickle cell, it got taken away from me. I received a miracle from God.” A few had prayed to God for a “cure” or asked God why they or other family members had SCD. Two others discussed how they “pushed away” from God because their SCD worsened and then returned to God after a successful transplant. Four reported having “religious” parents who prayed for their successful transplant.

Failed transplants.: Two recipients with lower scores across most of the eight subscales indicated that their transplant was initially successful. They then went on to describe how the confluence of several factors contributed to the movement along a continuum from success to eventual failure. The older man simply could not tolerate the anti-rejection medication. After months of extreme discomfort he asked his healthcare team to take him off the medication. He indicated that he would rather have SCD symptoms and treatment than the side effects he was experiencing while on the anti-rejection medication: “[The transplant] didn’t take because I couldn’t take the medication, it made me sick, but for 7 or 8 months I didn’t have pain crises.” He posited that his age and a lifetime of progressive organ damage from SCD made him unable to tolerate the medication. His transplant fully failed within a year. Although he expressed disappointment with his transplant outcome, he had a positive attitude and expressed that he had “a lot of faith” and left the fate of his health in God’s hands, “I know if I asked God something that he ultimately can do it.” He was told in the past that he was not going to live past 30 years of age and he has lived to over 50. His positive attitude and faith in God may have contributed to his high MH score (100) which may have mitigated his other lower subscale scores.

The younger recipient whose subscale scores were among the lowest, reasoned that her transplant failure was tied to the confluence of several contextual factors including seasonality, family trauma, and her misunderstanding of the recovery process. She thought that getting the transplant during the winter was the first reason her transplant was destined to fail. She talked about how her body responded badly to the cold weather. During this time, she also experienced several deaths in her family. In the recovery period, she explained that her financial obligations and misjudgments about recovery accumulated as stressors that also worked against her. She explained that she felt deeply depressed and isolated herself during recovery. She stopped taking her medications, avoided telephone calls, home visits, and did not attend her clinic appointments.

Both recipients with failed transplants lamented about being unprepared for the emotional toll the transplant would have on them. Both also expressed having reservations about getting the transplant, but decided to move forward with it anyway. On the positive side, they described how attractive the reversal of SCD symptoms would be; they talked about the stoppage of frequent pain episodes and hospitalizations. They described that having a chance to live longer was compelling. Even though they both had reservations about the transplant, they described why they overrode these feelings. They both talked about feeling obligated to get the transplant because they did not want to disappoint their family members, friends and the providers who encouraged them to get the transplant.

Theme 2. Shifting Expectations of Personal Life Goals.—In describing their transplant stories, most recipients were able to reflect on shifting pursuits of their personal life goals as these related to current and future employment and their career, attending school, volunteering, or working on their own time. The three successes with the higher subscale scores pointed out that the transplant success allowed them to pursue their personal life goals (see Table 1). As the teen recipient with the highest subscale scores remarked, “I work… and I’m going to junior college now, and after I finish, I’m out of here.”

Four of the nine with a successful transplant and with the highest MH scores were working outside the home *and* attending college or planning to finish their bachelor’s degree, and two also expressed interest in joining the military. A 29 year old man, who attended college and was working, saw the military as a means to expand on his education. He explained,

I was forced to drop out [of college] because I was so behind. Made me feel terrible, but since now that I’m healthy, I’m trying to get back to school by any means – which is why I’m looking into the [military] to help me back with school. Just help me get back to what I’m trying to do because, I’m trying to get into my IT career … So my options are kind of open.

The teen recipient with the highest subscale scores and who was attending college and working described how he had always hoped that he could join the military. After the transplant, his hope was restored. He elaborated at bit about his personal life goals transition,

> Prior [to the transplant] I wanted to be a pilot, and then I decided I’m going to shoot even higher. You know, fly higher, I guess (laughing). And I decided I wanted to be an astronaut … Since a little kid I want to join the military and now I think I actually might get a chance to especially since the transplant and everything. So that’s a fantastic thing, and now I just want to be in the military and afterwards get my degree and become an astronaut … I’m going to junior college at home now.

Despite having AVN, two other young men, only needed a few more credits to finish their 4-year college education. Both talked about how they were motivated to move forward with these plans. Both men had high RE scores of 100 even though their RP scores were quite low (25, 0). One of these men who was no longer on anti-rejection medication and recovering from a procedure to stabilize his hip stated,

> I don’t have to worry anymore. Even just looking for jobs, I don’t have to worry about staying close by [family] anymore because of my health and being so close to the health professionals here. I need one more job credit to get my [business] degree, so I need to fill that out and then I can start working with that degree.

