The relationship between unmet cancer care needs and self-rated health among adolescents and young adults with cancer

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Abstract

Background Adolescents and young adults (AYA) with cancer face unique psychosocial challenges that often impact their outcomes, including self-rated health. To date, few studies have focused on AYA cancer survivors' multidimensional unmet needs of cancer care in relation to their health status.

Methods/Procedure This study surveyed 324 AYA cancer survivors in a cross-sectional design using the Cancer Needs Questionnaire – Young People (CNQ-YP). In addition to descriptive statistics and bivariate correlations, multinomial logistic regressions were used for analysis.

Results AYA cancer survivors' daily life needs were found to be significantly and negatively associated with self-rated health, OR = 0.910, 95% CI 0.843, 0.983, p < 0.01, and OR = 0.888, 95% CI 0.818, 0.966, p < 0.01. In addition, the unmet work needs were significantly and positively associated with participants' self-rated health, OR = 1.207, 95% CI 1.003, 1.452, p < 0.05.

Conclusions Moving beyond simply describing the unique psychosocial needs confronting AYA cancer survivors, this study empirically identified two specific dimensions of unmet needs of AYA cancer survivors that were significantly correlated to their SRH, both of which should be considered in future service and intervention research to support AYAs with cancer.

Keywords Adolescent and young adult · Self-rated health · Unmet needs

Background

Adolescent and young adult (AYA) cancer survivors are an age-defined population (15 to 39 years old), including patients receiving active cancer care and post-treatment survivors. [1] The National Cancer Institute (NCI) estimated over 87,000 new cases of cancer among AYAs in 2022 and nearly 633,000 survivors of AYA cancer in the United States in 2020. [2, 3] In addition to challenges common to cancer survivors across the age spectrum (e.g., treatment-related side- or late-effects), AYA cancer survivors face unique biopsychosocial concerns, such as issues of onco-fertility, occupational difficulties, stress related to family making, among others. [4-6] These unique challenges confronting AYA cancer survivors have been consistently linked to their health and mental health outcomes, e.g., psychological distress, psychosocial functioning, quality of life, and general health. [7-9] One salient patient-reported outcome (PRO) that has not been sufficiently evaluated among AYA cancer survivors is self-rated health (SRH).

SRH is a patient-perceived indicator of health status, which integrates the biopsychosocial and functional aspects of an individual's health, including cultural beliefs and health behaviors. [10] Typically measured via a single question, "In general, would you say your health is …," an individual responds to a 5-point Likert scale of "excellent," "very good," "good," "fair," or "poor" to indicate their perceived health status. [11]

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SRH is one of the shortest, yet most powerful measures of general health with its well-validated predictive power of individual mortality across diverse populations and strong connection with multiple biomarkers of physical health. [10-13] Most importantly, SRH has been extensively validated in the cancer population across the age spectrum, racial/ethnic groups, and cancer status. [14-16]

Specifically, SRH remains a well-validated measure of general health status and is a strong indicator of survival and mortality rate (as well as a broad scope of PROs, such as general wellbeing and quality of life) among AYAs with cancer. [17, 18] Given that AYA cancer survivorship remains a relatively young field of science, there exists limited investigation on risk factors impacting AYA cancer survivors' SRH. In a recently published scoping review of the AYA cancer literature (between 2015 to 2020), [19] Telles reported that most research in AYA cancer has focused on understanding the experiences and needs of this population (n = 118, 73.3%), leaving a small portion of studies focusing on interventions to improve AYA cancer survivors' experiences and needs (n = 30, 26.7%). The four main areas of focus include: 1) health system/treatments, 2) quality of life, 3) sexual health, and 4) social issues, indicating that few studies have focused on AYA cancer survivors' SRH.

