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Original Article

Barriers to the Use of Psychosocial Support Services Among Adolescent and Young Adult Survivors of Pediatric Cancer

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Purpose: Adolescent and young adult (AYA) survivors of pediatric cancer commonly report both functional and emotional difficulties, yet many of their mental health needs are not met. Given the unique needs of these survivors, this study examined barriers to psychosocial support service utilization in this population, including accessibility, personal preferences, and practical barriers such as insurance and transportation.

Methods: Thirty-six adolescent and young adult survivors of pediatric cancer (aged 15–29) with mental health difficulties (i.e., anxiety or depression) completed surveys assessing access and utilization of services and barriers to utilization. Services assessed included the use of mental health professionals, a pastor or someone in a place of worship, and support groups.

Results: Half of the participants utilized a mental health professional, but other forms of support were used less frequently. Utilization of services was related to insurance status and use of prescription medication. Greater time since completion of treatment was a barrier to utilizing psychosocial support services.

Conclusion: Use of psychosocial support services is linked closely with use of other healthcare services, including taking prescription medication for mood difficulties. Results have implications for how primary care and oncology providers address barriers to these services among AYA survivors of pediatric cancer.

Keywords: survivorship, psychosocial support services, barriers, healthcare utilization

IMPROVED MEDICAL TREATMENTS and supportive care have resulted in high survival rates of children and adolescents diagnosed with pediatric cancers, with overall 5-year survival rates approaching 85%.[1] It is estimated that approximately 1 in 640 young adults in the United States aged 20–39 is a childhood cancer survivor.[2] Adolescent and young adult (AYA) survivors of pediatric cancer generally do not experience lasting negative psychological outcomes,[3,4] although a small subset do experience functional and emotional challenges.[5] Commonly reported functional difficulties include obtaining employment and lack of insurance.[6–8] Emotional difficulties include post-traumatic stress disorder and post-traumatic stress symptoms.[9–11] Qualitative studies examining difficulties experienced by this population suggest that they feel sadness and anger about their cancer experience[12] and fear and uncertainty about relapse/recurrence.[13]

Despite these reported difficulties, a significant portion of AYA survivors of pediatric cancer—particularly those within the 20–29 age range—report that their mental health needs had not been met.[14,15] Specifically, survivors report needing mental health counseling and support groups but being unable to either access or utilize these services.[14,15] There is a dearth of literature examining reasons for limited utilization of psychosocial support services by AYA cancer survivors, despite evidence that the services are needed.

The adult cancer survivorship literature has identified several barriers to utilization of psychosocial services, including practical barriers, personal attitudes, and social norms. Practical barriers such as low income, limited insurance coverage, and lack of knowledge about services are associated with decreased use of mental health services.[16,17] Commonly-identified personal attitude barriers leading to less use of services include embarrassment about using psychosocial support services and avoidance of sharing emotional difficulties with religious leaders, other survivors, or support groups.[16,18] Treatment stigma is reported as a social norm barrier to psychosocial support service use among adult cancer survivors.[19]

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In contrast to the adult literature, few studies have investigated barriers to utilization of these resources in the AYA population. In one published study on this subject, Kirchhoff and colleagues explored psychosocial support service utilization and found that cost was one of the largest barriers to accessing healthcare in general among AYA cancer survivors, and that this was especially pronounced for those without insurance coverage.[20]

Given the unique needs of AYA survivors of pediatric cancer, it is important to assess barriers to the use of psychosocial support services. The present study explores barriers to utilization of these services among AYA survivors of childhood cancer, including practical barriers, personal attitudes, and social norms.

Methods

Participants

Participants were identified through a survivorship clinic at a large southeast United States tertiary care cancer clinic affiliated with a major university. All patients seen through the survivorship clinic complete a questionnaire assessing all systems, including mental health. Upon completing this questionnaire, patients (aged 19 or older) or patients and their caregivers (aged 18 or younger) have the option to agree to be contacted about future possible survivorship research studies based on the information provided at their survivorship clinic visit, which includes information from the survivorship questionnaire in this study. All participants in the current study provided this consent. Eligibility criteria included: (1) currently 15–29 years old; (2) diagnosed with pediatric cancer between birth and age 18; (3) ≥ 2 years post-treatment completion (2 years post-completion of all medical treatment is an eligibility requirement for most survivorship clinics); (4) endorsed mental health difficulties (i.e., anxiety or depression) on our survivorship questionnaire, completed either by themselves (age 19 or older) or by a caregiver (age 18 or younger) during a previous clinic visit; and (5) English speaking. Eighty-three patients were eligible for the study during the recruitment period of February–July 2013.

