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ORIGINAL ARTICLE

Distress among young adult cancer survivors: a cohort study

**Betina Yanez · Sofia F. Garcia · David Victorson ·
John M. Salsman**

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Abstract

Purpose Being diagnosed with cancer as a young adult can lead to significant psychological distress and impaired quality of life. Compared to children and older adults diagnosed with cancer, fewer studies have addressed psychological distress among young adult cancer survivors. This study sought to identify the prevalence of, and factors associated with, distress among young adult cancer survivors (ages 18–39).

Methods Young adult cancer survivors ($N=335$, mean age=31.8, women=68.4 %) were recruited from an online research panel and stratified by cohort (time postactive treatment: 0–12, 13–24, and 25–60 months). Participants completed measures assessing demographic and clinical characteristics, global impact of cancer, cancer-related education and work interruption, and cancer-specific distress using the impact of event scale (IES).

Results The mean score on the IES ($M=31.0$, range=0–75) was above the cut point of 20, suggesting clinically elevated distress. Analysis of covariance revealed significant main effects for cohort, global impact and cancer-related education/work interruption, and an interaction between cohort and cancer-related education/work interruption on distress. Although there was no significant effect of education/work interruption on distress for those in the 0–12 month cohort ($p=.88$), survivors in the 13–24 and 25–60 month cohorts reporting education/work interruption were significantly more distressed than those not reporting education/work interruption in the respective cohorts ($p<.05$).

Conclusions Young adult cancer survivors face unique challenges. These data underscore the importance of attending to cancer-related distress beyond the completion of treatment and may help inform targeted interventions to prevent or reduce significant distress and related sequelae in this population.

Keywords Young adults · Survivorship · Cancer · Distress · Psychosocial

Introduction

Although most individuals diagnosed with cancer are living longer, the cancer incidence among young adults has been on the rise compared to children and older adults [1]. One of the most consistent demographic predictors of poor quality of life in adult survivors is young age [2]. However, the preponderance of psychosocial oncology research has focused on samples of older cancer patients [3] or adult survivors of childhood cancer [4], and there are scant data on cancer-related emotional distress in young adult survivors diagnosed between the ages of 18–39.

Among middle and old aged adults, a diagnosis of cancer has the potential to result in marked psychological distress and life disruption. Several studies targeting middle-aged adults (aged <50) suggest that poor psychological outcomes are more frequent or severe in middle-aged adult cancer survivors when compared with the general age-matched population without cancer and when compared to older adults with cancer (aged >50 years) [5, 6]. To date, only a

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B. Yanez (✉)
Center for Healthcare Studies, Northwestern University Feinberg School of Medicine, 750 N. Lake Shore Drive, 10th floor, Chicago, IL 60611, USA
e-mail: betina.yanez@northwestern.edu

B. Yanez · S. F. Garcia · D. Victorson · J. M. Salsman
Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL 60611, USA

S. F. Garcia · D. Victorson · J. M. Salsman
Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL 60611, USA

S. F. Garcia
Department of Psychiatry and Behavioral Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL 60611, USA

few psychosocial studies are available on young adults under age 40 and those have focused on healthcare needs [7], positive and negative life impact of cancer [8], and fertility concerns [9].

Lifespan theories of human development suggest the type of cancer-related disruptions and the meaning attributed to these disruptions may vary by lifespan stages [10, 11]. Young adults, endowed with the expectations of lengthy futures, focus on future-oriented goals such as education and career planning, establishing independence from their parents, identity development, and building committed relationships and families that may yield benefits in the future [10, 11]. Meeting educational goals and obtaining gainful employment are tasks that can be especially salient to this group of individuals. As a result of their cancer, they may experience greater disruptions in life goals and prematurely confront mortality, which can produce substantial distress during formative developmental years.