Based on the limited studies that have focused on risk factors impacting AYA cancer survivors' SRH, comorbid chronic health conditions (e.g., cardiovascular disease, hypertension), mental health challenges, and health-related behaviors are commonly identified correlates of SRH. [20-22] Though highly valuable, these findings reflect a key gap in the AYA cancer literature, as few have considered the unique unmet biopsychosocial needs of AYA cancer survivors in relation to their SRH. Published conceptual frameworks [4, 6] have articulated that the unmet needs of AYA cancer survivors often lead to compromised health and mental health behaviors, which, in turn, are associated with AYA cancer survivors' SRH. Therefore, it is reasonable to expect plausible connections between the unmet care needs and SRH among AYA cancer survivors. This line of investigation extends beyond the existing literature by 1) evaluating the unmet care needs of AYA cancer survivors in relation to their SRH and 2) testing the conceptually supported relationships using empirical data. Most importantly, this study utilized the multi-dimensional unmet needs measure for AYAs with cancer – the Cancer Needs Questionnaire – Young People (CNQ-YP) to comprehensively evaluate the unmet needs of AYA cancer survivors. [23, 24] Specifically, in this study, we aim to determine if any (specific dimension) of unmet AYA cancer needs is associated with better SRH. Given the exploratory nature of this study, we do not hold any pre-specified directional hypothesis.

Methods

Study design

We administered an exploratory cross-sectional survey to evaluate the unmet needs of AYAs diagnosed with cancer who are receiving or have received care at the University of Michigan Health System (UMH). The study's primary objectives were: 1) to describe the unmet psychosocial needs of AYA cancer survivors; and 2) to evaluate AYA cancer survivors' SRH. The study was approved by the University of Michigan IRBMED (HUM00180540), and was performed in accordance with the ethical stands as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Participant recruitment and study procedure

To be eligible for participation, a participant must be between the age of 15 to 39 years old, with a current diagnosis of cancer, or a survivor of cancer diagnosed within the previous 10 years with at least one appointment for cancer care at UMH between 2020 and 2021. Upon IRB approval, the investigative team utilized the cancer registry at UMH to identify potential participants, i.e., convenient sampling. The query yielded medical record number (MRN), class of case (i.e., shows the role the reporting institution played in the patient's diagnosis or treatment), current age (date of birth), date of first and last contact with UMH, first and last name, primary cancer site, histo/behavior ICD-O-3 diagnostic codes, current address, and vital status (i.e., if a patient/survivor is still living or deceased). A total of 3,823 potential participants were identified in this manner and they were contacted via mail.

Surveys and consent forms (N = 3,823) were mailed to participants between August 2021 and February 2022. Participants opted to complete the survey by paper or via Qualtrics. By the end of the study period, we received a total of 830 returned mails, including 506 invalid returns (e.g., address no longer active) and n = 324 valid returns (n = 318 by paper, n = 6 by Qualtrics). Upon receiving valid returns from study participants, the investigative team members (NJL and DM) tracked and documented all returned surveys and extracted data to a database internally stored in a University of Michigan firewall-protected server. The study principal investigator (AZ) randomly selected and double-checked the data extraction of 25% of all valid surveys, revealing a 99.9% inter-extractor reliability rate. All enrolled study participants were tracked and reported in the clinical and translational oncology research platform – OnCore. Participants were mailed a $15 incentive to thank them for their participation.

Measurements

Self-Rated Health (SRH) SRH was measured by a single question "In general, would you say your health is?" A participant responds to a 5-point Likert scale of "5 = excellent," "4 = very good," "3 = good," "2 = fair," or "1 = poor" to indicate their perceived health status. Given the distribution of this variable, SRH was regrouped into "excellent or very good health," "good health," or "poor or fair health."

The unmet needs of AYAs with cancer This construct was measured by the Cancer Needs Questionnaire – Young People (CNQ-YP). CNQ-YP was specifically developed to evaluate the unmet needs of AYA cancer survivors via a comprehensive literature review, focus groups with AYAs, and feedback from health care providers, researchers, and other professionals. [23, 24] CNQ-YP contains 112 questions that cover 6 main factors (areas of needs): 1) treatment environment and care, 2) daily life, 3) feelings and relationships, 4) information and activities, 5) education, and 6) work. CNQ-YP has been well-validated by published literature, indicating strong psychometric properties. [24-26] All six dimensions of CNQ-YP in this study reported satisfactory internal consistency, with Cronbach's alphas ranging from 76 to 82%.

Demographic and clinical variables We also collected study participants' self-reported age (in years), race (recoded into non-Hispanic White versus others given the distribution of this variable), gender identity (1 = women/girl, 2 = man/boy, and 3 = nonbinary and others [transfeminine, transmasculine, two-spirit, prefer not to say, open-response free-text]), and a survivor's current cancer status (1 = active treatment, 2 = within 1 year post-treatment, 3 = 1–3 years post-treatment, 4 = 3–5 years post-treatment, and 5 = 5 or more years post-treatment).