Procedure

This study was approved by the university institutional review board. Participants who met eligibility criteria were mailed a letter explaining the purpose of the study, and a consent form, survey, and stamped envelope with which to return the survey. If the survey was not received within 2 weeks, a research assistant contacted the participant by phone and gave them the opportunity to participate over the phone. All participants completed the surveys themselves; caregivers completed a separate survey (not included in this study). Participants were also approached during a visit to the survivorship clinic if they met eligibility criteria; these participants completed the informed consent and survey during their appointment. It was not required that participants were actively seen in the survivorship clinic for participation.

Measures

Survivorship questionnaire. Items about mental health from the survivorship questionnaire determined eligibility for the current study. This questionnaire, which was completed 0–4 years prior to the current study during their visit through the survivorship clinic, included the following: ''Are you currently having chronic problems with any of the conditions below: Increased worries or upsetting thoughts? Problems with anxiety/panic attacks? Frequently feeling sad, blue, or depressed?'' These items were rated as ''yes''/''no.'' If participants rated any of these items as ''yes,'' they were invited to participate in the current study.

Several questions on the in-clinic survivorship questionnaire were rated on a 6-point Likert scale ranging from ''None of the time'' to ''All of the time,'' including: ''These questions are about how you feel and how things have been with you during the past 4 weeks. For each question: please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks … Have you been a very nervous person? Have you felt so down in the dumps that nothing could cheer you up? Have you felt downhearted and blue?'' Participants who answered ''All of the time,'' ''Most of the time,'' or ''A good bit of the time'' to any of these questions were invited to participate in the current study.

Survey. At the time of the study, participants completed a survey (created by the authors with input from pediatric oncologists, a psychologist, and oncology nurse practitioners) to assess access to/utilization of psychosocial support services and barriers since participants' completion of cancer treatment. The content of the survey is briefly summarized below and is presented in its entirety in the online appendix (Supplementary Appendix can be found online at www.liebertpub.com/JAYAO). Based on research with adult cancer populations,[18] three types of services were assessed: utilization of a mental health professional (i.e., psychologist, counselor, or therapist), a pastor/someone in place of worship, and a support group. For each service, participants rated availability, use, personal beliefs, and family's beliefs about utilizing the service. The survey also assessed insurance status, availability, and use of a primary care provider, current or past use of prescription medications for mood difficulties, and practical barriers (e.g., limited financial resources, limited/lack of insurance coverage, transportation/scheduling difficulties, and limited knowledge of available resources). The included barriers attempted to capture a range of difficulties experienced by both AYA and adult cancer survivors.

Medical information. Medical charts were reviewed to obtain each participant's gender, age, diagnosis, age at diagnosis, and time since treatment completion.

Analyses

The primary outcome of interest was utilization of three types of psychosocial support services: a mental health professional, a pastor or someone in one's place of worship, and a support group. The following predictors were included in bivariate correlations with utilization of each service: access to each psychosocial support service; access to and use of a primary care provider; insurance status; past and current use of prescription medication for mood difficulties; number of barriers to psychosocial support service utilization; personal preference toward using each service; perceived social norm toward using each service; and perception of their ability to share information if each service was utilized. Any variables significantly correlated with utilization of each resource were retained for further analyses. Chi-square analyses were used to more closely examine differences on significant variables among participants who reported utilizing versus not utilizing each of the three psychosocial support services.

Results

Participants

A total of 281 patients aged 15–29 were seen through the survivorship clinic during 2009–2012. Of these patients, 147 (52%) did not endorse symptoms of anxiety or depression on the survivorship questionnaire. Fifty-one patients (18%) did not fill out the survivorship questionnaire on their visit to the clinic. This left a total of 83 patients who met the inclusion criteria. Of these 83, 10 (12%) declined to participate and 37 (45%) could not be reached due to missing/incorrect contact information.

Of the final 36 participants, 21 (58%) mailed in the survey, 12 (33%) completed the survey over the phone, and 3 (8%) completed the survey in-person. The majority of participants were Caucasian (Table 1), and there were nearly equal numbers of male and female participants (19 and 17, respectively). The most common diagnosis was leukemia ($n=14$). There were no differences on demographic or medical variables (gender, race, age at study, age at diagnosis, time since completion of treatment, and diagnosis) among those who participated, declined to participate, or could not be contacted, as analyzed via t-tests.