Despite the documented increase in young adult cancer diagnoses and the potentially deleterious effects of cancer on the developmental trajectory of young adults, studies have not assessed cancer-specific distress in young adult cancer survivors. Furthermore, little is known about how young adults' perceptions of the impact of cancer on their lives is related to cancer-specific distress. To that end, the purpose of this study was to (1) determine the prevalence of emotional distress among a sample of young adult cancer survivors (aged 18–39) who were stratified by time since treatment completion (0–12, 13–24, and 25–60 months) and (2) identify variables associated with distress. Three cross-sectional cohorts based on time since active treatment completion were established to capture variability in the cancer survivorship reentry period (generally 1–2 years posttreatment) [2] and longer survivorship (3–5 years posttreatment).

Guided by theories of lifespan development, we hypothesized that greater cancer-related education/work interruption and greater perceived global impact of cancer would be associated with greater distress. We hypothesized that closer proximity to treatment completion would be indicative of greater distress such that survivors within the 0–12 month cohort would report the greatest amount of distress and that individuals in the 25–60 month cohort would report the least amount of distress relative to the other cohorts. We were also interested in the interaction between cohort and cancer-related education/work interruption on distress. We hypothesized that cancer-related education/work interruption would exacerbate distress most in the 0–12 month cohort relative to other cohorts. We expected that all relationships would be significant after adjusting for relevant covariates including income, gender, age, and physical symptom level. Finally, we were interested in determining whether age interacted with cancer-related education/work interruption. Therefore, we proposed an exploratory aim to investigate whether age and cancer-related education/work interruption interacted with distress.

Methods

Participants

Following a screening process to ensure eligibility, a cross-sectional sample of participants (N=484) was drawn from the general population by Toluna, an Internet panel company (http://www.toluna-group.com). Internet panels are increasingly used as a viable means of data collection due to the widespread availability of the Internet among diverse groups and the low cost and efficient means of online data collection [12]. Moreover, Liu et al. have shown the representativeness of Internet data is comparable to data from probability-based general population samples [13]. In our study, participants were eligible if they were diagnosed with cancer (excluding basal cell skin carcinoma), between the ages of 18–39, within 0–60 months posttreatment, had access to the Internet, and were able to read and understand English. Exclusion criteria included a recurrent diagnosis of cancer and receipt of palliative or hospice care. The Institutional Review Board approved the study.

We used a targeted recruitment approach in order to obtain approximately equal numbers across three groups of young adult cancer survivors posttreatment. Participants provided informed consent, then completed demographic information, medical and medical/treatment information (stage, treatment, diagnosis, physical symptom level) [14], and study measures. Participants who completed the survey were eligible for prize or incentive-based compensation through Toluna. Participants who answered more than 15 items in <2 s or those who skipped >20 items had their session terminated. Procedures for data quality control are described at http://us.toluna-group.com/toluna-difference/quality/. Once we received the data from the panel company, we excluded participants who did not provide an identifiable cancer diagnosis (n=59, 12.2 % of the total sample) or who engaged in straight-line responding by endorsing the same response choice for every item in study measures with reverse-scored items (n=90, 18.6 % of the total sample). We analyzed responses from the remaining 335 participants.

Measures

Impact of event scale The impact of event scale (IES) is a well-established 15-item self-report measure of intrusive and avoidant cognitions that is frequently used in evaluating stress reactions after traumatic experiences [15]. The IES was keyed to the experience of cancer (i.e., "Indicate how frequently these comments were true for you during the past 7 days with respect to your experience with cancer"). Participants were provided with four response options (total possible range 0–75). Higher scores indicate greater distress. Coefficient alpha for the IES total score was 0.91.

Global illness impact To assess the global impact of cancer, participants were asked an item created as part of the Patient-Reported Outcomes Measurement Information System (PROMIS) cancer supplement and originally administered with the PROMIS illness impact item banks [16, 17]: "Overall, how much has having your illness affected your views about yourself and your life?" Responses ranged from "not at all" to "very much."

Cancer-related work interruption was assessed by a single author-constructed item that asked participants "did you stop working because of your cancer?" Cancer-related education interruption was assessed by a single author-constructed item that asked participants "did you stop school because of your cancer (e.g., high school, college, graduate school)?" Both questions required a yes/no response. We combined responses to the education and work interruption questions into a single dichotomous cancer-related education/work interruption variable in order to identify participants who endorsed either cancer-related interruption versus those participants who did not endorse any type of education or work interruption.

