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Age-Specific Patient Navigation Preferences Among Adolescents and Young Adults with Cancer

Samantha T. Pannier[1] · **Echo L. Warner**[1,2] · **Brynn Fowler**[1,7] · **Douglas Fair**[3,4] · **Sara K. Salmon**[5,6] · **Anne C. Kirchhoff**[1,4]

Abstract

Background Patient navigation is increasingly being directed at adolescent and young adult (AYA) patients. This study provides a novel description of differences in AYA cancer patients' preferences for navigation services by developmental age at diagnosis.

Methods Eligible patients were diagnosed with cancer between ages 15 and 39 and had completed at least 1 month of treatment. Between October 2015 and January 2016, patients completed semi-structured interviews about navigation preferences. Summary statistics of demographic and cancer characteristics were generated. Differences in patient navigation preferences were examined through qualitative analyses by developmental age at diagnosis.

Results AYAs were interviewed (adolescents 15–18 years N = 8; emerging adults 19–25 years N = 8; young adults 26–39 years N = 23). On average, participants were 4.5 years from diagnosis. All age groups were interested in face-to-face connection with a navigator and using multiple communication platforms (phone, text, email) to follow-up. Three of the most frequently cited needs were insurance, finances, and information. AYAs differed in support, healthcare, and resource preferences by developmental age; only adolescents preferred educational support. While all groups preferred financial and family support, the specific type of assistance (medical versus living expenses, partner/spouse, child, or parental assistance) varied by age group.

Conclusions AYAs with cancer have different preferences for patient navigation by developmental age at diagnosis. AYAs are not a one-size-fits-all population, and navigation programs can better assist AYAs when services are targeted to appropriate developmental ages. Future research should examine fertility and navigation preferences by time since diagnosis. While some navigation needs to span the AYA age range, other needs are specific to developmental age.

Keywords Adolescent and young adult (AYA) · Patient navigation · Adolescent · Young adult · Emerging adult · Cancer navigation

For adolescents and young adults (AYAs) ages 15–39 years at diagnosis [1], cancer can be especially difficult, affecting educational attainment, relationships with peers, ability to form and/or maintain intimate relationships, financial stability, and fertility [2]. Competing demands (e.g., family, work) experienced by AYAs also produce barriers to care [3]. Furthermore, during survivorship, AYAs suffer poorer health-related quality of life and are at greater financial risk than older patients [4]. Given their unique developmental needs during cancer treatment and survivorship [5, 6], patient navigation has been

✉ Samantha T. Pannier
samantha.pannier@hci.utah.edu

[1] Huntsman Cancer Institute, Cancer Control and Population Sciences, 2000 Circle of Hope, Salt Lake City, UT 84112, USA

[2] University of Utah, College of Nursing, 10 S 2000 E, Salt Lake City, UT 84112, USA

[3] Primary Children's Hospital, 100 Mario Capecchi Drive, Salt Lake City, UT 84132, USA

[4] Department of Pediatrics, University of Utah, 100 N Mario Capecchi Drive, Salt Lake City, UT 84132, USA

[5] Huntsman Cancer Hospital, Cancer Learning Center, 2000 Circle of Hope, Salt Lake City, UT 84112, USA

[6] Intermountain Healthcare, 5121 Cottonwood Street, Murray, UT 84107, USA

[7] Department of Pediatrics, The University of Chicago, 5841 S. Maryland Ave, MC 4060, Chicago, IL 60637, USA

identified as a potential avenue for addressing the unique circumstances of AYAs with cancer.

Patient navigation is a tailored healthcare delivery and support strategy used to help patients coordinate healthcare services [7]. Typically, a patient navigator helps to guide patients through the complexities of the healthcare system to access needed services. Patient navigation has been applied in many settings to address the healthcare needs of underserved populations [8], especially in cancer care. AYAs with cancer may benefit from patient navigation in particular as many patients in this age group find themselves caught in a healthcare divide between pediatric and adult care [9–11].

AYAs are often considered a homogenous group despite considerable variation in developmental age (defined by Arnett as adolescence, emerging adulthood, and young adulthood) between the ages of 15 and 39 years [12, 13]. Across developmental ages, there are likely differences in how patients prefer to interact with a patient navigator and in the types of navigation services they desire. For example, younger AYAs ages 18–29 report needing assistance with information and supportive care needs more than AYAs ages 30–40 [14]. Other needs, such as fertility services, are unique to AYAs with cancer and are consistently acknowledged by AYAs as important [15–18].

