

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

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Abstract

Background Young adults (YA) with cancer have unique psychosocial and medical needs. The objective of this study was to identify information and service needs important to YA cancer patients.

Methods A supportive care needs survey was administered to ambulatory patients (<age 35 years) who were within 5 years of completing therapy at an adult hospital. Participants were asked to rate the importance of 18 sources of

information or resources on a scale from 1 to 10. The relationship between gender, type of cancer, current treatment status, and marital status on the importance of these factors was explored using ANOVA.

Results Median age of 243 respondents was 28 years (range 17–35); 61 % male. The most common diagnoses were: lymphoma (28 %), leukemia (19 %), testis (16 %), CNS (9.5 %), and sarcoma (8.6 %). Forty percent were currently receiving treatment; the majority were single/never married (67 %). Thirty-eight percent of respondents felt it was important or very important to receive care in a dedicated unit with other young people. More than 80 % rated the following items at least 8/10 in importance: information on their specific malignancy (treatment, risk of recurrence), effects of treatment on fertility, information on maintaining a healthy diet, and exercise/physical fitness during cancer treatment. Women were more likely to consider information/service needs more important than men.

Conclusions YA's have clear supportive care preferences and needs. Developing programs that incorporate the services identified as important should improve quality of life, psychosocial adjustment, and other outcomes during and after cancer therapy.

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Introduction

Young adults (YA) with cancer are a constituency facing disparities of care which affect quality of life and other outcomes [1]. Approximately 800 new YA are diagnosed

with cancer yearly at Princess Margaret Cancer Center (PMCC), in Toronto, Ontario, Canada, the largest adult tertiary cancer center in Canada. They represent approximately 10 % of all cancer patients at that hospital. YA are affected by malignancies which are rarer and more diverse (i.e., lymphoma, germ cell tumors, sarcomas) than those affecting older adults (lung, colon, prostate) [2, 3]. As cancer treatment is organized around organ system of origin (i.e., breast, hematology, genitourinary), YA patients span multiple sites and are therefore not collectively recognized as a group with unique needs.

Adolescents who develop cancer are well documented in the pediatric literature to have unique psychosocial and medical needs because of their age and life stage [4–8]. Adolescents are transitioning through important milestones in their lives at the time of their cancer diagnosis [6, 9, 10]. Most information describing needs of YA arises from the survivorship literature describing the needs of survivors of pediatric cancer [7, 11, 12]. Recently, Zebrack et al. described the needs of adolescents and young adults within 4 months of their cancer diagnosis who report an unmet need with regard to cancer information, infertility information, and diet/nutrition information [13]. There is a high cure rate for YA with cancer [14, 15], so identifying their needs and improving their cancer journey *early on* may help in dealing with longer-term physical and psychological effects of cancer. The objective of this study was to identify information and service needs important to YA who are on, or soon after active therapy for cancer, and treated exclusively at an adult institution. We aim to use the results of our study to inform innovate programming to address these needs.

Methods

Appropriate institutional review board approval was obtained.

Questionnaire

A cancer needs questionnaire was used to assess needs based on modification of a form developed by Zebrack [12]. The original form by Zebrack consisted of a list of 17 information and supportive care needs and asked participants to endorse one of the following response categories: have used and would like to use more, have used and have no further need, have not used but would like to, and have not used and have no need. The current form includes the same 17 items used by Zebrack but asked participants to indicate on a 10-point Likert scale “How important you think it would be to include that resource as part of a program for young adult cancer survivors.” The form was changed as many services are not available at our institution and thus assessing “prior use” would not be appropriate. An 18th item asking about educational and/or vocational counseling to assist with obtaining appropriate employment was added to the survey

because of the availability of this service for YA survivors of childhood cancers in Toronto. This program has been used primarily by survivors of brain tumors and childhood cancer who, as a result of their disease and/or treatment, have developed learning difficulties that interfere with achievement of their educational and career goals. Patients were also asked to complete questions about their diagnosis, alcohol and cigarette consumption, family and living situation, and family doctor availability in order to help identify factors that may influence the profile of needs identified. Finally, patients were asked if they wanted to meet other young people with cancer (and if so, how would they prefer to do so: one-on-one, support groups, on-line) and whether they would want their cancer care delivered in a unit dedicated to young people since isolation is a key issue for YA. This information was important to inform local program development since dedicated units for adolescents and YA have been expanding in other countries [16, 17]. The questionnaire was then piloted on a sample of 10 patients and 10 health care providers. Minor modifications, mainly with regards to formatting, organization, and grammar, were made in response to feedback after the initial pilot; the revised questionnaire was administered to the larger sample of participants.

