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# Patient Navigation Preferences for Adolescent and Young Adult Cancer Services by Distance to Treatment Location

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**Purpose:** To describe how distance to treatment location influences patient navigation preferences for adolescent and young adult (AYA) cancer patients and survivors.

**Methods:** This study is part of a statewide needs assessment to inform the development of an AYA cancer patient and survivor navigation program. Participants were recruited from outpatient oncology clinics in Utah. Eligible participants had been diagnosed with cancer between ages 15–39 and had completed at least 1 month of treatment. Participants completed a semi-structured interview on preferences for patient navigation. Summary statistics of demographic and cancer characteristics were generated. Thematic content analysis was used to describe navigation preferences among participants classified as distance ( $\geq 20$  miles) and local ( $< 20$  miles), to explain differences in their needs based on distance from their treatment center.

**Results:** The top three patient navigation needs were general information, financial, and emotional support. More local patients were interested in patient navigation services (95.2%) compared to distance participants (77.8%). Fewer local (38.1%) than distance participants (61.1%) reported challenges getting to appointments, and distance patients needed specific financial support to support their travel (e.g., fuel, lodging). Both local and distance patients desired to connect with a navigator in person before using another form of communication and wanted to connect with a patient navigator at the time of initial diagnosis.

**Conclusion:** Distance from treatment center is an important patient navigation consideration for AYA cancer patients and survivors. After initially connecting with AYAs in person, patient navigators can provide resources remotely to help reduce travel burden.

**Keywords:** patient navigation, distance, travel, rural, supportive care

**I**MPROVING OUTCOMES for adolescent and young adult (AYA) cancer patients and survivors, diagnosed between 15 and 39 years, is a national priority.<sup>1</sup> AYA cancer patients and survivors experience barriers to accessing information and support services, because they often receive care in oncology settings that may not provide targeted AYA services.<sup>2–4</sup> AYAs are often uninsured, have limited healthcare access, and experience delays in cancer diagnosis.<sup>1,5,6</sup> These challenges may be exacerbated for AYAs living far from their cancer treatment center.<sup>7</sup>

Patient navigators provide coordinated, patient-centered services that guide individuals through complex medical

systems and to community resources.<sup>8</sup> Integrating patient navigators into clinical cancer care may help reduce healthcare delivery barriers and improve care coordination.<sup>8</sup> Patient navigators reduce healthcare disparities for rural cancer patients in general.<sup>9</sup> Yet, there is little known about the unique navigation preferences of AYAs and the potential benefits of patient navigation for rural AYAs.<sup>10</sup>

Utah's largest cancer treatment providers, Huntsman Cancer Institute (HCI) and Intermountain Healthcare (IH), jointly support a new AYA cancer program. HCI, located in Salt Lake City, Utah, is the only National Cancer Institute-designated Comprehensive Cancer Center in the Mountain West.<sup>11</sup> IH is a

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system of 22 hospitals throughout the Mountain West, including a children's hospital and pediatric oncology clinic, that serves patients from Utah, Idaho, Wyoming, Montana, Nevada, Eastern Colorado and Northern Arizona. Together, HCI and IH treat over 85% of cancer patients in Utah, many of whom live in rural and frontier areas that require traveling long travel distances for their care.<sup>12,13</sup>

We report patient navigation preferences from a statewide needs assessment for this AYA cancer program. Our goal was to examine the patient navigation preferences of AYA cancer patients, including survivors, to describe how patient navigation services could be tailored based on patient's travel distance for treatment. Patients were grouped as distance ( $\geq 20$  miles) and local ( $< 20$  miles). A qualitative semi-structured interview approach facilitated the distinction of multiple perspectives and provided insights that would not have been obtained with a survey.