Predictors of psychosocial support service use

Descriptive statistics of predictor variables and their correlations with utilization of psychosocial support services are in Table 2. Twenty-one (58%) participants perceived access, and 18 (50%) participants utilized a mental health professional. The use of this service was significantly associated with the use of prescription medication for mood difficulties and insurance status. Chi-square analysis revealed that the percentage of participants who had seen a mental health professional varied according to if they had been prescribed medication for mood difficulties (χ^2 [1, $N=36$] = 11.69; $p=0.001$); of the 18 participants who had talked to a mental health professional, 12 (67%) had also been prescribed medication. The percentage of participants who had seen a mental health professional also varied by type of insurance (χ^2 [1, $N=36$] = 4.21; $p=0.040$). Of the 22 participants who had private insurance, 8 (36%) had talked to a mental health professional and 10 (71%) of the 14 participants who had government-sponsored or no insurance had talked to a mental health professional. Participants who were older at diagnosis perceived greater access to mental health professionals ($r[34]=0.40$; $p=0.02$).

Table 1. Demographic and Medical Data on AYA Survivors of Pediatric Cancer ($N=36$)

Characteristic	n *(%)*	*Mean (SD)*	*Range*
Gender			
Female	17 (47)		
Male	19 (53)		
Race			
Caucasian	31 (86)		
African American	4 (11)		
Hispanic	1 (3)		
Age at study (years)		19.9 (4.0)	15–29
Age at diagnosis (years)		7.1 (5.0)	birth–17
Time since treatment completion (years)		10.7 (4.6)	10–22
Diagnosis			
Leukemia	14 (39)		
Lymphoma	9 (25)		
Brain tumor	4 (11)		
Other pediatric cancer[a]	9 (25)		

[a] Other (n) = Wilms tumor (3), Ewing sarcoma (3), neuroblastoma (1), rhabdomyosarcoma (1), and post-transplant proliferative disorder (1).

AYA, adolescent and young adult; SD, standard deviation.

For the other two types of psychosocial support services, 21 (58%) participants perceived access, and 8 (22%) participants had talked to someone in their place of worship. Six of those participants also utilized a mental health professional. The use of someone in their place of worship was unrelated to any predictor variables. Similarly, only two (6%) survivors had participated in a support group, and both had also utilized a mental health professional. Again, the use of this service was unrelated to any predictor variables.

Barriers to psychosocial support service use

Barriers to the use of psychosocial support services were varied. The most common reported reasons for not using a service were: difficulty scheduling around work/school (17%), cost of care/financial limitations (14%), lack of knowledge about available resources (14%), needing to travel a great distance to get to a resource (11%), mental health providers not accepting the participant's type of insurance (8%), and transportation difficulties (5%). Seventeen (47%) participants reported no barriers to using these resources, 11 (31%) reported one barrier, and 8 (22%) reported two or more barriers. Greater time since completion of treatment was associated with more barriers to the utilization of psychosocial support services ($r[34]=0.38$; $p=0.02$). Finally, a trend was noted for more frequent use of a primary care provider being associated with fewer barriers to the use of a mental health provider ($r[34] = -0.31$, $p=0.07$).

Discussion

This study expands on the limited available literature examining barriers to the use of psychosocial support services by AYA survivors of pediatric cancer. We found that although all survivors in the current sample reported mood difficulties (i.e., anxiety or depression), only half had talked with a mental health professional about these difficulties. Use of this resource was not related to personal beliefs or perceived social norms about utilizing psychosocial support services. Even fewer survivors utilized someone in their place of worship or a support group. Although participants perceived the same level of access to a mental health professional and someone in a place of worship, these services were utilized at varied rates. Patients who endorse mental health difficulties may be more often referred to a psychologist or counselor. It is also likely that support groups were infrequently utilized due to the lack of perceived access among our sample. Future studies should examine additional reasons that these resources were not utilized as a source of support.

Our results support previous findings that the use of psychosocial support services is closely linked with the use of

TABLE 2. DESCRIPTIVE STATISTICS OF PREDICTOR VARIABLES AND CORRELATIONS WITH PSYCHOSOCIAL SUPPORT SERVICE UTILIZATION

	Descriptives		*Utilization of psychosocial support services*		
Predictor variables	*Mean/%*	*SD*	*Mental health professional*	*Pastor*	*Support group*
Primary care provider					
Have an available primary care provider	83%	—	0.15	−0.12	0.11
See primary care provider less than once a year	61%	—	0.31	−0.04	0.17
Private insurance	61%	—	−0.34*	−0.12	−0.06
Use prescription medication	39%	—	0.57*	−0.15	0.06
Number of barriers to psychosocial support service	0.89	1.09	0.10	−0.01	0.03
Personal preference					
Mental health professional	3.50	1.13	0.15	—	—
Pastor	3.61	1.10	—	0.19	—
Support group	3.58	1.03	—	—	−0.02
Social norm					
Mental health professional	4.11	1.01	0.28	—	—
Pastor	4.19	0.89	—	0.19	—
Support group	4.11	0.79	—	—	−0.04

