

Identifying Religious and/or Spiritual Perspectives of Adolescents and Young Adults Receiving Blood and Marrow Transplants: A Prospective Qualitative Study



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ABSTRACT

The potential benefits (or detriments) of religious beliefs in adolescent and young adults (AYA) are poorly understood. Moreover, the literature gives little guidance to health care teams or to chaplains about assessing and addressing the spiritual needs of AYA receiving hematopoietic stem cell transplants (HSCT). We used an institutional review board–approved, prospective, longitudinal study to explore the use of religion and/or spirituality (R/S) in AYA HSCT recipients and to assess changes in belief during the transplantation experience. We used the qualitative methodology, grounded theory, to gather and analyze data. Twelve AYA recipients were interviewed within 100 days of receiving HSCT and 6 participants were interviewed 1 year after HSCT; the other 6 participants died. Results from the first set of interviews identified 5 major themes: using R/S to address questions of “why me?” and “what will happen to me;” believing God has a reason; using faith practices; and benefitting from spiritual support people. The second set of interviews resulted in 4 major themes: believing God chose me; affirming that my life has a purpose; receiving spiritual encouragement; and experiencing strengthened faith. We learned that AYA patients were utilizing R/S far more than we suspected and that rather than losing faith in the process of HSCT, they reported using R/S to cope with illness and HSCT and to understand their lives as having special purpose. Our data, supported by findings of adult R/S studies, suggest that professionally prepared chaplains should be proactive in asking AYA patients about their understanding and use of faith, and the data can actively help members of the treatment team understand how AYA are using R/S to make meaning, address fear, and inform medical decisions.

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INTRODUCTION

Adolescents/young adults (AYA) receive hematopoietic stem cell transplantation (HSCT) for a variety of illnesses and conditions, all of them life threatening. HSCT offers hope of health and, in some cases, cure. The process of HSCT brings considerable challenge in the form of physical pain and often psychosocial trauma, in addition to the normal developmental challenges of adolescence and young adulthood [1,2]. For many patients facing life-threatening conditions, religion and/or spirituality (R/S) provide support [3]. Unmet spiritual needs are associated with an increase in depression and decrease in spiritual well-being in adults [2]. One study links R/S use with improved quality of life and with longer survival after HSCT for adult patients [4]. Hospitalized adult patients with unmet spiritual needs report less satisfaction with care [5]. Although there is growing evidence linking R/S of adults to health care outcomes, this link has not been as thoroughly explored with AYA [6].

Religion and spirituality are resources for many AYA. Over 90% of adolescents in the United States report a belief in God; several studies describe adolescents' use of religion

and spirituality for coping with health concerns [7,8]. Young adults' religious and spirituality behaviors, such as prayer and service attendance, have been demonstrated to have a relationship with their health behaviors [9]. The way AYA make meaning of their illnesses has been the subject of study, yielding some surprising results; for instance, Haller et al. found several studies indicating that young people had “a wide array of views on the causes of illness that often differ from the biomedical view” [10]. An earlier qualitative study found that adult HSCT patients viewed their suffering as a “wake-up call from God,” whereas others saw their suffering as a “test from God” [1]. Very few studies have examined how AYA use religion to help them understand and cope with their illness and their HSCT. Our study explored how R/S beliefs provide a way of understanding and coping with illness for AYA patients receiving HSCT, and whether the experience of HSCT led to change in the AYA patients' understanding of R/S. Our goal was to provide data to inform health care teams about R/S as a resource for AYA HSCT patients and to promote evidence-based pastoral care interventions for the chaplains on the health care team.

Religion and spirituality have been defined as distinct from each another in the literature; neither term has a generally accepted definition [11]. For the purposes of our paper, we define *religion* as the formal organization of sacred beliefs, rituals, and traditions held in a community of like-minded believers [11,12]. We define *spirituality* as any way of seeking or relating to whatever a person considers sacred [13]. In this paper, we combine these concepts and refer to them as R/S.

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METHODS

We chose to use qualitative methodology as a way to explore the participants' understanding of their R/S and to determine whether and how it helped them, hindered them, and changed from the time they received their HSCT to 1 year after transplantation. We used grounded theory as a way to collect data via interview and to analyze our data by coding [14]. Grounded theory is a method of qualitative research drawn from the premise that not enough is known about the subject to have an informed hypothesis. Grounded theory seeks to explore a little-known subject by gathering data based on the experience of the participants, analyzing the data using iterative coding processes to identify key themes, and proposing hypotheses for further study. The ultimate goal is to develop a theory of how the process—in this case the process of AYA use of R/S—functions. Semistructured interview questions guide the interviewer and help keep the participants focused on the subject of interest for the research question. Interviews provided a way to explore patients' perspectives and ways of making meaning [15].

