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Prevalence and Correlates of Fear of Recurrence among Adolescent and Young Adult Versus Older Adult Post-Treatment Cancer Survivors

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Abstract

Purpose—We sought to: (1) assess prevalence of fear of recurrence among cancer survivors diagnosed as adolescent and young adults (AYA; 15–39 years) versus those diagnosed at a later age (40+ years), and (2) identify factors associated with fear of recurrence in each group.

Methods—We used logistic regression to determine the correlates of fear of recurrence by age group at diagnosis among survivors responding to the 2010 LIVESTRONG Survey.

Results—Prevalence of fear of recurrence was significantly higher among AYA survivors (85.2%) than those diagnosed at an older age (79.7%). Among AYA respondents, being employed and less than five years off treatment were positively associated with fear of recurrence while those with thyroid cancer and those who participated in a clinical trial were less likely to experience fear of recurrence. Among older adults, receipt of surgery was associated with fear of recurrence whereas having insurance coverage through Medicare or Medicaid and positive patient-provider communication were negatively associated with fear of recurrence.

Conclusions—For both AYA and older adult survivors, changeable factors such as having a more positive cancer care experience, may impact fear of recurrence. Our findings highlight the need to identify and understand aspects of the communication process that can be targeted in future interventions with survivors and healthcare providers to ensure that fear of recurrence is being appropriately managed. Factors associated with fear of recurrence differ for AYA and older adult survivors; thus, interventions would likely benefit from tailoring based on age at diagnosis.

Keywords

Fear of recurrence; cancer survivor; adolescent and young adult; prevalence; correlates

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Conflict of Interest
The authors have no conflicts of interest.

1. Introduction

Adolescents and young adults (AYAs) aged 15 to 39 years at the time of cancer diagnosis represent an overlooked and underserved population [1]. Cancer is the leading cause of disease-related death among AYAs [2], and improvement in 5-year survival outcomes over the past two decades lagged significantly behind that for both younger and older age groups [3]. AYAs who survive cancer have the potential for another four to six decades of productive life, a fact that underscores the importance of improving not only their duration of survival but also their quality of life [4]. Emerging research suggests, however, that AYAs report a number of unmet needs in the period of survivorship [5], with management of fear of recurrence representing a key unmet psychosocial need [6].

Fear of recurrence is defined as the worry that cancer will return or progress [7,8], and it is one of the most common experiences following cancer diagnosis and treatment, affecting over half of all cancer survivors [9,10]. Although fear of recurrence can be viewed as a normative response to the possibility of recurrence, it is possible for such fear to become excessive and problematic [11]. According to Lee-Jones and colleagues' conceptualization [12], external (e.g., interactions with health professionals) and internal (e.g., somatic symptoms) stimuli activate cognitions, beliefs, and emotions which comprise fear of recurrence. Cognitions include thoughts about the past experience of cancer and its treatment that impact beliefs regarding personal risk of recurrence and, combined with worry that the cancer will return, result in heightened fear of recurrence with associated behavioral and psychological consequences (e.g., increased body checking/scanning, increased healthcare utilization, increased anxiety). Increased fear of recurrence also has been associated with poorer health-related quality of life [13,14] and psychosocial well-being [15].

Examination of factors associated with fear of recurrence among cancer survivors suggests that younger age is the most consistent predictor of increased fear of recurrence [10–11;16]. Other factors significantly associated with increased fear of recurrence include presence of physical symptoms, poor quality of life, and maladaptive coping responses. More moderate evidence exists for perceptions of vulnerability whereas inconsistent or weak evidence exists for sociodemographic and disease-related factors such as race, education, cancer type, and years since treatment [9–11;17]. Although not directly tested to date, Lee-Jones et al.'s conceptualization [12] suggests that survivors' perceptions of their cancer care experience as it relates to interactions with the healthcare team, including patient-provider communication, also may be associated with fear of recurrence. Emerging research in this area suggests that a more negative patient-provider relationship is associated with higher self-reported anxiety among cancer survivors, with such anxiety contributing to increased fear of recurrence [18].

