

Measuring the Impact of an Adolescent and Young Adult Program on Addressing Patient Care Needs

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Purpose: We aimed to evaluate the effectiveness of an adult-based adolescent and young adult (AYA) cancer program by assessing patient satisfaction and whether programming offers added incremental benefit beyond primary oncology providers (POP) to address their needs.

Methods: A modified validated survey was used to ask two questions: (1) rate on a 10-point Likert scale their level of satisfaction with the information provided to them by their POP and (2) did the AYA consult provide added value on top of their POP. Young people at PM were recruited over two separate time points spaced 1 year apart. Descriptive statistics was used to report demographics and survey responses. Differences in demographics between cohorts 1 and 2 were compared using Student's *t*-tests.

Results: Participants were an average of 31 years (range 15–39) of age; (Cohort 1 = 137; Cohort 2 = 130) and were dominated by diagnoses of leukemia, lymphoma, and breast cancer. More patients had a consultation with the AYA program in 2016 (Cohort 2 = 55/130, 42%) compared to 2015 (Cohort 1 = 34/137, 25%, $p = 0.026$). Mean satisfaction scores (\pm SD) with information provided by POP in AYA domains in both cohorts combined were highest among (1) cancer information (8.09 ± 2.22), (2) social supports (7.45 ± 2.52), and (3) school/work (7.42 ± 2.88). When evaluating the incremental benefit of the AYA-dedicated team, statistically significant added value was perceived in 5/10 domains, including school/work ($p < 0.001$), social supports ($p < 0.001$), physical appearance ($p = 0.009$), sexual health ($p = 0.01$), and fertility ($p < 0.001$).

Conclusions: Participants were satisfied with the information provided by their POP and still declared incremental added benefit of the AYA program. Cancer centers should continue to advocate for AYA focused programming with ongoing evaluation.

Keywords: program evaluation, information needs, patient satisfaction

Introduction

COMPARED TO THEIR older counterparts, adolescents and young adults (AYAs) with cancer require additional attention to specific needs,¹ including fertility preservation (FP), body image, exercise/fitness, and sexual health.² In adult oncology care settings, these unique needs are not necessarily routinely identified or addressed, rendering patients susceptible to anxiety, depression, and high levels of distress during their cancer journey.³ In response, dedicated AYA support services have emerged as young people are advocating for age-

appropriate facilities and staff to support them during their cancer experience.⁴

AYA-focused programming has been recommended internationally as a centralized approach to bridging the gaps in younger adult cancer care delivery^{2,5,6}; however, to date, the systematic evaluation of their effectiveness has been challenging. For example, the United Kingdom and Australia have built AYA-specific inpatient units, supported by robust multidisciplinary services.⁷ In comparison, programs in North America are structured on personnel (including nurses, social workers, and/or

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psychologists) who provide patient navigation and social supports.^{8,9}

In 2014, a program for young people with cancer was established at the Princess Margaret Cancer Center (PM) with a mission to improve the quality of care experience for younger adults at all stages of their illness trajectory (from diagnosis to survivorship or palliation). The program is made up of four key components as follows: (1) patient consultations delivered by a Clinical Nurse Specialist (CNS), (2) clinician education delivery to primary oncology disease sites, (3) infrastructure development (screening tool implementation, webpage and social media launch, patient and clinician education materials, and (4) research (primarily programmatic evaluation).

Given the multipronged AYA service initiatives, we hypothesize that (1) patient satisfaction in information received from primary oncology team will have improved over time, and (2) the AYA program patient consultation provides added value beyond the primary oncology team. We are using satisfaction and “added value” as a way of assessing effectiveness of our program. To our knowledge, this is the first quantitative evaluation study that demonstrates improvement in patient satisfaction in the early stages of AYA-dedicated programming development versus the time following completed AYA program implementation.⁴

Methods

AYA program implementation

The AYA program began its rollout across cancer disease sites in April 2014 at PM. The program includes a team made up of a Medical Oncologist, CNS, project manager, and aligned psychosocial and rehabilitation specialists. The clinical component of the program involves individualized consultations performed by a CNS for referred patients guided by an in-house screening tool that lists concerns important to younger adults with cancer. During the one-hour consultation, the CNS offers education and decision-making support (especially regarding FP and sexual health interventions), reviews relevant resources (peer support programming, exercise, nutrition, finances, and school/work transitions), and provides referrals onto other specialized services (such as reproductive endocrinology, psychology, psychiatry, cancer rehabilitation, exercise programs, dietician, and gynecology or urology for identified sexual health concerns) based on patient responses to the tool. Patients are then invited to share their email address in order to receive the AYA program’s monthly newsletter and to remain updated on AYA-related activities.

