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Exploring the Cancer Experiences of Young Adults in the Context of Stem Cell Transplantation

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Abstract

Background—Cancer is the leading cause of non-accidental morbidity and mortality among young adults (YAs) in the United States. Stem cell transplantation (SCT), a treatment modality for a variety of YA malignancies, often requires prolonged hospitalization and immune-compromising treatment regimens. SCT may isolate YAs physically and emotionally, contributing to uncertainty about treatment processes, outcomes, and long-term sequelae. Studies in this population suggest that uncertainty can contribute to difficulty accomplishing basic developmental tasks. Few studies have examined the experiences of YAs in active cancer treatment, particularly those undergoing SCT.

Objectives—This study explored the cancer experiences of YAs age 18-25 leading up to SCT and explored how YAs construct issues of uncertainty related to the transplantation experience.

Methods—Interviews with 14 YAs conducted within 24 hours of admission to undergo SCT were analyzed using thematic analysis from a medical ethnographic perspective.

Results—Themes emerged within two domains: relational and psycho-emotional. The relational theme of “altered relationships” included subthemes of “moving from” and “moving toward.” The psycho-emotional theme of the “power of perspective” included subthemes of “optimism,” “acknowledgment of death,” “informational empowerment,” and “developing a new outlook.”

Conclusions—Our findings offer new insights into the YA experience in the context of active cancer treatment, specifically how the cancer experience impacts relationships, and how this experience is influenced by YAs’ perspectives.

Implications for Practice—This study provides a foundation for addressing the psycho-social needs of YAs hospitalized for SCT, paying particular attention to the development of specific interventions.

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Introduction

Research is increasingly being focused on the cancer care needs of adolescents and young adults (YAs), commonly defined as individuals age 18-34 years.¹ Despite advances in treatment and outcomes, YAs experience lower five-year overall survival rates and higher mortality rates than children under age 15 and adults over age 50 with similar disease presentations.¹ Research consistently shows that cancer has a psycho-emotional impact on YA patients, including in the areas of sexuality, autonomy, spirituality, and peer relationships.²⁻⁶ However, two challenges remain with the application of this evidence: First, YAs were often studied in samples with adolescents, despite the unique developmental stage each group represents; second, most studies examined YAs post-treatment and in survivorship. While this research is significant and valuable to the care of this population, studies evaluating YAs separately from adolescents and in the context of active treatment are needed. This study aimed to augment the existing literature by examining the cancer experiences of YAs age 18-25 who were hospitalized to undergo stem cell transplantation (SCT). We provide an overview of the qualitative findings from a mixed-methods study examining mood, quality of life, and uncertainty within this population.

Background

Cancer in Young Adults

Cancer is the leading cause of non-accidental morbidity and mortality among YAs in the United States, for whom there has been no significant improvement in survival rates in nearly 30 years; cancer accounts for over 16,000 deaths in this population annually.^{7,8} Contributing factors to these survival outcomes include delayed diagnosis of primary cancers, poor access to and underrepresentation in clinical trials, and poor understanding of the biology and etiology of cancer presentation in this cohort.⁷ The unique psychosocial and supportive care needs of the YA population also have been identified as a potential contributor to survival outcomes.⁷ YAs are commonly studied in combination with pediatric and older adult cancer patients, for whom the disease experience occurs at distinctly different developmental points, contributing to an inadequate understanding of the unique psychosocial challenges YAs face.⁷ Successful management of cancer in YAs requires awareness of the psychosocial context in which they experience cancer, including assessment of and attention to unique cognitive, psychiatric, and psychosocial issues.⁹

Researchers suggest that the cancer experience for YAs has a distinct impact that is unlike the experience of other age cohorts because of their unique developmental challenges and needs, processes that may be blunted or reversed by the illness experience.¹⁰ The developmental needs of YAs that have been identified include establishing identity; developing a positive body image; risk taking; exploring and confirming one's sexual identity; establishing autonomy from parents; increasing involvement with peers and dating; and beginning to make decisions about employment, higher education, and family commitments.⁶ Health professionals define the hallmarks of this unique stage of development, which include risk taking as a means of testing one's mortality, exploring one's sexuality, and establishing independence from parents.¹¹ The establishment of peer support and peer group acceptance has been identified as an essential component of the transition

into young adulthood.¹¹ The aspirations of YAs with cancer are often constrained by illness and treatment, but the unique relationship between illness and YA life must be evaluated in the context of their development.¹² It has been asserted that care of YAs with cancer must be provided by specialized, multidisciplinary teams with an understanding of the unique needs of YAs during treatment and survivorship.¹³

