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A New Lease on Life: Preliminary Needs Assessment for the Development of a Survivorship Program for Young Adult Survivors of Cancer in South Texas

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Abstract

Priorities for young adult survivorship care from the survivors' perspective are not well documented. To address this within our patient population, we conducted a multi-method needs assessment of young adult survivors of pediatric, adolescent, and young adult cancer in South Texas to get a better understanding of the ongoing challenges and priorities for their survivorship needs and related services. Participants were 18 to 39 years at the time of the needs assessment and predominately Hispanic. In an online survey, survivors most commonly cited being concerned about their physical and mental health, long-term treatment effects, recurrence, and health insurance issues. Participants stated that they received critical support from family, friends, and medical staff, but they would like to receive additional support from other cancer survivors through peer mentorship opportunities and survivor retreats/social events.

Keywords

cancer; survivorship; needs assessment; young adult

Introduction

Previous studies have identified significant disparities in health outcomes and health-related quality of life among adolescents and young adults (AYAs) diagnosed with cancer relative to other cancer populations [1–3]. Poor outcomes for cancer in the AYA population may occur

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Ethical approval: All procedures performed in this study involving human participants were received prior approval from our institutional review board.

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for any number of reasons [4], including a lack of knowledge surrounding the most effective treatment protocols [3, 5, 6], high rates of being uninsured or underinsured [7–9], and the reality that this group can fall into a “no man’s land” between pediatric and adult cancer [3, 5]. Young adults in particular, whether they are survivors of pediatric or AYA cancer, face additional challenges as their diagnoses/recovery coincide with critical life transitions, as individuals are finishing college, starting their careers, establishing families and forging independence [3]. A cancer diagnosis and the associated long-term effects of cancer treatment (physical, psychological, and/or financial) may exacerbate many of the common stressors occurring during this stage of life, including financial challenges and transitions to school or work [10–12]. Effective AYA survivorship programs could help ease the transition from treatment to long-term survivorship by providing programs and services to mitigate these stressors specifically targeted toward the needs of the young adult population [13]. Proposed areas where survivorship can be improved include patient navigation [14], advocacy skills [15], physical and psychosocial well-being [16]. For instance, by providing navigation services to the survivor population, individuals are more likely to receive the most up-to-date survivorship plans and have access to resources to address their physical health and psychosocial needs [14]. While some of these approaches are successful in improving survivorship care, few studies to date have been conducted to evaluate preferences among young adult survivors for the services offered by a survivorship program; instead these programs often rely heavily on physician-focused guidelines to inform program structures and contents [3, 17].

A survey of 179 Children’s Oncology Group institutions showed that 87% of these have some type of survivorship program. However, these services are often aimed at child and adolescent survivors: 47% of these institutions transition survivors to adult providers when they reach adulthood, whereas 44% continue to see survivors indefinitely at their original pediatric treatment facility [18]. There are currently only a handful of institutions that have survivorship programs aimed at the particular needs of AYA survivors and this number is growing [19]. Several academic comprehensive cancer centers have AYA programs that utilize the combined resources of pediatric and adult oncology programs. Each has a slightly different model, some with separate outpatient space and dedicated pediatric and adult providers [19]. While different models exist, few studies have documented how young adult survivors view these programs and what they would like to see offered to help them transition from being patients to becoming long-term survivors. One survey showed that AYA survivors, aged 12 to 25 at time of survey completion, were most interested in learning how to regain their physical strength and reintegrate back into sports [16]. Another study among pediatric and AYA cancer survivors, aged 3 to 29 at survey completion, revealed that this population was interested in programs providing information about weight control and healthy eating [20]. In addition, different age groups valued different models of survivorship programs. Childhood cancer survivors valued camp-based programs, while older AYAs valued computer or mail-based programs [20]. However, none of these studies were conducted with the goal of developing a survivorship program based on the needs and priorities of this vulnerable population. Additionally, none of these studies have been conducted in a largely Hispanic population, a growing demographic projected to become a majority in the coming decades with unique cultural needs. Therefore, in order to learn more

about the ongoing unique challenges and priorities for accessing recommended care and survivorship services in the young adult population, we conducted a needs assessment among young adult survivors of pediatric and AYA cancer in South Texas by utilizing both qualitative and quantitative research methods.