Follow-up appointments are offered to patients based on need, and they are also offered to reconnect with the program as needed at any point in their illness trajectory. Referrals to the AYA program are made by the primary oncology team (physician, nursing, or allied health), family, or self; not every patient at PM is seen by the AYA program. Based on anticipated need, we projected that approximately one third of all patients would need an AYA consultation.

The program also promotes healthcare provider education through rounds, lectures, awareness events, and dissemination of consultation notes to referring teams. The education sessions have had a positive impact on the rate of documentation of FP conversations suggesting that providers have additional resources and support since implementation of the

AYA program. AYA awareness initiatives in the format of education sessions delivered by the CNS were launched globally throughout the hospital and also for healthcare teams in each cancer disease site at PM to explain the program’s mission and encourage referrals.

Furthermore, the AYA program has established partnerships with relevant stakeholders who have expertise in the younger adult oncology population, including psychosocial, reproductive endocrinology, urology/gynecology, and rehabilitation services.

Study design

A nonrandomized prospective study design was used to collect data from two AYA cohorts. The study received approval from our institutional research ethics board and complied with all its regulations. The data collection period was over a 3-month period for 2 consecutive years: June–August 2015 (cohort 1) and June–August 2016 (cohort 2). The purpose of having two separate cohorts was to determine if patient satisfaction with information provided either by primary team or the AYA program had changed over time (Supplementary Fig. S1; Supplementary materials are available online at <http://www.liebertpub.com/jayao>).

Study sample

Potential participants were identified through an AYA database, which captures clinic visits for all younger patients based on age. If participants met study inclusion criteria (<40 years of age, patient at PM, and being followed in an ambulatory care clinic for a leukemia, lymphoma, breast genitourinary, central nervous system, head and neck, sarcoma, gastrointestinal or gynecological cancer), the research assistant would request the primary team to introduce the study to the patient. If the patient expressed interest in study participation, consent was obtained. The study survey was administered as a paper copy by research assistants who were not directly affiliated with the AYA program or providing care to the participants. Patients on and off active cancer treatment were approached. Patients who met the study criteria were approached consecutively based on their ambulatory clinic appointment. Patients from the two cohorts were not matched in terms of sex, age, or cancer type. Consultation with the AYA program was not required for study inclusion as we hypothesized that information delivered by the primary team would also improve following AYA program implementation.

Study measures

The participant satisfaction survey asks patients about their satisfaction with care related to important areas of need for young people. The survey has not yet been formally validated, however, was adapted from a previously validated survey assessing information and service needs of younger adults with cancer.² Additional items regarding (1) financial resources, (2) physical appearance, and (3) navigation of the hospital system were added to reflect the items discussed during an AYA program consultation. The revised patient survey was initially piloted on a sample of five healthy younger adults within the same age group for face validity. Minor changes, mainly with respect to formatting and grammar, were made in response to the feedback obtained

from the initial pilot. The revised survey was then administered to the AYA study participants.

Patients who agreed to participate in the study were asked two primary questions: (1) to rate on a 10-point Likert scale their level of satisfaction for the information and resources provided to them from their primary oncology team and (2) whether the AYA-dedicated care team provided any more help/added value over and above that of the primary oncology team (yes, not sure/no, or not applicable). In addition, patients were asked to complete demographic data (age, gender, and cancer type).