In Utah, there are almost 1000 AYAs diagnosed with cancer annually, and approximately 80% are treated within one of two major healthcare systems. The Huntsman Cancer Institute (HCI) is part of the University of Utah, whereas Intermountain Healthcare (IH) has 22 hospitals throughout the state and includes Utah's only pediatric oncology clinic, Primary Children's Hospital. In late 2016, HCI and IH launched the Huntsman-Intermountain Adolescent and Young Adult Cancer Care Program, with the goal of providing patient navigation to all AYAs with cancer in Utah. Prior to the start of this program, we interviewed AYA cancer patients about their preferences for patient navigation. Because little is known about how preferences for patient navigation services vary among AYAs with cancer by age [19], our goal was to identify age-specific patient navigation preferences based on developmental age—adolescence, emerging adulthood, and young adulthood—to ensure the delivery of developmentally appropriate patient navigation in this new program [12, 13].

Methods

This analysis is part of a larger study examining the patient navigation preferences of AYAs with cancer in Utah. The University of Utah's Institutional Review Board approved this research. Informed consent was obtained from all individual participants included in the study.

Participants and Data Collection

Eligible patients were diagnosed with cancer between ages 15–39 and had completed at least one month of treatment. They were identified through chart review, existing research protocols, and recruitment posters placed at pediatric and cancer hospitals in Utah from October 2015 to January 2016. The majority of participants were approached during clinic visits to confirm eligibility and obtain informed consent. Seven participants from a previous research study were approached and consented over the phone. Semi-structured interviews with all participants were conducted either in person or by phone.

Interviews included questions about demographics, cancer characteristics, and participants' cancer experience. Participants were also asked to describe their needs during and after treatment with regard to a patient navigation program. The patient navigator was defined to participants as "someone who is available for you to contact with questions related to your cancer, healthcare, or other types of services." Interviews were recorded, transcribed, and quality checked. Of the $N = 47$ patients who were approached for participation, $N = 43$ patients were enrolled and $N = 4$ were lost to follow-up, leaving $N = 39$ who completed interviews (participation rate 90.7%).

Demographic and Cancer Characteristics

Demographic and cancer characteristics were collected at the end of the interview and included current age, gender, annual household income, race/ethnicity, health insurance, marital status, language spoken at home, age at diagnosis, years since diagnosis, and cancer diagnosis.

Developmental Age at Diagnosis

We defined developmental age at diagnosis according to Arnett's theories of adolescence, emerging, and young adulthood [13]. According to Arnett, adolescents ages 15–18 years derive much of their identity from peers and usually live at home with parents [13]. Emerging adults, ages 19–25, do not fit a normative pattern of development [12, 13]. Instead, they often start families, pursue education, and work at different times during this period [13]. A hallmark of emerging adulthood is exploration and identity formation [12, 13]. Compared to their younger counterparts, young adults ages 26–39 are more frequently parents, have started on their long-term career path, and are married or partnered [12, 13]. Participants were classified into one of three categories based on their age at initial diagnosis: adolescents (15–18 years, $N = 8$), emerging adults (19–25 years, $N = 8$), and young adults (26–39 years, $N = 23$).

Data Analysis

Descriptive statistics were calculated for demographic and cancer characteristics using Fisher's Exact and one-way ANOVA tests to compare the proportions and means of participant data by developmental age in Stata version 13. Qualitative data were analyzed through two cycles of iterative, grounded theory methods to generate categories, themes, and subthemes. Three members of the research team read the interviews and memoed first impressions of the data. Then, 20% of the interviews were coded by three members of the research team in two iterations for a final coding agreement of 99.7%. In the first coding cycle, 60 subthemes were created using in vivo coding, a qualitative method that uses participants' own words. In the second coding cycle, ten descriptive themes were created via axial coding to organize subthemes. Axial coding is a grounded theory technique used to compare and contrast the characteristics and attributes of themes [20]. Themes were iteratively reviewed to create definitions, boundaries, and reduce overlap. Similar themes were organized into four broad categories of patient navigation preferences: Format, Support, Healthcare, and Resources. Qualitative analysis was performed in NVIVO version 11.

Finally, differences in the positive or negative endorsement of patient navigation preferences were examined by developmental age (15–18, 19–25, 26–39 years). In Table 2, all subthemes are reported by age and accompanied by illustrative quotes as relevant. A positive endorsement (+) was defined as any request for a specific navigation service or support. For example, "my idea of a navigator would be to call me to check up on what I'm doing…" A negative endorsement (−) was defined as a participant indicating they would not want to use a particular service or the navigator's support in certain ways. For example, "I wouldn't want [the navigator] making choices for me." Themes where both positive and negative endorsement were identified were coded as mixed (+/−).