Methods and Materials

For our needs assessment, we utilized a two-stage study design. First, we recruited five young adult cancer survivors, aged 18 to 39 living in or around our service area, from the South Texas Pediatric Cancer Survivorship Database to participate in a 90-minute key informant interview about survivorship needs and concerns in December 2014. We originally mailed 100 invitations to survivors, of which 26 were returned and 1 survivor was confirmed deceased. Follow-up calls yielded six volunteers as the vast majority of numbers where disconnected or out of date. Five young adults participated. During the group interview, survivors were asked to provide feedback about preferences and priorities for developing an AYA survivorship program (see Supplement A for the interview guide). Informed consent was obtained from all participants prior to the start of the session and participants received a \$25 gift card for their participation.

The insights gained during the group interview informed the development of the second stage of the needs assessment, particularly in developing response categories for survivorship needs questions. Together with items from previously validated surveys such as the National Health Interview Survey (NHIS) [21], the Behavioral Risk Factor Surveillance System (BRFSS) [22], and the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study [23], we developed an online cancer survivor survey using REDCap [24] that queried participants about their concerns and challenges as cancer survivors and what resources or services they would like to see provided in a survivorship program (see Supplement B for the questionnaire). To identify potential participants, we used the South Texas Pediatric Cancer Survivor Database in combination with a separately maintained mailing list used to send newsletters to survivors of pediatric and AYA cancers and their families. The survey was fielded among survivors aged 18 to 39 during April and May of 2015. A total of 397 paper invitations containing an informational letter about the survey as well as the link/ QR code to the REDCap survey were mailed. Of these, 43 letters were returned with incorrect addresses, 1 patient was deceased, and 4 persons who received the invitation indicated ineligibility (e.g. not between ages 18–39, did not have a previous cancer diagnosis, or did not speak English). One reminder was mailed to non-respondents. Of 349 potentially eligible participants, 31 completed the survey. However, one survey was completed by the parent of a survivor under the age of 18 and thus was later deemed ineligible. 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). Before completing the survey, participants were provided with an institutionally approved research study information sheet detailing general information, the purpose of the study, study procedures, risks, benefits, participant payment, confidentiality, as well as contact information. This information sheet was provided in HTML as part of the survey and as a downloadable PDF file. As there was no face to face

contact, no signed consent forms were collected. Participants received a \$10 gift card for their participation in the survey.

After data collection was completed, we examined both closed and open-ended responses for common themes. In this paper, we describe the survivorship concerns and support needs reported by this sample as well as their survivorship program interests. This needs assessment was evaluated and approved by the UTHSCSA Institutional Review Board.

Results

Demographic and Cancer Characteristics

Survey respondents were predominately female (63.3%) and Hispanic (83.3%) (Table 1). On average, participants were 24.8 years of age at the time of the survey and had been diagnosed with cancer at age 13.3. In contrast, the survivors in the database were 42.3% female, 74.8% Hispanic, had been diagnosed on average at 14.1 years of age and were on average 24.0 years at the time of the survey invitation. A majority of survey respondents were either employed or a student at the time of the interview (30.0% each). Half of the respondents had an annual household income of less than \$20,000, while 40.0% had employer-sponsored insurance either through their own employment or as a dependent (i.e. through a spouse or parent). A large percentage (83.3%) of cancer survivors surveyed indicated they had completed treatment at least 24 months ago.

Survivorship Concerns and Service Needs

Survey respondents were asked about their concerns about growing older as a cancer survivor. Dealing with the long term effects of cancer treatment (83.3%), recurrence or a new cancer diagnosis (73.3%), and staying healthy in general (70.0%) were the three most commonly cited concerns among all survivors (Table 2). Less common, but still important to half or more of respondents were concerns related to health insurance coverage (53.3%) and feelings of anxiety or depression (50.0%). There were some notable differences in the primary concerns reported by male and female survivors. For men, the most common concern was staying healthy (81.9%), while women were most often concerned about longer term effects of treatment (89.5%). Both genders described significant concerns about recurrence/new diagnosis (72.7% for males and 73.7% for females) and insurance coverage (54.6% and 52.6%). Additionally, over half of female survivors cited concerns about feelings of anxiety or depression (52.6%).

Support Needs and Survivorship Program Interest

When asked about current sources of support, survivors most commonly mentioned receiving support from their families (60.0%) and doctors (48.4%) (data not shown). However, in addition to these sources, survivors *wished* they received additional support from cancer survivor groups (40.0%) and retreats (30.0%) (Table 3). Finally, study participants were asked what kind of things they would like to see in a survivorship program aimed at young adult survivors of cancer who had completed treatment (Table 3). Both men and women indicated a desire for a young adult survivorship program to include activities to socialize with other survivors (63.6% and 58.8%, respectively), opportunities to mentor AYA

cancer patients currently undergoing treatment (45.5% and 58.8%, respectively), and healthy eating and living courses (63.3% and 52.9%, respectively). Additionally, more than half of female respondents also indicated a desire for stress management courses to be included (58.8%). A small number of respondents (all male) were not interested in any aspect of a survivorship program (7.1%, n=2).

