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Survivorship Care Planning and Unmet Information and Service Needs Among Adolescent and Young Adult Cancer Survivors

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Purpose: To examine whether survivorship care planning (receipt of written treatment summary or instructions for follow-up care) is associated with unmet needs among adolescent and young adult (AYA) cancer survivors (aged 15–39 at diagnosis).

Methods: We used data from the 2010 LIVESTRONG Survey for People Affected by Cancer. Outcome variables were survivor reports of unmet needs, including information on late effects of cancer treatment, fertility issues, cancer recurrence, and family cancer risk. We used multivariable logistic regression models to determine whether receipt of either a treatment summary or follow-up care instructions was associated with each unmet needs after controlling for sociodemographic and cancer history factors.

Results: Of the AYA respondents (N=1395), only 30% reported receipt of a written treatment summary and 86% received instructions for follow-up care. The most commonly reported unmet need was addressing recurrence concerns (80%), followed by information on late effects (78%), family risk of cancer (51%), and fertility information (45%). In multivariable analyses, receipt of a written treatment summary was associated with lower odds of having unmet needs about late effects information (odds ratio; OR=0.51 [0.37–0.71]) and recurrence concerns (OR=0.55 [0.39–0.79]). Receipt of follow-up care instructions was associated with lower odds of unmet needs about late effects information (OR=0.29 [0.15–0.58]) and fertility information (OR=0.62 [0.42–0.91]).

Conclusions: Survivorship care planning including written treatment summaries and follow-up care instructions may help reduce unmet information and service needs of AYA survivors. This study provides further evidence for the importance of survivorship care planning as a way to improve survivor outcomes.

Keywords: survivorship care plan, information needs, treatment summary, survivors

Introduction

A DOLESCENT AND YOUNG ADULT (AYA) cancer survivors (those aged 15–39 years at diagnosis) represent a unique and understudied subgroup of cancer survivors. 1,2 With often aggressive treatment regimens at an early age and the prospect of many years of survival after treatment, AYA survivors are at risk for developing a wide range of late effects of treatment, ranging from development of secondary cancers to pulmonary or cardiovascular complications as well as infertility. In addition, young adults also may struggle with psychosocial issues and financial hardships as they transition to adulthood while managing a chronic disease. Furthermore, the rapid developmental, social, and emotional changes among individuals aged 15–39 years mean that AYAs with

cancer may have different information and supportive care needs than older patients. Thus, provision of information to AYA survivors should be sensitive to these developmental issues.

Data from the first large national survey of AYA survivors (AYA HOPE study) recently found that 53% of AYA cancer survivors reported having six or more unmet information needs and that 35% had unmet service needs, and that having unmet information or service needs was associated with poorer health-related quality of life. Some of the most commonly identified unmet needs were regarding information about developing another type of cancer, signs of cancer recurrence, late effects of cancer, family members' risk of cancer, financial needs, and fertility issues. Another study found that unmet information needs were one of the strongest

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predictors of increased anxiety among AYA cancer patients, even after controlling for disease and treatment status.⁷

Survivorship care plans, including written treatment summaries and plans for follow-up care, have been suggested as a means for providing adequate information and improving survivor outcomes. In 2006, the Institute of Medicine (IOM) published its report From Cancer Patient to Cancer Survivor: Lost in Translation and introduced the concept of a survivorship care plan as a possible solution to the lack of care coordination between active treatment and long-term survivorship. In this report, the IOM recommended that at the end of active treatment for patients' primary cancer, every survivor be given a written summary of his or her treatment (including, but not limited to, diagnostic test results, tumor characteristics, dates of treatment initiation and completion, types, and doses of treatment) and a follow-up care plan (including but not limited to information on possible late effects of treatment, recommended cancer screening schedules, and referrals to specific follow-up care providers).8

In the decade since the IOM's landmark report, many practice organizations and treatment guidelines have recommended or advocated for the use of survivorship care plans. ^{9,10} In addition, agencies, including the American College of Surgeons, now require oncology practices to provide survivorship care plans to survivors after active treatment for its Commission on Cancer accreditation. ¹¹ Despite widespread advocacy for survivorship care plans, their use in practice remains suboptimal ¹² and the evidence base surrounding their impact on survivor outcomes is lacking. ¹³ The potential impact of survivorship care plans is particularly understudied among AYA survivors. ¹³ To our knowledge, no prior studies have looked at the association between survivorship care plans and unmet needs among AYA survivors.

