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“Making my own decisions sometimes”: A pilot study of young adult cancer survivors’ perspectives on medical decision-making

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Abstract

Objective—This study aimed to provide a better understanding of the medical decision-making preferences and experiences of young adult survivors of pediatric, adolescent, and young adult cancers.

Methods—We conducted key informant interviews and a cross-sectional mailed survey with young adult survivors (currently aged 18–39 years) of pediatric, adolescent and young adult cancers in South Texas.

Results—Of the responding survivors, almost all wanted to be actively involved in medical decision-making, but preferences regarding family and doctor involvement varied. In open-ended responses, the most commonly reported concerns related to medical decision-making were feelings of uncertainty and fear of receiving bad news. Survivors reported that they desired more information in order to feel better about medical decision-making.

Conclusions—Due to the variety of preferences regarding decision-making and who to include in the process, physicians should be prepared to ask and accommodate patients regarding their decision-making preferences.

Keywords

medical decision-making; cancer survivors; pilot study; adolescent and young adult

INTRODUCTION

As treatment and outcomes improve for both childhood, adolescent and young adult (AYA) cancer patients, the young adult cancer survivor population continues to grow [1]. Like other emerging young adults, survivors of childhood and adolescent cancer must transition from pediatric to adult medical homes, a process associated with changes in medical decision-

making roles [2]. However, for young adult cancer survivors, a rich history of familial decision-making during cancer treatment may complicate the transition of roles played by the patient, the family, and the doctor in adulthood.

Among young adults with chronic health conditions, research has found that young adults want to be included in the medical decision-making process, and a successful transition from pediatric to adult medical homes may be dependent on the patient taking ownership of his or her own disease management [2–4]. In other clinical contexts, studies have found the family to play varying roles in the medical decision-making process [5–8]. For young adult cancer survivors, medical decision-making preferences may differ from those of other young adult populations as well as from cancer survivors in other age groups. Existing literature focuses on the continuation of a strong familial role in the young adult cancer survivor's healthcare, even after the transition to an adult medical home has taken place [2, 9–11]. Less understood are the medical decision-making preferences of the young adult cancer survivors themselves.

Without an understanding of the medical decision-making preferences of young adult survivors of pediatric and AYA cancers, physician recommendations for supporting medical decision-making cannot be established. Thus, in order to better understand medical decision-making preferences in this population, we conducted a small pilot survey in South Texas. In this report, we explore both the medical decision-making preferences of young adult cancer survivors and the factors that may make the medical decision-making process more or less difficult for this population.

METHODS

We conducted a needs assessment using a two staged study design. First, we recruited 5 young adult survivors of pediatric and AYA cancers (aged 18–39) from the South Texas Pediatric Cancer Survivor Database, which has a majority-Hispanic catchment area. Survivors participated in a 90-minute key informant interview about survivorship needs and preferences as well as medical decision-making. Informed consent was obtained before the group interview began. Then, we developed an online REDCap survey using the insights gained from the group interview and elements from previously validated surveys [12, 13]. The survey queried participants about their socio-demographics, cancer characteristics, survivorship needs and concerns, and medical decision-making preferences.

During April and May of 2015, we contacted a total of 397 potential respondents from the South Texas Pediatric Cancer Survivor Database as well as a mailing list used to distribute newsletters to survivors of pediatric and AYA cancers and their families. Invitations as well as one reminder were sent by mail and contained an informational letter about the survey and the link/QR code to the REDCap survey. Forty-three invitations were returned with incorrect addresses, one patient was deceased, and four persons indicated ineligibility (e.g. not between ages 18–39, did not have a previous cancer diagnosis, or did not speak English). Of 349 potentially eligible participants, 31 completed the survey. One respondent was later deemed ineligible, as they were a parent of a minor survivor, making the response invalid. As such, a total of 30 valid responses were received. We calculated the response rate to be 8.6% (30 responses/(397 invitations – 43 returned letters – 1 deceased – 4 ineligible – 1

invalid response)*100). This needs assessment was evaluated and approved by our Institutional Review Board.