Because the majority of research on fear of recurrence has been conducted with older or mixed-age samples of breast cancer survivors, it remains unknown how this construct may manifest itself among younger survivors of mixed cancer types. Additionally, a comparison of the prevalence and predictors of fear of recurrence among the two age groups at diagnosis (i.e., aged 15–39 years at diagnosis and aged 40 or older at diagnosis) is needed to determine whether interventions should be tailored by age at diagnosis. Accordingly, this exploratory study sought to: (1) assess the prevalence of fear of recurrence among post-treatment AYA cancer survivors compared with older adults, and (2) identify factors associated with fear of recurrence in each age at diagnosis group. In line with previous research, we hypothesized that: (a) AYA survivors will be more likely to report fear of recurrence compared with older adult survivors, and (b) survivors' perceptions of their cancer care experience will be associated with fear of recurrence such that more positive cancer care experiences will be associated with lower odds of reporting fear of recurrence.

2. Methods

We conducted a secondary analysis of data from the 2010 LIVESTRONG Survey for People Affected by Cancer. The survey assessed physical, emotional, and practical concerns of cancer survivors, in addition to survivors' perceptions of their health information-seeking behavior and overall cancer experience [19]. The survey also contained questions that examined the impact of cancer on family members, caregivers, and other loved ones.

The survey was available through the LIVESTRONG website and was launched in June 2010; data were collected through March 2011. To recruit survey respondents, LIVESTRONG sent email notifications to its constituents and posted messages regarding the survey on its social media profiles (i.e., Twitter, Facebook). LIVESTRONG also reached out to partner organizations worldwide, including members of the LIVESTRONG Survivorship Center of Excellence Network, to encourage these organizations to share the survey with their respective constituents. To facilitate this process, LIVESTRONG provided organizations with a toolkit consisting of a flyer describing the survey, as well as content appropriate for inclusion in a newsletter, an email, and a social media post for both Twitter and Facebook. Passive consent in the form of a returned survey was used and respondents were told that they could withdraw their consent and stop the survey at any time. The survey protocol was reviewed and approved by the Western Institutional Review Board.

2.1. Study Sample

The 2010 LIVESTRONG survey was administered to post-treatment cancer survivors, cancer survivors in active treatment, and other individuals without a personal history of cancer but who were affected by cancer (e.g., caregivers). Of 12,037 individuals who responded to the survey, 4,286 identified as post-treatment survivors. Of these, we excluded 277 survivors who did not provide a date of cancer diagnosis because we could not assign them to the AYA or older adult survivor age group. An additional 144 were excluded who were diagnosed before the age of 15.

2.2. Measures

2.2.1. Outcome variable—Fear of cancer recurrence was assessed with a single question from the Quality of Life in Adult Cancer Survivors Scale [20]. Respondents were asked whether they worried about cancer coming back since completing treatment. Response options included yes, no, and don't know. Due to a small number of respondents (n=79; 2%) selecting "don't know", we excluded these participants from the analyses,

2.2.2. Correlates—Sociodemographic characteristics, cancer history, and perceptions of cancer care experience were selected for analysis based on previous literature [10,11,16–18]. Analysis categories for all correlates are shown in Table 1.

Sociodemographics: Variables assessed included age at survey completion, gender, race, marital status, educational attainment, employment status, total household income, and insurance status.

Cancer history: The survey assessed self-reports of age at cancer diagnosis, type of cancer, time since last treatment, current healthcare provider, type of treatment(s) received, and whether the respondent participated in a clinical trial. Two additional items from the Centers for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS; http://www.cdc.gov/brfss) assessed whether the respondent had ever received a written cancer treatment summary and whether the respondent had ever received instructions from a health professional regarding post-treatment cancer care.

Perceptions of cancer care experience: Variables assessed included: whether there was a dedicated patient navigator on the health care team who helped guide the respondent through the cancer experience and the extent to which information about late effects and risks of treatment met the respondent's needs. In addition, five items from the National Cancer Institute's Health Information National Trends Survey (HINTS; http://www.hints.cancer.gov) assessed how often respondents perceived that they: were given a chance to ask health-related questions, were given attention to their feelings and emotions, made sure they understood things needed to care for their health, were helped to deal with feelings of uncertainty, and were involved in decisions about health care as much as they wanted. Item responses ranged from 0 (Never) to 3 (Always). A summary score was created from these five items, ranging from 0 to 15 with higher scores representing more positive patient/provider communication.