Participants

Inclusion criteria for participation in the study were: YA between 18 and 35 years of age, receiving active cancer therapy or within 5 years of completing cancer treatment, followed at PMCC. The study coordinator obtained a list of patients by age and disease from each weekly clinic list, and recruited patients from clinics that contained the highest proportion of patients less than age 35 years with a malignant diagnosis. These included lymphoma, leukemia, testes cancer, sarcoma, and brain tumors. Patients were accrued consecutively over time, and differences in frequency of diagnoses reflect patient volume within each clinic. Patients were asked to complete the questionnaire, which required about 10–15 min of their time, while they waited for their ambulatory clinic visit.

Data analyses

Survey responses were collated, and item responses were averaged for the entire sample. Next, we were interested in studying the relationship between the 18 importance items rated in the survey and patient demographic variables, including sex, living situation, children (yes or no), diagnosis, and whether or not a patient is actively on treatment. ANOVAs were employed to test for significant associations between all combinations of importance items and patient demographics. Pairwise comparisons of significant effects were further explored using *t* tests. A *p* value of less than 0.05 was considered statistically significant. We are aware of the risk of type I error associated with multiple comparisons; however, because this

study is exploratory we included all comparisons that were of interest from a clinical and program development perspective, and set $p \leq 0.05$ as our significance level. There are differences in opinion regarding the appropriate significance level correction [18] and results should therefore be interpreted with caution.

Results

Sample

Two hundred and fifty-three YA were approached for the study in ambulatory clinics at PMCC from June 1 to November 30, 2010, of whom 243 consented. The demographics of the respondents are described in Table 1, demographic information.

Median age of the respondents was 28 years (range 17–35); 61 % were male. The most common diagnoses were: lymphoma (28.4 %), leukemia (18.9 %), testis (16.5 %), CNS (9.5 %), and sarcoma (8.6 %). Almost half (40 %) were receiving active cancer treatment. The majority of respondents were single/never married (67 %). Many lived at home with their parents (47 %) or with a partner (34 %); 49 (20 %) had children.

Resource needs

Study participants were asked how important it was to them to get information on a certain resource as part of a program for young adult cancer survivors, or have it included in the program. Means and standard deviations of the importance scores for each questionnaire item are listed in Table 2, summary of service and information use. The needs with the

Table 1 Demographic information

Variable ($n=243$)	Level	N	Percent, %
Sex	Male	149	61.3
	Female	94	38.7
Cancer diagnosis	Brain tumor	23	9.5
	Breast, cervical, ovarian	19	7.8
	Leukemia	46	18.9
	Lymphoma	69	28.4
	Sarcoma	21	8.6
	Testicular	40	16.5
	Colon, other	25	10.3
Currently receiving treatment	Yes	97	40.1
	No	145	59.9
Age	Median 28 (17–35)		
Number of cigarettes per day	Median 0 (0–50), mean 1.32 (SD 5)		
Number of drinks per week	Median 0 (0–40), mean 2.1 (SD 4.6)		
Relationship status	Single, never married	162	66.7
	Married/common-law	68	28.0
	Separated	1	0.41
	Divorced	3	1.23
	Other	9	3.70
Living situation	With parents	114	47.5
	With partner/spouse	81	33.7
	Alone	22	9.2
	With roommate(s)/other	23	9.6
Kids	Yes	49	20.3
	No	193	79.8
Do you have any physical or mental health conditions other than cancer?	Yes	38	15.7
	No	196	81.0
	Not sure	8	3.3
Do you have a family doctor?	Yes	222	91.7
	No	20	8.3
Have you met other YA cancer patients?	Yes	85	35.1
	No	157	64.9

