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Provider perceptions' of a patient navigator for adolescents and young adults with cancer

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Abstract

Purpose—Healthcare providers (HCPs) and other staff at a comprehensive Cancer Center were interviewed on how to best implement a patient navigator position when working with adolescents and young adults (AYA) with cancer. Research objectives included assessing staff perceptions of (a) barriers to optimal care for AYA, (b) roles and responsibilities for a patient navigator, and (c) training needed for future patient navigators.

Methods—Semi-structured interviews were conducted with 17 staff members providing care to AYA. Verbatim transcripts were hand-coded using inductive content analysis.

Results—Roles and responsibilities of a patient navigator were described as needing to coordinate services, be knowledgeable of resources inside and outside the Cancer Center, provide emotional support, advocate for AYA, assist with financial and insurance issues, and serving as the first point of contact.

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Compliance with ethical standards

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Conclusions—Staff serving AYA reported the desired roles and training they wished a patient navigator to possess. This study contributes to the literature by conducting stakeholder assessment of the goals and roles of an AYA patient navigator (PN). PN positions should be adapted to the workflow and ethos of the institution.

Keywords

Adolescent and young adult; Patient navigator; Cancer; Qualitative; Health services

Introduction

Adolescents and young adults (AYA) with cancer ages 15–39 years account for approximately 70,000 new invasive cancer diagnoses in the USA annually [1]. Improvements in survival estimates in AYA are lower than younger and older patients [2], regardless of disease [1], which is attributed to reduced access to cancer care, delays in diagnosis, non-adherence to treatment, age-specific psychosocial factors (e.g., increased risk- behaviors) and challenges in accessing supportive cancer care services, and lower levels of participation in clinical trials [2, 3]. AYA with cancer experience more complex and long-lasting distress than older adults or younger children with similar diagnoses [4, 5]. Unique psychosocial issues have been i dentified among AYA, distinguishing them from pediatric and adult populations. These include concerns about future romantic and peer relationships and interrupted life plans, limited availability of mental health services and social support networks, increased parental dependence, disruption in school or career paths, and concomitant financial challenges [6, 7].

A patient navigator (PN) is a position based on a patient-centered, intervention model with the goal of reducing barriers during cancer care [8]. A PN provides services to individual patients for a defined period, targets a set of health services and patient specific barriers, and aims to reduce delays in accessing services. A traditional navigator's primary responsibilities include explaining medical procedures and appointments, eliminating barriers in treatment participation and adherence, coordinating communication among the medical team, identifying potential patients in need of follow-up, building networks, documenting necessary action steps by the patient or medical team, and supporting research [9]. Common barriers addressed by a PN include financial and insurance concerns, transportation issues, and managing feelings or fear related to cancer [8]. A PN has been found to increase cancer screenings and timely resolution of cancer screening abnormalities, leading to reductions in the prevalence of late-stage disease [10–12]. In addition, a PN was associated with improved quality of life and cancer survival [10–12].

Despite these findings, there is no "one-size-fits all" approach to a PN position and service delivery should be tailored to specific barriers of the individual or population and fit the workflow and ethos of the institution [13]. In an effort to tailor a PN specifically for AYA with cancer, we interviewed AYA in a previous study to determine barriers to care during and after cancer treatment [14]. AYA reported the following barriers: (1) lack of communication regarding transitioning to survivorship, (2) difficulty managing and communicating with the Cancer Center about financial and insurance issues, and (3) managing psychological and physical symptoms throughout treatment [14].

The overall research objectives of the current study were to gather perceptions from HCPs and other hospital staff on: barriers to optimal care for AYAs, roles and responsibilities for a PN, and training needed for future PNs. While the extant literature has examined perceptions to inform AYA program development and functioning, this study specifically aimed to identify ways that a PN could best serve AYA in a large, freestanding Cancer Center.

Methods

Recruitment

Staff at a designated National Cancer Institute and Comprehensive Cancer Center with a clinical program dedicated exclusively to AYA care were interviewed to identify perceived barriers to optimal care during cancer treatment, as well as the desired roles, responsibilities, and training of an AYA PN to fit within the workflow and ethos of the institution. Optimal care was intentionally not defined for staff to prevent bias in gathering information on perceived barriers.

The physician leader of the AYA program and a supportive care clinician identified potential staff across a range of occupations based on their frequency of interactions with AYA. Staff were considered eligible if they had worked at the Cancer Center for at least 6 months and were in a position where they provided care to AYA. Thirty-one providers were contacted via email, and 17 (54.8%) responded to the email and agreed to participate in an interview. Incentives were not offered. The study was approved by the Cancer Center’s Institutional Review Board.