Results

Demographic and Cancer Characteristics

The average time since initial diagnosis for all age groups was 4.5 years (SD = 5.1). Emerging adults were the furthest from diagnosis at an average of 7.0 years (SD = 7.9) whereas adolescents were 5.5 years (SD = 6.2) and young adults were 3.3 years (SD = 2.9). Young adults reported a higher annual household income (69.6%, > $50,000) than adolescents (25.0%) and emerging adults (12.5%, $p = 0.01$, Table 1). More young adults were currently married (82.6%) than emerging adults (50.0%) and adolescents (25.0%, $p < 0.01$). Lymphoma (62.5%, adolescents), sarcoma (37.5%, emerging adults), and breast (30.4%, young adults, $p < 0.01$) were the most common cancers in this sample (Table 1).

Format

Navigator role Both the adolescent and young adult age groups thought a patient navigator should "fight for" them or act as an advocate during active treatment, while emerging adults did not discuss this idea (Table 2). Adolescents wanted to interface directly with the navigator instead of asking a parent or healthcare professional for access to navigation services. Young adults wanted the navigator to be an advisor on questions to ask their healthcare team or to inform them about services (e.g., fertility preservation). All age groups felt uncomfortable asking their medical team about issues they perceived as "random questions" or not directly related to their cancer treatment and were worried about seeming "needy." AYAs felt they had many questions over the course of treatment, especially concerning finances, home life, and insurance, which went unasked and unanswered because they were uncomfortable broaching non-medical issues with their healthcare team. AYAs thought a navigator could bridge this divide by raising questions patients feel uncomfortable bringing up on their own.

A few other age-specific differences emerged regarding the navigator role. Both adolescents and emerging adults thought a navigator could help to normalize their experience by reinforcing that other patients had similar questions and by validating their concerns. Emerging and young adults wanted the navigator to provide expectations before treatment commences and to be a neutral third party who could act as a sounding board for decision-making.

Communication Mode Participants expressed both positive and negative endorsement regarding a variety of communication modes with the navigator. Adolescents and emerging adults wanted face-to-face meetings with the navigator especially at the beginning of the relationship. While most young adults wanted face-to-face meetings, some were concerned about the potential inconvenience of meeting with a navigator in person. After establishing a relationship, in-person interaction was not always seen as necessary among participants. Preferences for mode of communication (e.g., phone, text, postcard, email) varied widely, with some adolescents and emerging adults stating they did not regularly check email, whereas young adults preferred email. All age groups, however, agreed that phone calls were important. Many participants were comfortable with exclusively digital forms of communication like texting, messaging within electronic medical record systems, video, and web chat. Convenience of communication was also discussed, with several participants indicating that they wanted to be able to contact the navigator outside of regular working hours.

Timing of interaction All age groups wanted access to patient navigation during all phases of treatment and thought the navigator would be particularly helpful in

Table 1 Demographic and cancer characteristics by developmental age at diagnosis

	Total ($N = 39$)	Age group at diagnosis			*p* value[d]
		Adolescents (15–18 years) $N = 8$	Emerging adults (19–25 years) $N = 8$	Young adults (26–39 years) $N = 23$	
	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)	
Current age at interview	31.2(8.0)	21.3(6.0)	29.9(8.7)	35.1(4.6)	*< 0.001*
Years since diagnosis	4.5(5.1)	5.5(6.2)	7.0(7.9)	3.3(2.9)	0.17
Gender	*N*(%)	*N*(%)	*N*(%)	*N*(%)	
Male	17(43.6)	6(75.0)	2(25.0)	9(39.1)	0.14
Female	22(56.4)	2(25.0)	6(75.0)	14(60.9)	
Annual household income					
< $25,000	8(20.5)	3(37.5)	4(50.0)	1(4.3)	*0.01*
< $35,000	7(18.0)	2(25.0)	2(25.0)	3(13.0)	
< $50,000	5(12.8)	1(12.5)	1(12.5)	3(13.0)	
> $50,000	19(48.7)	2(25.0)	1(12.5)	16(69.6)	
Race/ethnicity					
Non-Hispanic White	33(86.8)	6(85.7)	7(87.5)	20(87.0)	0.99
Hispanic/Latino	5(13.2)	1(14.3)	1(12.5)	3(13.0)	
Health insurance[a]					
Public (Medicaid, Medicare)	9(23.1)	3(37.5)	3(37.5)	3(13.0)	0.20
Private (employer/military, individual, Obamacare)	30(76.9)	6(75.0)	5(62.5)	21(91.3)	0.12
Marital status					
Married/partnered/engaged	25(64.1)	2(25.0)	4(50.0)	19(82.6)	*<0.01*
Single/separated	14(35.9)	6(75.0)	4(50.0)	4(17.4)	
Language spoken at home					
English	37(94.9)	8(100.0)	7(87.5)	22(95.6)	0.66
Other	2(5.1)	0(0.0)	1(12.5)	1(4.3)	
Treatment location					
Children's hospital	9(23.1)	7(87.5)	1(12.5)	1(4.3)	*<0.01*
Adult hospital	27(69.2)	1(12.5)	7(87.5)	19(82.6)	
Other[b]	3(7.7)	0(0.0)	0(0.0)	3(13.0)	
Cancer diagnoses					
Sarcoma	9(23.1)	3(37.5)	3(37.5)	3(13.0)	*< 0.01*
Thyroid	3(7.7)	0(0.0)	1(12.5)	2(8.7)	
Lymphoma	6(15.4)	5(62.5)	1(12.5)	0(0.0)	
Brain/central nervous system	4(10.3)	0(0.0)	1(12.5)	3(13.0)	
Breast	9(23.1)	0(0.0)	2(25.0)	7(30.4)	
Other[c]	8(20.5)	0(0.0)	0(0.0)	8(34.8)	