## Methods

### *Sampling, ethical approvals*

Eligible patients were diagnosed with cancer between 15–39 years and completed  $\geq 1$  month of treatment. These criteria were chosen to elicit detailed accounts of patient navigation preferences among individuals who would be able to recall and identify patient navigation needs. To ensure a variety of perspectives were captured across the cancer continuum, we included older individuals who were diagnosed as AYAs. Schedules were reviewed from oncology clinics that frequently see AYA cancer patients at HCI and IH (e.g., pediatric oncology, leukemia/lymphoma, central nervous system, head and neck, solid tumor clinics), and cross referenced with patient charts to assess eligibility. Patient charts were reviewed to identify eligible participants; no data were collected from the charts. Other participants were identified via flyers and an existing AYA research protocol. Potential participants were approached during outpatient visits. Informed consent was obtained and interviews took place in person or over the phone. The University of Utah's Institutional Review Board approved this research.

### *Data collection and participants*

The research team included individuals from both rural and urban backgrounds, including health services researchers, a patient navigator, and oncology physicians. The team member who oversaw the interviews had extensive interviewing experience and trained an additional staff member. The interview script was developed based on existing cancer survivorship literature, prior research experiences with AYA cancer patients and survivors, and feedback from the research team and a patient advisory board (Supplemental Data; Supplemental Data are available online at [www.liebertpub.com/jayao](http://www.liebertpub.com/jayao)).<sup>14–16</sup> The data collection instrument was adapted to clarify that participants were being asked to describe both their current preferences and those at initial diagnosis. Data were collected from November 2016–January 2017. Data collection ended when saturation was reached, the point at which no new themes emerged from the interviews.<sup>17</sup> Demographic and cancer-related characteristics were collected at the end of the interviews, which lasted 46 minutes on average. Interviews were audio recorded, transcribed, and quality checked. Participants received a \$25 gift card. Of 47

eligible patients: 3 declined, 1 was lost to follow-up, and 43 were enrolled. Of patients who enrolled,  $n = 39$  completed interviews (completion rate:  $39/43 = 90.7\%$ ).

### *Demographic and cancer measures*

Demographics included current age, gender, race, ethnicity, annual household income, marital status, health insurance status, and residential ZIP code. Cancer characteristics included age at diagnosis, time since diagnosis, and cancer diagnosis.

### *Rurality and distance from treatment center*

Rurality was classified using rural-urban commuting area codes according to population density and commuting time. Using the 2010 ZIP code tabulation area (ZCTA) data from the U.S. Census Bureau, a ZCTA was geocoded for each participant using ArcMap 10.3.1.<sup>18</sup> Patients whose ZIP code did not match with a ZCTA were manually matched to a ZCTA. Distances between the population-based centroid of each ZCTA to patients' reported cancer treatment center were calculated using Euclidean distance, which is an accepted estimate for driving distance and time.<sup>19</sup> Participants were stratified based on the travel distance from their residence to their primary cancer treatment center as distance ( $\geq 20$  miles) or local ( $< 20$  miles). The cutoff of 20 miles represents the geographic metropolitan area of Salt Lake City, Utah where HCI's and IH's centers are located. As relevant, we describe findings for participants who were living over 100 miles away from their cancer center ( $n = 6$ , 15.4%).

### *Data analysis*

Iterative thematic content analysis was applied concurrently with data collection to enhance reflexivity.<sup>20</sup> Weekly meetings were held to review data, discuss emerging codes, and gain consensus in interpretations. First 10% of the interviews were inductively coded by three researchers to develop a codebook (average of 65.5% coding agreement). The codebook was refined by identifying coding discrepancies, problematic codes, and areas with zero or negative agreement. Another 10% of the interviews were coded with an average of 99.7% coding agreement. The codebook was finalized and applied to the remaining interviews.<sup>21</sup> Method (memoing) and investigator (involvement of multiple coders) triangulation brought together information from multiple sources to validate findings.<sup>22</sup> Reflexive and interpretive memos were created throughout the interviewing and coding process to note interpretations, meaning of ideas, and procedural irregularities.<sup>23,24</sup> Memos were reviewed during bi-weekly meetings. Multiple investigators were involved in interviewing, memoing, coding, and interpreting the data.<sup>22</sup> Codes were aggregated into main themes: patient navigation preferences (general cancer information, financial support, and emotional support), distance-related concerns, and patient navigation delivery preferences (timing, format).