Table 2 Summary of service and information use

Information variable	Median	Range	Mean (SD)	Mean males only (SD)	Mean females only (SD)
Information (printed material or web-based) about your illness (i.e., treatment, risk for recurrence, etc.).	10	1–10	8.64 (1.92)	8.41 (2.16)	9.00 (1.42)
Information on alternative therapies (herbal treatment, acupuncture, massage therapy, meditation, etc.).	8	1–10	7.44 (2.68)	7.19 (2.83)	7.83 (2.35)
Information about effects of cancer treatment on your ability to have children in the future and how to preserve your fertility before starting treatment (if applicable).	10	1–10	8.77 (2.23)	8.45 (2.34)	9.28 (1.94)
Information on treatment for infertility, and other options for having children (i.e., artificial insemination, in vitro fertilization, surrogacy, adoption, etc.).	9	1–10	7.81 (2.85)	7.50 (2.90)	8.30 (2.72)
Information about maintaining a healthy diet during cancer treatment.	10	2–10	8.84 (1.66)	8.71 (1.70)	9.04 (1.58)
Information about exercise and physical fitness during treatment.	10	1–10	8.75 (1.73)	8.72 (1.70)	8.79 (1.78)
An actual exercise and physical rehabilitation program at the hospital while you are receiving cancer treatment	9	1–10	7.94 (2.53)	7.60 (2.67)	8.47 (2.21)
Information on internet sites that offer cancer education or support specific to young adults.	8	1–10	7.59 (2.49)	7.31 (2.55)	8.03 (2.33)
Support groups at the hospital specifically for young adults to help cope with illness and treatment.	7	1–10	6.96 (2.72)	6.44 (2.86)	7.79 (2.25)
Automatic referral to a social worker as soon as you are diagnosed to help deal with the emotional, financial, and organizational aspects of diagnosis and treatment.	8	1–10	7.55 (2.66)	6.93 (2.86)	8.52 (1.95)
Counseling related to sexuality or intimacy during treatment (chemotherapy, surgery, and/or radiation).	7	1–10	6.28 (2.97)	6.05 (2.98)	6.64 (2.94)
Counseling for your family to help them cope with your diagnosis and treatment.	8	1–10	7.24 (2.62)	6.82 (2.66)	7.89 (2.42)
Referral to community centers, camps, retreats, or adventure programs that offer cancer education or support appropriate for young adults.	6	1–10	5.93 (2.88)	5.44 (2.87)	6.70 (2.74)
Organized child care at the hospital for when you are at the hospital.	4	1–10	4.61 (3.62)	4.69 (3.55)	4.48 (3.74)
Counseling to help with problems related to alcohol or drug use.	2	1–10	3.52 (3.10)	3.06 (3.19)	5.07 (4.37)
Religious/spiritual support or counseling.	4	1–10	4.24 (3.13)	3.90 (2.95)	4.77 (3.34)
Educational and/or vocational counseling to assist with returning to school/work during or after cancer treatment.	8	1–10	6.88 (2.93)	6.68 (2.90)	7.20 (2.95)
Counseling to help with anxiety, depression, or emotional stress.	8	1–10	7.26 (2.91)	6.85 (3.00)	7.91 (2.63)

highest scores included more information on specific malignancy, effects of treatment on fertility, maintaining a healthy diet, and accessing exercise programs while on treatment. More than 80 % of participants ranked these four items as very important, with a score $\geq 8/10$. Fifty to eighty percent of respondents rated other items at $\geq 8/10$ in importance including: information on alternative therapy, treatment of infertility, automatic referral to a social worker, counseling to help family members cope, vocational training/education, and counseling for depression, anxiety, and emotional stress. Substance abuse counseling and spiritual care resources were rated at $\geq 8/10$ in importance by fewer than 20 % of the sample.

Medical care

Ninety-two percent ($n=222$) of respondents reported having a family doctor, of whom 87 % ($n=192$) stated they continue to

see him/her for general healthcare issues. Most ($n=187/192$, 97 %) were at least somewhat satisfied with the care received from their family doctor. However, less than 20 % of respondents reported that they would feel comfortable pursuing their oncology follow-up care upon completion of therapy by someone (i.e., nurse practitioner or family medicine general practitioner) other than their primary oncologist. The model of follow-up care preferred did not depend on sex, diagnosis, marital status, or whether respondents were on or off active therapy (data not shown).

Meeting other young people with cancer

Sixty-five percent of respondents stated that they have not met other young people with cancer. Thirty-nine percent of them said they would like to do so, 66 (41 %) were unsure, and 32 (20 %) did not want to meet others. The preferred

meetings included the following: one-on-one, 84 (63 %); in-person support group, 79 (59 %); and on-line social media/chat rooms, 65 (49 %). Forty percent of respondents felt it was important (5–7/10) or very important ($\geq 8/10$) to receive their care in a dedicated unit with other young people.