Values in italics are statistically significant ($p < 0.05$)

[a] Numbers add up to over 100% as participants were allowed to select multiple forms of insurance

[b] Other includes $N = 1$ rural community hospital and $N = 2$ unknown

[c] Other includes $N = 1$ of uterine, testicular, gastric, melanoma, and multiple myeloma

[d] *P* value for Fisher's Exact and ANOVA tests comparing each demographic and cancer factor by developmental age at diagnosis

supporting them during periods of healthcare transition (e.g., starting a new treatment, entering survivorship). All age groups had interest in working with a navigator while transitioning to survivorship and wanted the navigator to check in regularly, both during and off treatment. Some adolescents wanted the navigator to strike a balance between the frequency of regular check-ins and becoming overbearing.

Table 2 Preferred format, timing, and navigator role by developmental age at diagnosis

Categories, *Themes* and Subthemes	**Adolescents (AD)**	**Emerging Adults (EA)**	**Young Adults (YA)**	**Example Quotes**
Format				
Navigator Role				
Navigator as advocate -“Fight for me”	+		+/-	*“[The navigator] could be helpful as somebody that a patient could directly contact, instead of through your parent or another person on the healthcare team.”* –AD *“If you need somebody to talk to, if you don’t have anybody showing up like me, I can’t think of the word right now, but they fought for me and got me everything that I didn’t know about because nobody told me about any of it.”* –YA *“I wouldn’t want [the navigator] making choices for me. I wouldn’t want them necessarily discussing things with my doctor that I maybe was just blowing off steam to them. You know what I mean, like I wouldn’t want them speaking for me.”*-YA
Someone to ask for help without feeling “needy”	+	+	+	*“I’m just another patient to them [my physicians], and I don’t want to be a burden upon them.”* -YA
Setting treatment expectations	+	+		*“I think it would be nice to talk to someone who had talked to a lot of other people about similar things. I think it would be maybe validating almost.”* -EA
Neutral third party		+	+	*“I guess it would just be kind of a third party to check in on me and see how I was doing. Not friends and family, but kind of an outside person, making sure things are going okay.”* -EA
Communication Mode				
Face-to-face	+	+	+/-	*“Actually talking to somebody or seeing them in person, I feel like you’re able to get the more personal information you need to help them and guide them to the direction they need.”* -EA
Email	+/-	+/-	+	
Phone call	+	+	+	
Text message	+		+	
Electronic medical record messaging		+	+	
Video/web chat		+/-	+	
Timing of interaction				
Throughout cancer trajectory	+	+	+	*It’s like, ‘Okay…we’ll send you off on your way.’ You feel like, ‘Wait. Is this something I can do on my own? Are you sure? I’ve been so vulnerable and relying on others, but now I have to have self-efficacy again, and I don’t know how to do that.”* – YA *“From diagnosis to like the first two years. It’s a huge learning curve. You have to just step into it, and you have a lot to learn.”* -YA
Consistent navigator follow-up	+	+	+	*“I guess my idea of a navigator would be to call me to check up on what I’m doing, as opposed to me having to go figure out who that was.”* –EA *“It would be helpful if that person could call you every three to five to 10 years and say, ‘you’re on this list. It looks like it’s been this many years since you had cancer. We’re just calling to make sure you’re getting your checkups.’ The further away you get from treatment, the more you forget about it.”* –AD

+ subtheme was positively endorsed by age group, +/− subtheme was both positively and negatively endorsed by age group, − subtheme was negatively endorsed by age group, blanks indicate theme was not present in interviews with age group

Support

Emotional, Social, and Peer All age groups wanted emotional encouragement from the navigator throughout treatment (Table 3). However, other aspects of emotional, social, and peer support varied by developmental age. Both emerging and young adults thought the navigator should help them to “feel less alone” in their cancer experience whereas this was not discussed by adolescents. Young adults were the only group to request formal referrals to psychological support services from a navigator. In particular, this desired support among young adults included a need to discuss the “life and death” nature of cancer and for someone to talk to outside of their family. While less common, a few emerging and young adults negatively endorsed emotional support from a navigator because they felt uncomfortable disclosing their emotions to “a stranger.”