Stem Cell Transplantation as a Treatment Modality for Young Adults

SCT is a treatment option for YAs with a variety of oncologic and hematologic diagnoses. Though the research is limited in this population and recommendations of the need for transplantation are inconsistent, there is evidence that SCT contributes to improved outcomes for YAs.^{14,15} The process of SCT is acute and often requires prolonged hospitalization and severely immune-compromising treatment regimens that may isolate YAs both physically and emotionally from their peers at a critical time in their psycho-emotional development. A study of YAs following SCT identified physical, psychological, social, and existential concerns—including fear of the future, uncertainty, and fear of death—and suggested that YAs may experience significant depression and anxiety, psychological issues that may be as challenging, if not more so, for healthcare providers to address than physical issues.¹⁶

Uncertainty in Young Adult Cancer Patients

Of the studies examining uncertainty in YAs with cancer, one qualitative study of six YAs (age 19-30 years) receiving chemotherapy for cancer identified three major themes: types of uncertainty, the helpfulness of uncertainty, and dealing with uncertainty.¹⁷ A prominent finding identified that “YAs facing uncertainty had difficulty accomplishing basic developmental tasks.^{17(pE25)}” A second descriptive, cross-sectional, comparative study of 193 adolescents and YAs diagnosed with cancer used the Mishel Uncertainty in Illness Scale to examine uncertainty across the cancer trajectory.¹⁸ The study compared the experience of uncertainty in three categories of individuals: those newly diagnosed, those diagnosed within one to four years, and those diagnosed within five or more years. The study included adolescents and YAs age 11-22 (mean age, 16). The study did not identify statistically significant differences in uncertainty; however, analysis of variance detected significant group differences. Newly diagnosed individuals expressed greater uncertainty regarding future pain, the unpredictable course of illness, and when and how they could care for themselves, whereas individuals five or more years out from diagnosis experienced greater uncertainty regarding knowing what was wrong and the probability of successful treatment.¹⁸

Aim

The aim of this study was to explore the cancer experience in YAs age 18-25 who were about to undergo SCT and to explore how YAs construct issues of uncertainty related to the transplantation experience.

Method

Design

Loosely structured interviews conducted with YAs, age 18-25, within 24 hours of admission to undergo SCT were analyzed using qualitative thematic analysis within a medical ethnographic framework. Clinically applied medical ethnography, as defined by Engebretson,¹⁹ offers an inquiry into human health and illness experiences through a focus on the shared patterns of values, behaviors, and beliefs of a culture-sharing group; in this study, a group of individuals experiencing a common illness. A clinically applied medical ethnography acknowledges the multifactorial attributes that contribute to a shared experience and seeks to address the clinical issues of how patients interpret their health experiences and their interaction with the healthcare system.^{19,20,21,22} Similar to a focused ethnography, which seeks to evaluate a shared experience within a subcultural group or institution,²¹ clinically applied medical ethnography offers the unique insight of defining health and illness culture as the setting within which unique groups of individuals with a shared experience may be evaluated.

Sample and Setting

The setting, a National Cancer Institute-designated comprehensive cancer center in the southwest United States, included a 26-bed pediatric oncology unit as well as a 72-bed adult transplant unit to which YAs may be admitted by request or owing to limited bed availability. Within this setting, the “Y” service was created to provide physical and psychosocial care to YAs, age 18-25, who are hospitalized to undergo SCT. Of more than 800 transplantations performed annually, approximately 70 recipients are YAs. The “Y” service consists of a team of multidisciplinary providers, including physicians, pharmacists, a social worker, and a child life specialist, each of whom provides age- and development-specific care in the context of SCT. In addition to specialized clinical care, the “Y” service offers a YA support group and activities to engage these individuals during hospitalization for transplantation.

The study sample was individuals who were admitted to the “Y” service at a National Cancer Institute-designated cancer center. Participants were admitted to undergo autologous or allogeneic (matched related, matched unrelated, haplogeneic, or umbilical cord donor) SCT. Participants were purposively selected to reflect the diversity of the patient population at the study setting in terms of sex, age, and race, as well as any additional identified characteristics that would lend depth to the data collection, including, but not limited to, the diagnosis, type of transplant, any previous transplant, marital status, and whether or not the participant had children. Participants were selected until thematic saturation was achieved.