We attempted to recruit all 15 patients eligible for our study; which is to say, receiving HSCT, well enough to communicate verbally, and between the ages of 13 and 29 inclusive, from December 1, 2010 until February 1, 2012. Twelve agreed to participate. Although faith development has been demonstrated to begin earlier than adolescence, we sought participants who had a more evolved cognitive understanding of what they believed. Each participant received a description of this study based on our institutional review board–approved protocol. The chaplain on the HSCT service or 1 of the HSCT nurse coordinators worked with staff to determine which patients met the study criteria and were well enough to be interviewed. The chaplain or nurse coordinator explained to the patient and, if a minor, to her or his parents, that we were conducting a study to explore how AYA used faith in the process of their HSCT. Patients either consented or assented to participate. When the patient was a minor and assented, his or her parent or guardian also provided consent. Our study originally proposed to interview HSCT recipients just before they received HSCT, 100 days after HSCT, and 1 year after HSCT. We had a difficult time with this plan because of lack of availability of participants because of illness or being too busy with preparation for treatment to be interviewed. We amended our study to interview participants as close to the date of HSCT as possible and then 1 year after HSCT. Participants received the incentive of \$20.00 for the first interview and \$50.00 for the second interview.

The interviews were done by a PhD-prepared qualitative researcher with a background in chaplaincy or by a chaplain with master's level course work in qualitative research. The interviews were semistructured; Table 1 contains the interview questions guiding the interview. The interviews lasted between 10 and 50 minutes, depending on the length of time the participant chose to speak. The interviewer asked follow-up questions until the participant indicated he or she had completed addressing a question. Each interview was audiotaped and transcribed by a professional service. Each interview was reviewed for accuracy by 1 of the chaplain researchers by listening to the tape and editing the transcript, as necessary.

Interview texts were coded by an interdisciplinary team of coders using grounded theory methodology. Interviews were not separated by gender, age, faith, or diagnosis for purposes of coding. The first series of codes were open codes; they used the language of the participants. Codes were gathered into subject categories. We compared codes from the first and second set of interviews and arrived at saturation with 5 key themes for the first set series of interviews and 4 key themes for the second set. In grounded theory, saturation is reached when no new themes emerge from the interviews.

PARTICIPANTS

The demographics of study participants are shown in Table 2. Seven of the 12 participants were female, and ages ranged from 15 to 28 years. Five of the participants were male, and ages ranged from 15 to 19 years. All patients received allogeneic transplantation and 7 of 12 received a reduced-intensity preparative regimen. Six patients underwent transplantation for leukemia and the remainder underwent transplantation for immune deficiency or marrow failure. Nine patients identified themselves as Christian in the first interview, 1 identified having no personal religious affiliation, and 2 were listed as Christian on the admission page of their medical record. Four participants were interviewed before HSCT, 1 at 3 days, 1 at 4 days, 1 at 6 days, and 1 at 12 days before HSCT. The other 8 participants were interviewed after HSCT: 7, 18 (2 participants), 21, 28, 35, 39, and 87 days after HSCT. The participants interviewed at 35,

Table 1

Interview Questions

First Interview: Semistructured Questions for before One Hundred Days after Transplantation
When did you learn you had this illness?
How did you come to be offered the option of receiving a bone marrow transplant?
Why do you think this has happened to you?
If you were raised with any type of religious belief or practices, how would you describe them?
How would you describe your faith beliefs (using whatever language the patient has used) today?
Has your faith changed since your diagnosis and, if so, how would you describe what's different now?
How is your faith helping you (or not) with what you're going through?
Is there anything about your faith that you question now, or wonder about?
Is there anything about this topic that you'd like to talk about?
How would you describe to someone who's never been through this what it has been like to have a bone marrow transplant?
How has your way of doing faith (using whatever words they have used) changed since your bone marrow transplant?
How do you see God or the Holy or your Higher Power in this experience?
Have you engaged in religious or spiritual activities since receiving BMT—such as prayer or talking with a spiritual leader or friend? How have these activities been helpful or unhelpful for you?
Has anyone said anything to you of a religious or spiritual nature that has been helpful or unhelpful?
What would you say to a person thinking of receiving BMT that you found helpful or wish someone had said to you?
If you could ask God or the Holy or your Higher Power any 2 questions, what would they be?
Is there anything else you'd like to say about this subject that I haven't thought to ask about?
Second Interview: Semistructured Questions for 1 Year after Transplantation
It's been a year now since you received your BMT—what has changed in your life since your treatment?
Did you ever feel any difficult feelings toward God or the Holy or your Higher Power?
Was your way of doing faith changed at all by this experience and if so, how?
If you're a person of faith, what kinds of questions would you want to ask God or the Holy or your Higher Power?
Sometimes in the middle of really hard times, people report having religious experiences. Did you ever have a religious experience you could describe?
Did any spiritual understandings come to you out of this experience that you think might be useful for others to know about?
Is there anything about this topic that you'd like to talk about?