## Results

Travel distance to participants' cancer treatment centers ranged from 1.5 to 276.7 miles (mean = 53.5, median = 18.3, standard deviation = 77.4). There were fewer distance (46.2%) than local (53.8%) participants. More distance participants were

male (61.1%) than local (28.6%,  $p=0.04$ , Table 1). Average current age was 31.2 years (median 31.4, 94.9% of participants were currently 15–39 years). About 72.2% of distance participants were classified as rural; 76.2% of local participants were classified as urban ( $p<0.01$ ). All participants had insurance: employer sponsored/military (74.4%), Medicare/Medicaid (23.1%), or individual policy (10.3%, data not shown).

Distance and local participants were similar in age at diagnosis and time since diagnosis. Time since diagnosis ranged from 0.5 to 23.8 years (mean=4.5, standard deviation=5.1). More distance participants had sarcoma (27.8%) and lymphoma (33.3%); more local participants had brain/CNS tumors (14.4%), breast (33.3%), and other cancers (33.3%,  $p=0.03$ ).

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF ADOLESCENT AND YOUNG ADULT CANCER PATIENTS BY DISTANCE FROM TREATMENT CENTER

	<i>Residential distance from cancer treatment center</i>				p
	<i>Local &lt;20 miles (n=21)</i>		<i>Distance ≥20 miles (n=18)</i>		
	n	%	n	%	
Current age					
15–24	2	9.5	6	33.3	0.21 <sup>a</sup>
25–34	9	42.9	7	38.9	
35–44	8	38.1	5	27.8	
45–50	2	9.5	0	0.0	
Gender					
Female	15	71.4	7	38.9	0.04 <sup>b</sup>
Male	6	28.6	11	61.1	
Race					
White	18	85.7	16	100.0	0.24 <sup>a</sup>
Other	3	14.3	0	0.0	
Ethnicity					
Non-Hispanic	17	80.9	16	94.1	0.35 <sup>a</sup>
Hispanic	4	19.0	1	5.9	
Annual household income					
<\$25,000	3	14.3	5	27.8	0.68 <sup>a</sup>
\$25,000–\$34,999	4	19.0	3	16.7	
\$35,000–\$49,999	2	9.5	3	16.7	
\$50,000–\$74,999	5	23.8	4	22.2	
>\$75,000	7	33.3	3	16.7	
Marital status <sup>c</sup>					
Married	14	66.7	11	61.1	0.72 <sup>b</sup>
Not married	7	33.3	7	38.9	
Rurality of residence					
Urban	16	76.2	5	27.8	<0.01 <sup>b</sup>
Rural	5	23.8	13	72.2	
Age at diagnosis					
15–24	5	23.8	9	50.0	0.28 <sup>a</sup>
25–34	11	52.4	7	38.9	
35–39	5	23.8	2	11.1	
Time since diagnosis					
≤5 years	14	66.7	13	72.2	0.36 <sup>a</sup>
6–10 years	6	28.6	2	11.1	
11–15 years	0	0.0	2	11.1	
>15 years	1	4.8	1	5.6	
Diagnosis					
Sarcoma	4	19.0	5	27.8	0.03 <sup>a</sup>
Lymphoma	0	0.0	6	33.3	
Brain/CNS tumor	3	14.4	1	5.6	
Breast	7	33.3	2	11.1	
Other <sup>d</sup>	7	33.3	4	22.2	

<sup>a</sup>p value for Fishers exact tests.

<sup>b</sup>p value for chi-square tests.

<sup>c</sup>Married includes 2 respondents who were engaged or in a long-term relationship, other includes those who are not married, divorced, separated, widowed and those who selected “other”.

<sup>d</sup>Other includes: leukemia (1), thyroid cancer (3), ovarian (2), testicular (1), gastric (1), melanoma (1), and multiple myeloma (1).

