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Can You Tell Me Why You Made That Choice

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“Can you tell me why you made that choice?”: A qualitative study of the influences on treatment decisions in advance care planning among adolescents and young adults undergoing bone marrow transplant

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Abstract

Background: Adolescent and young adult advance care planning is beneficial in improving communication between patients, surrogates, and clinicians. The influences on treatment decisions among adolescents and young adults are underexplored in the literature.

Aim: The aim of this study was to explore and better understand the influences on decision-making for adolescent and young adult bone marrow transplant patients about future medical care.

Design: Clinical case studies and qualitative inductive content analysis of treatment decisions made during the Respecting Choices® Next Steps Pediatric Advance Care Planning conversation as a component of the Family-Centered Advance Care Planning Intervention.

Settings/participants: A total of 10 adolescent and young adult patients (aged 14–27 years) undergoing bone marrow transplant at an academic Midwest children’s hospital were involved in the study.

Results: Influences on participants’ decisions were consideration for family, quality of life, and awareness of self. Desire to avoid suffering and maintain an acceptable quality of life was often in competition with participant’s concern over the perceived negative impact of discontinuing treatment on their families.

Conclusion: This study highlights that adolescent and young adult bone marrow transplant patients are capable of meaningful deliberation about future treatment decisions. Influences on decision-making should be incorporated into advance care planning conversations to facilitate communication between patients and their surrogates. Longitudinal research is needed to explore these influences throughout the trajectory of illness.

Keywords

Advance care planning, adolescents, young adults, palliative care, decision-making

What is already known about the topic?

- The influences on future treatment decisions among adolescent and young adult bone marrow transplant patients in advance care planning have not been explored.
- The Family-Centered (FACE) Advance Care Planning intervention has demonstrated benefit for adolescents and young adults and their surrogates regarding future medical decisions.

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What this paper adds?

- Adolescents and young adults on the challenging journey of bone marrow transplant exhibit mature and thoughtful decision-making that goes beyond their awareness of self, and extends to a consideration of their family, and of their own quality of life.
- Treatment decisions reflected a struggle between the competing demands of maintaining their perceived quality of life with their concern of being a burden to their families.

Implications for practice, theory, or policy

- Clinicians caring for adolescent and young adult bone marrow transplant patients should incorporate known influences on decision-making into conversations about goals of care.

Introduction

There are an estimated 70,000 new cases of cancer annually in the United States among adolescents and young adults.¹ Cancer is the leading cause of death from disease in adolescents.¹ Bone marrow transplant, a potentially curative treatment, carries an approximate mortality risk of 25% and may lead to treatment-related morbidities. Therefore, pre-transplant discussions of patient goals and preferences in the event of complications are recommended to provide care that is consistent with patient wishes.²⁻⁴

Emerging literature demonstrates the benefits of adolescent and young adult advance care planning, including the avoidance of unnecessary or undesired treatments,⁵ helping to communicate desired care with providers,⁵ and improvement in congruence between patients and their surrogates in end-of-life medical decision-making.⁶⁻¹⁰ Research has predominantly focused on the impact of advance care planning on decision-making in adults.¹¹⁻¹⁴ Little is known about how adolescent and young adult perspectives and decision-making processes may differ from adults. Very few studies have examined the experience of, and preferences for, end-of-life care in adolescents and young adults with cancer.¹⁵ Adolescence is characterized by the establishment of individual identity, a sense of self, independence and autonomy from parents, and the importance of peer relationships.¹⁶⁻¹⁹ Serious illness may lead to a loss of identity and loss of control of their evolving autonomy.^{20,21} The bioethical core values of patient autonomy, informed decision-making, and control over the dying process dominate the United States, European, Canadian, and Australian principles of advance care planning. Whether or not minors have the legal right to execute medical decisions (aged 18 years in the United States), giving adolescents a voice in their own health care decisions respects their developmental stage in life and supports their evolving autonomy.²²

Our aim was to explore and describe the influences on decision-making for adolescent and young adult bone marrow transplant patients about future medical care.