39, and 87 days after HSCT were quite ill and died within the year. Of the twelve patients who participated in the first interview, 6 participated in the second interview. The diagnoses of these 6 patients participating in the second interview included acute lymphoblastic leukemia (1), acute myeloid leukemia (2), aplastic anemia (2), and non-Hodgkin lymphoma and X-linked lymphoproliferative disorder (1). The other 6 participants died in the course of the year after transplantation.

The 3 patients who declined to participate were 2 males ages 18 and 1 female age 15. One male was Asian and the other 2 patients were Caucasian; 1 male was Buddhist and the other 2 patients were Christian; all 3 patients were to receive HSCT for immunodeficiency/bone marrow failure. Two refused with no explanation; the other said he was Buddhist and chose not to participate.

Although the data for our study were drawn from interviews, we did consult the patients' medical records to

Table 2
Characteristics of Patients

UPN	Age, yr	Faith (Family)	Faith (Personal)	Diagnosis	Race	Gender	Donor Source	Conditioning Regimen
1	16	Presbyterian	Presbyterian	ALL	Caucasian	M	BM, related donor	CY/TBI/ATG
2	28	Christian	Christian	AML	Afr-Am	F	BM (first); cord (second) [*] unrelated donors	CAM/FLU/MEL
3	21	Methodist	No response	Schwachman Diamond Anemia	Caucasian	F	BM, unrelated donor	CAM/FLU/MEL
4	23	Christian (per chart)	Christian (per chart)	XLP-like immune deficiency	Caucasian	M	PBSC, unrelated donor	CAM/FLU/MEL
5	15	Baptist	Baptist	NHL and XLP	Caucasian	M	BM, related donor	CAM/FLU/MEL
6	15	None	None	AML	Hispanic	M	BM, unrelated donor	BU/CY/ATG
7	19	Baptist	Baptist	CGD	Caucasian	F	BM, related donor	BU/CY/ATG
8	20	Catholic	Catholic	AML	Hispanic	F	BM, unrelated donor	BU/CY/ATG
9	15	Christian	Christian	Aplastic anemia	Caucasian	F	BM, related donor	CY/ATG
10	19	Roman Catholic	Roman Catholic	HLH	Caucasian	F	BM, unrelated donor	CAM/FLU/MEL
11	19	Christian	Christian	CML	Caucasian	M	BM, unrelated donor	CY/TBI/ATG
12	21	Baptist	Baptist	Aplastic anemia	Caucasian	F	BM, unrelated donor	CAM/FLU/MEL

Afr-Am indicates African American; ATG, antithymocyte globulin; BM, bone marrow; BU, busulfan; Cam, campath; CGD, chronic granulomatous disease; CY, cyclophosphamide; Flu, fludarabine; HLH, hemophagocytic lymphohistiocytosis; Mel, melphalan; NHL, non-Hodgkin lymphoma; PBSC, peripheral blood stem cells; XLP, X-linked lymphoproliferative disorder; UPN, unique patient number; ALL, acute lymphoblastic leukemia; AML, acute myelogenous leukemia; CML, chronic myelogenous leukemia; TBI, total body irradiation.

* UPN 2 received a second graft for treatment of failed engraftment with the first graft.

clarify diagnoses. In 2 cases in which the interviewer failed to ask the participants about faith tradition, that information was also accessed via the medical records. Although data for this grounded theory study were drawn exclusively from interviews, we needed to access the medical records to describe the demographics of our participants.

RESULTS

First Set of Interviews

Review of the first set of interviews (n = 12) resulted in 5 major themes raised by participants: asking, “why me,” asking, “what will happen to me,” believing God has a reason, using faith practices, and benefitting from spiritual support people.