*$p < 0.05$.
SD, standard deviation.

other healthcare resources.[21] Survivors who had ever been prescribed prescription medication for mood difficulties were more likely to utilize psychosocial support services. There are several potential explanations for this link. It is possible that survivors who utilized a mental health professional were further referred for medication, or that patients who utilized this service had a greater severity of symptoms, thus prompting therapy and/or medication. It is also possible that survivors who had been prescribed psychiatric medication for mood difficulties were also referred to a mental health professional. It could also be that a mental health professional actually prescribed the medication. Future research should examine the longitudinal use of both mental health professionals and medication management for mood difficulties among AYA cancer survivors to determine cause and effect of utilization.

Of note, use of a primary care provider was associated with fewer barriers to accessing or utilizing psychosocial support services, again suggesting that ties to general healthcare may increase knowledge of and reduce barriers to utilizing psychosocial support services. A visit to a mental health professional may require a referral from a primary care provider, and therefore primary care providers may provide the avenue for accessing this type of service. Furthermore, although patients may be aware of mental health providers in their area, a referral from a trusted primary care provider may provide more guidance than choosing a provider on their own. In our study, participants who were older at diagnosis perceived greater access to care, and those further out from treatment had more barriers, which highlights specific populations that may be most vulnerable to low access to psychosocial support services. Primary care and oncology providers can help by being aware of groups that may be at risk for difficulties accessing supportive services. Reestablishing connections between AYA survivors of pediatric cancer and their primary care providers following treatment completion may be a first-line intervention to increase service utilization for mental health issues in this population. Including caregivers when providing referral information may also be beneficial for younger patients who may have difficulty independently accessing these services.

Interestingly, the use of a mental health professional was associated with government-sponsored or no insurance coverage. This finding is inconsistent with other studies among healthy children and adults assessing the link between prescription medication use and insurance status. Specifically, private insurance is linked with increased use of psychiatric medication, while having no insurance is linked with unmet prescription medication needs.[22,23] Importantly, these studies investigated a different mental health variable (medication use) than our study (mental health professionals) in relation to insurance status and type. Although we expected to see associations in the opposite direction, it could be that type of insurance is tied to other variables that were not included in the present study, or our sample size limited the conclusions that can be drawn between these two variables. For example, it could be that families with private insurance have a co-pay, while those with government-sponsored insurance do not, thus reducing the financial demand. Additional research is needed to elucidate these findings either through the inclusion of additional variables of potential interest or through in-depth analysis of insurance coverage, psychosocial support benefits, and access to care.

The small sample size in this study precluded us from conducting more rigorous analyses of predictors of psychosocial support service utilization among this population. Future studies would benefit from a larger sample size to more clearly examine these associations. The directionality of the link between predictor variables and use of psychosocial resources is also unclear. Future research would benefit from longitudinal analyses assessing barriers to and use of psychosocial support services over time. Additionally, participants were not provided the opportunity to state that they did not feel they needed any support, which may explain the low utilization rates, or to list other types of psychosocial support services they utilized, such as online groups or social media. It could also be that participants may not have accurately recalled utilization of psychosocial support services, especially if they were young at the time of use. Also, the survivorship questionnaire was designed for clinical purposes and it not a validated tool. Future research should clarify AYA cancer survivors' beliefs about their mental health needs and assess additional psychosocial support services that may be of use to cancer survivors. Finally, our sample was composed primarily of Caucasian survivors, and it is therefore difficult to generalize to minority populations.

Conclusion

Our study is among the first to examine access to psychosocial support services among AYA survivors of childhood cancer. The findings suggest ways in which care providers may identify patients who are at risk for decreased access to or utilization of psychosocial support services. First, providers for childhood cancer survivors should discuss available psychosocial support services and encourage their use with all patients, but particularly for those who do not regularly follow up with their primary care provider, are younger, are further out from the completion of their medical treatment, or have not utilized psychiatric prescription medication. Second, social workers may be able to help mitigate practical difficulties, such as transportation, associated with decreased use of psychosocial support services. More research in this area is needed to identify barriers specific to AYA survivors of childhood cancer. Future research should investigate these and other barriers, looking in particular at the relationship between ties to the healthcare system (e.g., prescription medication, insurance coverage) and utilization of psychosocial support services.

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Author Disclosure Statement

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