We used transcripts of participant advance care planning conversations and abstracted clinical data to gain a more complete understanding of the complex influences that inform serious illness decision-making in this population.

Methods*Participants and setting of the study*

The study included participants undergoing bone marrow transplant who were aged 14–27 years at the time of enrollment, English-speaking (the questionnaires are only available in English), not known to be developmentally delayed (defined as IQ > 70 if assessed by a neuropsychologist), and who had an identified surrogate decision maker. The study was conducted at an academic children's hospital with a long-standing bone marrow transplant program.

All participants were provided with written informed consent (or parental consent and participant assent for those below the age of 18). Human subjects protections included referrals to ethics, chaplaincy, and/or social work in the event of conflict or excessive emotional distress related to the discussion. This study was approved by the Institutional Review Board. Patients reported in this article were enrolled between January 2017 and January 2019.

Data were abstracted from the medical record, clinician report, and conversation transcripts to construct clinical cases. To protect patient confidentiality, participants were de-identified using gender-neutral pseudonyms, characterizing participants aged 14–17 years as “adolescents” and those aged 18–27 years as “young adults,” and by generalizing diagnoses.

Procedures

FACE-BMT intervention. The FACE-BMT intervention included a three-session protocol involving the participant and their surrogate (see Table 1).⁶ This analysis describes the influences on decision-making about serious illness-based situations during the Respecting

Table 1. The FACE-BMT intervention including a three-session protocol.

Session	Session timing	Session goals	Session process
1. Lyon Family-Centered Advance Care Planning Survey	During workup week, prior to admission for BMT.	To assess the participants' values, beliefs, and life experiences with illness and end-of-life care.	Social worker trained and certified by Respecting Choices orients the family to the study, providing information, such as the right to change your mind or the right of patients who decide to forgo life-sustaining treatment to be offered other important treatments and to not be abandoned. AYA is surveyed separately from surrogate; surrogate surveyed privately with regard to what they believe their AYA prefers and attitudes about end-of-life care. Interviewer brings AYA and surrogate together and highlights similarities and areas of difference for further discussion.
2. Respecting Choices® Next Steps Pediatric Advance Care Planning Conversation	Within 48 h of hospital admission for BMT.	To facilitate conversations and shared decision-making that allows the AYA to express their stated preferences of care for serious illness-based situations and to prepare the surrogate to be able to fully represent the AYAs' wishes.	<i>Stage 1</i> assesses the AYA understanding of their current medical condition, prognosis, and potential complications, as well as their hopes, what it means to live well, worries, and fears. <i>Stage 2</i> explores current experiences and how they may impact future medical decision-making. <i>Stage 3</i> briefly reviews the rationale for future medical decisions the AYA would want the surrogate to understand and act on. <i>Stage 4</i> explores four serious illness-based situations using a 6-step procedure and Respecting Choices SoTP form to elicit care preferences when a complication occurs, resulting in an unacceptable outcome. <i>Stage 5</i> summarizes the conversation and encourages ongoing conversations. <i>Stage 6</i> creates a follow-up plan for coordination of care and services.
3. Review of prior sessions and SoTP, follow-up for any issues that arose during Sessions 1 and 2.	Within 48 h of Session 1.	To ensure that Sessions 1 and 2 did not create distress or unresolved questions or issues. To confirm answers on the SoTP are representative of the AYAs' decision.	Social worker meets with AYA and surrogate to review any questions or concerns. SoTP is produced and AYA is offered opportunity to revisit or change any responses. SoTP is scanned into EMR with permission of AYA and surrogate.

BMT: bone marrow transplantation; AYA: adolescent and young adult; EMR: electronic medical record; SoTP: statement of treatment preferences.

Choices® Next Steps Pediatric Advance Care Planning conversation (Session 2). Facilitators of the conversations were pediatric bone marrow transplant social workers (two Caucasian women and one African American male) and were certified through a certification course. Two experts in the field reviewed the first three conversations to ensure competency criteria and fidelity. One author (J.S.N.) reviewed the subsequent transcripts and then reviewed with the facilitators.

