

## Adolescent and Young Adult Patients with Cancer: Perceptions of Care

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**Background:** Adolescent and young adults with cancer (AYACs) face unique medical, psychosocial, and supportive care needs. The purpose of this study was to identify AYACs perceptions and expectations of cancer care services on and off treatment.

**Methods:** Semistructured interviews were conducted with 23 AYACs aged 19–38 years (13 on and 10 off treatment), who were receiving care at a comprehensive cancer center. Verbatim transcripts were created from audiotaped interviews and hand coded using inductive content analysis methodology.

**Results:** Perceptions of optimal care were reported by AYACs through two main themes as follows: perceived barriers and facilitators during treatment. Within each main theme were three subthemes, including perceived facilitators reported as the provision of social support, the website and patient portal, and the educational information provided by the cancer center. Younger female AYACs (age 19–31) on active treatment reported perceived barriers to optimal care related to the management of physical and mental health symptoms, while older patients (age 32 and up) on active treatment endorsed a fear of cancer returning. The third perceived barrier equally endorsed by patients both on and off treatment and across age ranges included limited assistance with financial issues.

**Conclusions:** AYACs reported perceived barriers and facilitators to optimal care. Implications for these findings are discussed in the context of the importance of adding a patient navigator to the AYACs care team.

**Keywords:** barriers, patient needs, quality of care, qualitative, health services

### Introduction

**D**EFINED NOT BY CANCER TYPE, but age, the population of adolescent and young adults' with cancer (hereafter referred to in this article as AYACs) currently accounts for ~2% of invasive cancers with 2.7 times more patients diagnosed in the second 15 years of life compared to the first.<sup>1</sup> The age range for AYACs varies by organization and institution, but is typically defined as 15–39 years, cutting across primary reproductive years.<sup>2</sup> The incidence of cancer in AYAs varies across the age continuum, but the most common types include the following: sarcoma, breast, testicular, and hematologic cancers.<sup>1</sup>

Survival rates for AYACs have not improved at the same pace as for pediatric or older adult populations<sup>3</sup> and cancer remains the leading cause of disease-related death in this

population.<sup>4</sup> Lack of improvement in survival rates has been attributed to many factors, including reduced access to cancer care, delays in diagnosis, patient nonadherence to treatment recommendations, low participation rates in clinical trials, and AYACs' unique psychosocial needs.<sup>3,5</sup>

A number of psychosocial issues have been identified among AYACs distinguishing them from pediatric and adult populations. These issues include concerns about future family and interrupted life plans, limited availability of mental health services and social/peer support networks, increased parental dependence, and disruptions in school or career paths, all with concomitant financial challenges.<sup>5,6</sup> Research suggests that as a group AYACs tend to experience more complex, severe, and longer lasting distress than younger children or older adults with similar cancer diagnoses.<sup>6-8</sup> Barriers to optimal care also exist because when AYACs turn 18 they

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may suddenly be treated as adults in terms of their medical care, with no clear structure or transition.<sup>9</sup> This practice ignores standards of optimal care that suggest delivering age-appropriate information across the various developmental stages of AYACs<sup>10</sup> and creating a clear systematic care transition when entering adulthood.<sup>9</sup>

Recognizing that AYACs and survivors constitute a medically underserved population that needs specialty treatment from a medical and psychosocial standpoint, in 2011 the cancer center leading the present study dedicated a clinical program exclusively to improving the care of AYACs.<sup>11,12</sup> Despite efforts across the United States to improve health service delivery for AYACs, they remain an underserved population with poor outcomes.<sup>13</sup> In this study we sought to examine perceptions and expectations of optimal care among AYACs patients and survivors. We specifically examined perceived barriers and facilitators to optimal care in a group of AYACs, on and off treatment, in a comprehensive cancer center in the south.

## Methods

### Recruitment

AYACs receiving care at a comprehensive cancer center in the south were recruited through the electronic health record system. For the purpose of this study, AYACs were considered to be anyone between 15 and 39 years old who either has cancer, on or off treatment, or has a history of cancer that was diagnosed between 15 and 39 years old. The goal of recruitment was to obtain AYACs across a variety of cancer types and to equally represent patients on and off treatment.

Patients were considered eligible if they were: (1) diagnosed with cancer between 15 and 39 years old and between 15 and 39 years of age at the time of interview; (2) receiving or had received their primary oncologic care at the cancer center (treatment status could be on or off at the time of interview); (3) capable of reading and speaking English; (4) willing and able to participate in a 30 minute semistructured interview; and (5) provide informed consent. Participants could elect to have the interview conducted at the cancer center in concert with a scheduled visit or by telephone.