TABLE 2. COMPARISON OF THEMES AND SUBTHEMES FROM IN-DEPTH INTERVIEWS BY DISTANCE FROM THE CANCER TREATMENT CENTER

	<i>Residential distance from cancer treatment center</i>					
	<i>Total (n=39)</i>		<i>Local &lt;20 miles (n=21)</i>		<i>Distance ≥ 20 miles (n=18)</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
<b>Patient navigation preferences</b>						
Thinks a navigator would be helpful	34	87.2	20	95.2	14	77.8
General information support	20	51.3	11	52.4	9	50.0
Financial support	17	43.6	11	52.4	6	33.3
Emotional support	15	38.5	8	38.1	7	38.9
Someone “who knows options”	15	38.5	8	38.1	7	38.9
Provide guidance to the “right person”	11	28.2	5	23.8	6	33.3
Answer non-medical questions	10	25.6	5	23.8	5	27.8
Health insurance support	7	17.9	4	19.0	3	16.7
Social support	6	15.4	5	23.8	1	5.6
Transition support	3	7.7	2	9.5	1	5.6
Fertility assistance	1	2.6	1	4.8	0	0.0
Distance-related concerns	19	48.7	8	38.1	11	61.1
<b>Patient navigation delivery preferences</b>						
<b>Timing of navigation</b>						
At first diagnosis	25	64.1	15	71.4	10	55.6
Active treatment	22	56.4	11	52.4	11	61.1
Survivorship	12	30.8	8	38.1	4	22.2
<b>Format of navigation</b>						
Face to face	18	71.8	9	42.9	9	50.0
Phone-audio	22	56.4	14	66.7	8	44.4
Email	15	38.5	9	42.9	6	33.3
Portal (MyChart)	13	33.3	6	28.6	7	38.9
Phone-text messaging	6	15.4	2	9.5	4	22.2

### *Patient navigation service preferences*

Of distance participants, 77.8% ( $n=14$ ) compared to 95.2% ( $n=20$ ) of local participants thought support from a patient navigator would be helpful. The most common type of patient navigation that participants endorsed included providing general cancer-related information ( $n=26$ , 51.3%), financial support ( $n=17$ , 43.6%), and emotional support ( $n=15$ , 38.5%, Table 2).

### *General cancer-related information*

Approximately half of distance ( $n=9$ , 50.0%) and local participants ( $n=11$ , 52.4%) wanted a patient navigator to offer general information on their cancer. Such services included addressing nonemergency questions about health/treatment, providing relevant information about their cancer, and “checking in” to see how they are doing. Other less common services included being someone “who knows options” about cancer-related decisions and providing guidance to the “right person” to answer their questions.

### *Financial support*

Financial support was more commonly endorsed among local participants ( $n=11$ , 52.4% vs. distance  $n=6$ , 33.3%). Local participants wanted the navigator to provide information about financial counseling, medical debt, and health insurance coverage. Distance participants wanted specific information about financial support for lodging, fuel, and educational scholarships. A distance participant explained

the need for financial assistance from a navigator compared to other members of the healthcare team, “We feel like it’s a burden to ask doctors about things unrelated to our health. So to say, ‘We need financial help’...We don’t turn to our doctors about that.” Distance participants who were over 100 miles away from their treatment center emphasized the financial strain related to traveling and staying away from home, and wanted a navigator to share financial aid resources for fuel, hotel stays, and meal discounts. For example, a distance participant stated, “If you couldn’t afford a motel, you could get one. [The navigator] would help you out with discounts.”

### *Emotional support*

Regardless of distance, over one-third of participants wanted emotional support from a navigator ( $n=15$ , 38.5%). A local participant felt that a navigator could be supportive during the transition period after treatment, stating, “Okay, you have cancer, and have gone through your treatment, and everything looks good now...You feel like, ‘Wait. Is this something I can do on my own?’” A distance male participant said, “...hearing someone over the phone and being able to hear them say it’s going to be alright. Giving you that motivation... that can help emotionally, and socially.”