Data Collection

Approval was obtained from the study setting's Institutional Review Board. The study was explained to potential participants, and informed consent was obtained. Participants were enrolled and interviews were completed at one time point, within 24 hours of admission to the inpatient unit. Although the interviews were conducted with the participant only, a familial caregiver was present when the participant requested it. A loosely structured

interview guide employed a narrative approach to explore the experience of YAs leading up to SCT. In this context, narrative interviewing was used to explore a specific episode or course of action during a prescribed period.²³ Each participant was asked to tell the interviewer “about your experience leading up to your stem cell transplant.” Open-ended questions were then used to encourage participants to expand and elaborate their narrative about their experience leading up to hospitalization for SCT, and probing questions were used to seek deeper meaning and clarification. An additional question asked of all participants was to tell the interviewer “about any concerns you have or had during this experience.” This was followed with the probe to tell the interviewer “about anything that was uncertain or unclear during this experience.” Reflective interviewing technique was used throughout the interview to ask for clarification on any topics, issues or “concerns” raised by respondents, e.g. “you mentioned that the cancer diagnosis caused friends to become distant from you, can you tell me more about this?” Data were collected in an iterative manner, with the interview guide being modified in response to concurrent and ongoing data analysis. This approach allowed for the exploration of emerging analytic constructs in subsequent study interviews and guided sampling and data collection from subsequent participants.²⁴

All interviews were completed by a primary investigator, a doctoral candidate with a clinical background as a clinical nurse specialist in SCT and academic training in qualitative research methodologies. Though not a clinician on the “Y” service, the investigator had five years of experiencing working with SCT patients at the study setting in the CNS role on the adult inpatient units, and prior to the completion of this qualitative work, had been immersed with the YA SCT population for over a year conducting quantitative data collection with this population. During this time the investigator met frequently with YAs admitted to undergo transplantation, dialoguing with them to increasingly familiarize herself with their language regarding and attitudes toward their treatment and hospitalization, as well as their broader world views.

The interviews were audiotaped and submitted electronically with password protection and encryption to a transcriptionist. Interviews occurred over 30 minutes, with some lasting up to an hour. The investigator reconciled the transcriptions with the audio recordings. In addition to the interviews, the investigator collected field notes taken during and after the interview session, noting any key points elicited, reflections on analyses, interview techniques, and/or study methods, consistent with the ethnographic approach. Examples include dialogue with participants at quantitative data collection time points on the day prior to transplantation and the day of discharge, as well as intermittently throughout hospitalization. Following these interactions the investigator maintained notes on follow-up concerns, questions and comments shared by the participants. In this way, the investigator's immersion into the YA population in the study setting contributed to more authentic and complete field notes and observations, not limited solely to the time of the interview, but also during these subsequent interactions over the course of participant hospitalization. Demographic information (sex, race or ethnicity, age, type of transplant, and underlying diagnosis) was obtained from the participants' medical records.

Data Analysis

The analytic approach of interpretive ethnography was used with thematic analysis to produce a thick description, i.e. a narrative that describes in detail the experience of YAs in relation to the SCT.²¹ In addition to the interview data, field notes and observations collected during the interviews and prior and subsequent interactions with participants were incorporated into the analysis and interpretation of the data. Specifically these observations were used to elucidate interview data, as in the case of the participant who made the decision to donate his unborn child's cord blood for potential future transplants, information not revealed in his interview, but which complemented the desire to give back to the community as a result of the cancer experience.

Thematic content analysis, as described by Saldana,²⁵ was used in the context of clinically applied medical ethnography to ensure a thorough investigation of the content of the interviews. An iterative approach was utilized to reflexively analyze the data in relation to field notes, the interpretive understanding of the researcher, and consecutively collected interview data, connecting this content with emerging insights so as to progressively lead to a refined and focused understanding.²⁶ Data analysis began upon the completion of the first participant's interview with reconciliation of the audio recordings with the transcriptions and continued through multiple readings of the text; the identification of initial themes; and the classification, prioritization, integration, and synthesis of the data into themes and subthemes. Data analysis contributed to the formation of domains, which were further analyzed consistent with Spradley's²⁷ methodology for domain analysis. Peer debriefing²⁸ was conducted with three individuals, nurse faculty and qualitative researchers, who were not members of the research team to ensure consistency with and authenticity to qualitative research methodology, as well as to diminish potential researcher bias and enhance the overall rigor and credibility of the analysis. The peer reviewers, who had experience in varied qualitative methodologies and populations, including AYAs, served to assure that exemplars provided accurate documentation of study findings. During the debriefing session the investigator presented data collected, preliminary coding and thematic analysis about which the reviewers asked exploratory questions and offered critique, insights and/or affirmation of the data analysis and resultant findings.

Findings

Of 17 patients approached to participate in the study, 14 agreed to participate. The three female individuals who chose not to participate stated a discomfort with being interviewed. Participant demographics are presented in Table 1.

The narratives yielded significant data, and we present here an overview highlighting select exemplars. Major themes emerged and were classified within either relational or psycho-emotional domains. The main theme that emerged in the relational domain was altered relationships, with subthemes of moving toward and moving from. The main theme that emerged in the psycho-emotional domain was the power of perspective, with subthemes of optimism, acknowledgment of death, informational empowerment, and developing a new outlook. These themes are presented graphically in the context of an explanatory model

presenting the YA as both an influencer of and as influenced by the cancer experience (Figure 1).