Procedures

Semi-structured interviews were conducted to elicit HCP’s perceptions regarding barriers to optimal care for AYA with cancer, as well as services and support needed during cancer care that could be provided by a PN. Interviews ranged between 30 and 60 min ($M = 45$ min). Sample questions included the following: (1) “What are the biggest barriers to optimal care that AYA experience during treatment?” (2) “Which services at [Cancer Center] have been helpful in addressing these barriers?” (3) “What additional services could a patient navigator provide/what role could a patient navigator fill?” (4) “What training should a patient navigator have?” Interviewers were trained on potential follow-up questions and probes to gather more information on specific barriers (e.g., financial issues), services, or training.

Trained doctoral level investigators, unaffiliated with the Cancer Center, conducted interviews with staff. Seventeen interviews were completed to allow all who indicated interest in participating, the opportunity to share their views. The themes saturated on final analysis and refer to the point in which no new information is forthcoming [15]. Specifically, there was no content in any of the interviews that was not duplicated by others. Saturation was determined by study team discussions about the content of the interviews during the coding process. In total, 16 interviews were conducted in person and one by telephone. Interview modality did not cause variation in the quality, length, or content of the interview.

Analyses

Audiotaped interviews were transcribed verbatim and analyzed through inductive content analysis [15]. This form of analysis aids in establishing clear links between the intended questions (a priori themes) from the interview guide, as well as any emergent themes that may arise [15]. Open coding was used to create initial impressions, and initial codes were compared across four independent coders to develop a codebook. The codebook was refined to be representative of selective coding using the constant comparative method [16]. The research team repeatedly met to discuss coding, which resulted in creating a definition for each code with examples and non-examples. Reflexivity was practiced at each study team meeting prior to, during, and after the interviews with group discussion to ensure meaning of terms and that language and expressions were mutually understood [17]. A final revised codebook was created for coding, which was utilized for re-coding of the transcripts and the establishment of inter-rater reliability (IRR). Themes were then created from the code groupings.

IRR was established between two separate teams of two coders each at the initial, middle, and final stages of data collection to ensure consistency of coding over time. At each time point, IRR remained at a kappa value of 0.80 or above. Rigor was ensured through the use of verbal debriefing, crosscoding, and the establishment of IRR [18, 19].

Results

Staff in this study represented a variety of positions (e.g., oncologists, Advanced Registered Nurse Practitioner) and were mostly female (59%; Table 1). All staff were at least 30 years old and most were White (82%).

Barriers to optimal care for AYA

Themes deriving from code groupings for staff reported barriers to optimal care for AYA included *financial and insurance needs, psychological needs and symptoms,* being *unprepared for the unexpected*, and experiencing *fertility-related concerns.* In addition, staff noted AYA had difficulty *balancing medical appointments with the rest of their life* due to work, school, or starting a family. Finally, staff described barriers for AYA in navigating their medical care with their *parents as protectors* (Table 2). Staff perceptions of barriers to optimal care for AYA were congruent with those reported by AYA in our earlier study [14].

Role and responsibilities of a patient navigator

Staff members described what roles, responsibilities, and training they believed a PN should have. Themes are discussed below and further delineated in Table 3.

Coordination of services—All staff described the PN as coordinating services in order to “fill in the gaps” in AYAs’ care. One employee described the need to prevent AYA from “falling through the cracks,” indicating that patients may not be getting connected or referred to the proper departments in order to meet their needs.

> "I see a lot of youngsters definitely falling through the cracks...if there is something systemically that we can do...to make things better, we should be doing it." (Female, MD)

In terms of the PNs' role in systematically coordinating services, another staff member described the navigator as someone who guides a boat and keeps it on course, despite not being the person to steer it:

> "The navigator doesn't steer the boat, but.knows where the boat needs to go.so helping the patient plot that course.knowing where the recent shows are, knowing where the heavy wind is, the light wind is, all those things. That would be the navigator's role. " (Male, Patient Relations)

Yet another staff member described more specifically how he saw the PN guiding AYA through treatment. This staff member was a financial analyst, who was also an AYA cancer survivor.