### *Distance-related concerns*

Interestingly, both distance and local participants expressed challenges getting to oncology appointments, although this was much more common for distance patients

(61.1% vs. 38.1%; Table 2). Barriers included the distance traveled, travel time, problems arranging transportation, out of pocket costs, time off of work, being unable to drive due to side effects, and relying on others for transportation.

Many distance participants had established clear strategies for ameliorating travel burden like scheduling multiple appointments on the same day, using community transportation, and arranging for others to drive them. Yet, there were specific instances when distance participants expressed frustration with long travel times, poor weather conditions, transportation expenses (e.g., fuel, lodging), and scheduling conflicts that could potentially be addressed by a navigator. A distance participant described traveling to her cancer treatment center only to have her appointment cancelled, “Once or twice when I went up there [my doctor would] have emergency surgery, and the appointment would get cancelled on me. That was a little difficult, because it was a wasted trip... I would just have to reschedule.” Travel distance was identified as the most difficult barrier in getting to appointments among participants who lived over 100 miles away.

#### *Patient navigation delivery preferences*

**Timing of navigation.** Distance and local participants agreed that navigation support was most desirable at initial diagnosis, but that it is important for the navigator to be available throughout treatment and survivorship. The majority of participants desired meeting a navigator at initial diagnosis ( $n=25$ , 65.1%) or during active treatment ( $n=22$ , 56.4%). There were fewer endorsements for initiating contact with a navigator during survivorship ( $n=12$ , 30.8%), although this could have been due to about half of participants having not yet reached survivorship.

Fewer distance participants ( $n=10$ , 55.6%) felt the navigator should initiate contact at diagnosis compared to local participants ( $n=15$ , 71.4%). A local participant stated, “Initially, you really need somebody to anchor yourself to... So it would be super nice to have, you know, somebody that you know is responsible for helping you.” A distance participant discussed the importance of long-term patient navigation, saying, “It would be helpful if [the navigator] could call you every three to five to 10 years and say... We’re just calling to make sure you’re getting your checkups.”

#### *Format of navigation*

Most participants expressed a desire to receive navigation services in person ( $n=18$ , 71.8%), and this was the most highly endorsed format for distance patients. The second most common format was telephone communication, endorsed by 44.4% ( $n=8$ ) of distance and 66.7% ( $n=14$ ) of local participants. Email was more highly endorsed among local ( $n=9$ , 42.9%) than distance participants ( $n=6$ , 33.3%). Some participants preferred receiving navigation services over the phone due to distance. A distance participant said, “Probably over the phone given the distance we are from the hospital and then face-to-face if we happen to be up there.” Besides travel, another distance participant desired online communication, “For the role of a navigator... the most effective method would likely be something like email, because then the navigator has time to look into the person’s specific situation...and then have the time to respond, to make efficient use of their time.” All participants who lived over 100

miles away wanted to use portal (MyChart), phone, or online tools to interact with the navigator.

#### **Discussion**

We found that the majority of AYA cancer patients and survivors—regardless of their distance from their cancer treatment center—thought a patient navigator would be helpful. These findings detail important patient navigation preferences for AYA cancer patients in the Mountain West, many of whom travel long distances for healthcare services. Our findings have implications for researchers and AYA clinicians who serve patients in broad geographic areas. To our best knowledge, this study is the first of its kind.

Eliminating barriers that prevent patients from accessing timely healthcare<sup>8,25</sup> and coordination of healthcare services<sup>8,25</sup> are fundamental principles of patient navigation. Interestingly, AYAs in our study experienced travel-related barriers, regardless of where they lived. While a patient living nearby their treatment center may feel burdened by traveling a short distance very frequently, those living further away are accustomed to traveling long distances for healthcare, attempt to coordinate same day appointments, and thus see travel as less burdensome. This is likely in part due to limited access to healthcare services in rural areas but may also be related to rural cancer patients’ willingness to travel to receive care from trusted providers.<sup>16</sup> Patient navigators could help ease travel burdens of AYAs by coordinating same-day appointments, assisting with finding on-site childcare, and linking AYAs who are unable to drive with free or low-cost transportation.