Exploratory analyses: effects of demographic variables on importance ratings

Female YA rated most items on the survey as more important than males did, including information about diagnosis ($F(1, 241)=5.53, p=0.019$), fertility preservation methods ($F(1, 239)=8.24, p=0.004$), risk of infertility ($F(1, 239)=4.58, p=0.033$), exercise ($F(1, 239)=6.92, p=0.009$), and internet resources ($F(1, 241)=5.00, p=0.026$). Females also rated several supportive care resources as more important than males including: support groups ($F(1, 241)=14.92, p<0.001$), social worker referrals ($F(1, 241)=22.45, p<0.001$), family counseling ($F(1, 239)=9.95, p=0.002$), program referrals to community centers/camps/retreats ($F(1, 240)=11.52, p=0.001$), religious counseling ($F(1, 273)=4.51, p=0.035$), and psychological counseling ($F(1, 240)=7.92, p=0.005$; see Table 2 for mean values by gender). There were no differences between males and females on the remaining seven survey items.

Ratings for sexuality/intimacy counseling and access to child care varied by YA living situation (sexuality counseling, $F(3,233)=4.12, p=0.007$; child care, $F(3,233)=4.12, p<0.001$). Specifically, YA who were living with their partner or spouse were more interested in sexuality or intimacy counseling than were YA who lived with their parents ($t(182.49)=3.29$ statistic, $p=0.001$) or roommates ($t(37.94)=-2.66, p=0.011$). YA living with their partner or spouse were also more interested in access to child care than were those living with parent, roommates or alone. Living situation did not impact on the importance of other information or service needs.

Interestingly, YA ratings of how important it would be to receive information on the risk of their cancer treatment on fertility was not significantly related to their living situation ($p=0.09$) or whether or not they had children ($p=0.65$).

Exploratory analyses: effects of disease variables on importance ratings

Cancer diagnosis was associated with different importance ratings for one information item and one supportive care item from the survey: information about cancer diagnosis ($F(6, 236)=3.30, p=0.004$) and referral to a social worker ($F(6, 236)=2.71, p=0.015$). Interestingly, YA with breast/cervical/ovarian, colon cancer, or lymphoma rated information about their cancer diagnosis higher

in importance compared to those with other cancer types such as leukemia or sarcoma [leukemia (breast/cervical/ovarian, $t(62.54)=-3.11, p=0.003$; colon, $t(69.98)=2.59, p=0.012$; lymphoma, $t(64.14)=2.66, p=0.010$) or sarcoma (breast/cervical/ovarian, $t(25.90)=-2.48, p=0.020$; colon, $t(26.98)=2.16, p=0.040$; lymphoma, $t(23.36)=-2.12, p=0.044$]. YA with testicular cancer rated information about their diagnosis as more important than those with leukemia ($t(82.13)=2.27, p=0.026$). Patients with leukemia, brain tumors, and breast/cervical/ovarian cancer rated the need for an automatic referral to a social worker higher in importance than the other groups with significant differences between YA with leukemia and those with lymphoma ($t(111.67)=-2.65, p=0.009$), testicular cancer ($t(78.21)=-2.63, p=0.010$) and colon cancer ($t(37.93)=-3.06, p=0.004$). Importance ratings from YA with colon cancer were lower than those with brain tumors ($t(44.77)=-2.52, p=0.015$) and those with breast/cervical/ovarian cancers ($t(41.43)=-2.32, p=0.025$).

Although 60 % of our sample had completed active cancer treatment at the time of survey, they had information and service needs similar to those who were on active treatment. However, those who had completed treatment rated receiving information about their diagnosis and cancer as more important compared to those who were on active treatment ($F(1, 240)=6.17, p=0.014$). They also tended to rate receiving information about fertility as more important than those who were on active treatment ($F(1, 238)=3.82, p=0.052$).

Discussion

YA with cancer have identified specific information and service needs that they deem to be important to include in a program dedicated to their age group. Information on their specific cancer diagnosis, fertility preservation, diet, and exercise were the items most often identified as important, and were important for those both actively receiving and those who had recently completed cancer treatment. It was important for us to identify the needs of YA with cancer in order to accurately inform dedicated program development which is underway at our institution. We anticipate that addressing the needs of YA while in active care will lessen their overall distress, improve their cancer experience, and subsequently empower patients to more easily re-enter normal life upon completion of their cancer journey. In comparison to a recent multi-center survey among adolescents and YA treated at pediatric and adult institutions [13], our cohort was predominantly male and treated exclusively at an adult institution, but our study findings are similar. Older adults also request information about their cancer and exercise [19], but the consistent need for information about fertility seems to be specific to younger patients [20].