Thus, the aim of this study is to determine whether two components of survivorship care planning (receipt of a written treatment summary or instructions for follow-up care) were associated with unmet needs among AYA cancer survivors.

Methods

Data for this secondary analysis came from the 2010 LIVESTRONG Survey for People Affected by Cancer. The 2010 LIVESTRONG survey was developed to assess the physical, emotional, and practical needs of post-treatment cancer survivors. It was conducted online and is available on the LIVESTRONG website. Details about survey administration have been published. 14 Cancer patients and survivors who were previously associated with the LIVESTRONG foundation were notified about the survey through email, Twitter, and Facebook. In addition, LIVESTRONG worked with community, national, and international partners, including state cancer coalitions and comprehensive cancer centers, to recruit survey participants. Data were collected through the online survey from June 2010 through March 2011. The survey was reviewed and approved by the Western Institutional Review Board. 14

Sample

A total of 12,037 respondents (including cancer patients, survivors, caregivers, and family members) completed the online survey, of these 4286 identified themselves as off-treatment cancer survivors. We excluded from this analysis

280 respondents who had missing data for date of diagnosis or birthdate as we were unable to calculate the age at diagnosis. In addition, we excluded 114 survivors who were less than the age of 15 at the time of their cancer diagnosis and 2497 who were aged 40 or older at the time of diagnosis, leaving 1395 AYA survivors for analysis.

Study variables

The outcome variables of interest were survivor reports of unmet information and service needs around four topics known to be important to AYA survivors^{3,4,15}: late effects of cancer treatment information, fertility information, cancer recurrence concerns, and family risk of cancer concerns.

Unmet needs. For concerns about unmet information needs regarding late effects of cancer treatment, survivors were asked to rate the extent to which the information provided by their healthcare team before treatment about the possible aftereffects of treatment met the survivor's needs (rated on a five-point scale from "Met none of my needs" through "Met all of my needs" with an additional option of "I did not receive information"). Those who reported not receiving any information or receiving information that met less than "all" of their needs were categorized as having an unmet need for late effects information.

For concerns about unmet information regarding fertility problems, survivors were asked to complete the statement "I feel that the information I received about possible fertility problems before treatment started met ..." with a five-point response scale from "None of my needs" through "All of my needs" with an additional option of "Not applicable"). Those who reported receiving information that met less than "all" of their needs were categorized as having an unmet need for fertility information. Those who reported that the information met "all" of their needs or rated the item as not applicable were categorized as *not* having an unmet need.

For concerns about unmet service needs regarding cancer recurrence and family risk of cancer, the survivors were first asked whether they had the concern ("I have worried about cancer coming back" and "I have worried that my family members were at risk of getting cancer"). Reponses to these questions were rated as "Yes," "No," or "I don't know." For each question, those that responded "Yes" or "I don't know" were asked whether they received help for the concern (rated as "Yes," "No," or "I don't know"). Survivors who indicated that they received help were also asked whether the help they received met their needs (rated on a fivepoint scale from "Met none of my needs" through "Met all of my needs"). Those who reported having the concern and not receiving any help for their concern or receiving help that met less than "all" of their needs were categorized as having an unmet need. Those who said that they did not have the concern at all or who received help that "Met all of my needs" were categorized as *not* having an unmet need.

Survivorship care planning. The two components of survivorship care planning (treatment summary and plan for follow-up care) each were measured with a single item on the LIVESTRONG survey, adapted from the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System. ¹⁶ To measure receipt of a written treatment

summary, participants were asked, "Did any doctor, nurse, or other health professional ever give you a written summary of all cancer treatments you received?" Receipt of instructions for follow-up care was measured with the question, "Have you ever received instructions from a doctor, nurse, or other health professional about where you should return or who you should see for routine cancer check-ups after completing your treatment for cancer?" Both questions had three response options ("Yes," "No," and "I don't know/I am not sure"). Ten percent (n=118) and 3% (n=36) of participants responded with "I don't know/I am not sure" to receipt of a written treatment summary and receipt of instructions for follow-up care, respectively. For both variables, we collapsed the responses into two categories for analyses (yes and no/don't know).