Potential AYACs meeting study criteria were identified by examining clinic schedules for those providers who typically see large numbers of AYACs. Each potential participant was identified in consultation with his or her primary oncologist to ensure that contact was appropriate (e.g., capable of reading and speaking English; cognitively competent).

A research coordinator obtained written consent for the interview and gave participants a demographic form to complete. Then, a trained, advanced doctoral, or postdoctoral student conducted the interview by telephone or in person. Each participant received a \$25 gift card upon completion of the interview. The study was approved by the cancer center's Institutional Review Board.

### Procedures

A semistructured interview guide, including six essential questions, was used to conduct individual in-depth interviews. Sample interview questions included the following: (1) "Now that you're in treatment/While you were in treatment what were/are some of your top concerns?"; (2) "Have you/did you use any of the resources at {cancer center} to

address your concerns?"; (3) "From your perspective, what kind of resources would be helpful for patients undergoing treatment and why?"; (4) "Has anyone talked to you about planning for survivorship?"; (5) "If we created a position that was completely devoted to addressing the various needs of AYACs, would you be interested in utilizing that person and their services?"; and (6) "What kind of digital services could be useful for AYACs?" Interviewers were expected to use probing questions to gather information; therefore, the total number of questions varied, but the six essential questions were included in every interview.

### Analyses

Interim analysis was conducted on three occasions (initial, middle, and final) as interview to assess saturation. It was determined that saturation was met by the 23rd interview. Qualitative analyses were then conducted through inductive content analysis. Audio-recorded interviews were transcribed verbatim, and initial impressions created through open coding were compared across four independent coders conducted to create a codebook. Upon continued use of the constant comparative method, the codebook was refined to be representative of selective coding. *A priori* and emergent themes were refined through the constant comparative method<sup>14</sup> and axial grouped in a pair to recode the transcripts using selective coding, as well as to establish inter-rater reliability (IRR). IRR was established across three time points at a Kappa value of 0.80 and above to ensure that coders had not drifted over time. Rigor was ensured through the use of verbal debriefing, cross-coding, and the establishment of IRR.<sup>15</sup>

## Results

Twenty-six AYACs at a comprehensive cancer center in the south were invited to participate in the study, and 23 were enrolled and completed individual in-depth interviews. Interviews ranged in length from 20 to 30 minutes. In total, 10 interviews were conducted in-person and 13 by telephone. The quality, length, and content of the interview did not vary by interview modality.

Fifty-seven percent of patients were female and 65% were White. Eighty-seven percent of the sample was non-Hispanic, and 56% of the patients were on treatment. The majority of the patients were diagnosed with lymphoma, sarcoma, or breast cancer. Demographic information (see Table 1) was self-reported by participants, whereas type of cancer diagnosis was derived from medical chart extraction.

Analyses revealed two main themes as follows: perceived facilitators of care during treatment and perceived barriers to overall care. With each main theme, three sub-themes emerged. Examples are provided, as well as additional exemplar quotes (see Table 2). Differences based on demographics are indicated if there was a noteworthy difference in which the demographic characteristic represented 55% or more of the subset.

### Perceived facilitators during treatment

**Social support.** The majority of patients (87%; 55% female) reported that their social support system was a major resource during treatment. Respondents specifically referred to their family as their primary source of support and reported

TABLE 1. DEMOGRAPHIC INFORMATION FOR ADOLESCENT AND YOUNG ADULT CANCER PATIENTS

Characteristics	N (%)
Treatment status	
On treatment	13 (56)
Type of cancer	
Lymphoma	7 (30)
Sarcoma	6 (26)
Breast	5 (22)
Pancreatic	1 (4)
Melanoma	1 (4)
Tongue	1 (4)
Rectal	1 (4)
Kidney	1 (4)
Stage of disease	
Stage 1	3 (13)
Stage 2	8 (35)
Stage 3	4 (17)
Stage 4	8 (35)
Age at diagnosis	
18–25	8 (35)
26–30	5 (22)
31–35	6 (26)
36–39	4 (17)
Age at time of interview	
19–25	7 (30)
26–30	4 (17)
31–35	5 (22)
36–39	7 (30)
Gender	
Female	13 (57)
Race	
White	15 (65)
African American	3 (13)
Asian	1 (4)
American Indian/Alaskan Native	1 (4)
Not indicated	3 (13)
Total participants	23

Percentages are rounded and do not add up to 100%.

that family members did things for them such as cooked dinner, brought them to appointments, cared for their children, and took them on family trips. However, others also mentioned that they received excellent social support from the cancer center during treatment, stating that their nurses and doctors were available almost any time they had a question or concern.