Respecting Choices Next Steps Pediatric Advance Care Planning. The Respecting Choices Next Steps Pediatric Advance Care Planning conversation is a decision-making conversation for individuals actively treating their serious medical condition and who may experience a complication.^{23,24} The overall objective of the conversation is to open communication between the participant and

surrogate. For this article, we focused on documented choices on the Statement of Treatment Preferences (SoTP) form that documents goals of care, treatment preferences, and additional instructions for care using four illness-based situations: (1) high treatment burden/low survival, (2) high treatment burden/limited prolongation of life, (3) high survival/functional disability, and (4) high survival/cognitive disability. Patients chose one of the three options for each situation: "continue treatment," "discontinue treatment," or "unsure." All conversations were audiotaped for fidelity and analysis and were professionally transcribed.

This article reports on Situations 2 and 4 based on the richness of the data and variability of responses. We excluded Situation 1 from the analysis due to 80% of subjects choosing to continue treatment and Situation 4 due to 40% of subjects answering unsure. Situation 2 was "If I

reach a point in the progression of my disease where it has spread and treatments will extend my life by no more than 2 to 3 months, and the side effects of treatment are serious . . . I would choose the following” and Situation 4 was “If I have a serious complication and have a good chance of living through this complication, but it was expected I would never know who I was or who I was with and would require 24 hour nursing care . . . I would choose the following.”

Analysis

In this study, the treatment preference (SoTP) form and the transcripts of the conversations of the first 10 participants in the FACE-BMT study were the source of qualitative data. The first phase of the analysis consisted of examining each participant’s response to Situations 2 and 4. An inductive content analysis was conducted.^{25,26} Content analysis is a research method for making replicable and valid inferences from data to their context, with the purpose of providing knowledge, new insights, and a representation of facts.²⁷ Data were placed into matrices, a format to display data for coding created in MS Word.^{28,29} First, individual transcripts were coded to develop the individual case analyses. The data were then coded across participants and clustered into categories.

Researchers performed the analyses separately and then as a team to compare findings. Consensus was reached using the Consensual Validation Method.³⁰ Six authors (J.S.N., C.P.-M., J.L., K.K., N.S., and A.S.) reviewed the transcripts and compared patients’ recorded treatment preference form decisions to qualitative responses regarding their treatment choice. These individual determinations were then discussed as a whole to achieve consensus.

Results

In this section, we first describe the clinical experience of participants in the FACE-BMT study. This is followed by our analysis and reporting of three categories illustrating the influences on decisions for participants: consideration for family, quality of life, and awareness of self.

Participant descriptions

Among eligible participants, the enrollment rate was 71% (10 of 14 consented). Among the 10 participants, the median age was 19 (range = 14–23) years, 70% were male, and 80% were Caucasian. Six participants (60%) underwent bone marrow transplant for malignancy. Mortality for the cohort was 20%.

Chris is a young adult with relapsed malignancy 4 years after his first transplant. Chris’s father was the surrogate. During completion of the SoTP, Chris’s primary concern

was about diminished quality of life. The emotional and financial burdens on the family were a consistent consideration in the treatment decisions. Chris had another relapse of leukemia 9 months after transplant and is undergoing additional therapy.

Pat is an adolescent with a hematologic disorder diagnosed shortly prior to transplant. Pat participated in the conversation with both parents. Pat commented that the situations were too “nebulous” and “ambiguous” to offer clear decisions. The transplant course was uncomplicated.

Drew is a young adult undergoing transplant after an initial diagnosis of malignancy 9 years prior. Drew’s family strongly relied on faith during Drew’s illness and in their decision-making. Drew deferred nearly all decision-making to the mother. Drew answered “unsure” to both situations. Drew wanted to avoid suffering but was conflicted about the impact these decisions to discontinue treatment would have on the family. The post-transplant course was complicated by multiple admissions to the ICU. Drew was discharged from the hospital 3 months after transplant but was readmitted 3 days later with multisystem organ failure. Drew died 8 months after transplant following the parent’s decision to discontinue mechanical ventilation.