For this report, we examined whether survivors had received a summary of their treatment plan as well as a survivorship plan after completing treatment, whether they had a usual source of care for their medical needs, a modified medical control preference scale [14] as well as two open-ended questions about what made them anxious about making medical decisions and what would make such decisions easier for them. All closed-ended items were examined by age at survey completion (18–22 vs. 23–39). A thematic analysis was conducted to examine the open-ended questions. We used qualitative content analysis approach in which themes and categories are derived from the data in the context of pre-determined research questions because it is especially useful for understanding processes (such as medical decision-making) and the meaning of these processes to participants [15]. Three authors (LAS, SS, and SC) independently coded the responses and then worked together to find consensus in themes.

RESULTS

A total of 30 young adult survivors completed the survey (Table 1). Respondents were majority female (63.3%) and Hispanic (83.3%), with a mean age of 24.8 years at the time of the survey. In contrast, the broader sample of survivors who were sent the survey were 42.3% female, 74.8% Hispanic, and had a mean age of 24.0 years at the time of the survey.

Among respondents, the average age at diagnosis was 13.3 years. Additionally most respondents were more than two years off active cancer treatment (83.3%), and just over half reported having a physician that coordinates all of their care (56.7%). Less than half of respondents reported having received a written treatment summary (43.3%) or survivorship care plan (46.7%). Other respondent characteristics are shown in Table 1.

Decision-making preferences

Almost all survivors (90%) wanted to be involved in making decisions about their medical care as a young adult survivor, but preferences for who else would be involved in the decision-making process varied widely. Overall, 43% (n=13) reported that they wanted to make the decision together with their doctor and their family. Twenty percent of respondents preferred to make their medical decision alone (n=6), 17% (n=5) wanted to make the decision together with only their doctor, and 10% (n=3) wanted to make the decision together with only their family. Only 10% of respondents (n=3) reported that they did not want to be involved in the decision-making and preferred instead for their family to decide. While this pilot study was not powered for statistical testing, we observed some differences in these preferences by age at survey completion (Table 2). In particular, a larger proportion of the older respondents (those aged 23–39 years at the time of survey) versus younger respondents (those aged 18–22 years) stated that they preferred to make decisions alone (39% vs 6%). Conversely, a smaller proportion of older respondents stated that they preferred to make the decision with both their doctor and their family (31% vs 53%).

Qualitative results

When asked, “What part of medical decision-making is difficult or makes you anxious?” survivors reported a wide range of concerns (Table 3). The most common type of concern, reported by 30% of the respondents (n=9), was related to feelings of uncertainty about which option to choose, followed by receiving or fear of receiving bad news (n=5; 17%). Other types of responses included anxiety about discomfort (n=2; 7%) or difficulties related to their family’s involvement (n=2; 7%). Illustrative quotes for each of these themes are displayed in Table 3. There was also a subset of survivors (n=5; 17%) who reported having no difficulties or anxieties related to making decisions as a young adult survivor, with one survivor stating, “Well, being in the cancer world for nearly 6 years, decision-making doesn’t make me anxious.”

When asked, “What would make it easier for you to make medical decisions you can feel good about?” survivors’ responses generally fit into four themes: additional information, external support, trust in the medical team, and internal support (Table 3). The desire for more information was the most common type of response (n=9; 30%), followed by a desire for external support (n=8; 27%), including the support of the medical team and family as well as more structural support. Survivors also reported on the helpfulness of having trust in their medical providers as a means of making medical decision-making easier (n=4; 13%). Another 10% of survivors (n=3) described sources of internal support that were helpful, including positive thinking and relying on oneself to make decisions. See Table 3 for corresponding survivor quotes.

DISCUSSION

The aim of this needs assessment was to gain insights into the medical decision-making preferences of young adult survivors of pediatric and AYA cancers. We found that most young adult cancer survivors involved in this pilot study wanted to actively participate in medical decision-making, and many also wanted to include their family in the process. These findings are supported by other evidence that physicians responsible for the healthcare of young adult cancer survivors should be prepared to include the family in medical decision-making [2, 9–11]. Interestingly, in our study, preferences differed for younger respondents compared to older respondents; while a higher proportion of younger respondents reported wanting to include their family in the decision-making, a higher proportion of older respondents preferred to make the decision without family involvement. This may reflect a gradual transition for these patients from a dependent role in medical decision-making to a more independent role. In other patient populations, medical decision-making preferences have been found to vary based on many factors, including demographics and type of decision to be made, and these preferences may evolve over time based on a patient’s experiences [16, 17]. Because of the variability in preferences seen across studies and expressed within this pilot survey, physicians treating young adult cancer survivors should be prepared to ask their patients for their preferences before making assumptions about how the survivor would like to make decisions and who to involve in the process.