Analysis

Descriptive statistics were calculated for demographic and medical/treatment characteristics. Covariates were identified through examining associations between distress and demographic and medical/treatment variables. Analysis of covariance (ANCOVA) and hierarchical multiple regression were used to examine the relationships with distress. Post hoc comparisons and simple main effects were conducted for significant group differences.

Results

See Table 1 for demographic and medical/treatment characteristics. Thirteen participants who did not complete all items contributed to missing data, which were handled by listwise deletion. Cohort sizes were 118, 98, and 106 for the 0–12, 13–24, and 25–60 month cohorts, respectively, for a final sample size of 322 survivors. The 25–60 month cohort was distributed such that 41 % of survivors were three years post treatment completion, 31 % were four years post treatment completion, and 28 % were five years post treatment completion.

The mean score on the IES ($M=31.0$, $SD=17.6$, range=0–75) was above the cutoff score of 20 designating clinically elevated distress [18]. Based on a more conservative cutoff score of 27 proposed by Coffey et al. [19], 56.5 % of the sample scored in a range that is suggestive of clinically elevated symptoms. In response to the global impact question, 5 % responded "not at all," 10 % responded "a little bit," 29 % responded "somewhat," 28 % responded "quite a bit," and 28 % responded "very much." In response to the item on cancer-related work interruption, 67.1 % of the sample responded that they did not stop working because of cancer. In response to the item on cancer-related education interruption, 88.2 % of the sample responded that they did not stop school because of cancer. When cancer-related education and work interruption were combined, 61.8 % of the sample reported no education/work interruption (see Table 1 for more detailed information on education/work interruption by cohort).

There were no differences on education interruption, work interruption, or global impact variables by cohort (p values=.11, .30, and .39). Physical symptom level was associated with distress such that individuals with the greatest level of physical symptoms were more likely to experience elevated distress than individuals with the lowest physical symptom level ($p<.001$). Gender was also associated with distress such that men reported more distress than women ($p<.01$). Neither income nor age was significantly associated with distress (p values=.53 and .31, respectively).

Levene's test for equality of error variances indicated homogeneity of variance ($p=.44$). After adjusting for physical symptom level and gender, the only covariates significantly associated with distress, a three-way ANCOVA revealed significant effects for cohort $F(2, 310)=4.59$, $p<.05$ (see Fig. 1), global impact $F(4, 310)=9.95$, $p<.001$, and cancer-related education/work interruption $F(1, 310)=9.49$, $p<.01$ as well as a significant interaction between cohort and cancer-related education/work interruption $F(2, 310)=4.03$, $p<.05$ on distress.[1]

Follow-up comparisons (Sidak correction for multiple comparisons) adjusting for physical symptom level and gender revealed that survivors in the 13–24 months cohort experienced significantly greater distress compared to the 25–60 months cohort ($p<.01$) and marginally significantly greater distress compared to the 0–12 months cohort ($p=.10$), but mean scores on distress did not differ between the 0–12 and 25–60 month cohorts ($p=.67$). Additionally, survivors

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[1] Based on reviewer suggestions to explore gender differences among young adult cancer survivors, we conducted an ANCOVA to determine whether gender interacted with cancer-related education/work interruption or cohort after adjusting for all other relevant covariates. There were no significant interaction effects for gender and cancer-related education/work interruption on distress or gender and cohort on distress (p values=.91 and .34).