Statistical analysis

Descriptive statistics was used to report the demographic characteristics and survey responses of the participants; mean ± standard deviation [SD] for patient satisfaction scores, median ± interquartile range [IQR] was used for nonparametric data, and proportions for dichotomous data. Differences in the demographics between cohorts 1 and 2 were compared using Student’s *t*-tests and exact tests of goodness of fit. Given that study participants in cohort 1 and 2 were unmatched, Student’s *t*-tests were used to compare patient satisfaction scores between cohorts, and Chi-squared goodness of fit was used to compare dichotomous data between cohorts. These comparisons were performed for each survey domain, as well as globally based on summation of the survey domains. Univariable and multivariable regression analyses were used to identify predictive factors for patient satisfaction, including gender, age, diagnosis, and cohort. Significance level was set at alpha of 0.05 for inferential analyses. All data were analyzed using R version 3.3.1 (R Foundation for Statistical Computing, Vienna, Austria).

Results

Demographics

A total of 267 AYA participants (cohort 1, *n* = 137; cohort 2, *n* = 130) had a median age of 31 years (range 15–39) and the majority were female 54% (*n* = 143). Twenty-eight (9.5%) patients declined. The majority of patients had leukemia, lymphoma, or breast cancer (Table 1). In cohort 1, 16 patients who were approached declined to participate and in cohort 2, 12 patients declined to participate. There were no differences in demographics between cohort 1 and 2 except for slight increase in genitourinary (GU) patients in cohort 2. More patients met with the AYA-dedicated care team in 2016 (cohort 2, 55/130, 42%) compared to those in 2015 (cohort 1, 34/137, 25%) (*p* < 0.03), suggesting an increased awareness of the AYA program over time. For those who did meet with the AYA-dedicated care team, surveys were completed within 2 months (range 1–3) after having had a consultation with the AYA program. Overall 89 (33%) participants had accessed an AYA program consultation compared with 178 participants who had not. Since a concurrent initiative of the AYA program since its inception was building cancer disease site capacity in AYA-specific care interventions, we expected that not all younger people at PM necessarily needed to access the AYA program if patient care needs were sufficiently addressed by primary oncology teams.

Patient satisfaction and impact of AYA consult

Mean patient satisfaction scores (±SD) of information provided by primary team are shown for each of the items in the survey (Table 2). Both cohorts together reported highest

TABLE 1. DEMOGRAPHICS OF ALL PARTICIPANTS

	Overall	Cohort 1 (2015)	Cohort 2 (2016)	p-value
Participants: <i>N</i> (%)	267 (100)	137 (51)	130 (49)	
Age: Median (IQR)	31 (24–35)	31 (24–36)	31 (26–35)	0.93
Age group: <i>N</i> (%)				
15–19	24 (9)	9 (7)	15 (12)	0.31
20–24	45 (17)	31 (23)	14 (11)	0.02
25–29	49 (18)	20 (15)	29 (22)	0.25
30–34	64 (24)	34 (25)	30 (33)	0.71
35–39	85 (32)	43 (31)	42 (32)	0.91
Gender: <i>N</i> (%)				
Male	124 (46)	65 (47)	59 (45)	0.65
Female	143 (54)	72 (55)	71 (55)	1.00
Cancer site: <i>N</i> (%)				
Leukemia	56 (21)	31 (33)	25 (19)	0.50
Lymphoma	86 (32)	46 (34)	40 (31)	0.59
Breast	46 (17)	24 (18)	22 (17)	0.88
Genitourinary	16 (6)	3 (2)	13 (10)	0.02
Gastrointestinal	15 (6)	10 (7)	5 (4)	0.30
Sarcoma	18 (7)	4 (3)	14 (11)	0.03
Eye	5 (2)	5 (4)	0 (0)	0.06
Gynecological	4 (1)	3 (2)	1 (1)	0.62
Other	2 (1)	2 (1)	0 (0)	0.50
15 (6)	9 (7)	6 (5)	0.61	
4 (1)	0 (0)	4 (3)	0.125	
AYA consult <i>N</i> (%)	89 (33)	34 (25)	55 (42)	0.03
Months between AYA and survey: median (IQR)	2 (1–3)	2 (1–3)	2 (1–3)	

AYA, adolescent and young adult.