Family Participants felt the focal point of the navigator’s role in connecting with family members was to support

Table 3 Preferences for patient navigation support, healthcare, and resource services by developmental age at diagnosis

Categories, *Themes* and Subthemes	**Adolescents (AD)**	**Emerging Adults (EA)**	**Young Adults (YA)**	**Example Quotes**
Support				
Emotional, social and peer				
Encouragement	+	+	+	
"Feel less alone"		+	+	*"Everybody feels alone and not everybody wants to talk to their family."* –YA
Social support (peers, navigator, patients)	+	+/-	+/-	*"I know there was a support group, but it wasn't something that I wanted to take time out of my schedule to do."* –YA *"Emotional support seems like it wouldn't be so great, because [the navigator is] a stranger. So that might be kind of odd."*-EA
Psychosocial referrals			+	
Family				
Childcare	+	+	+	*"I think, especially where right now, I'm going to be going back to work and all that. The thing that always crosses my mind, or causes the most stress, is childcare."* -EA
Caregivers and parents	+		+	*"I even think it would've been helpful [for] my parents to have someone."*-AD
Spouses, partners and children			+	*"I would be so excited to have [someone to] point me in the direction of how to talk to my kids and [who] was able to talk me through some of the concerns that I had for me and my husband."*-YA
Healthcare				
Insurance and finances				
Explain insurance	+	+		
Review medical bills		+	+	
"Step-by-step" explanation of payments		+	+	
Financial assistance—living expenses		+	+	*"Staying up here, the travel, the extra food. I'm going to have to supply the household food and continue to pay rent and all those expenses."* -EA
Financial assistance—medical expenses			+	
Survivorship and late effects				
Updated information	+	+	+	*"In survivorship, you get pretty disconnected from that world, but then every once in a while, you have things come up where you need some answers, or you get worried about something and you're not quite sure what to do. So it would be nice to have that person who's still in charge of helping you."* -YA
Fertility and infertility			+	*"Maybe a navigator could've talked to me more in depth about what my fertility plans actually were, and maybe could've given me a heads up, like, 'Okay, maybe you don't want to have kids immediately, but maybe, should you consider freezing your eggs, because that might be necessary if you want to have kids in the next five to seven years, too.'"* -YA
Care coordination				
Single point of contact	+	+	+	*"I used to have so many doctors who were not coordinating well—someone to help with that would have been good."* -YA
Medical team too busy	+		+	
Resources				
Information needs				
Non-medical/simple questions	+	+	+	*"It's my responsibility to take care of myself, but [if someone] took some of the responsibility of research away, because I don't think about that stuff." -AD*
Access to community resources		+	+	*"If [the navigator] could help you find the [service] closer to home, I think that would be really beneficial."*-EA
Education				
College applications/scholarships	+			
Learning support (e.g. homeschool, working with teachers)	+			*"I've always homeschooled. School resource people didn't have a clue."*-AD

+ subtheme was positively endorsed by age group, +/− subtheme was both positively and negatively endorsed by age group, − subtheme was negatively endorsed by age group, blanks indicate theme was not present in interviews with age group

AYAs' caregivers and children. All age groups, including those diagnosed as adolescents, expressed needing assistance accessing childcare services. Both young adults and adolescents wanted their parents to have a relationship with the navigator as well. Young adults also wanted the navigator to help support their spouse/partner, help navigate changes in their relationships, and share advice about how to discuss cancer with their children.

Healthcare

Insurance and Finances Insurance and financial supports were frequently discussed across all age groups (Table 3). Adolescents and emerging adults wanted the navigator to explain how their treatment was paid for using insurance. Emerging and young adults wanted to review their medical bills with the navigator, have "step-by-step" explanations of payments, and requested that the navigator help them access financial assistance for daily living expenses (e.g., travel, childcare, household costs). Young adults requested financial assistance to pay for treatment.

Survivorship and Late Effects Across age groups, participants who were off therapy and further from diagnosis felt disconnected from their cancer experience and wanted the navigator to share updates on results of clinical trials, survivorship information, and late effects. All age groups felt as though regular contact with the navigator when they completed treatment would help them feel supported and part of the wider cancer community. Adolescents felt especially disconnected because they did not remember the specifics of their treatment regimen or follow-up care plan after treatment. Only young adults wanted the navigator to provide information about fertility preservation before treatment and infertility after treatment.

Care Coordination All age groups envisioned the navigator as a "single point of contact" who could direct questions to the right clinician or service. Both adolescents and young adults thought that a navigator could help with communication between busy healthcare providers and systems, particularly if they were receiving care at multiple institutions. Specifically, AYAs preferred to contact the navigator for non-emergent issues and questions first before trying to reach their busy medical team.