Sociodemographic characteristics. Age at diagnosis was computed for each survivor using survivors' birthdate and the date of their diagnosis. Self-reported sociodemographic variables included age at the time of the survey, sex, race, current level of education, current marital status, and current employment status. Cancer history variables included years since last treatment, type of cancer, and whether or not the survivor was currently seeing an oncologist or primary care physician. Measurement categories for each of these variables are provided in Table 1.

Data analysis

We first considered differences in survivors' unmet needs across the four areas (i.e., late effects of cancer treatment, fertility issues, recurrence concerns, and family risk of cancer) by receipt of a treatment summary and by receipt of instructions for follow-up care using unadjusted, univariable logistic regression analyses. Next we used an adjusted, multivariable logistic regression model for each outcome to determine whether receipt of a treatment summary or receipt of instructions for follow-up care was associated with each of the unmet needs after controlling for age at diagnosis, current age, race, sex, level of education, marital and employment status, years since treatment, type of cancer, and whether survivors were currently seeing an oncologist or primary care provider. All statistical tests were run in IBM SPSS Statistics version 23 with a predetermined alpha = 0.05.

Results

AYA respondents (N=1395) were on average 30 years old at the time of diagnosis (standard deviation [SD]=6.6) and 38 years (SD=9.2) at the time of survey completion (Table 1). More than half of respondents were female, white, married, and had relatively high levels of education and income (Table 1). Only 30% reported receipt of a written treatment summary, whereas 86% received instructions for follow-up care. The most commonly reported unmet need was addressing recurrence concerns (80%), followed by information about late effects (78%), family risk of cancer (51%), and fertility information (45%).

Late effects of treatment information

In unadjusted models (Table 2, Column 1), receipt of a written treatment summary and instructions for follow-up

Table 1. Characteristics of Participants (N=1,395)

	N (%)
Unmet needs	
Late effects of treatment information	949 (77.9)
Fertility information	629 (45.4)
Recurrence concerns	1035 (79.7)
Family risk of cancer concerns	629 (51.3)
Survivorship care planning	250 (20.4)
Receipt of written treatment summary	370 (30.4)
Receipt of instructions for follow-up care	1049 (86.3)
Sociodemographics	29.2 (0.2)
Age at survey completion (mean, SD)	38.2 (9.2)
Female Race	828 (59.7)
White	1215 (88.3)
Other	161 (11.7)
Marital status	101 (11.7)
Married/domestic partner	870 (63.0)
Other	510 (37.0)
Educational attainment	
Less than high school/high school degree	
Some college/technical/associate's degree	524 (38.3)
Bachelor's degree	452 (33.0)
Graduate/medical degree	285 (20.8)
Employment status Employed (full or part-time)	1037 (78.4)
Not employed (student/caregiver/retired)	285 (21.6)
Insurance status	203 (21.0)
Private/military	906 (86.3)
Medicare/Medicaid	59 (5.6)
Other/none/don't know	85 (8.1)
Cancer history	
Age at cancer diagnosis (years)	
15–20	153 (11.0)
21–29	453 (32.5)
30–39	789 (56.6)
Type of cancer	212 (15.2)
Breast	213 (15.3)
Colorectal Leukemia	44 (3.2) 55 (3.9)
Lymphoma	261 (18.8)
Melanoma	77 (5.5)
Sarcoma	69(5.0)
Testicular	253 (18.2)
Thyroid	89 (6.4)
Other	331 (23.8)
Time since last treatment	` ,
Less than 5 years	810 (60.9)
Five+ years	521 (39.1)
Currently seeing an oncologist	644 (52.7) 645 (52.7)
Currently seeing a primary care physician	

SD, standard deviation.

care were both significantly associated with lower odds of reporting unmet needs around information about late effects of treatment (odds ratio; OR [95% confidence interval] = 0.42 [0.32-0.55] and 0.24 [0.13-0.44], respectively). These findings remained significant in the adjusted model after controlling for sociodemographic and cancer treatment variables (Table 2, Column 2; treatment summary OR = 0.56 [0.39-0.80], follow-up instructions OR = 0.25 [0.11-0.57]). In addition, female survivors were significantly more likely to report unmet needs about late effects of treatment information than