The Relational Domain

The relational domain encompasses participants' views related to the impact of the cancer experience and SCT process on their familial, sexual, spiritual, and peer relationships. The main theme, altered relationships, reflected that all relationships were impacted in some capacity through the YAs' cancer and transplantation processes. Within the theme of altered relationships, a relational magnetism emerged, through which participants were drawn nearer to or away from others, and at times experienced both within the context of the same relationship, thereby defining the subthemes of “moving toward” and “moving from.”

Moving toward—The subtheme of moving toward reflects the experience of individuals from a diversity of relationships drawing nearer to the participant as a result of the cancer diagnosis. Participants reported that relationships with parents, siblings, significant others, friends, and even entire communities evolved during the cancer experience. This occurred in relationships that were already close, those that were estranged, and those that were newly established. One participant described the support of his community: “They're all there for you, you know, it's a hell of a town...and everybody's there for me. People you don't even know reach out to you. Like they were your best friend.” Another spoke to the relationship with her family, stating, “They're here like every step of the way like, my aunts, my uncles, my cousins, my best friends, like, people I went to school with. It's like I have a great support system.” Another participant spoke to re-establishing broken relationships: “People that I guess I've fell out of, out of contact with or our relationships are strained or no longer exist...they've made efforts to get back into my life and reconnect with me, and so we've mended bridges and fences and all that.”

While participants reported that the strengthened relationships were often a source of encouragement, they also felt that some of the individuals moving toward them during their illness were insincere. This occurred when the participant perceived that the individual seeking to support the participant did so to make himself or herself feel good or “in the know” because he or she reached out to the patient. This was felt to be particularly disingenuous when friends and even family members who had not previously had a close relationship with the participant sought to establish such a relationship during the cancer experience. One participant expressed the following:

[P]eople find out that I'm sick and all of a sudden now they wanna be friends. And I don't like that—you're either here all the time, or none of the time. You don't pick and choose when you want to be in my life. And don't, I don't want your pity. I don't want your pity friendship. I want you to be my friend because you like me, and not 'cause you feel bad for me.

This participant added: “My dad's dad, he's not a good person, and he has never been a good grandparent to me. I don't even call him grandpa. And all of a sudden now he cares, and that's very frustrating.”

Several participants reported that the cancer experience had helped them move toward a deeper spiritual relationship, whether with God, the universe, or a self-identified higher power. The belief that the outcome of the cancer was in the control of this power was often identified as comforting to participants. One participant stated the following:

I think one of the purposes [of her cancer experience] is for people to see what God puts people through, but also what God can do and to know that [in] everything there is a purpose, and to know that if God puts them into one situation, doesn't matter how hard it can be, He'll get you out. And if He doesn't get you out whenever you think He'll get you out, He'll give you the strength and He'll give you everything that you need.

Another stated: "God is just there. You know, I mean, you don't know how He works or what He does but He's just there with you. I mean, He's never gonna let you go. Knowing that somebody's there with me, looking out for me—it just makes me feel great."

Another reiterated the idea that God has a plan for the participant, stating: "I pray every night and I'm like, 'God, I know you have a plan for me and it's all gonna work.'" Yet another participant reinforced the belief that the outcome of the treatment process was God's decision, stating: "So it's like I pray when I'm down. I pray when I'm up. I just go to Him and ask Him to like, 'Please heal me from the top of my head to the bottom of my feet,' like I just talk to Him. Cause I mean, it's His decision at the end of the day." Another participant emphasized this finding, stating: "I do believe God has some kind of plan for me or He's holding on to me because this isn't the first time I've been in a life-threatening situation."

Four of the participants received stem cells from a sibling donor. The experience of moving toward another in the context of this relationship was particularly profound. One participant spoke of the closeness of his relationship with his sister donor and how that proved challenging for him in accepting her marrow:

We've always been really close. I'm really proud of her for being so generous and courageous in this process because I know she doesn't like needles just like I do, and they kinda have to use a big needle for the marrow extraction process so, I mean I'm sad this has to happen to her, but she's willing to make the sacrifice to help me live. So, I mean, I'm a little conflicted about it. At the end of the day I would probably rather die than let my sister be in pain to give me marrow, but that's just me.

Another participant said, in reference to his donor sister: "I protect her like she is everything. Like if someone tried to hurt her I would probably kill them immediately. Like I won't let her do anything. I wanna just keep her in a glass box, at least until she can heal me." A third participant spoke to how her relationship with her donor sister was strengthened by the SCT experience: "It's definitely made us stronger. I mean we've always been close but we are five and a half years apart. But it's been good. It's made us a lot closer."