Asking, “Why me?”

Most participants (n = 11) used R/S to wrestle with the questions of why they had a life-threatening illness and the related question of what would happen to them. Participants offered the following comments exemplifying this category: “I feel like emotional, like why me? (tearful) Like why this point in my life when I’m just about to go off to college and like I’ve been working so hard and now I can’t go right now,” and “ ‘Why’ was the main thing, why He made me...why it was me. I know I didn’t want to play the, ‘Woe is me,’ but when I first got sick, I was upset about it.”

Asking, “What will happen to me?”

The physical question of whether they would live or die was accompanied for some by the spiritual question of whether, if they died, they would go to heaven or hell. One participant said, “I thought there was a chance that this can...the bone marrow transplant, there’s a chance that it will kill me and I knew that I had to go through it, and I don’t want to go to hell.” Two of the participants addressed the spiritual question of eternal life with the concrete action of requesting and receiving the Christian rite of baptism. One participant did not use R/S, but rather answered the question, “why me?” with a scientific understanding of genetics and with a philosophy that bad things happen for no reason.

Believing God has a reason

Those using R/S shared a belief that God had a reason. Participants in the first series of interviews did not always have an answer about what the reason was: “Well, I know that He is there and He is helping and there is a reason why I have to go through this.” Participants tended to assume it was either a vote of confidence in their strength, a decision to use them in a meaningful way, or a test of faith and, therefore, an opportunity to develop spiritually. One participant succinctly said what several participants echoed: “He chose me ‘cause I’m strong. I understand what I have to go through.”

Using faith practices

Participants reported using practices such as prayer, Bible reading, speaking with youth ministers and with other spiritual support people, and listening to Christian music. These practices provided several participants with tangible comfort and encouragement. One participant said, “I pray when it just seems really bad, like I pray during my radiation treatments to get me through it.” Another said, “And just when I’m in pain and I pray for peace that I won’t, you know, let...that side effects won’t be too bad and that I will be healed from that and not feel the pain.” Being unable to attend church services or youth group because of immunosuppression was a reality for all who attended and a loss voiced by several participants.

Benefitting from spiritual support people

Several participants reported significant support from people from their congregations; 1 participant said, “My pastor’s wife is 1 of the biggest helps because she’s a pastor but she talks to me like I’m normal.” Other people had spiritually supportive family members such as aunts, a grandmother, or a grandfather. The content of the support varied based on the relationship; 1 participant’s support person was quite forceful: “ ‘(Name), you are acting as if you’re not a part of this family, that you’re not a child of God... He said you’re standing on the outside and He said come near.’ And just that once you realize that everything will be OK, but you have to accept that. It was true for me.”

Participants reported being encouraged and inspired by those who were formally or informally spiritual support people.

Second Set of Interviews

Review of the second set of interviews ($n = 6$), completed 1 year after HSCT, resulted in 4 themes identified by the participants: believing God chose me, affirming that my life has a purpose, receiving spiritual encouragement, and experiencing strengthened faith.

Believing God chose me

One participant gave language to this theme in this way: "It's just, it made me realize that God is using me in a big way and he's just using me to touch a lot of lives. Also, that he is also giving me another chance at life so... I plan on him working through me for the rest of my life."

Participants came to understand that God had chosen them, which seemed, in several cases, to lead to sense of being special to God. This category relates to the theme identified in the first set of interviews that God had a reason for allowing them to be ill enough to need to receive HSCT. Believing they were chosen by God also led some participants to have a sense of responsibility for understanding what God wanted them to learn from the experience of serious illness and receiving HSCT.

Affirming that my life has a purpose

This theme related to the theme from the first interview series of believing that God has a reason. One participant noted that trusting God's plan did not equate with knowledge of the actual plan: "I trust God's plan more (pause), and I know that He's got a reason even if it takes forever to figure out." Other participants reported that God was or would be using them in a significant way to help others: "I feel my heart just transformed and God really was speaking to me...He gave me my life to honor Him and that I should do all that I can to do that. The experience of illness and receiving HSCT led most participants to question their life path and reevaluate their values and behaviors."

Receiving spiritual encouragement

This spiritual encouragement was sometimes experienced as coming directly from God and other times was mediated by spiritually supportive people. One participant offered this story of the youth minister's visit:

Our heads were just kind of like bobbing around, not really knowing what's going on and the youth pastor came in and he just really kind of put us back in the...kind of relaxed mode and not really having many worries and just kind of putting us back on our feet and getting us back to the ground, and I think that really helped us get through it.