“I have great supportive family...I’m truly blessed to have a family like that...besides coming to (cancer treatment center) every three weeks for a three-hour time period, I honestly forget that I have cancer.”

(23-year-old, melanoma patient, on treatment)

**Website and patient portal.** Thirty-five percent of the respondents mentioned the benefit of the cancer treatment’s *website and patient portal*; of which 71% were female, on treatment, or under 31 years of age. One patient described this as the most helpful resource while undergoing treatment because of the research provided about her cancer diagnosis, while others described the benefit of the online information in

comparison to having paper versions they may eventually lose. Still others described the benefit of having the information easily accessible for use at their discretion rather than being overwhelmed with information all at once.

“The online system that they have is very handy. I can view everything there, in case I lose any paper of anything. I have a quick and easy way to access it. So that is very nice.”  
(27-year-old, lymphoma patient, on treatment)

**Information provided by cancer center.** Another perceived facilitator described by 26% of respondents (67% on treatment) was the educational *information* provided by the cancer treatment center on cancer diagnosis or treatment, or “pretty much any issue” AYACs experience given through the website, patient portal, pamphlets, brochures, or handouts. About half of the patients mentioned this resource as positive, emphasizing that any and all information they could possibly need was provided to them. However others felt this information was at times overwhelming and may evoke fear or anxiety upon reading it, resulting in the choice not to utilize this.

“There’s been nurses ... in the in-patient center who are extremely helpful...they give me printable handouts if I have questions...or they’ll print it out and they’ll highlight it, and they’ll talk about it before I leave...”  
(22-year-old, sarcoma patient, on treatment)

#### Perceived barriers for AYACs to overall care

**Lack of communication about transitioning to survivorship.** Seventy-four percent (53% female) of patients identified communication as a perceived barrier, particularly about survivorship. These same patients/survivors expressed that the first time survivorship was mentioned was outside of the cancer center.

“...It’s not a good transition, to be honest with you. I think they’re not terribly concerned where I’m at...I don’t suspect that the survivorship transition’s going very well as far as any kind of communication...”  
(31-year-old, lymphoma patient, off treatment)

Tied to the *lack of communication about transitioning to survivorship* was fear of recurrence, as well as a lack of understanding of what to do or what resources could be utilized, after completing treatment. When asked what the cancer center should know to provide a better experience for AYACs, the majority of patients wanted more resources on survivorship and recurrence. See Table 2 for several examples.

**Managing physical and psychological symptoms.** Ninety-six percent of AYACs (55% female/active treatment/ $\geq 31$  years old) reported that *managing physical and psychological symptoms* were their top concerns during treatment. Physical symptoms related to both the cancer itself and to managing side effects from treatment. Physical symptoms described included vomiting, fatigue, changes in weight, and hair loss. Some patients specifically identified dealing with their own psychological barriers as being the most difficult, as well as perceived psychological difficulties experienced by their caregivers.