Moving from—Participants also spoke to the experience of individuals moving from them in the context of the cancer experience. Most often this occurred with peers or significant others who did not know how to respond to or handle the participant's diagnosis, straining

the relationship. One participant said: “My friends...the ones that I knew—they just kind of pushed themselves away from me.” Another echoed this experience, stating: “I mean, they[‘re] [friends] just distant and I, I don’t try to bother them. I actually don’t talk to them at all.” Yet another stated: “A lot of people who I thought were my friends never came to visit me, you know, and they didn’t really care.” This experience of peers moving from the participants was best exemplified by one participant who stated: “You really find out, you know, who, who really cares, who really wants to, you know, be there for you. You know it kind of makes you feel like, ‘Okay, well my friends are putting me off.’”

The impact of individuals moving from the participants was perhaps most profound in the context of romantic relationships. One participant said: “When my girlfriend left, that was another thing that I had to deal with. It just like, somebody just....kicked the door down and just started beating me up. And I just had to stand there, and I was helpless.” Another stated: “It seemed like it was too much for [my girlfriend] to handle now. And she couldn’t handle it. She said she was gonna go visit her grandparents, but I knew what was happening. And then after that, I haven’t really heard from her.” Yet another spoke about the boyfriend and father of her baby, stating:

I guess when he found out that I had cancer, it was like a big deal. He was really scared and didn’t know what to do. So like a month straight, like I didn’t see him, I didn’t hear from him. I called him a coward. And I told him he was a sellout. Because if it was him I, I wouldn’t have, you know, vanished.

Just as the spiritual relationship for some participants was strengthened by the cancer experience, others experienced a moving from or reinforcement of an absence of a spiritual relationship. This experience was best exemplified by one participant who felt strongly that she had never considered herself religious and that this experience reinforced that belief for her. This participant said the following:

I’m just irritated with my body and with God, religion. But people think that, you know, there is this God. Why would a god do this? There is this magical God that all these people pray to and, um, Jesus Lord, but he kills a five-year-old child. That doesn’t make any sense to me. And my sister-in-law was like, ‘doesn’t this make you feel more religious?’ It did the opposite. It did the exact opposite.

These subthemes of moving from and moving toward were not mutually exclusive. This was demonstrated most prominently in the participants’ relationships with a parent. The idea that the parent was a source of care and support often conflicted with the feeling of needing space from the parent because he or she imposed on the participant’s sense of autonomy, usefulness, or self-worth. One participant said: “I mean [my mom’s] trying to protect me, and, you know, she wants to care about me and stuff like that, but I mean, at the same time, I don’t want to feel...useless.” Another participant stated: “Then my mom comes around, she wants to help and that frustrates me that she’s trying to help.” Another experienced a feeling of regression related to the cancer, saying: “...cause my mom has to take care of me and my brother and sister. And I feel like I’m a bother. You know? Cause I was—two years before this I was living by myself.” Another expressed the dichotomous relationship with his mother, saying: “She’s annoying most of the time but she’s there when I need her.” Several participants expressed the juxtaposition between feeling that the parent was overbearing or

intrusive on the participants' autonomy and stating that in times of concern, they sought out their parents as a source of support or to make things better.

The Psycho-emotional Domain

The psycho-emotional domain encompasses how the participants coped with the cancer experience. The main theme that emerged within this domain was the power of perspective, specifically, how individuals chose to integrate information, understanding, and attitude as a means of coping with and responding to the cancer experience. The subthemes that emerged were optimism, informational empowerment, acknowledgment of death, and an emerging new outlook.

Optimism—Participants spoke to the power of optimism in their ability to undergo treatment and cope with complications. Some spoke to optimism as a means of coping with the challenges of treatment, whereas others spoke to optimism as a means of controlling the outcomes of their treatment. One participant said: “I’m not concerned ... because I try to be positive about everything.” Another participant suggested that anyone going through this experience “...should always stay positive even if it’s a bad situation or if you don’t get the news you want.” One participant reflected on the fact that being negative would make her feel worse, therefore: “I choose to be happy, and I choose to be positive, and I choose, I guess, not to dwell on the fact that I don’t know because stressing myself out is not gonna help, it’s gonna do the opposite, so why not be happy?”

Several participants reflected on the influence of attitude on the outcome of treatment. One participant stated: “Whether you survive or not...I think it’s more of a will thing. If you want to make it, you will.” Another participant reflected on this, saying: “So I’ve talked to [my family] and I just think about what’s gonna happen and kinda just pump myself up. I’m just gonna go in there and get it done.”

