

## **Early education and employment outcomes after cancer in adolescents and young adults**

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## ABSTRACT

**Purpose:** This study describes the early educational and vocational outcomes of Australian adolescents and young adults (AYAs) after cancer diagnosis and examines factors associated with these outcomes.

**Methods:** Within this cross-sectional national Australian study, 196 AYAs aged 15-25 years at cancer diagnosis and within 6-24 months of diagnosis were recruited from 18 sites. Participants completed a survey that included questions about school and work outcomes, support received regarding necessary changes to education and vocation, and validated measures of anxiety, depression and post-traumatic stress.

**Results:** Almost half of the sample (43%) was not fully “back on track” with their previous educational and vocational plans. Post-traumatic stress and emotional symptoms were associated with poorer school/work functioning ( $\beta = -0.95$ ,  $p=0.009$  and  $\beta = -1.27$ ,  $p=0.001$ , respectively). Higher PedsQL school/work functioning was associated with a slightly greater likelihood of being “back on track” with education and work plans (OR 1.03,  $p=0.001$ ). AYAs who felt well supported regarding changes to education and work plans more frequently reported receiving support from formal sources and from more sources than those who felt less supported. Unmet need of accessing an educational or vocational advisor was significantly more frequent in adult than in pediatric settings (42% vs. 17%;  $p=0.024$ ). Parents were the most common source of educational or vocational support for AYAs rather than professionals.

**Conclusion:** This study highlights the connection between school and work participation and mental health in a national sample of AYAs with cancer. It suggests distinct benefits of educational and vocational support.

## INTRODUCTION

Education and employment are important determinants of future health and quality of life for all adolescents and young adults (AYAs).<sup>1</sup> In AYAs with cancer, both the cancer diagnosis and its treatment may potentially disrupt education and employment through interrupting day-to-day participation, affecting neurocognitive ability and functioning, and inhibiting autonomy and independence, among other factors.<sup>2</sup> Most previous studies have focused on educational and employment outcomes in AYA survivors of childhood cancer. For example, Mitby et al reported that leukemia and brain tumors were risk factors for dropping out of high school.<sup>3</sup> This risk was, however, largely mitigated if the patients received special educational support. In another study, the risk for never having been employed among survivors of childhood cancer (aged 18-48 years) was associated with female gender, young age at diagnosis (< 4 years), cranial radiation therapy and failure to complete high school.<sup>4</sup>

More recently, studies have begun to explore the impact of a cancer diagnosis during adolescence and young adulthood on education and employment.<sup>5,6</sup> These studies have included adults up to 39 years old, most of whom would have completed formal education and gathered reasonable employment experience when diagnosed. Given the extent of education and employment transitions within the 15-25 year-old period (e.g. completion of secondary education and entering the workforce for the first time), particular insights may be gained by studying a narrower age range.

Underpinning this period of critical role transitions around education and employment is the extent of neurocognitive maturation that occurs across these years. Adolescent brain development is now appreciated as second only to infancy in the significance of changes which extend into the third decade of life.<sup>7,8</sup> These neuronal processes are thought to explain, at least to some extent, why adolescence is also a time that most mental health disorders first emerge.<sup>9,10</sup> AYA cancer patients face a multitude of stressors, including premature encounters with mortality, social isolation and extreme fatigue, which increase their susceptibility to mental health problems.<sup>2,11</sup> Both mental health

problems and cancer treatments may negatively affect learning and neurocognitive functions, such as attention and memory.<sup>12-14</sup> However, few studies of the educational or vocational outcomes of cancer survivors have examined concurrent emotional symptoms.<sup>15,16</sup>

Considering the importance of education for future health and wellbeing, surprisingly little is known about the educational and vocational supports that AYA cancer survivors receive, nor of their effectiveness. The authors of a recent systematic review found no published interventions supporting AYAs' return to school or work after treatment and proclaimed the need for additional research on educational and vocational outcomes among AYAs.<sup>17</sup>

The aims of this study were: (1) to describe the early educational and vocational outcomes of a national sample of Australian AYA cancer survivors; and (2) to examine the associations of a) psychological risk factors and b) social support as a protective factor for AYAs' educational and vocational outcomes.