Resources

Information needs The most frequently requested resource from a navigator was providing information on non-medical concerns (Table 3). All age groups wanted a navigator as a convenient contact to answer and screen simple questions, or help direct AYAs to the right person to answer those questions. Emerging and young adults wanted the navigator to facilitate access to local non-medical resources (e.g., exercise programs) and encourage patients and survivors to use them.

Education Only adolescents endorsed support with their education from the navigator. They wanted assistance working with schools during treatment or help with homeschooling, and also thought a navigator could help to connect them with college applications and scholarships relevant to cancer patients.

Discussion

To our knowledge, this is the first study to describe variation in AYAs' navigation preferences using Arnett's developmental age classifications of adolescence, emerging, and young adulthood. Our findings build on earlier research that has identified gaps in care for AYAs with cancer including clinical (e.g., low clinical trial enrollment) [21], financial (e.g., lack of insurance, financial hardship) [22], and psychosocial needs (e.g., social isolation, post-traumatic growth versus stress) [23]. Using Arnett's developmental age groups to guide our qualitative analysis expands existing research by interpreting how stage of development influences AYAs' preferences for interacting with a patient navigator and the specific navigation services they desire. As more oncology programs are developed to meet the needs of AYAs with cancer [9], evaluations such as ours are essential to ensure these programs best address patient concerns.

Overall, our results demonstrate that AYA cancer patients and survivors have distinct preferences for the role of a patient navigator in their care. Unique developmental differences included that younger AYAs reported a direct need for assistance with school and wanted basic information about insurance. In contrast, older AYAs described more concerns about their family's well-being and finances. Some services were endorsed by all age groups. For example, regardless of age, AYAs want navigation support throughout the cancer continuum from initial diagnosis through survivorship. All age groups wanted support and encouragement from a navigator and were comfortable communicating both in person and virtually. Taken as a whole, these findings demonstrate that AYAs with cancer see a role for a patient navigator in their care and that providing developmentally tailored support for AYAs is an important consideration for navigators and patient navigation programs.

Providing navigation services to AYAs may require creative formats and schedules. Our participants emphasized that establishing trust with AYAs through initial face-to-face interactions at the beginning of treatment is essential for a new patient navigator interaction. Also, due to time constraints, some participants expressed reluctance to schedule a separate meeting with a navigator and preferred navigation to be integrated into regularly scheduled appointments. Such a format may require the navigator to reach out to patients first rather than waiting for them to self-refer. Navigators targeting AYAs should be comfortable using a variety of communication methods including text message and email, as well as meeting patients in person during medical appointments. Moreover, our findings underscore the need for patient navigators to be responsive to AYAs' schedules and competing life demands. Specifically, our sample wanted to be able to contact patient navigators outside of office hours and via a variety of communication platforms (e.g., text, email).

While access to emotional, social, and peer support was highly valued overall, an area of need consistently reported by our participants, regardless of age, was childcare. There is evidence that younger women may be less compliant with their cancer treatment due to the competing demands of childcare [24]. While navigators cannot directly provide childcare services, this does point to an important role of navigators in directing patients to community services that may be able to address such needs. Moreover, in working with the AYA population, it is essential that navigators be aware of and prepared to address the needs of caregivers and dependents of AYAs as family situations and types of caregivers (e.g., parent, friend, and spouse) vary during adolescence, emerging adulthood, and young adulthood.

A growing body of literature exists on the fertility and infertility support needs of AYAs. However, in our sample, only AYAs diagnosed as young adults discussed issues around fertility. We suspect that this could be a result of a potential lack of patient and provider education and communication on fertility issues, especially among younger AYA patients who may not be perceived as needing reproductive counseling [25]. In addition, the adolescents and emerging adults we interviewed were further on average from diagnosis than the young adults, which could potentially explain these differences as fertility concerns may be more salient for patients closer to treatment. Also, as the average age of young women at birth of first child in the USA is in the young adult age group at 26 [26], fertility issues may impact young adults more acutely than younger age groups who may not yet be trying to start a family. We suggest that future research explore age-related differences in fertility navigation needs and consider patients both on and off therapy to ascertain how their needs may change over time.

Insurance and finances were the most frequently cited themes for healthcare support, positively endorsed by all age groups. Compared to adolescents, who wanted general explanations of what insurance is and how it works, older AYAs wanted more detailed information about medical bills, insurance payments, and financial assistance. Emerging and young adults also requested navigator support for assistance with finding resources to help with rent, bills, and groceries. Financial independence and accepting personal responsibility are pivotal characteristics of emerging and young adulthood [13], but a cancer diagnosis often results in financial burden and employment limitations for patients. Patient navigators may have to be particularly sensitive in assisting this age group with resource support.