2.3. Data Analysis

We first compared whether survivors diagnosed as AYA and those diagnosed at a later age differed on fear of recurrence. In stratified analyses by age group, we examined univariable associations between fear of recurrence and independent variables using simple logistic regression. To identify correlates that remained significantly associated with fear of recurrence in adjusted analyses, we ran a multivariable logistic regression model for each age group, in which all variables with univariable associations of $p < .25$ were included in the models [21]. Analyses were conducted using SPSS Version 21 (Chicago, IL).

3. Results

3.1. Characteristics of AYA and Older Adult Respondents

We analyzed data from 3,892 post-treatment cancer survivors of whom 1,395 were AYA (aged 15–39 years at diagnosis) and 2,497 were older adult survivors (aged 40 years or older at diagnosis). Participants were majority female, white, well-educated, married, and employed (Table 1). Approximately half had household incomes in excess of $81,000 and over 80% had private or military insurance. Approximately one-third of the older adult group had a diagnosis of breast cancer, while the most common AYA diagnoses were lymphoma and testicular cancer. Most of the respondents were less than five years from active treatment. While almost 90% of participants reported having received post-treatment instructions, less than a third received a written cancer treatment summary, and very few received help from a dedicated patient navigator. Overall, participants rated their patient-provider communication positively and about a quarter stated that all of their needs were met regarding information about late-effects/risks of treatment.

3.2. AYA and Older Adult Respondents’ Fear of Recurrence

AYA survivors were significantly more likely to report fear of recurrence (85.2%) compared with older adult survivors (79.7%) ($\chi^2 = 17.57$; $p < .001$). In univariable analyses, factors associated with fear of recurrence at $p < .25$ in both AYA and older adult respondents included younger age at survey completion, female gender, being married or living with a partner, being employed, being less than five years since last treatment, currently seeing an oncologist, receipt of radiation, and receipt of surgery (Table 2). In both age groups, survivors were less likely to report fear of recurrence if they reported that they were currently seeing a primary care physician and that the information they received on late-effects/risk of treatment met all of their needs.

In addition to these common factors, among AYA respondents fear of recurrence was positively associated with older age at the time of diagnosis and with type of cancer diagnosis (Table 2). AYA survivors who participated in a clinical trial and who received a written or online cancer treatment summary were less likely to report fear of recurrence. In contrast, among older adult survivors, fear of recurrence was positively associated with white race, being younger at the time of diagnosis, currently seeing an oncologist, receipt of chemotherapy, and participation in a clinical trial. Older adult survivors were less likely to report fear of recurrence when they had insurance coverage through Medicaid or Medicare, had a patient navigator to help them guide through the cancer experience, and when they experienced positive patient/provider communication.

In the multivariable model for AYA respondents (Table 2), younger age at survey completion, being female, and being employed remained associated with greater fear of recurrence. A diagnosis of thyroid cancer, being five or more years since last treatment, participation in a clinical trial, and receiving information on late effects/risks of treatment that met all or some of one’s needs were negatively associated with fear of recurrence among AYA survivors. In the multivariable model for older adult respondents (Table 2), receipt of surgery was associated with greater fear of recurrence whereas having insurance coverage through Medicare or Medicaid, receiving information on late effects/risks of treatment that met all or some of one’s needs, and positive patient-provider communication were negatively associated with fear of recurrence.

4. Conclusions

Although previous research has consistently found an association between younger age and increased fear of recurrence among cancer survivors [10,11,16], our study is among the first to specifically document the greater prevalence of fear of recurrence among AYA cancer survivors compared to older adult survivors. Our finding that 85.2% of AYA survivors reported fear of recurrence was within the 33–96% range reported in previous research with cancer survivors of mixed ages [9,10] and supports recent findings indicating that among AYA survivors, learning how to handle and manage fear of recurrence represents a key unmet information need [6]. Because existing research suggests that fear of recurrence remains relatively stable over the course of survivorship [22] and AYA survivors will spend a considerable portion of their lives in survivorship [4], continued examination of fear of recurrence in this group of survivors is warranted.

Among both AYA and older adult survivors, those who reported having all of their information needs met related to late effects/risks of treatment were less likely to report fear of recurrence. Previous studies have documented that having healthcare professionals who are knowledgeable about cancer follow-up care is a highly ranked need among survivors [24], and healthcare providers who provide informational, practical, interpersonal/social, and/or emotional support can promote survivors' psychosocial and emotional well-being [25–28]. Although causation cannot be inferred, our results extend previous work by suggesting that meeting survivors' information needs can also hold important implications for their fear of recurrence.