Discussion

The goal of this needs assessment was to learn more about the ongoing unique challenges and priorities for accessing recommended care and survivorship services in young adult survivors of pediatric and AYA cancers in our predominately Hispanic population of South Texas. We found that young adult survivors were mainly concerned with staying healthy, long-term effects of treatment, recurrence or a new diagnosis, health insurance, and anxiety and depression. They also endorsed peer mentoring and networking as top priorities to be included in the development of a young adult survivorship program.

Previous surveys of young adult survivors at other institutions have emphasized individuals' concerns about their health and cancer recurrence as well as depression, academic challenges, and social isolation as broader psychosocial issues. They also noted a significant difficulty transitioning from pediatric to adult care [16, 25]. These studies are consistent with the concerns identified by our young adult survivor population. In addition, our group of survivors highlighted concerns related to health insurance coverage. Survivorship needs and concerns may vary based on sociodemographic and cancer characteristics such as age at diagnosis, gender, socioeconomic status, and minority status. Our study indicated that while concerns for male and female survivors of pediatric and AYA cancers were similar, priorities of these concerns may be different. Therefore, future program development should consider a tailored approach to best address survivor needs and concerns in this diverse population.

In terms of program interest, half or more of participants were interested in activities to socialize, healthy eating and living courses, opportunities to mentor AYA cancer patients, and stress management courses, while over a third endorsed a desire for help with coordinating healthcare needs. Our findings complement the findings of previous studies. For example, young adult survivors at one cancer center ranked increasing strength and physical endurance, re-integrating into sports, and dealing with the physical changes of treatment as a high priority [16]. Among pediatric and AYA survivors recruited from a Texas children's cancer hospital currently undergoing treatment or during follow-up, similar interests in terms of program content were mentioned [20]. Other surveys of survivors also identified interest in additional online resources for social networking, appointment scheduling, and educational materials [25, 26]. These findings are also supported by our survey of young adult survivors. However, unique to our study, our participants emphasized the desire to include peer mentoring and networking opportunities within a young adult survivorship framework. Inclusion of peer mentoring and networking opportunities can provide many benefits to this community of young adult survivors, as previous studies have shown that strong social networks during cancer diagnosis can reduce anxiety, improve quality of life, and enhance cancer outcomes [27]. As an added benefit, these goals may be achievable with relatively low cost to the sponsoring institution, particularly by employing

the leadership of a survivor advocate. By including less traditional survivorship programming such as mentoring and networking as additional psychosocial services, programs may have the added benefit of engaging more survivors over the long-term.

While our needs assessment highlights important survivorship needs and priorities from the perspective of young adults, the following limitations should be noted. First, due to our small sample size we were unable to conduct bivariate testing of differences and further subgroup analyses such as by time since treatment completion or type of cancer diagnosis. Subgroup analyses may be able to detect differences in overall service needs and priorities for survivorship programs. Second, due to the low response rate in our needs assessment we are not able to draw all-encompassing conclusions about our target population. Low response rates may have been the result of the timing of the data collection during April and May, which coincided with college finals. Another possibility is that some of the addresses listed in the database may be home addresses for survivors attending college or who have moved out of their parents' residence permanently without updating their address. As neither up-to-date phone numbers nor email addresses were available, reaching this highly mobile population was challenging. In addition, we were unable to follow-up with potential participants more frequently by mail due to limited resources and time constraints. The difficulty in recruiting young adult cancer survivors to research has been previously documented and highlights the importance of adequate resources for recruiting a sufficient sample size from this hard to reach population [28]. For future attempts to involve this population, email addresses should be collected as along with physical addresses to be better able to reach young adult survivors. However, we were able to obtain first insights into survivorship needs of young adults in our service area. Lastly, the invitations and study materials were provided in English only. This may have excluded survivors in the South Texas area who are not fluent in English from participating. Nevertheless, 100% of our key informant interview participants and 83% of survey respondents self-identified as Hispanics. While these limitations apply, our needs assessment served as a pilot study to contact young adult survivors of pediatric and AYA cancer and helped us identify that building a survivorship community was important for survivors in South Texas. In addition, it provided survivors with the unique opportunity to voice concerns and provide invaluable input for program planning to best serve their needs.