TABLE 2. THEMES AND SAMPLE QUOTES

Facilitators	Quotes
Social support	<p>“I have a lot of help which has been, you know, great and definitely helps I think with like the stress part, too. Just not having to worry about who’s going to pick up the kids for their dinner.”                      (37-year-old, breast cancer patient, on treatment)</p> <p>“But the doctors were very open. Their nurses—were awesome. As soon as I emailed, they’d call me right back. They were extremely willing to communicate with me and pretty much answered every question the best they could the whole time through”                      (35-year-old, tongue cancer patient, off treatment)</p>
Information provided by cancer center	<p>“If I possibly have any issue then I just need to call (cancer center) and tell them what it is and more than likely I’ll get some kind of pamphlet or information on it.”                      (19-year-old, sarcoma patient, on treatment)</p> <p>“They (cancer center) gave me a lot of paperwork that I never read. They probably gave me some paperwork...and it went in the pile with the other paperwork. It’s good information, I just—I don’t know. It wasn’t really that useful for me.”                      (35-year-old, rectal cancer patient, off treatment)</p> <p>“A lot of paper handouts. I got a lot of paper handouts, more than what I’d choose to read. It was information overload...I chose not to do a lot of studying on the disease itself because I know doing that would bring on more anxiety and more fear of what I was going through, so I did not want to go through that stress.”                      (32-year-old, lymphoma patient, off treatment)</p>
Website and Patient Portal	<p>“I think the patient portal...the way they set up the portal, you can get more research off that portal versus anything...you’ve got reviews on it and you’ve got the doctor’s point of view on it. “I ...like that my family has access to the portal because..., it’s just too much for me to read by myself and then call everybody.....”                      (30-year-old, breast cancer patient, on treatment)</p>
Barriers	
Lack of communication about transitioning to survivorship	<p>“I was going through treatment and one day my little brother (said) ...you know you’re a survivor now.’ I didn’t think about it until he said that.... Nobody said anything...I thought of me as just being a person who was fighting cancer. And so when my brother helped me put the light on...that was my ‘ah-ha’ moment.”                      (33-year-old, sarcoma patient, off treatment)</p> <p>“So, when I finally did see the doctor, the first thing that he said to me was like, ‘Okay, well yeah, you have leiomyosarcoma. It always comes back...’ So, he scared me before I even knew of anything else. And it’s just like—I try not to be on pins and needles wondering, well when is it going to come back?”                      (33-year-old, sarcoma patient, off treatment)</p> <p>“I’m sure you guys have resources, but just once you finish treatment, just the ongoing fear that it’s (cancer) gonna come back and things like that. And I guess that all kind of rounds back to: having some kind of blog or success stories would go a long way.”                      (35-year-old, tongue cancer patient, off treatment)</p>
Managing physical and psychological symptoms	<p>“He needs support. He needs to know what {to} expect with what was going on...he just got thrown in through a loop with me...somebody to talk to. So he knows he’s not going through this by himself, that there are other people who are doing the same thing as caregivers.”                      (38-year-old, pancreatic cancer patient, on treatment)</p>
Lack of communication regarding financial/insurance issues	<p>“...sometimes you get a bill that says...you have to pay \$40,000 next week. And I know it’s not right but sometimes it takes kind of a run around to get fixed...it’ll make your heart skip a little bit but it always gets resolved. When I was undergoing treatment, it was kind of a pain when you know, you’re not feeling so hot and then you have to resolve this issue...”                      (31-year-old, lymphoma patient, off treatment)</p>

“...I have pretty much one day a month...that I let everything catch up and you know I go outside and I cry, I let it out and then I am okay again.”  
 (36-year-old, kidney patient, on treatment)

Lack of communication regarding financial/insurance issues. Another perceived barrier discussed by 61% of the respondents (57% female) was *lack of communication and clarification regarding financial and insurance issues*. Patients on and off treatment and across the AYACs age range

endorsed this theme equally. Patients described the difficulty of handling financial stressors in combination with managing symptoms from treatment, as well as the sacrifices they made to continue to manage their finances during treatment.

“...I had my son on my lap. She (hospital worker) goes, ‘Well, if you can’t pay us \$400 every week for your weekly treatments, we can’t see you no more.’ My son’s like, ‘Mommy, you’re not going to get your chemo?’ So, at that point we had to see what we could do to fix our share of costs. So, my husband

quit his job. My share of costs went down. Finances are extremely hard, but I was able to get my treatment.”  
(36-year-old, breast cancer patient, on treatment)

Differences in experiences/perceptions between older and younger AYACs and those on and off treatment were identified. Themes endorsed predominately by older, female, AYACs on active treatment included *managing physical and psychological symptoms*. Older AYACs were also more likely to express a fear of the cancer returning, which was related to *lack of communication about transitioning to survivorship*. Younger females on treatment were more likely to endorse that the *website and patient portal* were perceived resources, and females were also slightly more representative in reporting *social support* as a perceived facilitator and *lack of communication about transitioning to survivorship and financial and insurance issues* as perceived barriers to optimal care. Those AYACs currently on treatment were more likely to report *information provided by the cancer center* as a resource.

## Discussion

In summary, AYACs described perceived facilitators to optimal care during treatment as having a positive *social support* system; using the *website and patient portal*; and *information* provided by the cancer center through pamphlets, brochures, and handouts. In a review of the extant literature, current research appears to be concentrated on identifying barriers to optimal care for AYACs.<sup>5,8</sup> This study contributes findings related to perceptions of facilitators to optimal care in this population. Ability to access information by both the AYACs and their support system was described as an important component in receiving optimal care in a review of factors that influence AYACs' outcomes.<sup>16</sup> These prior findings support the advantages described in the current study of having a website or patient portal that can be accessed by the AYACs or their support system at their own convenience, as well as their readiness for information.