> "The Patient Navigator is a person who.assists with the journey of the patient through their treatment.pos- sibly linking them to the correct resource specialist or financial counselor, to the emotional psychosocial component.if they feel that they are alone in this, 'No, hey here's person X who's gone through something similar. "(Male, Financial Analyst)

As equally important as what the PN should do, was what staff felt he/she should not do. One individual described the need for the PN to "stay on their own turf" and not try to fill the role of other positions at the Center:

> "I think that the navigator should.fill in the gaps.the worst thing that the navigator could probably do. would be to try to replace something that exists because that seems to be the biggest fear. So the navigator cannot say, 'Here's how I would treat your cancer,' because a physician - the physician backlog, backlash, will be horrific and the navigator will be run out of town. The navigator cannot do something that the nurses would consider in their domain. Nor should they tread on what the social workers exactly do at this point. I think of the navigator as being able to plug into any of those ser- vices.and then to make that referral. and see it through. " (Male, MD)

Knowledge of resources inside and outside of the center—The majority of staff also felt the PN should be knowledgeable of and connect the AYA to resources both within the Center and throughout the community.

> " …know the resources out in the community…that navigator is going to have to know the resources that we have available here [at Cancer Center] .you can't expect them to know everything about all of [state], but know.where to go to contact, to find out these resources." (Female, RN)

Provide emotional support and serve as an advocate for AYA with cancer—Almost all staff expressed the PN should be em-pathetic and non-judgmental, with strong listening and communication skills. This included providing emotional support and advocating for the AYA when necessary. Some providers noted this as important due to the protector role that parents may play during communication with the doctor, which may limit the AYAs' voice in the conversation.

> "They need to be able to listen. Honestly, not just talk to people.a quiet, safe environment where people can. sit still and talk if they need to. A comfortable… place to get a drink, or…Kleenexes…being flexible to allow that person to be where they are…" (Female, ARNP)

Help deal with financial and insurance issues—The majority of staff discussed the financial burden of cancer treatment and barriers when dealing with insurance. This was a concern staff felt the PN should play a large role in reducing barriers during treatment.

> ".for a lot of those patients, just having somebody to help steer them.getting them to whoever they need to see.they have a lot of needs.financial needs, insurance - which.is a ballooning problem - that's really what people need a lot of help with." (Female, MD)

Navigator as first point of contact and able to collaborate with other departments—The majority of staff also endorsed the PN as the first point of contact for AYA. In addition, staff felt the navigator should collaborate with various departments within the Cancer Center as an integral part of the health care team.

> "...I think the navigator would ensure the first days, or first weeks, or beginning-of-time experience with [Cancer Center] would be more consistent." (Male, MD)

> "If [the navigator] was an integral part of our team- When I give out a handout to new patients, it has the doctor's name and phone number. and...talks about our triage nurses... I think the navigator could be . introduced as an integral part of the team as well". (Female, RN)

Desired training of a patient navigator

Staff perceptions of the desired training for a PN included a preference for prior clinical training, particularly in the areas of nursing or social work. Overall, a nursing background was favored by MDs and ARNPs. Staff felt the navigator should be skilled in working with chronic health conditions and some respondents stressed the benefit of being knowledgeable about psychological aspects of coping with a chronic health issue (Table 3).

> "But you definitely have to have some sort of a medical background.. .I don't think it could just be a layperson. But I think a social worker. or a nurse, physician assistant." (Female, RN)

In addition, staff felt the PN should appeal to AYA by increasing the Cancer Center's online presence and use this to provide information regarding the Cancer Center's ability to serve the needs of the population. Last, a few felt it would be beneficial for the PN to be younger in age, to better connect and understand AYAs' needs. However, this desire was balanced by the greater priority for the PN to have clinical expertise. Because of the institution's ethos and priority focus on fertility preservation (designated Fertile Hope Fertility Preservation

Center of Excellence), staff felt the PN should have detailed knowledge of fertility and reproductive health related concerns.

Discussion

This study contributes to the literature by modeling the necessary steps to create a PN program for AYA, in addition to tailoring the role of the PN to the workflow and ethos of an institution, rather than implementing a “one-size-fits-all” approach. This is especially important, as AYA with cancer may not fit into traditional systems of care in adult or pediatric Cancer Centers due to unique psychosocial barriers [1–7, 14]. In order to design an AYA PN in a way that best suits an institution, we suggest gathering essential stakeholder perspectives (e.g., AYA patients, survivors, and staff) on barriers to optimal care. In addition, stakeholder input should be collected on the desired background, experience, and roles/ responsibilities of a PN, prior to outlining a job description and seeking to fill this position. Gathering stakeholder input assists in determining project feasibility, design, and implementation [20], and may be essential in generating buy-in to avoid the perception that the PN is overlapping existing roles or services.