Generally, rurality is associated with a higher likelihood of being uninsured,<sup>26</sup> cancer-related financial hardship,<sup>7</sup> and traveling long distances for cancer treatment.<sup>27</sup> Therefore, we expected more distance patients to endorse financial support, however, more patients living closer to their treatment center reported financial support needs. Individuals living further away focused on financial needs related to traveling and being away from home, whereas local participants emphasized needing guidance with health insurance policies and managing medical expenses. So, while distance patients may be more accustomed to traveling for their care, they still often need financial support. Patient navigators may help ameliorate financial needs by connecting distance patients with financial aid for travel and lodging, and assisting both local and distance patients with financial support for medical bills and understanding health insurance policies.

Additionally, patient navigators who serve rural patients may need to consider different modes of communication for patients who travel long distances. For practical reasons, these patients may not be able to meet in person regularly. Participants in our sample preferred to meet in person with a navigator initially, and have subsequent visits occur via telephone, email, or text messaging. Surprisingly, in-person meetings with the navigator were highly endorsed by distance participants, but only if scheduling could be coordinated with their other appointments. Given the variability of preferences for the format of patient navigation, communication format is important to discuss early in the patient-navigator relationship. Age may be particularly relevant in determining preferred communication format, as generational preferences for certain types of communication may differ between younger and older AYAs.<sup>28</sup>

While our main objective was not to study how patient navigation preferences change over time, navigation services that may be preferred soon after diagnosis may be less relevant over time (e.g., fertility preservation), and needs that were not apparent at initial diagnosis may become more important as AYAs transition through different stages of life (e.g., employer accommodations, childcare support). For example, one woman described how her transportation needs were different 11 years after diagnosis. When she was first diagnosed, a family member was able to driver her to appointments. Now that the family member was working full time and the participant needed transportation support and childcare assistance to attend long-term follow-up appointments. Examples such as this suggest that navigators working with AYAs may need to respond to changes in patient needs over time. In addition to age and time since diagnosis, other factors like gender and cancer type may influence which navigation services are most important to distance and local patients, but additional research is needed to differentiate these needs.

This study has limitations. Our results are based on a single state and thus may not be generalizable to all AYA cancer patients. Because all participants were insured, experiences of uninsured AYAs were not captured. Sarcoma patients were purposefully oversampled because these cancers are often underrepresented in AYA research,<sup>29</sup> and there were more distance than local participants with sarcoma. While underrepresentation of racial/ethnic minorities is a limitation, our sample does reflect the Utah population. Survivor bias may have influenced our findings, given that 30.8% of participants were over 5 years past diagnosis. Lastly, we underscore that patient navigators may not have the means or training to fulfill all unmet needs, nonetheless they play an essential role in providing referrals to internal and community resources to support AYA patients and survivors.

### Conclusions

This study elicited differences between patient navigation preferences of AYA cancer patients living near and far from cancer treatment centers. Travel burden constitutes a barrier to healthcare that affects AYA cancer patients in a profound way. Distance AYAs may need special attention from patient navigators to reduce transportation barriers, address financial needs, and obtain services in an appropriate format. AYA cancer patients who live near their cancer treatment center also reflect the burden of traveling to treatment centers when services are delivered in a fragmented way. Patient navigators are well poised to guide patients through the complexity of a healthcare system, coordinate access to internal and external services, and ultimately reduce the burden of traveling for cancer treatment among AYA cancer patients.<sup>8,26</sup>

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### Author Disclosure Statement

Dr. Randall receives honoraria from and has a consulting/advisory role with Daiichi Sankyo and Zimmer Biomet. Dr. Kirchhoff has an immediate family member who has stock or other ownership in Medtronic.

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