Several perceived barriers to optimal care were identified, including *managing physical and psychological symptoms*, *lack of communication about transitioning to survivorship*, and *difficulty managing and communicating about financial and insurance issues*. Findings are consistent with the extant literature on barriers to optimal care. A meta-analysis found that medical and psychosocial issues for AYACs were common across studies.<sup>17</sup> Research issues were also included as a common barrier, which was defined as a lack of progress in improving AYACs' cure rates, but also the need for improving AYACs' transition to survivorship.<sup>17</sup> Current guidelines suggest that discussion of survivorship and transitioning to survivorship should be discussed at the very beginning of treatment for cancer.<sup>4</sup>

Overall, patients' perceived barriers to optimal care were more similar than different across age groups consistent with previous findings in the literature that this population experiences unique medical, psychosocial, and supportive care needs.<sup>3,5</sup> Our findings indicate that AYACs may need more support than they are currently receiving in the areas of physical and psychological support and may require more communication about transitioning to survivorship and financial and insurance issues. Although the population of

AYACs can vary developmentally across the broad age span, findings were consistent with previous research indicating that disruptions in school or work life, leading to financial challenges,<sup>5,6</sup> are barriers for AYACs.

The current study adds to the existing literature on AYACs patient perspectives of facilitators to optimal care. Despite previous literature indicating that an issue for AYACs is limited availability of social/peer support networks,<sup>5</sup> the current study found that AYACs patients felt their *social support system* was a facilitator to optimal care. This *social support system* was defined as not only family members but also supportive doctors and nurses who were accessible. This indicates that care centers seeking to optimize care for AYACs should incorporate the support system in the AYAC's care as much as possible, while also serving as a support system themselves. Helping connect AYACs to a support system if they are lacking one may also be an important aspect of optimizing care.

While there appear to be many online resources for AYACs, no studies were identified citing the importance of a *website or patient portal* in facilitating optimal care. However, AYACs described this as an important resource during treatment due to the benefits of being able to access information whenever they needed it, as well as being able to share information with their support system. Others described the advantage of the *website and patient portal* over paper copy brochures and sheets they received because paper copies could be lost or felt overwhelming when provided all at once.

Limitations of the current study include the use of a convenience sample of AYACs in one hospital that were both on and off treatment and ranged in age at diagnosis. Furthermore, despite including AYACs ranging in severity of illness and stage of disease, some patients approached for the study were unable to participate because they said they felt too ill to participate at the time we met with them.

## Future directions

One purpose of conducting this study was to identify unmet needs for the development of an intervention for this population that may improve care and, potentially, outcomes. The extant literature has described Patient Navigation (PN) as an intervention model designed to reduce healthcare disparities by assisting patients in overcoming health system barriers to care.<sup>16,18</sup> PN was originally intended to assist medically underserved populations in following through with recommendations for diagnostic and clinical services after an abnormal cancer screening or cancer diagnosis. As such, PN has been associated with improvements in rates of cancer screening,<sup>19</sup> reductions in delays and improvements in adherence to diagnostic and clinical care,<sup>18,20-26</sup> reductions in late-stage disease,<sup>11,27-32</sup> and improvements in survival.<sup>11,27-30</sup>

The PN strategic aims are not just to reduce barriers and improve disease outcomes, but to reduce distress and enhance quality of life for the patient and family.<sup>20,24,32</sup> Therefore, perspectives of healthcare providers serving the AYACs population at the cancer center described in the current study should also be explored to assess whether PN might serve as a way to reduce barriers and capitalize on current facilitators to optimize care. Our results showed that communication about and transitioning to survivorship, managing physical and psychological symptoms, and financial concerns

were perceived as unmet needs of AYACs on and off treatment. In a meta-analysis of the literature regarding the unique medical and psychosocial needs of AYACs, receiving information on long-term survivorship and improving psychological care were noted as barriers to optimal care.<sup>33</sup> A study examining the long-term impact of cancer also found that AYACs reported more benefits than burden throughout cancer treatment, with the top burden reported as physical distress.<sup>34</sup> However, AYACs noted that they developed a more positive sense-of-self during cancer treatment, indicating that future support may focus on personal strengths and life purpose.<sup>35</sup>

The PN role should focus on these unmet needs of the AYACs both in person and by capitalizing on patients' social support system and provide information through websites and patient portals, as these were described as facilitators to care. Current models for PN have proposed the following roles for navigators: communicating with the patient's healthcare team, translating health information, serving as a support system, helping to coordinate healthcare services,<sup>36</sup> provide support in returning to work or school, dealing with fertility preservation issues, connecting AYACs to a support group, and preparing for survivorship.<sup>37</sup>

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### Author Disclosure Statement

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