Dana is a young adult with a high-risk malignancy. Both of Dana’s parents acted as surrogates during the interview. Decisions and perspectives during the conversation were strongly motivated by faith. Dana’s reasons for choosing to discontinue treatment related to concerns about being a burden to the family and being in pain. The transplant course was uneventful.

Alex is a young adult with a pre-cancerous hematologic disorder. Alex’s mother acted as the surrogate. Alex’s treatment decisions were motivated by a desire for a high quality of life, described as having “mental clarity” and to “live properly.” Due to severe graft versus host disease post-transplant, Alex was unable to return to college. Alex developed depression and attempted suicide. Alex is currently 2 years post-transplant and is back in college.

Ray is an adolescent with a relapsed malignancy. Ray’s faith was influential in decision-making. Ray’s father was the surrogate. Quality of life related to pain and suffering and the burden the illness would place on the family were major considerations.

Jesse is an adolescent who was undergoing their second transplant for relapsed malignancy. Jesse frequently deferred to the mother during the conversation. Jesse deliberated about the balance between time gained by treatment versus quality of life and the impact on their mother if they chose to discontinue.

Cory is a young adult and the second child in their family to undergo a transplant for an immunodeficiency. Cory’s mother was the surrogate and had been the primary caretaker during Cory’s sibling’s earlier transplant.

Cory’s treatment decisions were motivated by a desire to “live as long as possible.”

Ari is a young adult with a hematologic disorder who elected to pursue transplant because of the impact of the disease on their quality of life. Ari’s mother was a physician and acted as Ari’s surrogate. Ari and mother disagreed over Ari’s preferences to discontinue therapy or prolong life if death was a certainty. Ari specified continuing treatment for 3 months but requested discontinuation if there was not a return to a baseline level of functioning. Ari remained hospitalized post-transplant. Ultimately, Ari developed sepsis requiring mechanical ventilation and vasopressor support. Ari agreed to intubation on the last ICU admission, remained on mechanical ventilation and dialysis for 2 weeks and died 7 months after transplant following failed resuscitation.

Charlie is a young adult undergoing a second transplant for a secondary malignancy. Charlie chose discontinuing treatment with a clear definition of what constitutes “quality of life.” The primary motivation was avoiding uncomfortable symptoms or side effects, even if that meant a shorter life span.

Table 2 presents individual participant decisions on the treatment preferences form and their responses as to why they made that treatment choice.

Qualitative categories

The three categories that resulted from the content analysis of qualitative data as influences on participant’s decisions were as follows: consideration for family, quality of life, and awareness of self.

Consideration for family

The impact of decisions on family members was a primary concern for participants. Within this category, the considerations for family fell into three sub-categories: relational perspective, prioritization of others, and practical burdens.

Relational perspective. From a relational perspective, participants deliberated on how to balance their own individual desires with those of their families. The decisions

Table 2. Individual participant decisions on the treatment preferences form and their responses.