Medical decision-making preferences and experiences of young adult cancer patients and survivors are understudied areas. To our knowledge no other studies have investigated these

topics among young adult *survivors*, however, several studies have looked decision-making during active treatment among this group. Across studies the consensus is that levels of preferred involvement vary among young cancer patients, but most want to be engaged in the decision making process [18–20]. A 2016 study that compared cancer treatment decision-making between younger (aged 21–40 years) and older adults (aged 41–60 years) found no significant differences in the level to which family members were involved [21]. However, the study did not look at differences by age within the young adult group, or discuss the types of family members which were involved, which is likely to vary widely between a 21 year old and a 40 year old – a strength of our study.

In contrast to the dearth of literature related to young adult cancer survivor medical decision-making preferences, information needs have been well documented among cancer survivors [22–24]. Our pilot survey results support the existing literature, with a desire for more information being most commonly identified as a support for medical decision-making. This finding may be influenced by the fact that, similar to other studies among cancer survivors, less than half of survivors reported having received a written treatment summary or survivorship care plan [25, 26]. The lack of survivorship care planning also impacts the information available to primary care physicians that may follow survivors after active treatment. One recent study found that just under half of physicians treating adolescent and young adult survivors have never or almost never received a treatment summary [27]. This lack of information may impair the physician's ability, in turn, to adequately inform the survivor.

We found some medical decision-making anxiety to be related to uncertainty and fear of negative outcomes. A recent qualitative study found that fear of recurrence was endorsed by young adult survivors as one of their barriers to attending evidence-based medical follow-up visits [28]. Addressing fear of recurrence and uncertainty are central tenants of a physician's role in patient-centered communication, and the use of patient-centered communication may help to alleviate these survivor anxieties [29]. An aspect of patient-centered communication that may be unique to young adult survivors is the desire to involve family members in the decision-making process. Future studies should explore the physician's role as a facilitator of familial inclusion in medical decision-making, particularly in light of our finding that survivors reported support from and trust in the medical team as making medical decision-making easier.

While our study provides insights into the medical decision-making preferences of young adult survivors of pediatric and AYA cancers, we acknowledge the following limitations. Due to the small sample size, our results are not representative of the young adult survivor community. Our sample was predominantly Hispanic, representing the population of cancer survivors served by the local institution, and reflecting the changing demographics of the US as a whole. In addition, our study is not sufficiently powered for statistical testing and subgroup analyses. The study should be repeated in a larger sample of survivors to determine whether the findings here are generalizable to the broader population of young adult cancer survivors, including those of other racial and ethnic backgrounds. Another limitation is the high non-response rate, which may be due to a number of reasons, including the timing with the survey, a highly mobile target population, and limitations of our contact

database that included only street addresses and thus only allowed for using paper mailings. This difficulty in recruiting adolescent and young adult survivors has been seen in other studies and highlights the need for adequate funding and staff resources to enable the use of multiple points of contact to reach a sufficient sample size [30]. We suggest that email addresses should be included in contact databases to facilitate long-term follow-up with this highly mobile patient population.

This pilot study represents a first step at understanding the medical decision-making needs and preferences of young adult survivors of pediatric and AYA cancers. Future studies should be conducted to validate these findings among a larger, representative sample of young adult cancer survivors. Because we found that survivors vary in their desire for familial involvement, providers should ask survivors' about their medical decision-making preferences and work to accommodate preferences for family involvement by creating a welcoming environment for both survivors and their families.