Given evidence-supporting a PN in the extant literature [10–12], the Cancer Center was dedicated to creating a position targeted specifically for AYA. Interviews identified staff perceptions of barriers to optimal care for AYA with cancer, as well as the desired roles, responsibilities, and training of a PN with the goal of designing a role that fit with the culture of the institution. In a previous study, AYA reported barriers to optimal care included management of physical and mental health symptoms, fear of cancer reoccurrence, and limited assistance with financial issues [14]. Staff interviewed in the current study also noted financial and insurance issues, as well as psychological needs and symptoms as a barrier [14]; however, they described additional barriers including fertility concerns, AYA being unprepared to understand a health system and unprepared for an unexpected cancer diagnosis, as well as how to navigate their medical care with protective parents.

Staff believed the PN should fill the following roles or responsibilities: (1) coordinate services to ensure patient needs do not “fall through the cracks”, (2) be knowledgeable of and connect AYA to resources in and outside of the Cancer Center, (3) provide emotional support and serve as an advocate, (4) support AYA in dealing with financial and insurance issues, (5) serve as the first point of contact within cancer care, and (6) collaborate with other departments within the Cancer Center. These findings are consistent with previous literature indicating a PN’s primary responsibilities include eliminating barriers during cancer treatment and coordinating communication among the medical care team [9].

Staff reported the PN should have a nursing or social work background, which is also consistent with previous literature [8]. However, other studies note a PN may include cancer survivors [21], health educators, or lay navigators [22]. While staff noted the benefits of the PN understanding what AYA were going through during the cancer continuum, they reported the benefits of a professional PN were more important than those of a lay navigator. In addition, because of fertility preservation concerns in this population, as well as the particular emphasis of this area of concern at the institution, staff felt an AYA PN should play an essential role in initiating conversations regarding fertility preservation.

Novel staff perceptions of the PN's role included serving as an advocate and emotional support system for AYA. In a previous study [14], AYA with cancer discussed the process of losing and regaining their independence. They felt they were becoming adults and gaining their freedom, only to lose it and become dependent on their parents once again. HCPs and staff described a similar event when discussing the barrier of *parents as protectors,* noting that parents were often protective and AYA felt stuck between wanting someone to care for them and losing independence [23]. Providers noted the importance of the PN being empathetic, non-judgmental, a good listener, and an advocate when needed. These qualities were viewed as important in ensuring the AYAs' voice is heard within the triad of communication (AYA, parent, HCP) [24]. The PN may assist in promoting positive discussion among the triad, while reducing communication barriers, especially during critical conversations such as those regarding fertility.

PNs may also provide AYA with a safe place to share their voice and *serve as an advocate* to connect AYA to other services and systems. This is a concern that may be unique to AYA, particularly due to the barriers noted related to *losing and regaining independence* [14] and *parents as protectors* [25].

Although financial and insurance issues are identified in previous literature as concerns by all age ranges during cancer treatment, AYA may face unique challenges in this domain compared to older and younger age groups, as AYA are the highest uninsured group in the U.S. [1]. Findings suggests young, uninsured adults are more likely to be diagnosed at the advanced stage, be undertreated, or die after a cancer diagnosis compared to those who are insured [26]. In addition, despite the advances in cancer medicine, health disparities remain among those living in poverty, which has been linked to barriers in accessing care [26, 27]. In this light, a PN has been shown to improve the rate and timeliness of cancer care for low income and underserved patients [28, 29].

Staff noted AYA with cancer may have just begun their careers, still be in school, or have families, and may not have established health care benefits at the time they receive a cancer diagnosis or may have just started receiving state benefits as a result of their diagnoses. Staff also noted that AYA with cancer are likely to be inexperienced with navigating medical systems and insurance companies, which is a conclusion supported by other literature in this population [30, 31].

In summary, in an effort to tailor a PN specifically to AYA and work within the workflow and ethos of a comprehensive Cancer Center, staff perceptions indicated that a PN targeted for AYA may fill multiple roles and responsibilities, particularly based on unique barriers to optimal care faced by this population [1–7, 14].

Limitations

While this study has many strengths, it should be considered in light of its limitations, which include the use of a convenience sample of AYA staff in one comprehensive Cancer Center.

As such, and as with all qualitative research, results may not be generalizable to other healthcare facilities providing cancer care. Moreover, the Center was committed to hiring a PN and this mandate may have served as bias to our qualitative investigation.

Conclusion

A PN should be adapted to the workflow and ethos of the institution by conducting stakeholder assessment of the goals and roles of an AYA PN. Future research regarding a PN and AYA should emphasize the role of the navigator in increasing AYA participation in clinical trials, improving communication methods within the triad of communication, and connecting AYA to services related to reported barriers (e.g., physical and psychosocial needs, financial and insurance issues, and fertility). Further evaluation is needed on the efficacy of a PN for AYA, as well as what navigator activities are essential for improved outcomes.