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Table 2. Unadjusted and Adjusted Logistic Regression Models of Unmet Information and Service Needs Among Adolescent and Young Adult Survivors (n=1395)

rate effects in	formation	Fertility in	Fertility information	Recurrence concerns	concerns	Family risk of cancer concerns	ıncer concer
$Unadjusted^a$	$Adjusted^b$	Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted

Receipt of written 0.42 (0.32–0.55)° 0.56 (reatment summary Receipt of instructions 0.24 (0.13–0.44) 0.25 (for follow-up care

0.89 (0.64–1.24) **0.59** (**0.37–0.94**) 0.58 (0.32–1.03) **0.61** (**0.43–0.87**) 0.76 (0.49–1.19) 0.74 (0.57-0.96) 0.57 (0.39-0.84) 0.92 (0.66–1.27) **0.58** (**0.43–0.78**) 0.57 (0.37-0.88) 0.25 (0.11-0.57) 0.70 (0.50-0.97) 0.97 (0.78–1.23) 0.56 (0.39-0.80) $0.42 (0.32-0.55)^{\circ}$

^bEach adjusted column represents one multivariable logistic regression model, including both receipt of treatment summary and receipt of instructions for follow-up care, so that the impact of each can be evaluated while controlling for the other. The adjusted models also control for survivor age at the time of survey, sex, race, level of education, marital status, employment status, income, age at cancer diagnosis, type of cancer, time since last treatment, currently seeing an oncologist, and currently seeing a primary care physician. ORs for control variables can be found in ^aEach unadjusted column consists of two simple logistic models, one for the association of receipt of treatment summary and the specified outcome and the other for receipt of instructions for follow-up care and the specified outcome. the online

Cyalues depicted in bold text are statistically significant at p < 0.05

males (Supplementary Table S1; Supplementary Data are available online at www.liebertpub.com/jayao).

Fertility information

In unadjusted models, receipt of instructions for follow-up care (OR = 0.25 [0.11–0.57]), but not receipt of a written treatment summary (OR = 0.97 [0.78–1.23]), was associated with lower odds of reporting unmet needs about fertility information (Table 2, Column 3). Receipt of instructions for follow-up care remained significantly associated in the adjusted model (Table 2, Column 4; OR = 0.57 [0.37–0.88]). Factors associated with higher odds of unmet fertility information needs included being female, younger age at diagnosis, having a diagnosis of lymphoma or testicular cancer, and currently seeing an oncologist (Supplementary Table S1). Conversely, those with lower levels of education, currently married, or who had a diagnosis of melanoma were less likely to report unmet information needs concerning fertility issues (Supplementary Table S1).

Recurrence concerns

Both receipt of a written treatment summary and instructions for follow-up care were associated with lower odds of reporting unmet needs around recurrence concerns in unadjusted models (OR = 0.85 [0.43–0.78] and 0.59 [0.37–0.94], respectively; Table 2, Column 5). After controlling for sociodemographic factors and cancer history, receipt of a written treatment summary remained significant (OR = 0.55 [0.39–0.79]; Table 2, Column 6). Female survivors and those currently employed were more likely to report unmet needs around cancer recurrence concerns. Survivors who were currently seeing a primary care physician and who were younger at the time of the survey were less likely to report unmet needs about cancer recurrence concerns (Supplementary Table S1).

Family risk of cancer concerns

In unadjusted models, survivors who reported receipt of a written treatment summary and instructions for follow-up care were less likely to report unmet needs around concerns about family risk of cancer (OR = 0.74 [0.57–0.96] and 0.61 [0.43–0.87], respectively; Table 2, Column 7). However, in the adjusted model, these factors were not significant (Table 2, Column 8). Instead, factors associated with unmet needs around family risk of cancer included being female, having lower levels of education, and being married. Survivors with a history of leukemia, lymphoma, or other cancers had lower odds of reporting unmet needs around family risk of cancer (Supplementary Table S1).