Table 1 Sociodemographic and medical characteristics

Variable	Value or % (SD)			
	Total sample N=322	0–12 Months cohort N=118	13–24 Months cohort N=98	25–60 Months cohort N=106
Race (% white)	84.1	84.2	83.3	83.9
Gender (% women)	68.4	70.0	57.8	77.0
Age	31.8 (5.4)	31.6 (5.5)	31.4 (5.8)	32.2 (5.1)
Education (%)				
< College degree	39.2	41.2	34.3	41.6
≥ College degree	60.8	58.8	65.7	58.4
Household income (%)				
≤74,999	51.0	56.7	38.2	55.8
>75,000	49.0	43.3	61.8	44.2
Employment status (%)				
Employed	70.0	64.2	77.5	69.0
Homemaker	10.5	9.2	9.8	11.5
Unemployed	10.1	15.8	3.9	10.7
Student	7.8	9.2	7.8	6.2
Education/work Interruption (% no)	61.8	66.1	56.1	62.3
Months since diagnosis	21.2 (16.7)	–	–	–
Diagnosis (%)				
Breast	23.9	33.5	12.7	24.8
Cervical	11.6	12.5	10.8	11.5
Melanoma	11.0	10	12.7	9.7
Lung	6.9	5.8	7.8	8.0
Colorectal	6.3	6.7	8.8	3.5
Thyroid	6.3	5	3.9	9.7
Testicular	6.0	5.8	7.8	4.4
Stage (%)				
Local	67.4	66.7	57.4	77
Regional	24.9	27.5	32.7	15.0
Distal	4.5	2.5	5.9	5.3
Symptom level (%)				
Normal without symptoms	54.0	48.3	52.9	60.2
Some symptoms not requiring bed rest	37.9	39.2	44.1	31.9
Symptoms requiring bed rest	8.0	12.5	2.9	8.0

with highest global impact reported greater distress than those with lowest global impact (p<.05), and survivors who reported cancer-related education/work interruption reported significantly more distress than those who did not report work interruption (p<.05). Simple main effects analyses indicated that survivors in the 13–24 and 25–60 month cohorts who reported cancer-related education/work interruption were significantly more distressed than those not reporting cancer-related education/work interruption in the respective cohorts (p values<.05), but there was no significant difference of education/work interruption on distress for those in the 0–12 month cohort (p=.88) (see Fig. 1).

Hierarchical multiple regression did not reveal a significant interaction between age and cancer-related education/work interruption on distress after controlling for physical symptom level and gender b=.01, t(316)=.04, p=.97.

Discussion

To the best of our knowledge, this study is among the first to report the extent of cancer-related distress, classified by time post-treatment, among young adult cancer survivors. Findings indicate that on average, young adult survivors experience clinically significant levels of distress, with the highest level of distress endorsed by the 13–24 month cohort. After adjusting for gender and physical symptom level, results indicated that cohort, global impact of cancer, and cancer-related education/work interruption were significantly associated with distress as was the interaction between cohort and education/work interruption.

To put the findings into context, the mean IES scores in two samples of middle-aged breast cancer patients were 21.0 [20] and 15.9, respectively [3]. The elevated IES scores relative to other cancer samples are not surprising when considered within a developmental framework, which suggests that cancer may interfere with important issues and milestones unique to young adulthood such as educational achievement, career development, financial independence, identity development, and relationship/family building [10, 11]. For some young adults, a diagnosis of cancer may impede educational and career goals and can result in greater parental dependency at a time when young adults are striving to achieve independence. For others, a cancer diagnosis may impede social goals such as establishing a committed relationship and family and/or have a negative impact on body–sexual image and integrity [21, 22]. Additionally, young adults may also struggle with existential issues such as meaning making and ambiguity and uncertainty about their health [21].

Contrary to our hypothesis, participants in the 13–24 months cohort reported the most distress relative to the other cohorts. This finding can be interpreted in the context of the cancer survivorship trajectory. Prominent issues during the one-to-two year time frame after treatment completion, known as the cancer re-entry phase, are loss of the medical support and decreased social support, resumption of former roles, and enduring or late physical effects of cancer