A 43 year old man who had worked most of his life was no longer employed outside the home because of AVN pain. His RP (0), BP (41) and VT (25) scores were low, yet, his RE score was high (100). He was investing his time in creating a comic book to help others with SCD. He said, “It’s cool right now because I’m doing comic books, so I do that stuff on my own… I’m trying to help kids the way [my superheroes] helped me.” Two brothers, who received a transplant from an older sibling, considered themselves cured of SCD. Their passion was music; they were now involved in making music videos and hoped to pursue

this line of work. One of them with high PF (95) and RE (100) scores worked outside the home described his aspirations for finishing his college degree, “I definitely want to be a business owner, so that’s why I’m trying to obtain my bachelor’s in business because no matter what you do or anything, any and every road you go down, everything always results down to some type of business.”

Two with a successful transplant looked back at their past career choices and after the transplant explained how they were trying to balance their life stage with new and shifting personal goals. As one 32 year old woman with high PF (85), RE (100) and MH (80) scores said, “I’m getting older. Should I take another route? I wanted to be a pharmacist since the time is running out on me. I might graduate being 50 and I don’t want that because you have to go to school to do that.” She instead decided to pursue a pharmacy technician certificate to fulfill her goal.

The two recipients with transplant failure reverted back to a life focused on managing the challenges of an active chronic disease and its associated complications; they were not working at the time of the interview. However, the younger recipient indicated that despite the failure she was “feeling better” and was admitted less frequently to the hospital for symptoms. She indicated that earlier in the year she completed a technician course, was back to school and was getting her resume together to pursue employment. However, both recipients had lower PF, RP, BP, GH, RE scores and described how the returned SCD negatively affected and interfered with their ability to pursue their personal life goals.

Discussion

This mixed method analysis is one of the first to compare and contrast post-HSCT experiences of adult recipients with SCD to their HRQOL beyond the typical 1-year follow-up (Saraf et al., 2016). This approach provides insights into the ways that HSCT relates to the transplant success experience and personal life goals and are reflected in HRQOL scores; this analysis enhances the outcomes of each approach.

HRQOL scores varied among recipients and aligned fairly well with aspects related to the recipients’ views of HSCT success and their ability to pursue personal life goals one to four years after HSCT. As expected the objective HRQOL scores and recipients’ descriptions of their perception of levels of their HSCT success experience were complementary. Most recipients on the successful side of the continuum described being able to pursue personal life goals and this was reflected in their higher HRQOL scores. Despite a successful HSCT, a subset with AVN had mostly middle-range scores primarily related to physical role limitations due to bodily pain. But even with AVN, these recipients expressed the ways they were pursuing or had plans to pursue their personal life goals. Our findings also show that the healthcare team needs to stress and prepare patients about the relationship of pre-HSCT SCD-related complications, such as AVN and chronic organ injury, to post-HSCT HRQOL and HSCT success. This research suggests that the healthcare team pay special attention to these contextual issues so that patients’ expectations for success will be tempered and align more closely to reality.

The Merriam-Webster online dictionary (Cure, 2017) defines “cure” as “recovery or relief from disease”. In line with this definition, the word “cure” followed a continuum that reflected the various meanings of success related to HSCT. For some, cure was contingent on the taking anti-rejection medication. For others, pain relief determined cure. Generally, the focus on disease cure primarily has been presented from providers’ points of view (Euler, 1999; Prasad, 2015) and fewer have focused on what cure and success mean from the patients’ perspective. Nevertheless, Researchers (Chacinska, Brzostowska, Nojszewska, Podlecka-Pietowska, Jedrzejcsak, & Snarski, 2017) found that patients with multiple sclerosis, much like recipients of HSCT, defined cure as relief of symptoms. Yet, a subsample of recipients in our analysis not only described cure as relief of pain, but related cure to their continued connection to the treatment to ensure success (e.g., anti-rejection medication). More research on how recipients define cure is clearly needed.

Most recipients reframed the experience to make the transplant meaningful and even somewhat successful to them, no matter whether the medical classification of the outcome was success, failed, or had continued chronic pain symptoms. This pattern in SCD HSCT is similar to transplants for other conditions (Adelstein, Anderson, & Taylor, 2014; Park, 2010). Their beliefs, goals and sense of purpose guided the interpretation of their experience. Most found a way to convert what seems like a drawback to a point of strength or pride. Recipients were able to strengthen their endurance by actively making meaning of their experience and appreciating life after HSCT (Caird, Camic & Thomas, 2011), and for some, by having a strong faith-based system to help interpret their HSCT experience (Clayton-Jones & Haglund, 2016).