Informational empowerment—Information as a means of control and empowerment was evidenced in both information seeking and avoidance. Some participants spoke to information seeking, whether through Internet searches, information provided by healthcare professionals, or insights obtained from previous treatment (chemotherapy alone, and, in two cases, with previous transplantation) as a means of empowering them to know what to expect. This information demystified the transplantation process for them and enhanced their outlook that the transplantation and its complications would be manageable. One participant who had a previous autologous transplantation before being admitted for the current allogeneic transplantation stated: “I’m kind of glad I did the first one before doing this one, that way I can understand what I’m doing and, you know, how important it is to actually exercise, and how important it is to eat and drink, and, um, take my medicines.”

Previous experience with chemotherapy served to bolster participants' confidence in and perceived understanding of the transplantation process. One participant stated: “I’m kind of scared but it’s nothing I haven’t been through before, you know, a little nauseous, a little vomiting but, you always gotta look at the end result. You know I got through it and that kind of helps me out, knowing that I can do it.” Yet another participant spoke to the value of having his girlfriend’s mother tell him about her transplantation experience: “She just told

me a lot about it. That's why I don't really have any questions 'cause I've heard a lot about it.”

Alternatively, several participants spoke to information avoidance as a means of coping with the uncertainty of what the process and complications would be like. Information avoidance ranged from trying not to think about it, to asking minimal questions, to outright requests to not know the diagnosis or treatment complications. One said: “...there's times when I just like kind of blank out, almost, and kind of just not try to think about it.” Another participant expressed the desire to know as little as possible about her diagnosis and complications to remain positive about the process. She stated:

I have a type of lymphoma; it's kind of, I really don't know the exact name for it yet because I choose not to really...I'll figure that out when this is all done and then so I don't freak myself out. Just to be told you have cancer is already hard and so I just —like I don't—even to this day I don't like people telling me my side effects, you know, cause I feel if I'm a little bit oblivious, and I don't know, I fight harder.

Another participant summarized this perspective, saying: “Sometimes too much information is not good psychologically...so I'd rather not know more information about medical stuff.” This approach to informational empowerment enabled participants to take control of informational exposure as a way to cope with what lay ahead for them.

Acknowledgment of death—Despite an emphasis on optimism, there was also a consistent acknowledgment of the possibility of death. While some participants did not speak to this experience, many reflected that they knew they had a potentially terminal disease or that they could die from complications of the transplantation. One participant reflected on the possibility that the transplantation may not be successful: “What if it doesn't work and I have to—I don't know—be here in the hospital for more chemo, or, I don't know, maybe just die? So that's, that's in the back of my mind.” He also acknowledged that knowing he might die relieved him of some worry, stating: “You don't have to worry about nothing because I mean no matter what you do...when it's time, it's time.” Another participant acknowledged the possibility of relapse: “It's always a possibility that even after the transplant that the cancer does come back. And even like three or four years down the line I'm, you know, healthy and everything, it could come back.” Another participant reflected on the possibility of dying, stating: “You know, [I was] one of the best basketball players in the state, to a couple of months later, and you could die. You know, everybody dies at some point. You know, you just hope it ain't now.”

One participant reflected on a near-death experience and how that impacted his outlook: “Technically I did die. So, for about 10, 20 seconds...my heart stopped. So they had to resuscitate me. After that it's kind of like ‘whoa, you know, that just happened.’ And it wasn't painful, you know. So I'm not—I'm not worried to die.” Another participant gave a similar perspective: “There's nothing on earth that can scare me. I've already had somebody tell me that I'm gonna die. So it's not that bad...it really helps you a lot. If anything, it's a confidence booster. It's like that biggest fear you're supposed to have is gone.” Though many participants acknowledged the possibility of death, none spoke to this as a defeating experience, and several stated that acknowledging death contributed to the development of a

new outlook on life. One participant said: “My life [is unknown]. But the fact that it is unknown kinda makes you cherish things more, kind of makes you tell, like tell my mom I love her.”

Emerging new outlook—Participants reflected on the development of a new outlook on life related to the cancer experience. This theme was consistently expressed by participants who often juxtaposed this new perspective with that of their peers. The new outlook largely consisted of a renewed appreciation for life, the little things, the potential for death, and a desire to live life more fully as a result of the cancer experience. One participant said: “I feel like I won something, you know, and I wanna give back.” In fact, he and the mother of his child had decided to donate the baby's cord blood when she was born so that someone else might be able to use it for SCT. Another participant stated: “I don't take advantage of anything anymore. I see everything for what it is I guess. Um, little things are beautiful, you know? Like you tend to appreciate the world.” Several participants spoke to the new outlook they developed, including one who said: “I mean, like, a better outlook on life. Like, you know how sometimes you probably wouldn't just care too much about something and now it's like, life is short. You'll never know what will happen today or tomorrow, so it's better to take it serious.” Another reflected on the juxtaposition of his new outlook compared to the perspectives of his peers as expressed on Facebook and in other venues: “You got a new outlook on things, you know. You see people talking about their itty bitty problems and you're like, ‘Seriously?’ You go out and you go back home, you see things a little differently...you see it as a little more precious than it ever was before.” One participant described the transplantation experience as being “reborn,” while another stated: “I think, while I'm here, you only get to live once, and I'd like to make my name memorable.”