Statistical analyses

All data analyses were conducted using R statistical software (version 4.2.1). We first used means (M) and standard deviations (SD) for continuous variables and used frequency and percentages for categorical variables to describe the study population. Then, we evaluated the bivariate Pearson's correlations to explore the association between study variables. Finally, to evaluate the unmet needs of care among AYA cancer survivors in relation to their SRH, we conducted multinomial logistic regression by entering the SRH as the dependent variable and a set of demographic variables, cancer status, and the dimensions of unmet care needs as independent variables. A p-value of 0.05 was considered the threshold for statistical significance.

Results

Descriptive statistics of the study population

Between August 2021 and February 2022, we sent out n = 3,823 surveys and received 324 valid survey responses. The participants' age ranged from 16 to 39 years old, with an average age of 30.22 (SD = 6.50). Most of the participants identified as non-Hispanic White (n = 289, 89%), with the remaining comprised of 8 Black Americans (2.5%), 8 Asian Americans (2.5%), 8 Native Hawaiian or other Pacific Islander (2.5%), 1 American Indian or Alaska Native (0.3%), 5 Hispanic/Latino (1.6%), and 5 multiple racial participants (1.6%). Over half of the participants identified as women/girl (n = 215, 67.7%), 94 identified as man/boy (29.4%), and 9 identified as nonbinary and others (2.9%). Most study participants in the study were long-term survivors (i.e., more than 5 years post-treatment, n = 92, 28.5%), followed by 85 participants (26.3%) who were 1–3 years post-treatment, 56 participants (17.02%) who were 3–5 years post-treatment, leaving 45 (13.8%) and 46 (14.1%) participants who were receiving active treatment and within 1-year post-treatment, respectively. Over one-third of the study participants reported good health (n = 120, 37.3%) or very good health (n = 106, 32.9%), 63 participants (16.4%) reported fair health, leaving 28 participants (8.5%) and 7 participants (1.9%) reporting excellent or poor health, respectively. Descriptive statistics are presented in Table 1.

Bivariate pearson's correlation

At the bivariate level (Table 2), dimensions of AYA cancer survivors' unmet needs were significantly associated with each other, except for *educational* and *feelings and relationships*, $r = 0.075$, $p > 0.05$. Otherwise, the correlations between the six dimensions ranged from $r = 0.218$, $p < 0.001$, between *treatment environment and care* and *daily life*, to $r = 0.713$, $p < 0.001$, between *daily life* and *feelings and relationships*. Both the *daily life* and *feelings and relationships* were significantly correlated with participants' SRH, $r = -0.397$, $p < 0.001$, and $r = -0.392$, $p < 0.001$, respectively. Participants with greater unmet *daily life* and *feelings and relationships* needs were more likely to report lower SRH. Additionally, AYA cancer survivors' current cancer status was positively associated with SRH, $r = 0.119$, $p < 0.05$. The greater the number of years post-treatment, the more likely a participant was to report better SRH.

Multinomial logistic regression

Results of the multinomial logistic regression (Table 3), which controls for participant demographic and clinical

Table 1 Demographic and Clinical Characteristics (N = 324)

	Total Sample*
Age	30.220 / 6.501
Gender	
Women/girl	215 (67.7%)
Man/boy	94 (29.4%)
Nonbinary and others	9 (2.9%)
Race	
Black/African American	8 (2.5%)
Hispanic/Latino	5 (1.6%)
Non-Hispanic White only	289 (89%)
American Indian or Alaska Native	1 (0.3%)
Asian, non-Hispanic	8 (2.5%)
Native Hawaiian or Other Pacific Islander	8 (2.5%)
Multi-racial or others	5 (1.6%)
Cancer Status	
Receiving active treatment	45 (13.8%)
Within 1 year survivor	46 (14.1%)
1–3 years survivor	85 (26.3%)
3–5 years survivor	56 (17.02%)
> 5 years survivor	92 (28.5%)
Unmet Cancer Care Needs	
Treatment Environment and Care	3.995 / 0.613
Daily Life	2.189 / 0.935
Feelings and Relationships	2.131 / 0.890
Information and Activities	2.984 / 0.908
Education	2.966 / 1.255
Work	3.139 / 1.435
Self-Rated Health	
Poor	7 (1.9%)
Fair	63 (16.4%)
Good	120 (37.3%)
Very good	106 (32.9%)
Excellent	28 (8.5%)