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Table 1

Sociodemographic, Cancer, and Survivorship Care Characteristics of Young Adult Cancer Survivors Survey Participants (n=30), 2015

	Percent (n)
<i>Sociodemographic Characteristics</i>	
Sex	
Male	36.7% (11)
Female	63.3% (19)
Mean Age in years (STD)	24.8 (6.5)
Hispanic/Latino Ethnicity	
Yes	83.3% (25)
No	16.7% (5)
Race (not mutually exclusive)	
White	80.0% (24)
Non-White	20.0% (6)
Employment status	
Employed for wages	30.0% (9)
Student	30.0% (9)
Unable to work	16.7% (5)
Unemployed	16.7% (5)
Other	6.7% (2)
Education	
Some high school	10.0% (3)
High school graduate/GED	26.7% (8)
Some college or more	63.3% (19)
Household Income	
< \$20,000	50.0% (15)
\$20,000–\$49,999	33.3% (10)
\$50,000	16.7% (5)
Insurance Status	
Employee-sponsored (self or dependent)	40.0% (12)
Government-sponsored	26.7% (8)
Other (including self-pay)	20.0% (6)
Don't know	13.3% (4)
<i>Cancer Characteristics</i>	
Mean age at diagnosis in years (STD)	13.3 (7.9)
Cancer type	
Leukemia	23.3% (7)
Lymphoma	20.0% (6)
Sarcoma	20.0% (6)
Other (including Germ cell)	36.7% (11)
Time since last treatment	

	Percent (n)
< 2 years	13.3% (4)
2 years or more	83.3% (25)
Don't know/not sure	3.3% (1)
<i>Survivorship Care</i>	
Do you have a physician who coordinates all of your care?	
Yes	56.7% (17)
No	30.0% (9)
Don't know	13.3% (4)
Once you completed your cancer treatment did your medical team give you a written summary of your treatment?	
Yes	44.8% (13)
No	27.6% (8)
Don't know	27.6% (8)
Once you completed your cancer treatment, did your medical team give you a written plan for recommended medical care after your cancer treatment, sometimes called a Survivorship Care Plan?	
Yes	48.3% (14)
No	24.1% (7)
Don't know	27.6% (8)

STD: Standard deviation

Table 2

Medical Decision Making Preferences in Young Adult Survivors of Cancer in South Texas by Age at Survey Completion (n=30)

	Age at Survey Completion (in years)		
	All Survivors	18–22 (n=17)	23–39 (n=13)
We're also interested in hearing about how you make decisions about your medical care as a young adult survivor. Please select the response that best fits your preference.			
I like to make the decision myself	20.0% (6)	5.9% (1)	38.5% (5)
I like for my family to make the decision	10.0% (3)	11.8% (2)	7.7% (1)
I like to make the decision together with my family	10.0% (3)	11.8% (2)	7.7% (1)
I like for my doctor to make the decision	(0)	—	—
I like to make the decision together with my doctor	16.7% (5)	17.7% (3)	15.4% (2)
I like to make the decision together with my doctor and family	43.3% (13)	52.9% (9)	30.8% (4)
I like for someone else to make the decision	(0)	—	—
Don't know	(0)	—	—

Table 3

Qualitative Themes and Corresponding Survivor Quotes

“What part of medical decision making is difficult or makes you anxious?”	
Themes	Illustrative quotes
1. Uncertainty about which option to choose	“Deciding on the best route to go for treatment and if it is the correct treatment for your diagnosis.” “Deciding whether or not to try experimental trials with treatments or not.” “Making a decision on taking a medication that has not been used by a lot of people, not knowing the side effects that I may get.”
2. Fear of receiving bad news	“The possibility of finding out the cancer has returned. The period between the cancer screening tests and results is always the most stressful.” “The results.” “Thinking I’ll die.”
3. Fear of discomfort	“Having blood drawn or getting shots.”
4. Family Involvement	“Me and my family disagreeing on a topic.” “My family’s anxiety.”
“What would make it easier for you to make medical decisions you can feel good about?”	
Themes	Illustrative quotes
1. Information	“Having more information on the medical treatment/disease.” “Information that I can fully understand and know what I am getting into.” “Simpler terms in the case that I do not understand something.”
2. External support	“I like to have the support and opinion of my family and doctor.” “Making choices together with my family and choosing different options.” “Having insurance to have options and basic care” “To have transportation.”
3. Trust in medical team	“Knowing that doctors, nurses, and surgeons have high success rate.” “Genuine staff” “I think if I need to make a medical decision and I call the nurses were I was treated, I’d get enough info to make a decision.”
4. Internal support	“Just trying to feel more positive about the outcome.” “Making my own decisions sometimes.” “Praying about the decision.”