Collaborating with Adolescents and Young Adults with Cancer as Advisors

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There is a growing interest by both pediatric and medical oncologists to develop adolescent and young adult (AYA)-specific cancer programs. Input from AYA patients is critical to the successful design of these programs and to ensuring that patient needs are met. As traditional in-person advisory groups may not be the most appropriate means for engaging AYAs, this article describes the creation and implementation of a novel, developmentally appropriate, and efficient Young Adult Advisory Program. Reach, uptake, and participant demographic and clinical characteristics are presented alongside lessons learned. The findings are offered to assist others seeking to engage AYAs in program development and quality improvement efforts.

Keywords: Advisory Committee, patient engagement, healthcare systems, patient participation

Introduction

IN RECENT YEARS, a growing number of institutions have developed programs to meet the unique medical, psychosocial, and supportive care needs of adolescents and young adults (AYAs) with cancer (AYAs, individuals ages 15–39 years per the National Cancer Institute).^{1,2} As they begin to establish models of clinical care, AYA programs housed in both pediatric and adult hospitals face the challenge of understanding how best to care for a population whose needs differ from those of their primary patient base. Often clinician and hospital assumptions fall short of identifying AYA patient needs. Therefore, engaging AYAs with cancer as advisors is critical to developing patient-centered AYA programs and has the potential to improve clinical care processes. In other populations, such efforts have resulted in better health outcomes and increased patient safety.³

Traditional approaches to patient engagement are largely composed of in-person patient advisory councils which meet regularly at the hospital.^{4–6} Despite its success in other populations,^{5,6} this approach does not align with the busy and shifting schedules of AYAs or their preference for technology-based engagement. While utilizing a traditional in-person patient advisory council, we found it difficult to maintain AYA engagement, particularly as individuals transitioned to new life stages (i.e., college). Despite efforts to meet at times convenient for AYAs, generally only half of the 15 members attended each in-person meeting. Other barriers to the traditional in-person patient advisory council approach include the time and resources required to recruit patients (i.e., reminder

emails/calls), the selection bias inherent in in-person meetings (i.e., excluding patients who live far away, patients who do not want to engage socially with their care team or other patients, and patients preferring to provide feedback anonymously), and the lag time between an identified clinical need and receipt of patient feedback.

Given the limitations of the traditional in-person patient advisory council format, we engaged the AYA oncology team at our children's hospital to develop a novel and developmentally appropriate Young Adult Advisory Program. The purpose of this article is to discuss the key program development steps using the framework for engaging patient advisors as defined by the Agency of Healthcare Research and Quality (AHRQ).⁴ Patient engagement results for our first three clinical initiatives are presented along with lessons learned. To our knowledge, this is the first article to report on the development of an advisory program specifically for AYAs with cancer. We hope it can serve as a guide for other institutions seeking to engage AYAs with cancer in a developmentally appropriate, efficient, and sustainable manner.

Methods

All study procedures were approved by our hospital's institutional review board.

Young Adult Advisory Program development

AHRQ step 1: identify a team of liaisons⁴. Recognizing the limitations of the in-person advisory council format and the critical need for a novel method of engaging AYAs with

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cancer, we convened a team of experts in AYA oncology and marketing. The leadership team includes a psychologist, social worker, oncologist, and marketing and communications associate. The psychologist (first author) serves as the Faculty Leader and manages requests to obtain information from the Young Adult Advisory Program, oversees the development and implementation of feedback plans used to obtain information, tracks initiative results, and delivers regular reports to the multidisciplinary AYA oncology team. The social worker and oncologist provide clinical expertise to inform the development of feedback plans and approve materials sent out to participants. The marketing and communications associate manages the patient email list and email account and coordinates the design of collateral (i.e., flyers).

AHRQ step 2: identify opportunities for engaging patient advisors

The development of our Young Adult Advisory Program resulted from institutional efforts to provide developmentally specific care in our AYA Cancer Center. As part of these larger institutional efforts, a multidisciplinary AYA oncology team meets monthly to discuss AYA-specific initiatives. This monthly meeting is used, in part, to identify opportunities for utilizing the Young Adult Advisory Program.