Discussion

Our study is the first to look at the association between elements of survivorship care planning and unmet needs among AYA cancer survivors. Our findings provide support for the beneficial effect of survivorship care planning for AYA survivors. Consistent with studies among older adult cancer survivor populations, ¹⁴ we found that survivors who report having received written treatment summary or plan for follow-up care were less likely to report unmet needs. These findings, together with previous studies linking unmet needs

with poorer outcomes,^{5,6,15} suggest that providing AYA survivors with information about their prior treatment and a plan for future follow-up care may help avoid these poorer outcomes.

Similar to other studies, 4,15 we found high levels of unmet needs among AYA cancer survivors. In particular, more than three-quarters of respondents reported unmet needs around late effects of treatment information and recurrence concerns. This was slightly higher than the AYA Hope study that found that just more than half of AYA survivors surveyed reported these unmet needs.4 In addition, as has been found in other survivor populations, ¹² many AYA survivors did not receive survivorship care plans, with only 30% reporting that they received a written treatment summary. Owing to considerable advocacy about the importance of survivorship care planning⁸ and because it is required for accreditation by the American College of Surgeons Commission on Cancer, 11 use of written treatment summaries is expected to increase dramatically in coming years. Our finding that treatment summaries are associated with lower odds of common unmet needs suggests that AYA survivors may benefit significantly from this practice change.

Because AYA survivors, by definition, were treated for cancer at a young age, parents or other caregivers are often involved in the management of their active treatment. Adolescent survivors, in particular, may not have been actively involved in the decisions about their care and may not have accurate knowledge about their treatment history.¹⁷ In addition, there may be a gap of several years between the end of treatment for adolescent survivors and aging into adulthood. Thus, as adolescent survivors transition to adulthood and are expected to assume management of their survivorship care, having clear written documents that outline their care history and plan for follow-up care may be essential. 18 The use and impact of survivorship care plans have not been well studied among AYA survivors. Although this study provides initial evidence that survivorship care planning is associated with lower odds of unmet needs, this finding should be followed up with prospective and longitudinal studies to understand how survivorship care plans are used by AYA survivors and the pathways between survivorship care planning and improved outcomes.

In addition to the impact of treatment summaries and plans for follow-up care, our study also highlights the potential influence of the type of provider on survivor reports of unmet needs. Survivors who were currently seeing a primary care provider were less likely to report unmet needs around recurrence concerns, whereas those who reported currently seeing an oncologist were more likely to report unmet needs around fertility problems. Although the cross-sectional nature of this survey does not allow for evaluation of causation, this finding should be further explored and may indicate the benefit of connecting AYA survivors with a primary care physician after active treatment ends.

Our findings should be considered in light of several limitations. First, respondents to the LIVESTRONG survey are not representative of AYA survivors nationwide. The sample was largely white and well educated. Future studies should confirm these results among more diverse samples. Also, because the survey was anonymous and conducted online, we cannot calculate a response rate. However, this data set is unique in its ability to reach a sizable sample of AYA sur-

vivors, a population that is traditionally hard to reach for research studies. 19 Second, because this was a cross-sectional survey, we cannot determine whether survivorship care planning caused the lower rates of unmet needs. Survey questions about unmet needs around late effects information and fertility information were worded so that they asked about whether enough information was given by the healthcare team before treatment. Although survivorship care planning would not change the amount of information given before treatment, it may change the current perspective of survivors on whether their information needs were met on the whole. Longitudinal and intervention studies are needed to further explore these and other potential benefits of survivorship care planning. Third, because we tested for the association of survivorship care plan on several outcomes, there is an increased risk of type I error. For ease of interpretation, the results presented here were not adjusted for multiple comparisons. Finally, from the survey data available here, it is not clear what survivors actually received when they report having received instructions for follow-up care. They may have been given simple oral directions for when to come back for their next scans, but not received a written long-term plan that would qualify as part of survivorship care planning as outlined by National Cancer Institute.⁸ Regardless, our findings indicate that having instructions for follow-up care is associated with positive impacts for AYA survivors, even when they are not the formal plans currently recommended.

Conclusion

AYA survivors are a unique subset of survivors known to have high rates of unmet information and service needs. Our findings represent a first step at linking the use of components of survivorship care planning to reductions in unmet needs. Future studies should test what kinds of survivorship care plans may be most effective at decreasing unmet needs and whether this reduction in unmet needs can improve survivor outcomes.

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Disclaimer

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Author Disclosure Statement

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