* mean/SD for continuous variables, and N (%) for categorical variables

factors, are shown in Table 3. AYA cancer survivors' *daily life* needs were found to be significantly and negatively associated with SRH. For each unit increase in unmet *daily life* needs, participants were 9% less likely to report good health versus fair or poor health, $OR = 0.910$, 95% CI 0.843, 0.983, $p < 0.01$. Similarly, for each unit increase in participants' unmet *daily life* needs, they were 11.2% less likely to report excellent or very good health versus fair or poor health, $OR = 0.888$, 95% CI 0.818, 0.966, $p < 0.01$. In addition, the unmet *work* needs were significantly and positively associated with participants' SRH. For each unit increase in unmet *work* needs, participants were 1.2 times more likely to report excellent or very good health versus fair or poor health, $OR = 1.207$, 95% CI 1.003, 1.452, $p < 0.05$. Though

not statistically significant, a trend towards statistical significance ($0.05 < p < 0.06$) was observed for the just-mentioned relationship, $OR = 1.191$, 95% CI 0.994, 1.427, $p < 0.06$. For each unit increase in unmet *work* needs, participants were 1.19 times more likely to report good health versus fair or poor health.

Discussion

AYA cancer survivors are an age-defined population confronted with a unique set of care needs that are specific to their developmental stages. This study, to our knowledge, is among the first to comprehensively evaluate all dimensions of unmet care needs of AYA cancer survivors in relation to SRH, a salient indicator of their mortality and general wellness. [14, 20] At the bivariate level, five out of the six dimensions of the unmet needs were significantly correlated with each other, suggesting the interconnection between various unmet needs. Such a finding is consistent with the existing literature, for example, connecting AYA cancer survivors' emotional needs with their daily pragmatic challenges, and linking their daily life needs with socio-emotional needs to interact with peers. [27-29]

At the bivariate level, we were not surprised to see a significant positive association between AYA cancer survivors' cancer status and their SRH, indicating AYAs with cancer are more likely to report better health over time post-treatment. This bivariate level association, however, should be interpreted in the larger context that AYA cancer survivors continue to face various unmet needs and challenges, especially late effects and oncofertility challenges, regardless of the number of years post-treatment. [30, 31] In particular, the associations between cancer status and four (out of six) dimensions of unmet needs were statistically non-significant, indicating a stable manifestation of these unmet needs across cancer status.

Multinomial logistic regression revealed that the unmet daily life needs, e.g., the ability to cope with physical and appearance changes and the ability to manage medication and side effects, were significantly associated with lower odds of reporting good or very good/excellent health versus fair or poor health, suggesting these needs negatively impact AYA cancer survivors' general health. [32] Many AYAs, for example, report cancer-related post-treatment fatigue as one of the most prevalent and severe symptoms they experience, and cancer-related fatigues are persistently disruptive to their sleep quality and motivation. [33] Similarly, Brock and colleagues (2022) found that achieving maximum work ability is a major challenge for AYAs, and many reported compromised cognitive capacity (e.g., poor concentration or low attention span) for work. [34] This finding further highlights the significance of managing AYA cancer survivors' late

Table 2 Bivariate Correlation

	1	2	3	4	5	6	7	8	9	10	11
1 Treatment Environment and Care	1	.218***	.319***	.542***	.259***	.416***	.048	.031	.043	.094	.001
2 Daily Life		1	.713***	.322***	.188**	.179**	-.018	-.152**	.053	.067	-.397***
3 Feelings and Relationships			1	.464***	.075	.227***	.031	-.179**	-.077	.009	-.392***
4 Information and Activities				1	.288***	.430***	-.080	.045	-.010	-.008	-.109
5 Education					1	.272***	-.345***	.097	.220***	.007	-.110
6 Work						1	.036	-.022	-.082	.080	-.033
7 Age							1	-.085	-.085	-.010	-.050
8 Cancer Status								1	.290***	-.016	.119*
9 Gender									1	-.011	.057
10 Race										1	.068
11 Self-Rated Health											1

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

effects impacting their physical, appearance, and functional health on a daily basis, especially given its strong association with SRH, a compelling indicator of cancer survivors' mortality and general wellness.