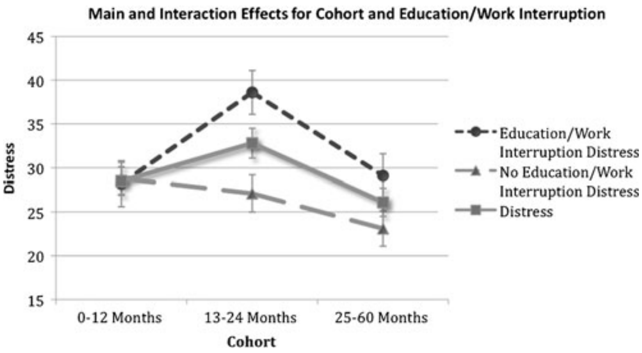

Fig. 1 Line graph illustrating means for main effect of distress (*solid line*) after adjusting for relevant covariates and means for interaction effect of cohort by cancer-related education/work interruption on distress after adjusting for relevant covariates (*dashed lines*)

treatments (e.g., fatigue, fertility complications) [2, 23]. For a subset of survivors, some of these cancer-related issues may not arise immediately and may take over a year to emerge. Furthermore, young adult cancer survivors who were anticipating a reduction in the presence of cancer-related symptoms and fewer life interruptions after treatment may become more distressed when they experience enduring or late onset physical, social, and functional impairments even a year after treatment.

Although we did not hypothesize any main effects for age, we explored whether it interacted with cancer-related education/work interruption on distress. Findings did not reveal a significant interaction for age and cancer-related education/work interruption on distress. However, cancer-related education/work interruption was important in another context as a significant interaction was observed between young adult survivors who experienced education/work interruption and elevated distress in the 13–24 and 25–60 months cohorts. One explanation for this interaction is that the interruption of education and work juxtaposed the additional reentry stressors young adults may be facing can exacerbate levels of distress. During the 13–24 months after treatment, survivors who experience cancer-related education/work interruption may be readjusting to the demands of their school and work load, adjusting to the impact of interruption on their educational goals and career advancement, or adjusting to the financial ramifications of not having been able to work or looking for new work. Although the difference in distress scores by education/work interruption was greatest for those in the 13–24 month cohort, the interaction remained significant for those in the 25–60 month cohort, suggesting that cancer-related education/work interruption is related to elevated distress even several years after treatment completion.

Our findings require interpretation in light of study limitations. Our stratification of participants by cohort provides an approximation of change over time, but the cross-sectional design of the study limits inference of causal relationships. The relative homogeneity of participants' race/ethnicity, symptom level, and income limits the generalizability of the findings. It is notable that the mean distress score was substantially elevated despite the current sample being relatively high functioning and affluent, perhaps suggesting those young adult survivors with fewer resources may report even greater levels of distress. Given the documented challenges in recruiting transient populations such as young adults, online research panels can be a useful strategy for initial forms of data collection [24]. Finally, the assessment of cancer-related education/work interruption was based on two items, and additional information pertaining to length of interruption or the context in which the interruption took place (e.g., working or unemployed before cancer) was not obtained. For example, some young adults may have taken a leave of absence from school or work as a result of their treatment, whereas others may have permanently left school or terminated their employment.

Further research is required to ensure adequate representation of diverse groups and to promote follow-up participation for young adult cancer survivors. Additional research on the impact of cancer-related education/work interruption will provide more specific information on how education/work interruption relates to distress. Other developmental factors such as the cancer-related impact on relationships, fertility, body image, and sexuality were not assessed in the present study but could provide valuable input on why study participants reported elevated distress. Longitudinal research on how distress among young adult survivors may change over time is also warranted.

In conclusion, young adult cancer survivors are an understudied group of survivors who face unique challenges in the posttreatment phase of cancer survivorship. These data underscore the importance of attending to the emotional impact of cancer on young adult survivors. On average, young adults' scores on the IES were suggestive of clinically elevated distress [18, 19]. Young adults who reported a greater global impact of cancer reported greater distress relative to participants reporting less global impact. Distress scores were highest for those in the 13–24 month cohort, especially among those who reported cancer-related education/work interruption. Among participants in the 25–60 month cohort, distress scores remained elevated for young adults who experienced cancer-related education/work interruption compared to participants who did not report cancer-related education/work interruption. These findings may be especially relevant for psychosocial oncology clinicians working with young adults. Having a greater understanding of the potential long-term implications of cancer in this population can inform the conceptualization, development, and targeted delivery of psychosocial services to prevent and/or reduce clinically significant levels of cancer-related distress.

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Disclosures None

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