Additionally, among older adult survivors, reports of positive patient-provider communication were negatively associated with fear of recurrence. Certainly, the preliminary nature of this finding and the lack of an observed similar association among AYA survivors suggest that further examination is needed to understand the interplay of fear of recurrence and patient-provider communication among survivors of all ages. Ten years have elapsed since publication of the seminal Institute of Medicine report [29] highlighting the need to better understand the survivor-provider communication process, and it is clear that more work needs to be done to understand and improve this process. There are very few interventions aimed at improving patient-provider communication in the period of survivorship, although there is preliminary evidence for the feasibility and perceived utility of a web-based, multimedia patient-provider communication training module among breast cancer survivors [30,31]. Because survivor-provider communication is modifiable, additional research is needed to identify and understand discrete aspects of the communication process that can be targeted in future interventions with cancer survivors and their healthcare providers to ensure that survivors' needs are being met. We also need to understand whether the communication process and its determinants are similar for different types of cancer and for characteristics such as gender and race/ethnicity.

Several factors associated with fear of recurrence showed different patterns of association between AYA and older adult survivors. Among AYA survivors, participation in a clinical trial was negatively associated with fear of recurrence. As clinical trials have resulted in increased knowledge on how to best treat cancer, improved survival and reduced mortality among trial participants has followed [32]. It may be that AYA survivors who participated in a clinical trial experienced these positive outcomes firsthand and, as a result, were less likely to experience fear of recurrence.

Our results must be interpreted in the context of certain limitations. Because our sample was predominantly female, White, married/partnered, well-educated, employed, and privately insured, our results may not generalize to other sociodemographic groups. It is possible that those who completed the 2010 LIVESTRONG survey differed from those who did not choose to do so. Data on non-respondents were not available. In future studies it would be useful to attempt to capture such data so that comparisons between respondents and non-respondents could be made. Survivors who participate in LIVESTRONG surveys may be accessing services provided by LIVESTRONG and thus may represent a group that is receiving a higher quality of patient support services than the general population. Additionally, the measure of fear of recurrence used in the LIVESTRONG survey was based on a single-item assessing worry regarding recurrence. This may cause a ceiling effect and only allows for examination of the presence or absence of fear of recurrence, but not its intensity. While many studies have used a single item measure of fear of recurrence (e.g. [33–35]), we do not know of another study that uses this particular single item measure as the outcome variable. However, cancer survivors diagnosed in adolescence and young adulthood are a hard-to-reach group and the LIVESTRONG survey offers a unique opportunity to have an adequate sample to compare the prevalence and correlates of fear of recurrence across age groups at diagnosis. Thus, we believe that even with the single item measure, this study provides an important first step for understanding how fear of recurrence among cancer survivors may be different by age at diagnosis. Given recent work suggesting that fear of recurrence may be multidimensional in nature [23], a more nuanced assessment of this construct is necessary in order to confirm the dimensions of fear of recurrence among cancer survivors and work toward establishing a gold-standard measure [22]. The cross-sectional design of the survey represents another limitation as it may have influenced the observed prevalence of fear of recurrence. For instance, fear of recurrence may have been heightened if survivors had an impending follow-up test or, conversely, fear of recurrence may have been minimized if survivors had recently been declared disease-free after a routine follow-up test. Future studies should employ a prospective design in order to document the trajectory of fear of recurrence over the period of survivorship and thus shed light on potential key opportunities for intervention.

Despite these limitations, our study highlights the need for interventions designed specifically to reduce fear of recurrence among cancer survivors, particularly AYA survivors. Beyond a small pilot intervention [36] and a currently ongoing randomized trial directly targeting fear of recurrence [37], other published reports of interventions have targeted similar concepts (e.g., uncertainty, fear of cancer progression) [38–41] or targeted fear of recurrence only as a secondary outcome [42,43]. Our study has identified several modifiable factors, all in the realm of patients' cancer care experiences, which should be further assessed and targeted in future interventions that seek to reduce fear of recurrence. Because of the observed differential associations between AYA and older adult survivors on some of the factors associated with fear of recurrence, these interventions would likely benefit from tailoring based on age at diagnosis.