AHRQ step 3: prepare medical team to engage with advisors

Once the Young Adult Advisory Program leadership team was established and standard operating procedures were finalized, the Faculty Leader presented to the multidisciplinary AYA oncology team. The presentation highlighted the value of patient engagement, the types of initiatives appropriate for the Young Adult Advisory Program, the various methods that could be used to solicit information (i.e., in-person focus groups, web-based surveys), and the standardized procedures for utilizing the Young Adult Advisory Program (i.e., who to contact, what information to provide).

AHRQ step 4: recruit advisors

Our team defined our target population as patients who were 15–39 years of age at diagnosis, currently ≥ 18 years of age, and treated at our institution since 2007. Patients could be on or off treatment. The age range of ≥ 18 years was selected as the needs, preferences, and values of this age group were expected to differ from those of the “typical” patient population at our hospital (children ages 0–17) and supported by the fact that adults have largely been excluded from hospital-wide advisory program efforts. After considering various recruitment methods (i.e., phone, in-person, email), email was determined to be the most efficient. To compile a master email list that would serve as our recruitment strategy for all Young Adult Advisory Program initiatives, we used a multimethod approach. First, an email was sent to all patients in our target population with an email address in our electronic medical record. The email detailed the purpose of the Young Adult Advisory Program and included an opt-out link. Second, we sent a paper mailer to all patients in our target population (i.e., those without an email address) describing the Young Adult Advisory Program and including instructions for being added to the email list. Third, our Social Work Leader

discussed the new program with other social workers and encouraged them to obtain email addresses of interested patients. Our group obtains an updated email list from the electronic medical record every 6 months and continues to present this opportunity in-person to new patients to ensure that our list is inclusive of all interested patients.

Young Adult Advisory Program implementation

AHRQ step 5: implement advisory program activities. To date, we have engaged the Young Adult Advisory Program to provide feedback on three clinical initiatives. As part of the first initiative, AYAs were asked to participate in one-on-one interviews to understand the needs of AYAs receiving care in a children’s hospital. In the second initiative, AYAs were asked to provide feedback on a video explaining digital patient care (e.g., remote monitoring of vitals). In the third initiative, AYAs were asked to provide feedback on how our medical team could improve their discussions regarding sexual health.

Patients

The target patient population includes patients who are currently ≥ 18 years of age, were diagnosed with cancer as AYAs (age 15–39 years), and received treatment at our institution since 2007. The target sample size for each initiative was determined based on guidelines relevant to patient advisory councils^{4,7} and the type of research being conducted (Initiative 1: qualitative interviews^{8,9}; Initiative 2: usability testing guidelines¹⁰).

Measures

The timeline detailing the Young Adult Advisory Program development and implementation was tracked prospectively by the Faculty Leader. All email requests were sent through MailChimp to record the number of bounce backs, unsubscribes, opens, and clicks. To enable tracking of AYA characteristics by initiative and over time, all participants completed an eight-item self-report demographic (age, gender, race, ethnicity, and distance from hospital) and clinical (cancer diagnosis, age at diagnosis, and treatment status) characteristic form on REDCap, a secure, web-based data collection and management application.

Data analysis

Descriptive statistics were used to explore patterns of AYA engagement and to detail the demographic and clinical characteristics of participants. Analyses were conducted using Microsoft Excel.

Results

Timeline

The need for a new advisory program was identified in March 2017. By April 2017, the leadership team was established, and responsibilities were identified. Standard operating procedures, including a feedback plan template used to track and manage new requests (Fig. 1) and agreed-upon practices regarding initiative identification, feedback solicitation and compilation, and reporting back to Advisory Program participants, were finalized in May 2017. In June 2017, the welcome email and paper mailer were sent, and the patient email list was finalized. In July 2017, the first request