The Role of Uncertainty

Though an aim of the study was to examine how YAs constructed uncertainty within the SCT experience, uncertainty ultimately was not a predominant theme that participants self-reported unless prompted to do so in the context of the interview. Primary concerns were related to not knowing how severe side effects of treatment would be. Several participants expressed uncertainty as to whether they would be able to have children and whether or not the cancer would come back after transplantation, ideas succinctly summarized by one participant, who wondered: “But like later down the road, you know, what if it comes back, you know, and since I'm female, am I going to be able to have kids?” Many of the participants felt they had a clear understanding of the transplantation process and its complications and that they could justify any uncertainties and incorporate them into their worldview. As stated by one participant: “Being here is the most important, and all the other unknowns I'm okay with.”

Discussion

Study data yielded rich findings, most notably the contribution toward two domains that establish categories in which subsequent thematic relationships could be established. Findings within the relational and psycho-emotional domains were used to construct an explanatory model that illustrates how YAs frame the experience of their SCT in terms of how it impacts and is impacted by both relationships and psycho-emotional responsiveness.

Whereas YAs are situated physically and psychologically within the cancer experience, they are also influenced by the various cultures in which they are situated socially, psychologically, spiritually, and sexually, which in turn impact how the YAs relate to others and cope within this experience. The explanatory model portrays the concurrent influence of the self on how the YA experiences cancer, and in turn how the cancer experience manifests within the relational and psycho-emotional domains. The YA, bringing to the cancer experience the diversity of cultures with which he or she identifies, in turn influences the impact that the cancer has upon these domains. The result is a confluent process within which the patient concurrently influences and is influenced by the cancer experience.

The relative absence of uncertainty is as significant as findings that were evident within the domains. Even when probed, most participants stated that they did not feel uncertain or have concerns about their treatment, which they largely attributed to experiential knowledge from previous treatments and the perception that those experiences prepared them for the physical sequelae of the transplantation process. This finding may be significant in that the uncertainty expressed by participants was largely related to symptom experience, which they felt was mitigated either through prior treatment-associated symptoms or through information provided by individuals who had undergone similar treatments. This suggests that a key interventional component to address YAs' learning needs in preparation for transplantation and subsequent treatment and complications may be the need to share information about treatment experiences, rather than a focus on uncertainty related to outcomes. The presence of latent uncertainty may be explored in further analysis to identify whether this experience exists, particularly in the context of the relational domain.

The idea that previous symptom experience informs YAs as to the nature and intensity of the SCT experience requires attention. This impression, expressed by several participants may prove misleading and reduce the capacity for fully informed consent given that the SCT process, both in terms of intensity, and particularly duration of symptoms, may be greater in magnitude and potentially more limiting to quality of life than previous treatment regimens. Individuals whose diagnosis may not require chemotherapy management prior to transplant (e.g. aplastic anemia) may be at a disadvantage in terms of symptom experience informing a precursory understanding of the SCT process. Ensuring that YAs, regardless of treatment history, are able to receive information, commensurate with their preferences, about anticipated acute and chronic side effects of SCT is critical to informed consent.

Respondents also echoed findings from a previous study, which indicated the possibility of growth through uncertainty, i.e. an individual's motivation to make the most of each day in the face of constant uncertainty.²⁹ Participants reflected that cancer changed their perspectives, attitudes, or behaviors for the better, including helping them reprioritize relationships, mature more quickly than their healthy peers, and have an increased appreciation for and enjoyment of life, which was consistent with previous study findings.^{30,31} Some YAs reported an increased connection with God as a result of their cancer experience and considered religious beliefs as a source of support and hope during treatment, which was again consistent with previous findings.³² Spirituality were identified as integral for coping with and making sense of the cancer experience. Participants in this study, as in the literature,³² reflected that cancer happened for a reason and changed their

lives for the better, particularly in terms of appreciation of close relationships and a greater understanding of the world around them.