Interestingly, AYA cancer survivors' unmet work-related needs were significantly and positively associated with their SRH. Higher work-related needs, e.g., "how much work I would miss", "how to ask managers/ co-workers for support", and "the manager/co-workers had support to help them cope" are associated with improved SRH. A possible explanation for this positive relationship is that those with higher SRH may be more physically or psychologically ready for work compared to those with lower SRH, resulting in higher reported work needs. In other words, it is possible that only those AYA cancer survivors who are physically well enough will have high

Table 3 Multinomial Logistic Regression

	Reference Group: Fair or Poor Health			
	Good Health		Excellent or Very Good Health	
	OR	95% CI	OR	95% CI
Intercept	–	–	–	–
Age	1.034	[.935, 1.143]	1.016	[.916, 1.126]
Gender[1]	–	–	–	–
Race (*ref:* race/ethnic minority)				
Non-Hispanic White	6.159	[.547, 69.382]	.780	[.141, 4.308]
Cancer Status (ref: > 5 years post-treatment				
Active cancer treatment	1.384	[.243, 7.867]	.507	[.059, 4.365]
Within 1 year post-treatment	1.129	[.188, 6.780]	.740	[.096, 5.713]
1 – 3 years post-treatment	.618	[.120, 3.177]	.419	[.078, 2.243]
3 – 5 years post-treatment	5.487	[.509, 59.136]	4.348	[.422, 44.831]
Unmet cancer care needs				
Treatment environment and care	.988	[.954, 1.024]	1.012	[.977, 1.048]
Daily life	.910**	[.843, 0.983]	.888**	[.818, 0.966]
Feelings and relationships	1.018	[.950, 1.091]	.953	[.883, 1.029]
Information and activities	.959	[.809, 1.138]	.911	[.761, 1.090]
Education	1.040	[.877, 1.233]	1.044	[.873, 1.248]
Work	1.191†	[.994, 1.427]	1.207*	[1.003, 1.452]

[1] The gender variable was controlled for in the model, but the coefficients were not estimated because there were not enough observations in the nonbinary and other category. Sensitivity analysis excluding this variable resulted in

† $p < 0.06$, * $p < 0.05$, ** $p < 0.01$

work-related needs, whereas those who report low work-related needs are not ready to work given their cancer progression. This finding is interesting because it highlights the importance of viewing unmet work-related needs from a strength-based perspective. For example, when AYA cancer survivors report a high level of unmet work-related needs, it is an area for psychosocial support but also a sign that they may be preparing – physically, psychologically, or financially – to confront their work-related needs.

There are several limitations that restrict the interpretation of the current findings. First, this is a clinic-based sample recruited using a convenient sampling strategy. As a result, the generalizability of study findings remains low. Second, with a cross-sectional design, all identified relationships are only associations but not causations, which limited the study's internal validity. Third, given the unique patient population at the study site, close to 90% of the study participants identified as non-Hispanic White, limiting our understanding of the investigated relationships among racial/ethnic minority AYAs with cancer. Finally, because the largest fraction of respondents was diagnosed more than 5 years previous (28.5%), many participants underwent treatment and initial surveillance prior to the COVID-19 pandemic and its paradigmatic effects on healthcare (e.g., increased centrality of telemedicine and eHealth services). Therefore, the sample comprises a diverse set of experiences with respect to the changing landscape of health care. Future investigations are advised to explicitly address the temporality of AYAs' treatment timeline (i.e., diagnosed/treated before/after the onset of COVID-19) as a factor impacting unmet needs and their proposed interventions.

Notwithstanding these limitations, this study is among the first to include all six dimensions of the unmet care needs of AYA cancer survivors in relation to their SRH. Moving beyond simply describing the unique psychosocial needs confronting AYA cancer survivors, this study empirically evaluated if and how these unmet needs impact their SRH, a compelling predictor of cancer survivors' mortality and overall wellness. Two specific dimensions of unmet needs of AYA cancer survivors were significantly correlated to their SRH, both of which should be considered in future service and intervention research to support AYAs with cancer.

Declarations

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