Young Adult Advisory Program Feedback Plan	
Content Leader (Your Name): _____	Request Date: _____
What question would you like the Young Adult Advisory Program to help you answer?	
Potential Members	
Our list of potential YA Advisory Program members includes patients who saw an Attending Oncologist more than once since 2007, were 15-39 years at diagnosis, and are currently 18 years of age or older.	
Are there specific criteria other than these that you need patients to meet? ☐ Yes ☐ No	
If yes (e.g., age, gender), list....	
Are these specific individuals who should be recruited? ☐ Yes ☐ No	
If yes, list their names...	
If yes, who will contact these individuals? _____	
Approximately how many participants to do you need?	
_____ Patients	
What is your deadline for receiving a list of potential participants (for in-person feedback) or having online questionnaires sent out? _____	
Methods of Soliciting Feedback	
The following methods will be used to obtain feedback:	
☐ Online Questionnaire	Description: _____
Do you need assistance developing a measure or survey? ☐ Yes ☐ No	
Do you need assistance compiling the results of the survey (e.g., statistics)? ☐ Yes ☐ No	
NOTE: If you have already developed the questionnaire or survey that needs to be sent out, please return it to the Faculty Leader with this form for approval.	
☐ In-Person Groups	# of Groups: _____
Do you need assistance developing questions or facilitating the group? ☐ Yes ☐ No	
Do you need assistance compiling the results of the group? ☐ Yes ☐ No	
Do you need assistance in booking a room for the group? ☐ Yes ☐ No	
NOTE: The Content Leader (individual completing this form) will be responsible for leading in-person groups. A member of the YA Advisory Program team will attend each in-person group as a facilitator and be in touch to coordinate scheduling.	
☐ Other (e.g., One on One Interviews)	Description: _____
Do you need assistance developing your tool for obtaining feedback? ☐ Yes ☐ No	
Do you need assistance compiling the results of your tool? ☐ Yes ☐ No	
Do you need assistance in booking a room? ☐ Yes ☐ No	
NOTE: The Content Leader (individual completing this form) will be responsible for scheduling and leading in-person one-on-one meetings.	
Reporting	
To maintain patient engagement, demonstrate appreciation to our patients, and illustrate the impact of the Young Adult Advisory Program, we ask that you provide feedback to participants regarding the results of the survey/feedback you receive and information as to how you plan to utilize these results to inform your work. The following methods will be used to provide feedback to the Young Adult Advisory Program:	
☐ Email	To be completed by: _____
☐ In-Person Feedback	To be completed by: _____
☐ Other (list):	To be completed by: _____

FIG. 1. Feedback plan template.

was sent to the Young Adult Advisory Program, resulting in 5 months from conception to implementation.

Reach

A total of 588 patients met all inclusion criteria. The introductory email describing the Young Adult Advisory Program was sent to the 371 patients with email addresses in our electronic medical record. The email was opened 342 times. A total of 13 emails bounced back, and four patients opted out (1% decline rate). An introduction was also sent through postal mail

to all 588 patients meeting inclusion criteria. No patients receiving the paper mailer opted out, and 10 asked to be included in the Young Adult Advisory Program email list. As a result, the Young Adult Advisory Program email list before the first initiative included 364 patients (62% of total patient population).

Patient engagement: project results

The reach and uptake of Young Adult Advisory Program initiatives are presented in Figure 2. Each email introducing an initiative was opened more than 200 times (range = 231–271).

FIG. 2. Reach and uptake of first three Young Adult Advisory Program initiatives.

Of the patients accessing each survey, 26%–89% started the survey. Survey completion rates ranged from 65% to 100%. The recruitment target for each initiative was exceeded (final $n=110\%$ – 140% of target n) within 2 weeks of sending the initiative email.

Participant demographic and clinical characteristics varied by initiative (Table 1). Most participants were 18 to 29 years of age and diagnosed as young adults with leukemia or lymphoma. The majority of participants were female (range = 64%–71%) and most were white (range = 86%–100%). While