Our study is strengthened by its conduction at the largest tertiary cancer care institution in Canada where all patients enjoy universal health care. In this setting, variables to care needs of YA such as health insurance [13, 21] and disparate access to already existing supportive care services were removed. Limitations of this study include the cross sectional design, use of a convenience sample, and the multiple comparisons made to analyze the results.

Our results suggest that the specific cancer diagnosis has an impact on the importance placed on the need for cancer-related information and the need for referral to a social worker. Our study was not designed to identify the specific reasons for these disparities among individual cancer sites; however, understanding these issues further will help in our specific program development to best meet the needs identified.

Fertility preservation is a growing concern for young men and women undergoing cancer treatment [22] and loss of fertility can be as distressing as the diagnosis of cancer [20]. Our study demonstrates that information on the effects of cancer treatment on fertility may be important to both men and women, to those who already have children and those who do not, to individuals with all cancer diagnoses and to those who are single or in a relationship. Furthermore, fertility information needs are present among YA who are on active therapy, as well as for those who have completed their active treatment. There is often a sense of urgency during the time of diagnosis to learn about the cancer and treatment, scheduling of tests, starting therapy, so that discussions regarding fertility and options for preservation are often not thoroughly explored. There is an extensive literature describing these barriers to offering fertility preservation to cancer patients, including cost, patient gender [23], knowledge and attitudes of health care providers, and methods of communication [24, 25]. Even a one-time fertility preservation consultation may not be enough to ensure appropriate education among patients [26]. Pre-treatment fertility counseling and fertility preservation have been shown to improve quality of life in women with cancer [27], warranting novel strategies of incorporating adequate counseling into the plan of care for newly diagnosed YA patients.

The importance of diet and exercise interventions following cancer therapy has been well studied [28–30]. Our study suggests that this information is important to YA *during* cancer therapy. YA cancer survivors want exercise information and programming in the form of brochures, internet, programs at local fitness centers and even walking programs [31]. Exercise, especially aerobic activity, improves cancer-related fatigue [32], and may increase cancer-related survival [33]. Facilitating its delivery necessitates programmatic attention for young adults with cancer. We were surprised by the

importance placed on exercise among our cohort, which appears to be independent of their sex, living situation, and specific cancer diagnosis. Moreover, treating oncology teams need to be aware of this need for their YA patients during cancer therapy. The internet is abound with advice on how to eat during cancer treatment, some of which is outlined by large organizations such as the American Cancer Society, Canadian Cancer Society and European Cancer Society. Patients need to be provided with links to the reliable sources of supportive care information available and a way to navigate these resources. Similar guidelines for appropriate exercise while on treatment seem to be desirable to YA cancer patients.

Various models of care to address the unique needs of YA have been proposed, however, are limited due to the lack of systematic, peer-reviewed evaluation of these delivery systems [34]. This limits the generalizability of methods across health care systems. The value of specialized units dedicated to YA have been described in the UK and Australia [35, 36]; in our study, just over one third considered such units an important support mechanism. The median age of our cohort was 28 years, which is older compared to the patients populating the aforementioned YA units, possibly explaining this difference. Furthermore, meeting other young people was only deemed necessary by some respondents; and even for those, meeting on-line was as viable as meeting in person or in a group. Although isolation is a key feature of the YA experience, it is perhaps unclear even to the YA themselves, how best to address this; perhaps receiving cancer treatment with other YA may not be necessary as long as other opportunities to connect with peers is available. It is also possible that the opportunity to re-connect with peers and re-assimilate back into their normal social trajectory upon completion of their cancer journey is more important.

Although the importance of late effects and systematic oncology follow-up is recognized for survivors of childhood cancer [37] and certain adult cancers, such as testes cancer [38] and lymphoma [39], the appropriate delivery, scheduling, required testing, and logistics of follow-up of late effects among YA cancer survivors has not yet been established. Aftercare clinics designed to off-load clinical burden from the primary cancer center and which provide a central opportunity for observational data on the late effects of treating YA have only just begun to emerge. Translating the importance of appropriate aftercare to patients and treating oncologists will be necessary, especially considering the majority of patients in our survey preferred to continue follow-up with their primary oncologist despite being satisfied with ongoing support from primary care physicians for general care.

In summary, we have demonstrated that young adults on or soon after the completion of cancer treatment have specific information and service needs which vary by sex,

and somewhat by specific cancer diagnosis. Dedicated attention to programmatic initiatives is required to ensure the appropriate delivery of supportive care mechanisms to address these needs.

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