In conclusion, by conducting a needs assessment, we were able to use a multi-step evaluation approach to gain first insights into service needs and survivorship priorities in our population in South Texas. Creating a community for young adult cancer survivors in South Texas remains a top concern and should be prioritized in the continued development and expansion of young adult survivorship programs. This pilot study can serve as a first step to understanding the most common domains that survivors want prioritized in the development of a young adult survivorship program and inform the future development of survivorship programs targeted at this vulnerable population in South Texas and beyond. By providing insights into the priorities of survivors in program development, providers and other stakeholders can identify best practices for combining the necessary and evidence-based components of survivorship care with the often less emphasized aspects of community-building and psychosocial health which were identified as key aspects by survivors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Sociodemographic and Cancer Characteristics of Young Adult Cancer Survivors participating in an online Survivorship Program Survey (n=30), 2015

	Percent (Number of Respondents)
<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	<15.0% (<5)
Education	
Some high school	<15.0% (<5)
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 (Number of Respondents)	
< 2 years	<15.0% (<5)
2 years or more	83.3% (25)
Don't know/not sure	<15.0% (<5)

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Table 2

Survivorship Concerns among Young Adult Cancer Survivors participating in an online Survivorship Program Survey (n=30), by Sex, 2015

	All Survivors	Males	Females
What concerns do you have about growing older as a young adult cancer survivor? ^I			
Dealing with long-term effects of cancer treatment	83.3% (25)	72.7% (8)	89.5% (17)
Recurrence/New cancer diagnosis	73.3% (22)	72.7% (8)	73.7% (14)
Staying healthy	70.0% (21)	81.8% (9)	63.2% (12)
Health insurance coverage	53.3% (16)	54.6% (6)	52.6% (10)
Feelings of anxiety or depression	50.0% (15)	45.5% (5)	52.6% (10)
Possible fertility issues	40.0% (12)	36.4% (4)	42.1% (8)
Flexible work/school arrangements	26.7% (8)	27.3% (3)	26.3% (5)
Relationships with friends	23.3% (7)	36.4% (4)	15.8% (3)
Relationships with family	16.7% (5)	27.7% (3)	10.5% (2)
Other	6.7% (2)	---	10.5% (2)
Total	30	11	19

^INot mutually exclusive categories

Table 3

Support Needs and Survivorship Program Interest among Young Adult Cancer Survivors participating in an online Survivorship Program Survey, by Sex, 2015

	All Survivors	Males	Females
In terms of survivorship support, what support/resources do you wish you were receiving? <i>I wish I received support/resources from...</i> ¹			
Cancer survivor group	40.0% (12)	45.5% (5)	36.8% (7)
Cancer survivor retreats	30.0% (9)	27.3% (3)	31.6% (6)
Friends	16.7% (5)	18.2% (2)	15.8% (3)
Online support group/forums	13.3% (4)	27.3% (3)	5.3% (1)
Peer mentors	10.0% (3)	---	15.8% (3)
Family	10.0% (3)	18.2% (2)	5.3% (1)
Other community and/or religious/spiritual group	10.0% (3)	---	15.8% (3)
Doctors	10.0% (3)	9.1% (1)	10.5% (2)
Social Workers	10.0% (3)	9.1% (1)	10.5% (2)
Others	13.3% (4)	9.1% (1)	15.8% (3)
None of the above	16.7% (5)	18.2% (2)	15.8% (3)
Support Needs (Total)	30	11	19
What kind of things would you most want to see in a survivorship program for young adult cancer survivors after they have completed treatment? ¹			
Activities for cancer survivors to socialize	60.7% (17)	63.6% (7)	58.8% (10)
Healthy eating and living courses	57.0% (16)	63.6% (7)	52.9% (9)
Opportunity to mentor AYA cancer patients currently undergoing treatment	53.6% (15)	45.5% (5)	58.8% (10)
Stress management courses	50.0% (14)	36.4% (4)	58.8% (10)
Help with coordinating healthcare need	35.7% (10)	36.4% (4)	35.3% (6)
Opportunity to be mentored by other AYA cancer survivors	32.1% (9)	27.3% (3)	35.3% (6)
Assistance with navigating the health insurance market and Medicaid	25.0% (7)	27.3% (3)	23.5% (4)
Other	---	---	---
None, not interested in a survivorship program for young adults	7.1% (2)	18.2% (2)	---
Survivorship Program Interest (Total)	28 ²	11	17

Notes:

¹ Not mutually exclusive categories

² 2 participants did not complete this section of the survey