The use of an ethnographic approach contributed insights as to how SCT care may further increase the sense of isolation for YAs, who expressed disconnect in some peer and familial relationships. SCT care includes reverse isolation (individuals entering the patient's room must wear a mask and gloves). This is further intensified if a patient requires isolation precautions for an infectious organism such as vancomycin-resistant enterococcus, thereby requiring all staff entering the room to wear a gown as well. Whenever such patients exit their rooms, they also must wear masks and gloves (and gowns, if applicable). While participants did not specifically mention a sense of isolation resulting from wearing a mask, they did reflect on the inability of their peers to know how to respond to them and the discomfort that being present with the participant in the inpatient setting caused their peers and significant others. These isolation practices, while necessary, may contribute to a literal sense of isolation that may further intensify the psycho-emotional and relational sense of isolation expressed by participants in this and other studies.² Thus, this artifact of the hospital culture in which YAs are immersed may contribute to a further sense of being isolated from individuals because of the cancer diagnosis and treatment. This juxtaposition is articulated in the very stage in which Erikson³³ places YAs, that of “intimacy vs. isolation.”

The study findings are novel in that they present the experience of YAs as a distinct cohort in the context of active treatment for transplantation. This is significant in that YAs experience cancer at a stage in their psychosocial development that is unique from adolescents and older adults.³⁴ While evidence suggests the need for an enhanced approach to family and relationship-centered care for individuals at any age, the fact that the developmental work of YAs is centered upon relationship building during this period indicates that the impact of cancer in disrupting such relationships can have not only long-term social, but also developmental sequelae. This data, distinct from studies that grouped YAs with adolescents or older adults, may be used to further explore whether and how YAs experience cancer differently from those groups. Such insights may further serve the development of interventions unique to YAs' needs, as suggested in the literature.^{9,34-36} In addition, the diversity of participants, particularly in terms of race and ethnicity, provides a richness to the study data given that the majority of allogeneic transplant recipients, 84% in 2013, identify as Caucasian, as reported by the United States Department of Health and Human Services.³⁷

The data provide a particular insight into the significance of relationships and perspective among YAs hospitalized to undergo SCT. The wealth of data present in these interviews necessitates further publications to explore content specifically within each of the domains, the phenomenon of growth through uncertainty, and the relationship between YAs' experiences and their psycho-emotional development. Future work will include such analyses as well as the development of emerging conceptual models.

Study Limitations

This study is limited in that data were collected only within 24 hours following hospitalization for SCT and therefore may not be reflective of the experiences of YAs during and after the actual transplantation procedure, including subsequent hospitalization, discharge, survivorship, or palliative care. Since non-English-speaking patients were excluded from participation in the study, the data collected are not necessarily reflective of the experience of non-English-speaking individuals, whose disease and treatment experiences may be significantly impacted by this important variable.

Implications for Practice

The similarity of findings regarding the impact of the cancer experience on YAs with previous literature suggests that there is sufficient evidence to develop interventions and interventional studies specific to this population. This study contributes to these efforts by highlighting the impact that cancer and hospitalization for SCT may have on YAs' perceptions of personal relationships and personal perspectives. Correlation between YAs' consistent vocalization of the impact of the cancer experience on relationships can and should emphasize the need for the creation and enhancement of interventions and support services for YAs that are developmentally specific, as consistent with suggestions in the literature. Specifically, findings from this study suggest the need to address how to support YAs to develop and sustain supportive relationships in the context of prolonged hospitalization and how to enhance the patient experience in the context of policies that may contribute to a further sense of isolation, such as isolation precautions and visitation restrictions. Findings that suggest the empowering experience of having individuals moving toward and supporting them through the treatment process highlight the need to engage such support persons collaboratively throughout the cancer and treatment trajectory, as determined by the YA patient, in a model of family-centered care.

Future research may focus on interviews at the completion of the transplantation process and into the survivorship period to further elucidate whether the uncertainties and expectations were commensurate with YAs' experiences. Though only peripherally addressed in this study, future research examining the relationship between YA patients and their sibling stem cell donors may provide insight into how best to support not only the patient but also the donor through the varying complications and outcomes of SCT. In addition, examining the feasibility of interventional work that engages peers and friends of YAs may engage these individuals identified by YAs as important in coping with and supporting the patient through the SCT experience. Such interventions require a truly multidisciplinary approach that addresses the numerous psycho-emotional domains impacted by the cancer experience. Understanding YAs as individuals who both influence and are influenced by the cancer experience, as reflected in the explanatory model, allows for a more holistic approach to assessing and supporting care needs in active treatment and beyond.

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Figure 1.
Explanatory model.

Table 1
Participant Demographic Characteristics

Variables	No. =14
Sex	
Male	8
Female	6
Race	
Caucasian	6
African American	3
Hispanic	5
Diagnosis	
Acute myelogenous leukemia	3
Acute lymphoblastic leukemia	3
Hodgkins Disease	4
Wilm's tumor	1
Aplastic anemia	2
T-cell lymphoma	1
Children	
Yes	4
No	10
Type of Transplant	
Autologous	2
Matched Related Donor	4
Matched Unrelated Donor	4
Haplogeneic	3
Cord Blood	1
Second Transplant	
Yes	2
No	12