Prayers were sometime crying out to God with anger and fear. Some participants felt it would demonstrate a lack of faith to speak to God about fear of death. One participant who felt freedom to voice anger in her prayers had support from her pastor who openly acknowledged that he too would be angry with God. Many participants found conversations with spiritually supportive friend/family/clergy to be very helpful. The participants' descriptions varied in terms of the content of conversation from spiritual support people but

they shared appreciation for these people who bolstered their faith.

Experiencing strengthened faith

All participants reported feeling that their faith had grown stronger in the process of receiving HSCT. In the second set of interviews, participants spoke of their faith in these ways: "I've gotten really close to God. Me and him haven't always been close and me going through this just opened my eyes and showed me that he is a very big part of everybody's life," and "I feel like my faith and my trust in the Lord has increased a lot and that I trust him more...I'm closer to Him." Participants' R/S stood the tests of fear and pain, and, in some cases, doubt.

Several participants who had struggled with what would happen if they died conveyed powerful experiences of God's presence: "And for me, it was do you stop believing just because things are not working out the way you expected? And, no, you don't give up hope, you don't give up faith. And maybe that's what builds it." These participants found a sense of reassurance that they would be safe in God's care whether they lived or died.

Overall, the second set of interviews resulted in some themes similar to those in the first set and some areas of change and growth. Participants had worked to make meaning of a very challenging experience and, in the second interview series, they had answers to some of the questions from the first set. The answers weren't conclusive for some participants; some continued to wrestle with "why me?" and "what will happen to me?" All participants in the second interview series said that their faith had grown stronger in the process of HSCT.

Listening to their language and analyzing their descriptions of faith, we noted an increased belief that God cared for them and many had the experience of actual presence and help in the context of HSCT. Some participants reported that they felt that having gone more deeply into their faith, they would be stronger, no matter what happened, either because of illness or, if they lived through this, in other life challenges.

DISCUSSION

AYA HSCT patients are thinking about and using R/S much more than we suspected. Using the method of interview allowed us to encourage AYA participants to describe their R/S experience. Several voiced appreciation of the interview itself as a time to talk about their faith. The literature suggests that a qualitative interview may serve as a chaplaincy intervention [16]. We did not ask participants in our study to comment on the impact the interview had on them. One study about the impact of qualitative interview on research participants found that "the interview had prompted them to look at things in a different way, often gaining insight" or that they "had a view that had now shifted" [17]. This study suggests that our method of qualitative interview might have caused the participants to think more or differently about their R/S than they otherwise would have.

From the first set of interviews, we learned that all participants using R/S to help them understand the world were using R/S to address the questions of "why me?" and "what will happen to me?" R/S was a lens through which our participants made meaning of their illness and their hope for recovery as they received HSCT. The 1 other R/S study of HSCT patients that we are aware of, an adult study by Pereira et al. [4], explored the relationship between spiritual

absence, quality of life, and mortality. Pereira et al. found a relationship between spiritual absence and likelihood of death 1 year after receiving HSCT. Their method, the Millon Behavioral Medicine Diagnostic, provided data about 7 domains; 1 domain, the Stress Moderator scale, assesses the degree to which patients lack religious or spiritual personal resources to cope with medical stressors" [4]. Data produced from this type of inquiry differs substantially from our qualitative interview data. Therefore, although we find their results interesting, we cannot compare our results with those of their study. We learned that several of the participants in our study had considerable fear that was based in their faith. Not only did they have the fear of pain and of possible death that most, if not all, HSCT recipients feel. They also had the fear of going to hell. This is certainly not the case for all who use R/S; however, the literature says that sustained spiritual struggle may create significant distress that leads to greater depression and negatively impacts quality of life in adult patients [3,18,19]. We do not know whether some AYA patients receiving HSCT have issues of sustained R/S struggle. Those in our sample reported spiritual struggle, but those interviewed a second time had worked through their R/S struggle using the tools of their faith: prayer, religious ritual, such as baptism, and receiving spiritual encouragement from others. Our AYA participants were able to use their faith to respond to fear created by their faith, and thus reported strengthened R/S to the point that some voiced gratitude for having the experience of illness and HSCT.