TABLE 2. PATIENT SATISFACTION SCORES

Domain	Mean satisfaction score (mean \pm SD)			p-value* (2015 vs. 2016)
	Overall	2015	2016	
Information	8.09 \pm 2.22	8.12 \pm 2.30	8.06 \pm 2.15	0.825
Social supports	7.45 \pm 2.52	7.50 \pm 2.44	7.40 \pm 2.61	0.753
Work/school	7.42 \pm 2.88	7.35 \pm 2.85	7.48 \pm 2.92	0.756
Fertility	7.28 \pm 2.89	7.19 \pm 2.89	7.36 \pm 2.90	0.678
Financial resources	7.27 \pm 3.06	7.16 \pm 3.10	7.38 \pm 3.03	0.625
Hospital system	7.24 \pm 2.60	7.38 \pm 2.54	7.09 \pm 2.66	0.385
Physical appearance	6.96 \pm 2.71	6.98 \pm 2.65	6.95 \pm 2.78	0.936
Child care	6.95 \pm 2.82	7.03 \pm 2.90	6.88 \pm 2.78	0.814
Physical activity/exercise	6.77 \pm 2.81	6.72 \pm 2.79	6.83 \pm 2.84	0.773
Sexual health	6.76 \pm 3.09	6.62 \pm 3.22	6.89 \pm 2.97	0.556
Diet/nutrition	6.57 \pm 2.93	6.38 \pm 2.93	6.77 \pm 2.93	0.304
Global	58.76 \pm 26.38	56.90 \pm 26.36	60.73 \pm 26.36	0.236

*Student's *t*-test.

scores for cancer information, social supports, and school and work. Satisfaction scores were lowest among diet and nutrition, sexual health, and physical activity and exercise. There was no statistical difference in the scores between those who did and did not see the AYA consult service (data not shown).

We next asked whether there was added benefit with an AYA program consultation beyond that provided by the primary care oncology team (yes vs. no vs. not applicable [n/a]). Differences in domain sample sizes are related to participants reporting domain (s) as n/a on the questionnaire. When evaluating the incremental benefit of the AYA-dedicated care team, statistically significant added value was perceived in 5 of the 10 domains, including work/school, social supports, physical appearance, sexual health, and fertility (Table 3). Patients reported added value in financial support, cancer information, diet, hospital system, and physical activity/exercise, but the differences were not significant. Childcare was the one domain where more

people stated that the AYA program consultation was not beneficial.

Potential predictive factors of patient satisfaction scores

Univariable and multivariable regression analyses were used to examine predictive factors for patient satisfaction scores (Table 4). Overall, the satisfaction scores of younger adults with cancer were significantly higher among patients treated for leukemia compared to other site groups, only by univariable analysis (63.7 vs. 54.1, $p=0.04$). There were no other differences in satisfaction scores based on age, sex, or cohort by either univariable or multivariable analysis.

Discussion

Many cancer centers have AYA programs^{7,10,11}; however, the quantifiable added value of these initiatives is yet to be evaluated. Our program has two main goals: (1) to have an AYA program consultation accessible to every younger adult receiving cancer care at PM, and (2) to educate primary

TABLE 3. DOMAINS AND WHETHER THERE WAS ADDITIONAL BENEFIT OF ADOLESCENT AND YOUNG ADULT CONSULTATION TO THE PRIMARY TEAM

Domain	Yes (%)	No (%)	p-value
Social supports ($n=81$)	66 (81)	15 (19)	<0.001 ⁺
Fertility ($n=77$)	54 (70)	23 (30)	<0.001 ⁺
Work/school ($n=77$)	53 (69)	24 (31)	<0.001 ⁺
Physical appearance ($n=70$)	46 (66)	24 (34)	0.009 ⁺
Sexual health ($n=72$)	47 (65)	25 (35)	0.01 ⁺
Physical activity/exercise ($n=78$)	45 (58)	33 (42)	0.17
Information ($n=78$)	44 (56)	34 (44)	0.26
Financial resources ($n=77$)	43 (56)	34 (44)	0.30
Hospital system ($n=77$)	43 (56)	34 (44)	0.30
Diet/nutrition ($n=82$)	44 (54)	38 (46)	0.51
Child care ($n=47$)	16 (34)	31 (66)	0.03 ⁻

Includes $n=89$ who had an AYA consultation.