We acknowledge that our age categories are generalized, and it is possible participants may function outside of their respective adolescent, emerging adult, or young adult age groups. In addition, the sample encompassed a broad range of experiences and each age group included participants who were less than a year from diagnosis and receiving active treatment to several participants who had been in survivorship for a decade or more. As participants were on average 4.5 years from diagnosis and had to have been at least 1 month into their cancer therapy to enroll in the study, survivor bias may have influenced the type of format or support services that participants requested. For the current report, we were unable to examine differences in preferences by time since diagnosis, but we suggest that as an important consideration for future studies of AYAs' navigation needs. That said, participants in our sample who had aged out of their age group at diagnosis or who were off therapy appeared to be better able to reflect on their treatment experience as a whole. Some participants felt disconnected from their cancer experience and requested information on survivorship needs such as late effects.

Despite these limitations, our analyses provide an important framework for developing navigation programs in AYA oncology. Since the Adolescent and Young Adult Oncology Progress Review Group was initiated in 2006, the number of AYA-focused programs in the USA has grown, but many have been constrained by limited budgets and a lack of metrics by which to measure success [9, 27]. Those interested in starting an AYA oncology program might begin with a low-cost intervention like patient navigation as a first step in establishing unique AYA services. Future assessments of AYA navigation services' impact on barriers to care, disease outcomes, and healthcare utilization [28] should employ an age-specific model to fully capture improvements and needs among the entire AYA age group. In addition, the young adults in our sample tended to be closer to diagnosis than adolescents and emerging adults, which may explain why this age group reported more specific concerns around fertility and finances. While outside of the scope of the current report, these findings demonstrate that navigation programs targeted to AYAs should consider not only the unique age differences, but potential difference by time since diagnosis in providing services to their patients.

As this study demonstrates, the needs of AYAs are many and varied. While navigators may not be able to meet all AYA needs alone, they can assist AYA patients and survivors in finding and accessing appropriate resources. Overall, AYAs in our sample preferred highly individualized attention. As such, it is important to recognize possible time and resource constraints on patient navigators as the needs of AYAs with cancer can be complex. Programs with large AYA populations who are considering patient navigation should establish realistic caseload limits and should consider using developmental stages as a guide for defining boundaries of patient navigation services. For instance, when working with young adults, navigators may focus more of their attention on financial support, whereas when working with adolescents, they may want to spend more time screening education needs. In addition, tailoring patient navigation services to age-specific preferences may help navigators to better meet the needs of their AYA patients while providing cost-savings for programs with limited resources.

Patient navigators, nurse/patient coordinators, and other supportive care professionals are well-poised to identify needs, values, and communication styles of their AYA cancer patients and survivors. While some navigation needs span the AYA age range (e.g., childcare and information needs), certain supports are pertinent to specific developmental ages (e.g., education) and should be addressed accordingly. This research provides important information about patient navigation preferences by developmental age to inform targeted navigation services throughout treatment and survivorship.

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Conflicts of Interest The authors declare that they have no conflicts of interest.