Respecting Choices® Statement of Treatment Preference (SoTP) form situations and responses		
	Situation	Situation
	“If I reach a point in the progression of my disease where it has spread and treatments will extend my life by no more than 2 to 3 months, and the side effects of treatment are serious . . . I would choose the following: Whatever my choice, I want to be kept as comfortable as possible.”	“If I have a serious complication from my bone marrow transplant and have a good chance of living through this complication, but it was expected I would never know who I was or who I was with and would require 24 hour nursing care . . . I would choose the following: Whatever my choice, I want to be kept as comfortable as possible.”
Participant	Participant treatment choice Representative quote from participant	Participant treatment choice Representative quote from participant
Chris	Discontinue “If the treatment gives you only two to three months to live with it, it makes no sense to make family members go through that for another two to three months and cause more of a rack up on bills with that.”	Unsure “I would [keep going] . . . unsure . . . It sucks.”
Pat	Continue* “So I would say I’ll continue, because . . . why not? I suppose, just keep trying . . . Out of these three, unsure is the best answer . . . but unsure is just nebulous.” *Qualitative data suggested the choice was <i>unsure</i> .	Discontinue* “Because if you’re not alive for very long, you can’t really do much, and quality of life is also really important . . . I suppose the length that it keeps going on for, or discomfort or burden on family would be true . . . I think there’s too much ambiguity to actually answer the question.” *Qualitative data suggested the choice was <i>unsure</i> .
Drew	Unsure* “I was unsure about that one, because what’s the point of going through some super-serious side effects if they’re saying that it can only extend you no more than two or three months.” *Qualitative data suggested the choice was <i>discontinue</i> .	Continue “It’s kind of scary to not know who you are or who your family members are . . . It would depend on them [family], not me, because at the end of the day, they’re the ones that have to live on. If they wanted me to continue living, and I didn’t want to, then they have to live with the fact that I wanted him here even though he wouldn’t have known who we were.”

(Continued)

Table 2. (Continued)

Participant	Participant treatment choice Representative quote from participant	Participant treatment choice Representative quote from participant
Dana	Discontinue “I don’t want to be alive for two or three months and sick to the point where it’s going to be hard to talk to people . . . It would be physically painful and very mentally painful at the same time.”	Discontinue “Because I wouldn’t be able to do anything at all, if I didn’t know who I was or where I was or who I was with. I wouldn’t even be able to play sports. It even occurred to me, I wouldn’t be able to hold a conversation with someone.”
Alex	Discontinue* “I would just do continue all treatments so long as I could live properly. That’s the thing, properly. Maybe I should mark unsure for that . . . If I could live for three weeks and be like, ‘Oh, I feel alright,’ and I live for three weeks, that may be better than living two to three months and I can’t even think.” *Qualitative data suggested the choice was <i>unsure</i> .	Discontinue “Stop all efforts to keep me alive, it’s okay if I die. How I lived my life is more important than how long I live.”
Ray	Discontinue “Okay, I would choose to stop all efforts to keep me alive, just because I wouldn’t want my last couple of months to be terrible. I guess I’d want to just kind of stop the treatments and be able to do something with my family and not just sit there and be in pain or have weird side effects happening, and the constant worry of not knowing when.”	Continue* “I guess I would want to continue all treatment so I could live as long as possible, but . . . so like if that did happen, I guess, I would want to then stop the efforts . . . I would want to be with my family. I wouldn’t want to have to live in a facility or something, and I wouldn’t want to have other people taking care of me, I guess, but I wouldn’t want to be a burden to my parents . . . That’s why I picked continue until it was real.” *Qualitative data suggested the choice was <i>unsure</i> .
Jesse	Discontinue “Because I would rather live as long as I can as healthy as I can than living a crappy life.”	Discontinue “Because it would depend on how it would affect my family in that situation. Like, if they would, like, want me alive or what.” Mother: “What if I wasn’t around and it was going to be a nurse [caring for you], you know?” Pt: “Then I would want to die, so the second option.”
Cory	Continue “So I can live as long as possible and just be with my family and friends for as long as I can before I go.”	Continue “Just like all the other ones, being able to stay alive.”
Ari	Discontinue “When you’re going to live . . . I’m not going to try to beg for two to three months of life . . . I’m only going to live three months. I just don’t want to do a bunch of operations and be in the hospital.”	Continue* “Stop all efforts . . . Because it’s not a life I would want. I guess you could do the wait three months thing . . . I would continue for three months and if there is no improvement, then I would stop . . . Yes. I’d happily rather be dead.” *Continue with qualifiers
Charlie	Discontinue “I’m not going to spend the last little amount of time I have left here [the hospital]. If I can I’d want to travel or, again, just be with my family. They’re the most comforting thing I have.”	Discontinue “I’ve had cancer treatment, a bone marrow transplant. I have a good chance of living, but I wouldn’t know any of it, that I did any of it. I wouldn’t know who I am. I wouldn’t know who my family is. I wouldn’t want to do that. I like to be aware of things.”