⁺Significant differences indicate a positive direction ($p>0.05$).

⁻Significant differences indicate a negative direction ($p>0.05$).

TABLE 4. POTENTIAL PREDICTIVE FACTORS IN ADOLESCENT AND YOUNG ADULT PATIENT SATISFACTION SCORES

Predictive factor	Univariable p-value	Multivariable p-value
Age		
30–34 (vs. <30)	0.66	0.85
35–39 (vs. <30)	0.16	0.17
Gender		
Female (vs. Male)	0.89	0.56
Cancer Diagnosis		
Leukemia (vs. Other)	0.04 ⁺	0.08
Lymphoma (vs. Other)	0.37	0.50
Breast (vs. Other)	0.09	0.60
Year		
Cohort 1 versus cohort 2	0.24	0.28

⁺Significant differences indicate a positive direction ($p<0.05$).

oncology providers (POP) to increase capacity within the adult center to understand the issues of young people with cancer and be able to deliver optimal age-appropriate front-line care. In order to evaluate the program's significance, we assessed patient satisfaction by asking if their unique care needs are being addressed by their POP and then assessed whether the AYA program consultation provided added value beyond the care provided by the primary oncology team. This is the first study, to our knowledge, to document the benefit of an AYA program. Patients reported that the AYA program consultation provided incremental benefit in key domains, including sexual health, fertility, social supports, physical appearance, and work/school issues. These are the core issues repeatedly identified as important to young people diagnosed with cancer. The added value of our program was evident in domains even when respondents were very satisfied with their primary team (social supports, school/work). This is affirming as the program has invested time in identifying psychosocial specialists with training in AYA cancer care, as well as collating and developing peer support networks for patients. In addition, the AYA program has created resources to address fertility-related concerns.¹² This study further highlighted that the number of AYA consultations increased when comparing cohort 1 and cohort 2 indicating that there was both an increase in awareness of the AYA program and its added value for young patients at PM over time.

We chose to use patient satisfaction as our metric of evaluating program effectiveness. Similar to other programs, the crux of our program is support, education, triage, and navigation, rather than improving cancer-related survival or alternate cancer treatments. We were able to demonstrate that patients were satisfied with the supports offered by the AYA program. Second, the participants' satisfaction with care delivered by their primary oncology teams lends to the AYA program's commitment to advancing healthcare provider knowledge on AYA unique issues at PM. Increasing knowledge and capacity has been an important focus for the program, which has been executed through formal lectures and rounds, in addition to standardized consultation notes available on patient charts.

Before the implementation of the AYA program, we had identified important gaps in patient resources and clinical care in the domains of: AYA-specific social supports, work/school, physical appearance/sexual health, and fertility which we prioritized since the early stages of program development. Initially, a large environmental scan of AYA-related community programs was conducted by the CNS to develop pathways and partnerships and streamline referrals for patients. Similar partnerships were also developed internally to ensure that work/school, exercise, sexual health, and psychosocial programming at PM were tailored by a multidisciplinary care team to meet the specific needs of this younger population.¹³

Recognizing gaps in management of younger adult-specific sexual health concerns, our AYA program launched an international sexual health symposium at the First Global AYA Cancer Congress (Edinburgh, 2016) where more than 30 AYA healthcare providers internationally shared both expertise and challenges in managing this population.¹⁴ Key partnerships have since been developed with local endocrinology, gynecology, and urology programs with expertise in managing the

sexual health and body image issues of AYA. Referrals to these programs are triaged and facilitated by the AYA CNS to ensure that patients' needs are optimally addressed.

Regarding oncofertility, the AYA program's initial platform was focused on increasing patient and provider access to fertility information and services. We previously demonstrated improvements in documentation of fertility risk and preservation following AYA program implementation.¹⁵ Memorial Sloan Kettering has also demonstrated advantages to their FP consultation service in improving rates of patient satisfaction and information received; this study did not comment on other aspects of AYA care.¹⁶ Given the extensive resources expended to develop our specialized AYA program, our observation that we have been successful in addressing the important needs of young people with cancer was reassuring.

