

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

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