An overarching finding from our analysis is that participants with faith were able to draw on their faith for tangible help with loneliness and fear. We learned that although AYA were very willing to talk about their R/S beliefs and experience in the context of the interview, several of them had not spoken with others about either the depth of fear they had or their use of R/S in medical decision-making. Although the relationship between medical decision-making and R/S was not a major category in our study, 1 YA participant told about privately relying on R/S to decide when to go home. It is increasingly clear that R/S is used by parents of pediatric patients as they make medical decisions for their children [20]. Seeking to understand how R/S informs medical decision-making for older adolescent patients, young adult patients, and parents of pediatric patients will be important in future studies.

Studies in R/S have examined ways patients use R/S for adherence. Given that AYA struggle with assuming health responsibilities [21], leveraging R/S to support greater responsibility in the AYA's own health care could serve AYA patients. This idea is supported by Mahoney's (2005) study on "sanctity of the body" beliefs in her study of 289 college students [22]. Our study did not address questions of how AYA patients understood their R/S as encouraging them, or not, to adhere to prescribed medical care. This could be an area for future research with AYA HSCT patients.

The literature has some studies suggesting that adolescents use R/S to cope with illness [6]; this is based in large part on survey responses. Our work provides a longitudinal study of 6 AYA HSCT patients offering in-depth descriptions of their journey from struggling with questions of "why?" to a deeper understanding of how R/S served them. Part of their reported growth in faith may be a result of natural development for AYA; between the ages of 18 to 25 [23], adults continue their identity development [9,23]. We anticipated that the experience of HSCT might lead to a change in

participants' R/S. Each participant affirmed a strengthening of his or her faith. For these participants, God is an active being helping them endure pain and suffering and fear.

The implication for care from our study is that AYA recipients of HSCT should have their R/S resources and concerns assessed and, if indicated, addressed as a routine part of their care. We recommend having a well-informed chaplain on the HSCT health care team as an essential support for the AYAs' R/S and to translate R/S concerns/beliefs to the interdisciplinary team. Meeting the R/S needs of patients and families will provide better care and result in greater satisfaction with care [24]. Religious beliefs and faith communities sometimes work at cross purposes from the medical team, especially at the end of life. Having a professional chaplain on the team will provide a liaison who understands the culture of both the R/S world and the health care world. Professional chaplains are academically and clinically educated to understand multiple faith traditions and to provide R/S resources appropriate to the patient's belief system. One study reported that in some end-of-life care situations, religious patients required "more aggressive medical care" than the medical team thought appropriate [24]. Balboni et al. speculated that some religious people see the medical team as God's method of providing a miracle. In this situation, the chaplain may provide a bridge of conversation between the religious community of the patient and the health care team. In an earlier study, Balboni et al. found that "patients ratings of support of their religious/spiritual needs are significantly associated with receiving pastoral care visits...suggesting that pastoral care is a key aspect of spiritual care" [25]. From this, we conclude that having a chaplain as a member of the interdisciplinary team addressing the R/S concerns is preferable to relying solely on R/S support from the patients' congregational clergy.

Limitations of our study include our extremely small sample size. Although appropriate for a grounded theory study, we affirm that our results are not to be generalized but rather may be used to create hypotheses. For instance, we would like to explore whether using interview-style questions might form the useful basis for spiritual assessment that could both improved R/S care for patients and also provide meaningful insight for the health care team. Another limitation of our study is the lack of faith traditions beyond Christianity in our sample. Our finding of the importance of R/S to the AYA participants in this study supports findings in adult R/S studies of patients facing life-threatening illnesses that quality of life is increased among patients receiving spiritual support from chaplains or from members of the medical team [26–28]. We affirm the findings of adult R/S studies suggesting that members of the medical team may assess interest and/or need by patients for R/S care, but that certified chaplains are the only members of the health care team educated and certified to provide in-depth spiritual assessments and R/S interventions [25,29]. On the basis of our study and the adult R/S literature cited, we suggest that chaplains consider being more proactive in assessing and responding to R/S needs of AYA patients. Two members of our research team have been chaplains with pediatric HSCT patients; neither had heard in routine pastoral care of the depth of religious experience that participants conveyed, in the context of responding to interview questions. This may be a failure of skill on the part of the chaplains or a result of chaplains' seeking to provide emotional support and

neutralize faith differences [30] or for some reason yet to be determined. Very few studies have been done on the efficacy of chaplaincy care [31]. Our study suggests that more assertive exploration of how AYA patients understand and use their faith will be meaningful for the patients and helpful for the health care team.

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