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Table 1

Sociodemographics, cancer history, and perceptions of cancer experience by age at diagnosis: Adolescents and young adults (15–39 years at diagnosis) versus older adults (40+ years at diagnosis).

	Age at Diagnosis	
	AYA (n=1395) %	**Older Adults (n=2497) %**
Sociodemographics		
Age at survey completion [median (min, max)]	38 (18–73)	55 (40–94)
Gender		
Male	40.3	34.6
Female	59.7	65.4
Race		
White	88.3	92.9
Other	11.7	7.1
Marital Status		
Married/domestic partner	63.0	73.7
Other	37.0	26.3
Educational attainment		
Less than high school/high school degree	7.8	9.6
Some college/technical/associate’s degree	38.3	35.5
Bachelor’s degree	33.0	30.7
Graduate/medical degree	20.8	24.3
Employment status		
Employed (full or part-time)	78.4	67.3
Not employed (student/caregiver/retired)	21.6	32.7
Total household income		
≤80,000	52.6	49.5
≥81,000	47.4	50.5
Insurance status		
Private/military	86.3	82.5
Medicare/Medicaid	5.6	10.8
Other/none/don’t know	8.1	6.7
Cancer history		
Age at cancer diagnosis (mean, SD)	30.0 (6.6)	51.2 (7.8)
Type of cancer		
Breast	15.3	34.0
Lymphoma	18.8	6.5
Melanoma	5.5	2.9
Testicular	18.2	2.7
Thyroid	6.4	2.4
Other	35.8	51.5
Time since last treatment		

	Age at Diagnosis	
	AYA (n=1395) %	**Older Adults (n=2497) %**
Less than five years	60.9	77.2
Five+ years	39.1	22.8
Currently seeing an oncologist	52.7	54.9
Currently seeing a primary care physician	52.7	61.5
Type of treatment(s) received		
Chemotherapy	62.4	57.3
Radiation	46.2	49.9
Surgery	73.1	76.9
Participated in a clinical trial	12.9	12.5
Received post-treatment instructions	86.3	89.8
Received written cancer treatment summary	30.4	33.1
Received online cancer treatment summary	9.0	12.2
Perceptions of cancer experience		
Dedicated patient navigator	2.7	4.8
Information on late-effects/risks of treatment met…		
All of my needs	23.0	28.3
Many of my needs	37.1	37.6
Some of my needs	25.6	23.1
Very few to none of my needs	14.3	11.0
Patient/Provider Communication Score (mean, SD)	10.4 (4.0)	11.0 (3.7)

Table 2

Univariable associations and multivariable logistic regression models of fear of recurrence among AYA (15–39 years at diagnosis) and older adult (40+ years at diagnosis) cancer survivors.

	Univariable Models % Fear of Recurrence				Multivariable models^a	
	AYA (n=1395)		Older adult (n=2497)		AYA (n=1034)^b	Older adult (n=1324)^b
Variables	**%**	**p-value**	**%**	**p-value**	**OR (95% CI)**	**OR (95% CI)**
Sociodemographics						
Age at survey completion (mean)	37.8	<0.01	55.1	<0.001	0.967 (0.942–0.993)	0.995 (0.951–1.041)
Gender						
Male	80.5		74.8		REF	REF
Female	88.4	<0.001	82.3	<0.001	1.918 (1.208–3.048)	1.192 (0.869–1.636)
Race						
White	85.5		80.1			1.567 (0.907–2.708)
Other	82.5	0.31	74.1	0.06		REF
Marital Status						
Married/domestic partner	86.0		81.0		1.236 (0.840–1.819)	1.109 (0.794–1.548)
Other	83.6	0.23	76.3	0.01	REF	REF
Educational attainment						
Less than high school/high school degree	85.3		83.3			
Some college/technical/associate’s degree	84.1		80.4			
Bachelor’s degree	84.6		78.9			
Graduate/medical degree	87.7	0.58	78.9	0.46		
Employment status						
Employed (full or part-time)	86.4		81.2		1.662 (1.080–2.558)	1.047 (0.734–1.494)
Not employed (student/caregiver/retired)	81.7	0.05	76.4	<0.01	REF	REF
Total household income						
≤80,000	84.6		79.4			
≥81,000	85.3	0.75	80.8	0.46		
Insurance status						