were rooted in their relationship with their parents. Participants recognized that their parents had to live with the decisions they made:

It would depend on them, not me, because at the end of the day, they’re the ones that have to live on. Like, if they wanted me to continue living, and I didn’t want to, and so the doctors

valued what I said and pulled the plug, then they have to live with the fact that, like man, I wanted him here even though he wouldn’t have known who we were. Just seeing his face-I didn’t want to bury my child. (Drew)

This reveals that participants were willing to consider sacrificing their own preferences for those of their parents.

Prioritization of others. Several participants made their decisions against their own preferences based on what they thought was best for the family:

That's why I put unsure, if I don't know who I am or who any of my family are . . . then what's the point of being here, you know. But like, even if I don't know who they are, if they want me here, then out of, like, consideration for them I'd stay. (Drew)

Practical burdens of illness. Participants were aware of, and gave strong consideration to, the burdens their illness placed on family. These burdens included the cost of treatment, care work burden, where they would live outside of the hospital, and who would be responsible to care for them:

If the treatment gives you only two to three months to live with it, it makes no sense to make family members go through that for another two to three months and cause more of a rack up on bills with that. (Chris)

I wouldn't want to live where . . . I would want to be with my family. I wouldn't want to have to live in a facility or something, and I wouldn't want to have other people taking care of me, I guess, but I wouldn't want to be a burden to my parents. (Ray)

Quality of life

All participants except one articulated a desire for meaningful time as opposed to being sick in the hospital. Meaningful time took on different definitions among participants including spending time with family and friends, being at home, avoiding complications/additional treatments if no potential for longer-term benefit existed, and what they wanted to do with their remaining time:

I would choose to stop all efforts to keep me alive, just because I wouldn't want my last couple of months to be terrible. I guess I'd want to just kind of stop the treatments and be able to do something with my family and not just sit there and be in pain or have weird side effects happening. (Chris)

Participants were clear that the burden of treatment should be proportional to the anticipated treatment outcome. When presented with 2–3 months of survival and high treatment morbidity, participants weighed the potential quality versus quantity of life in their remaining time:

I would not want to do treatment just to extend my life two to three months, especially when the side effects are so serious. I'd rather be living well during that time than getting really, really sick trying to make it two months longer. I think I'd rather value the time I have than get really sick like this. (Charlie)

Awareness of self

Participants discussed the implications of continuing treatment when their sense of self or their ability to participate in activities that give them pleasure were compromised. Participants desired a sense of agency so that they could live the future lives they imagined for themselves:

I like to be able to think; thinking is very important to me, so . . . if the drugs would never stop, and I would constantly just be a lump, and I would just be blah, then no. (Pat)

Because I wouldn't be able to do anything at all, if I didn't know who I was or where I was or who I was with. I wouldn't even be able to play sports. It even occurred to me, I wouldn't be able to hold a conversation with someone. (Dana)

There was a demonstrated relationship between awareness of self and perceived quality of life, most notably when neurologic impairment was described:

To not know who I am or who I'm with, I don't know, it doesn't sound like much enjoyment in that. Doesn't sound like there's any. Sounds like you'd be confused all the time so, I would say . . . stop all efforts to keep me alive, it's okay if I die. How I lived my life is more important than how long I live. (Alex)

Discussion

In this study, we demonstrated that adolescent and young adult bone marrow transplant patients had both the desire and insight to discuss goals of care related to future medical treatment in the face of complications. The qualitative analysis of these conversations further illustrates the complexity of reasoning regarding medical decision-making among this population. The richness of the data augments our understanding of the lived experience of these patients.