Added value of the AYA program was not as recognizable in the domains of financial support, cancer information, nutrition, hospital system, and physical activity/exercise. Given this feedback, our program has now prioritized AYA specific initiatives in the domain of exercise as exercise programming for young people with cancer continues to be a gap in both the hospital and community contexts. A partnership has further been made with our hospital-based dieticians to ensure that AYA patient education materials are expanded to include more nutrition related information relevant to this population. This feedback overall continues to motivate us to expand elements of the AYA program, as well as enhance the consultation process to provide additional focus around disease-related information, hospital navigation, and financial support.

PM is a very large tertiary care adult cancer hospital where approximately 1200 new AYAs are seen annually. Not all patients are seen by the AYA program and are rather identified as having more complex needs by their POP. Patients can also self-refer. Furthermore, supports and knowledge within specific disease site groups related to AYA-specific issues may also vary, impacting referral patterns seen. We therefore view our program as a natural supplement to patients who continue to have unaddressed needs and also to build capacity within sites to increasingly meet the needs of younger adults with cancer.

The results of this study should be considered in the context of potential study limitations. Patient satisfaction is generally dependent on disease trajectory and overall state of health. Furthermore, two different sets of unmatched patients were surveyed in the 2 consecutive years negating the opportunity to directly compare individual patient preferences over time. Ideally, we would have evaluated patient needs before and following program implementation; instead we chose 2 consecutive years following program start. Furthermore, only one third of the total population had actually met the AYA-dedicated care team. The study's strengths include large patient numbers and a sample of young people with cancer reflective of similar populations in other adult cancer centers.

In conclusion, we have demonstrated effectiveness of our AYA program confirming that dedicated AYA programming in an adult cancer institution is associated with improved patient satisfaction with the information provided in specific domains. However, this is only one component of AYA programmatic impact among others, including cost, rates of survival, and quality of life. It is critical that AYA program initiatives continue to endeavor to measure and report their impact and

effectiveness, to remain accountable to all stakeholders, especially patients. Young people with cancer at PM seem to generally be satisfied with the information given to them by their oncology team, with added value provided by the AYA program. Future work will focus on ensuring that all AYA-specific informational needs are being optimally met.

Author Disclosure Statement

No competing financial interests exist.

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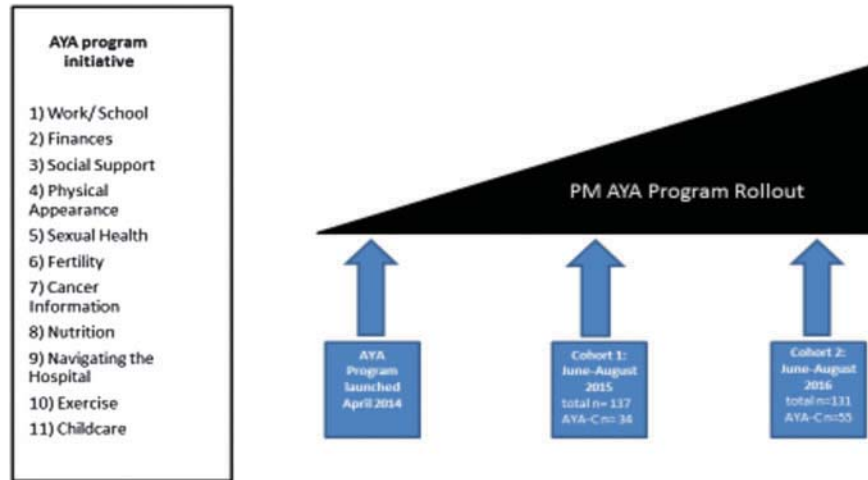
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Supplementary Data



AYA-C = No. seen by AYA CNC

SUPPLEMENTARY FIG. S1. AYA Program Study Design. AYA, adolescent and young adult.