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF YOUNG ADULT ADVISORY PROGRAM PARTICIPANTS

	<i>Original in-person group</i>	<i>Initiative 1: needs of AYAs</i>	<i>Initiative 2: digital patient care</i>	<i>Initiative 3: discussing sexual health</i>
Total participants, n	15 ^a	22	11	14
Age at diagnosis, mean (range)	19.35 (15–26)	18.23 (15–28)	17.00 (13 ^b –21)	21.43 (11 ^b –35)
Current age (years), n (%)				
18–24	6 (40)	7 (32)	6 (55)	4 (29)
25–29	4 (27)	11 (50)	4 (36)	3 (21)
30–34	3 (20)	3 (14)	1 (9)	2 (14)
35–39	1 (7)	1 (5)	0 (0)	2 (14)
>39	0 (0)	0 (0)	0 (0)	3 (21)
Gender, n (%)				
Female	8 (53)	15 (68)	7 (64)	10 (71)
Male	7 (47)	7 (32)	4 (36)	4 (29)
Prefer not to say	0 (0)	0 (0)	0 (0)	0 (0)
Race, n (%)				
White	13 (87)	20 (91)	11 (100)	12 (86)
Black or African American	1 (7)	1 (5)	0 (0)	0 (0)
Bi- or multiracial	0 (0)	0 (0)	0 (0)	1 (7)
Other race	0 (0)	0 (0)	0 (0)	1 (7)
Prefer not to say	0 (0)	1 (5)	0 (0)	0 (0)
Hispanic or Latino ethnicity, n (%)				
Yes	0 (0)	0 (0)	0 (0)	0 (0)
No	14 (93)	22 (100)	11 (100)	14 (100)
Distance from hospital, mean (range)	14.69 (4–31)	118.61 (5–850)	78.64 (6–371)	93.77 (2–500)
Diagnosis category, n (%)				
Leukemia or lymphoma	5 (33)	12 (55)	6 (55)	7 (50)
Solid tumor	4 (27)	6 (27)	2 (18)	6 (43)
Neuro-oncology	4 (27)	4 (18)	3 (27)	1 (7)
Treatment status, n (%)				
Active treatment	2 (13)	2 (9)	1 (9)	0 (0)
Completed treatment	13 (87)	19 (86)	10 (91)	13 (93)
Not sure	0 (0)	1 (5)	0 (0)	1 (7)

^aSome information missing for two participants.

^bAge at first cancer diagnosis, subsequent diagnosis at 15 years of age or later.
AYAs, adolescents and young adults.

small sample sizes precluded formal tests of statistical significance, the demographic makeup of participants in the new Young Adult Advisory Program initiatives appears similar to that of participants from the in-person group (Table 1 column 1). Of note, the new format of the Young Adult Advisory Program does appear to be successful in engaging participants who live further from the hospital, with the mean distance from the hospital (range=78.64–118.61 miles) exceeding the average distance of those participating in the in-person group (14.69 miles).

Discussion

By capitalizing on the expertise of our multidisciplinary team and learning from previous challenges to utilizing an in-person advisory group, we developed an efficient and sustainable process for engaging AYAs with cancer. From July to October 2017, our Young Adult Advisory Program provided feedback on three clinical initiatives. Response rates were considered sufficient as they resulted in achievement of each recruitment target within 2 weeks and were consistent with rates from web-based surveys with similar design features (i.e., no follow-up reminder, no incentive).^{11,12} Participant demographic and clinical characteristics were similar to those of the in-person group, with the exception that the new program includes patients who live further away from the hospital.

The standardized operating procedures enable all processes to run efficiently. Individuals interested in seeking feedback from our Young Adult Advisory Program meet with the Faculty Leader to discuss the pros and cons of various methods of data collection (i.e., one-on-one interviews, focus groups, and online surveys). This flexible approach to data collection has enabled individuals to obtain the information they need while minimizing patient and leadership team burden. Recruiting participants through email and allowing them to participate online have not only allowed us to exceed all recruitment goals but also minimized staff time and resources by eliminating the need for sending meeting reminders, scheduling a room, and ordering catering. Of note, should recruitment challenges arise in the future, our team is prepared to implement strategies associated with higher web-based survey response rates (i.e., reminder contacts, personalized emails).^{11,12}

While this article reports on a novel approach to engaging AYAs with cancer, future research is needed to determine the sustainability and impact on patient/clinical outcomes of such programs. In summary, it is hoped that this article provides a guide for those interested in creating new developmentally appropriate and efficient strategies for partnering AYAs with cancer to inform clinical service development.

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