Three categories of reasons for treatment decisions emerged, including family considerations, quality of life, and awareness of self. Consideration of family was demonstrated among participants who desired to avoid suffering and discontinuing treatment but strongly considered the impact of these decisions on their parents. When the outcome involved severe neurologic impairment, participants made treatment choices based on how that impairment impacted their awareness of "self." Participants also had varying definitions of what constitutes quality of life for them; some referenced pain and suffering, while others considered the inability to participate in their previous life activities as unacceptable. These findings add depth to our understanding of how interventions can best support decision-making.

Desire to avoid suffering and maintain an acceptable quality of life was often in competition with participants' concern over the perceived negative impact a decision to

discontinue treatment, with resulting death, would have on their families. How end-of-life decisions are navigated in the context of “relationships with others” among pediatric cancer patients has previously been reported.³¹ Adult studies have also described family burden as a significant reason in participants’ perspectives about the type of end-of-life care they desire.^{32,33} Our finding supports the importance of dyadic advance care planning discussions between adolescents and young adults and their surrogates. By facilitated discussion of these difficult topics, participants and their surrogates can express unspoken fears and develop a better mutual understanding of important treatment considerations.

Hypothetical situations to elicit treatment decisions were useful in stimulating thoughtful discussions about acceptable risks and outcomes for participants. Importantly, for the two patients who died, the ultimate treatment decisions were consistent with their documented preferences to continue all treatments (one preferred treatment for 3 months with discontinuation if no improvement; however, died after 3 weeks of life-sustaining treatment, and the other ultimately deferred to parental decision-making). However, participants actively deliberated with the situations, consistently offering “what ifs . . .” to make a choice beyond “uncertain.” Some participants expressed that the situations were “unrealistic,” “ambiguous,” or “too vague” for them to make a decision at that time. This is similar to evidence in adults, suggesting that completion of advance directives may be hindered by the unpredictability of the clinical course, uncertain long-term outcomes, and difficulty in predicting what might be desired in the future.^{34–41} Conducting ongoing discussions, especially when clinical circumstances change from hypothetical to real life, may yield more fruitful deliberation about treatment decisions. By opening this dialogue, advance care planning can function to help make the best possible “in-the-moment” decision.⁴²

Strengths and weaknesses of the study

This is the first study conducted and the first qualitative analysis to explore the influences on future medical decisions among adolescents and young adults undergoing bone marrow transplant. The training for certification and fidelity monitoring of the conversation ensured the conversations were reliable. Factors influencing the transferability of findings included, this study is a small cohort of predominantly Caucasian patients from a single center with heterogeneity in their diagnoses, illness history, and prior experience, all of these factors which may have influenced their prior conversations and perspectives related to end-of-life care.

Conclusion

Supporting adolescents and young adults in medical decision-making is consistent with the United Nations Convention on the Rights of the Child,⁴³ professional position statements,^{2,3} and the Institute of Medicine, stating that they “. . . should have the opportunity to participate actively in their health care decision-making throughout their lives and as they approach death, and receive medical . . . services consistent with their values, goals and informed preferences.”⁴ Further understanding of the appropriate timing, frequency, and comprehensiveness of adolescent and young adult interventions to achieve optimal patient-centered outcomes is needed.

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Author contributions

J.S.N. was the PI of the study and was responsible for the design of the work, analysis, and interpretation of data; she drafted the manuscript and approved the submission. C.P.-M., J.L., and K.K. performed the qualitative analysis of the transcripts, participated in drafting the manuscript, and approved the submission. N.S. was responsible for analysis and interpretation of the data, participated in drafting the manuscript, and approved the submission. A.S. was the co-PI of the study and was responsible for the design of the work, analysis, and interpretation of data; she participated in the writing of the manuscript and approved the submission. S.E.S. was responsible for interpretation of the data, participated in drafting and revising the manuscript, and approved the submission. M.E.L. developed the FACE intervention, provided oversight in study design and execution, participated in revising the article, and approved it for submission.

Research ethics and patient consent

All participants provided written informed consent (or assent for patients below the age of 18). This study was approved by the University of Minnesota IRB (1512S80885, November 2016).

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