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Table 1

Demographic information for staff

Variable	*N* (%)
Gender	
Female	10 (59)
Male	7(41)
Position	
Medical doctor	7(41)
Registered nurse (e.g., ARNP; RN)	4 (24)
Social worker	2(12)
Psychologist	1 (6)
Patient and family services	1 (6)
Financial analyst	1 (6)
Patient relations	1 (6)
Age	
40 +	10 (59)
Race	
White	14 (82)
Asian	2(12)
African American	1 (6)
Ethnicity	
Hispanic	3(18)
Non-Hispanic	14 (82)

Percentages are rounded and may not add up to 100%

Table 2

Barriers reported by providers

Barriers	Provider quotes
Financial and insurance issues	“…it would be great if every patient…not even just uninsured patients, but even some patients that have insurance -if we [comprehensive Cancer Center] took everyone’s insurance.But, unfortunately. [we] could do better.to be on more health care plans…” (Male, MD)
Psychological needs and symptoms	“We have some patients that need just true psychological or psychiatric care, and getting them that kind of help, that level of help promptly is really hard.” (Female, MD)
Unprepared for the unexpected	“I think the usual shock and denial when you are diagnosed with cancer I think they are…in that stage of.life where they have started college or got a job. When they do accept.they have cancer, there is this feeling. ‘I am not gonna tell anybody. ..I’ll move on.’ There’s not an understanding of what the whole cancer picture could look like.” (Female, Social Worker)
Fertility concerns	“Some patients need to start treatment [for cancer] yesterday. We see a ton of patients on a daily basis, and so I can understand why there might be some patients falling through the cracks and not aware of what their fertility preservation choices are.” (Male, Financial Analyst)
Balancing medical appointments with the rest of life	“For. the young adults who are kind of new to the system.a lot of them are either.early in their working careers and probably have young families. And so,.financial issues, family issues, childcare issues, are. definitely kind of the immediate concerns.how do you get time off to come to appointments and all that.” (Male, MD)
Parents as protectors	“they have [AYA] just become independent and now their parents are hovering.the physician will often speak with the parents, which is a problem. In some ways, there’s ambivalence there for the young adult. They do want to be taken care of. This is a nightmare and they regress back to this horrible place of being a baby who needs to be taken care of.” (Female, Social Worker)

Table 3

Themes and sample quotes regarding patient navigator

Roles and responsibilities of a patient navigator	
Coordination of services	“The role of the patient navigator is to make sure that the patients’ treatment, or that the time that they are at [comprehensive Cancer Center] goes well, and that they are aware of all these different services that are available for them.” (Male, Financial Analyst)
Knowledge of resources inside and outside of the comprehensive Cancer Center	“I would want to make sure that they know about all the programs specifically for young adults. So that would be the lounge, that would be Meet Up, that would be Art Up, these sorts of events where they can interact with people. That they know that there are events coming up.and how to get in touch with people.” (Male, MD)
Provide emotional support and serve as an advocate	“I think a Navigator is the go-to person who’s non-judgmental, non-medical, who’s kinda like your new best friend. Combination of advocacy but to just kind of making it human. It just seems, this person…would fill that role of making [AYA’S] life a little smoother and less distressed.” (Female, Psychologist)
Help deal with financial/insurance issues	“. the Navigator needs to work hand-in-hand with our financial counselors and with our resource specialists to be able to assist them [AYA] through this process.” (Male, Financial Analyst)
First point of contact/collaborate with other departments	“I think they could be that first look, that first line, first point of connection here.just start with that. Really introducing them to the whole hospital experience.” (Female, Social Worker)
Desired training of a patient navigator Nursing background	“I probably would like to see it be a nurse, but I am a nurse. And so I think that nurses know the systems well. I think they are trained in biopsychosocial and. that would be helpful to patients. And.it would be better to have a younger nurse. And I mean somebody that’s in their 30s, 40s, that’s had some experience, but rather than somebody in their 60s and 70s. “ (Female, ARNP)
Social work background	“Truthfully, I would think of.Bachelors of Social Work, or…in psychology. Something where they have been exposed to courses that will help them.understand human personality and adjustment to illness. It’s almost like they are gonna be doing a.mini-assessment. It does not mean they are getting into depth and detail about any of these things.they would be.referring out, but they have to know the right questions to ask. “ (Female, Social Work)