	Univariable Models % Fear of Recurrence				Multivariable models[a]	
	AYA (n=1395)		Older adult (n=2497)		AYA (n=1034)[b]	Older adult (n=1324)[b]
Variables	**%**	**p-value**	**%**	**p-value**	**OR (95% CI)**	**OR (95% CI)**
Private/military	85.8		81.9			REF
Medicare/Medicaid	80.7		69.8			0.597 (0.368–0.969)
Other/none/don’t know	85.5	0.58	82.8	<0.001		1.315 (0.694–2.493)
Cancer history						
Age at cancer diagnosis (mean)	30.1	0.02	50.7	<0.001	1.013 (0.978–1.049)	0.993 (0.949–1.040)
Type of cancer						
Breast	91.7		79.7		REF	
Lymphoma	85.6		82.7		0.709 (0.285–1.760)	
Melanoma	89.5		87.7		0.787 (0.254–2.433)	
Testicular	82.1		74.6		0.548 (0.217–1.384)	
Thyroid	83.9		83.3		0.303 (0.110–0.838)	
Other	83.5	0.05	79.0	0.36	0.481 (0.217–1.066)	
Time since last treatment						
Less than five years	89.4		81.1		REF	REF
Five+ years	79.2	<0.001	75.2	<0.01	0.515 (0.327–0.812)	0.813 (0.532–1.245)
Currently seeing an oncologist						
Yes	87.6		82.1		1.166 (0.767–1.772)	1.394 (0.995–1.952)
No	81.7	<0.01	75.1	<0.001	REF	REF
Currently seeing a primary care physician						
Yes	82.6		77.5		0.902 (0.594–1.368)	0.983 (0.717–1.347)
No	87.3	0.02	81.2	0.05	REF	REF
Type of treatment(s) received						
Chemotherapy						
Yes	85.7		81.5			0.893 (0.641–1.244)
No	84.4	0.51	77.2	<0.01		REF
Radiation						
Yes	86.6		80.9		1.282 (0.876–1.877)	0.985 (0.733–1.324)

	Univariable Models % Fear of Recurrence				Multivariable models[a]	
	AYA (n=1395)		Older adult (n=2497)		AYA (n=1034)[b]	Older adult (n=1324)[b]
Variables	**%**	**p-value**	**%**	**p-value**	**OR (95% CI)**	**OR (95% CI)**
No	84.0	0.18	78.5	0.15	REF	REF
Surgery						
Yes	86.6		80.9		1.352 (0.873–2.095)	1.432 (1.032–1.986)
No	81.4	0.02	75.7	<0.01	REF	REF
Participated in a clinical trial						
Yes	81.3		82.4		0.595 (0.358–0.991)	1.218 (0.779–1.903)
No	85.5	0.17	78.8	0.19	REF	REF
Received post-treatment instructions						
Yes	87.5		78.9			
No	84.1	0.36	80.8	0.54		
Received written cancer treatment summary						
Yes	81.5		78.3		0.751 (0.507–1.113)	
No	86.3	0.03	79.3	0.63	REF	
Perceptions of cancer experience						
Dedicated patient navigator on health care team						
Yes	87.1		69.9			0.616 (0.352–1.076)
No	84.8	0.72	79.4	0.03		REF
Information on late-effects/risks of treatment met…						
All of my needs	74.8		69.5		0.526 (0.284–0.977)	0.410 (0.207–0.811)
Many of my needs	87.4		83.1		1.022 (0.562–1.857)	0.700 (0.364–1.350)
Some of my needs	88.2		79.7		1.187 (0.633–2.227)	0.500 (0.262–0.951)
Very few to none of my needs	87.3	<0.001	87.9	<0.001	REF	REF
Patient/Provider Communication Score (mean)	10.4	0.97	10.8	<0.001		0.949 (0.901–1.000)

AYA, adolescent and young adult; OR, odds ratio; CI, confidence interval

[a] All variables significantly associated with fear of recurrence in univariable analyses at the $p < 0.25$ level were entered into multivariable models; shaded cells reflect variables not entered into multivariable models.

[b] AYA and non-AYA sample size for multivariable analyses was reduced due to missing values on some of the variables of interest.