The literature clearly shows that context of care, beyond that of the immediate medical procedure, is a major determinant of health outcomes (Abel et al., 2016; Weiner et al., 2010). From this sample of recipients, we support that there is a deeply complex aspect to peoples’ lives that needs to be accommodated prior to and after HSCT. We learned that ability to process the details of the medical information, corral appropriate levels of social support, ensure continued access to care, arrange for care for the family, ability to meet financial responsibilities, and a balanced emotional state all played a role in shifting the outcome of HSCT along the success-failure continuum. In addition to health care providers correctly applying the science of transplantation, addressing psychosocial and contextual life challenges in the care plan is as important.

Contextual errors occur when health providers treat the condition rather than the person with the condition (Weiner & Schwartz, 2016). The care plan, prior to recommending treating SCD with HSCT must include these larger factors related to a person’s everyday life context. For health providers to “contextualize care” they need to carefully assess life context in clinical encounters in several areas: recognize contextual clues that indicate readiness or reservation, probe for more contextual information, include a broader set of contextual factors relevant to the short- and long-term care plan, and then address the contextual factors in the ongoing care plan (Weiner & Schwartz). As the two recipients with an failed HSCT looked back, they reminisced about some of the contextual factors that they thought influenced their decision to proceed with HSCT. While it is unknown if these recipients shared their reticence about undergoing HSCT at the pre-transplant assessment

when a comprehensive clinical and psychosocial evaluation is conducted to identify risk factors for response and recovery to HSCT, it behooves health providers to look closely at psychosocial and contextual factors throughout the entire HSCT experience and to determine which patients might need extra support. Perhaps a difference between emotional preparation for HSCT for SCD compared to HSCT for cancer is that people with cancer had a pre-cancer baseline of health, whereas people with SCD had a baseline of unpredictable acute and chronic disease. Integrating a comprehensive evaluation of contextual factors pre- and post-HSCT may help to improve outcomes including HRQOL and future pursuits.

There are several limitations to the study. First, 4 of the 15 recipients of HSCT for SCD declined to participate. Their views on HSCT outcome and personal life goals and their HRQOL remain unknown. Second, our cross-sectional, retrospective cohort study was conceived and designed after the recipients received their HSCT one to four years earlier. At one 2-hour session, we asked recipients to think back one to four years and answer questions about their HSCT experience. While most recipients told their deeply meaningful and emotional personal stories behind their experience, some did not recall specifics about their pre- and post-HSCT experiences. Conducting a longitudinal, prospective cohort study that collects information from recipients before, during and after HSCT can reveal their views about their personal life goals and HRQOL with less recall difficulties and shared and changing experiences can be explored at different points over time.

Assessing HRQOL and personal life goals is an important aspect of the overall HSCT experience. Future research should investigate the complex relationships among physical and mental health in HSCT and document how these are intertwined and change over the life course of recipients. Deeper understanding of the HRQOL benefits and risks can assist adults with SCD to make informed decisions, and possibly attract more adults with SCD to choose HSCT. Strong evidence that HSCT for SCD improves career/educational attainment might lead to more insurance approvals of coverage for HSCT, because of the long-term economic “return on investment.” When health care providers recognize these parameters, they will be able to design and implement appropriate interventions leading to improvement of post-HSCT outcomes and the eventual ability of recipients to foresee, set, meet realistic expectations in post-HSCT life.

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Table 1.

Recipients' Characteristics and SF-36 Subscale Scores

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Age at HSCT	Years Post-HSCT	ARM	SF-36 Subscales							
			PF	RP	BP	GH	VT	SF	RE	MH
Successful HSCT, No AVN										
19	2.3	Yes	95	100	100	95	85	80	100	88
29	3.8	--	95	100	74	90	75	80	100	96
36	2.7	Yes	100	75	74	75	70	80	100	92
34	2.6	Yes	85	100	64	60	45	60	100	80
32	2.1	Yes	85	50	52	60	60	40	100	80
Successful HSCT, With AVN										
28	4.1	--	95	25	51	45	65	60	100	64
24	1.3	--	45	0	62	65	45	50	100	64
43	3.2	Yes	50	0	41	50	25	50	100	76
23	3.8	Yes	65	25	52	50	40	30	0	45
Failed HSCT, No AVN										
52	1.0	--	55	0	22	40	50	60	33	100
38	2.6	--	45	25	31	25	5	20	0	28

Note: ARM = Anti-rejection medication; SP-36 subscales were rounded to a whole number; PF = physical functioning; RP = role limitations, physical; BP = bodily pain; GH = general health; VT = vitality; SF = Social functioning; RE = role limitations, emotional; MH = mental health