References

1. National Cancer Institute and the LiveStrong Young Adult Alliance (2006) Closing the gap: research and care imperatives for adolescents and young adults with cancer. Report of the adolescent and young adult oncology program review group. US Department of Health and Human Services, National Institutes of Health, National Cancer Institute, LIVESTRONG Young Adult Alliance. Available at: https://www.cancer.gov/types/aya/research/ayao-august-2006.pdf
2. Keegan THM, Tao L, DeRouen MC et al (2014) Medical care in adolescents and young adult cancer survivors: what are the biggest access-related barriers? J Cancer Surviv 8:282–292. https://doi.org/10.1007/s11764-013-0332-4
3. Smits-Seemann RR, Kaul S, Zamora ER et al (2017) Barriers to follow-up care among survivors of adolescent and young adult cancer. J Cancer Surviv 11:126–132. https://doi.org/10.1007/s11764-016-0570-3
4. Husson O, Zebrack BJ, Block R et al (2017) Health-related quality of life in adolescent and young adult patients with cancer: a longitudinal study. J Clin Oncol 35:652–659. https://doi.org/10.1200/JCO.2016.69.7946
5. Bleyer A Young adult oncology: the patients and their survival challenges. CA Cancer J Clin 57:242–255
6. Weiss AR, Nichols CR, Freyer DR (2015) Enhancing adolescent and young adult oncology research within the National Clinical Trials Network: rationale, progress, and emerging strategies. Semin Oncol 42:740–747. https://doi.org/10.1053/j.seminoncol.2015.07.012
7. Rocque GB, Pisu M, Jackson BE et al (2017) Resource use and medicare costs during lay navigation for geriatric patients with cancer. JAMA Oncol 15:1–15. https://doi.org/10.1001/jamaoncol.2016.6307
8. Loskutova NY, Tsai AG, Fisher EB et al (2016) Patient navigators connecting patients to community resources to improve diabetes outcomes. J Am Board Fam Med 29:78–89. https://doi.org/10.3122/jabfm.2016.01.150048
9. Reed D, Block RG, Johnson R (2014) Creating an adolescent and young adult cancer program: lessons learned from pediatric and adult oncology practice bases. J Natl Compr Cancer Netw 12:1409–1415
10. Christen S, Vetsch J, Mader L et al (2016) Preferences for the organization of long-term follow-up in adolescent and young adult cancer survivors. Support Care Cancer 24:3425–3436. https://doi.org/10.1007/s00520-016-3157-7
11. Albritton KH, Wiggins CH, Nelson HE, Weeks JC (2007) Site of oncologic specialty care for older adolescents in Utah. J Clin Oncol 25:4616–4621. https://doi.org/10.1200/JCO.2006.08.4103
12. Arnett JJ (2001) Conceptions of the transition to adulthood: perspectives from adolescence through midlife. J Adult Dev 8
13. Arnett JJ (2000) Emerging adulthood:a theory of development from the late teens through the twenties. Am Psychol 55:469–480. https://doi.org/10.1037//0003-066X.55.5.469
14. Zebrack B (2008) Information and service needs for young adult cancer patients. Support Care Cancer. https://doi.org/10.1007/s00520-008-0435-z
15. D'Agostino NM, Edelstein K (2013) Psychosocial challenges and resource needs of young adult cancer survivors: implications for program development. J Psychosoc Oncol 31:585–600. https://doi.org/10.1080/07347332.2013.835018
16. Warner EL, Kent EE, Trevino KM et al (2016) Social well-being among adolescents and young adults with cancer: a systematic review. Cancer 122:1029–1037. https://doi.org/10.1002/cncr.29866
17. Munoz AR, Kaiser K, Yanez B et al (2016) Cancer experiences and health-related quality of life among racial and ethnic minority survivors of young adult cancer: a mixed methods study. Support Care Cancer 24:4861–4870. https://doi.org/10.1007/s00520-016-3340-x
18. Gupta AA, Edelstein K, Albert-Green A, D'Agostino N (2013) Assessing information and service needs of young adults with cancer at a single institution: the importance of information on cancer diagnosis, fertility preservation, diet, and exercise. Support Care Cancer 21:2477–2484. https://doi.org/10.1007/s00520-013-1809-4
19. Zebrack B (2014) Patient-centered research to inform patient-centered care for adolescents and young adults (AYAs) with cancer. Cancer 120:2227–2229. https://doi.org/10.1002/cncr.28734
20. Saldaña J (2013) The coding manual for qualitative researchers, 2nd edn. Sage, Los Angeles
21. Jacob SA, Shaw PH (2017) No improvement in clinical trial enrollment for adolescents and young adults with cancer at a children's hospital. Pediatr Blood Cancer:e26638. https://doi.org/10.1002/pbc.26638
22. Rosenberg AR, Kroon L, Chen L et al (2015) Insurance status and risk of cancer mortality among adolescents and young adults. Cancer 121:1279–1286. https://doi.org/10.1002/cncr.29187
23. Lang M, Giese-Davis J, Patten S, Campbell DJT (2017) Does age matter? Comparing post-treatment psychosocial outcomes in young adult and older adult cancer survivors with their cancer-free peers. Psychooncology. https://doi.org/10.1002/pon.4490

24. Pan I-W, Smith BD, Shih Y-CT (2014) Factors contributing to underuse of radiation among younger women with breast cancer. J Natl Cancer Inst 106:djt340. https://doi.org/10.1093/jnci/djt340
25. Kirchhoff AC, Fowler B, Warner EL, et al 2017. Supporting adolescents and young adults with cancer: oncology provider perceptions of adolescent and young adult unmet needs. J Adolesc Young Adult Oncol jayao.2017.0011. https://doi.org/10.1089/jayao.2017.0011
26. Mathews TJ, Hamilton BE (2016) Mean age of mothers is on the rise: United States, 2000–2014. NCHS data brief, no 232. Hyattsville: National Center for Health Statistics
27. Ferrari A, Thomas D, Franklin ARK et al (2010) Starting an adolescent and young adult program: some success stories and some obstacles to overcome. J Clin Oncol 28:4850–4857. https://doi.org/10.1200/JCO.2009.23.8097
28. LaRosa KN, Stern M, Bleck J, et al 2017. Adolescent and young adult patients with cancer: perceptions of care. J Adolesc Young Adult Oncol jayao.2017.0012. https://doi.org/10.1089/jayao.2017.0012