## **METHODS**

### **Study background**

The Youth Friendly Cancer Care study included a national survey of AYAs and their parents who were recruited from 17 hospitals (5 pediatric, 12 adult) and one AYA charitable organization in five States in Australia. The detailed study protocol has been published previously.<sup>18</sup> In brief, after obtaining ethics approval from study centers, potentially eligible participants were identified and mailed a survey package. Participants provided written consent at the start of the survey.

### **Participants**

Eligible patients 1) were diagnosed between September 2010 and December 2012 when aged between 15-25 years old; 2) had a first diagnosis of cancer, new recurrence or relapse of cancer, or diagnosis

of a second cancer where the first cancer had been previously treated; 3) were 6-24 months from diagnosis; and 4) were literate, cognitively capable and sufficiently well to complete the survey themselves. Patients with stage 1 and 2 melanomas were excluded since treatment is minimally disruptive compared to other cancer types. The final sample included 196 AYAs, whose age distribution, sex ratio and proportion living in metropolitan areas were similar to AYAs in the Australian Cancer Database.<sup>19</sup> The main differences were the lower proportion of melanomas (4% vs. 23%) and the higher proportion of leukemias (31% vs. 9%) in our study population than in national data.

### **Demographic measures**

Socio-demographic and treatment data were collected on age, gender, relationship status, living arrangements, cancer type, treatment modalities and type of hospital (pediatric/adult).

### **Educational and vocational outcomes**

School and work participation were assessed by a single question, “What is your current education or employment status?”. Response options included high school student, technical and further education (TAFE) student, university student, working, unemployed and homemaker/family caregiver. Each could be designated as full- or part-time. Data were cleaned to allow only sensible combinations (e.g. a full-time high school student could not be unemployed although they may have wanted part-time work).

AYAs indicated what kind of impact cancer had on their education and work plans using a 5-point Likert scale (from “*very negative*” to “*very positive*”), as in the AYA HOPE Study.<sup>20</sup> Responses of “*very negative*” and “*somewhat negative*” were combined as “negative impact”, while responses of “*somewhat positive*” and “*very positive*” were combined as “positive impact”. Additional items assessed whether AYAs had been able to get “back on track” with their education and work plans and activities (response options “*yes*”, “*no*” and “*to some extent*”). For a binary “back on track” item,

education and work plans were combined. Response combinations of “yes” and “yes” or “yes” and “to some extent”, were collapsed into “yes”; responses of “no” and “no”, or “no” and “to some extent”, were collapsed into “no”.

Participants completed the PedsQL Generic Core Scales Young Adult version, a validated measure of health related quality of life (HRQOL).<sup>21</sup> The PedsQL consists of four dimensions: physical, emotional, social and school/work functioning. Possible scores range from 0 to 100, with higher scores indicating better HRQOL. In this study, Cronbach’s  $\alpha$  was 0.93 for the complete PedsQL and 0.86 for the school/work functioning dimension. The school/work functioning dimension scores are reported to facilitate international comparisons.

### **Psychological risk factors**

The Post-traumatic Stress Disorder Checklist specific version (PCL-S) was used to rate the 17 symptoms of post-traumatic stress disorder (PTSD) as defined in DSM-IV.<sup>22</sup> Each symptom is measured on a 5-point Likert scale (from “not at all” to “extremely”). A total score is derived by adding the 17 items, yielding a range of possible scores from 17 to 85. Cut-off scores of 30 and 40 have been used to identify patients at risk of PTSD.<sup>23,24</sup> Cronbach’s  $\alpha$  for this study was 0.91.

The Kessler Psychological Distress Scale (K10) was used to measure anxiety and depressive symptoms.<sup>25</sup> The K10 consists of 10 questions rated on a 5-point Likert scale. Scores range from 10 to 50, with higher scores indicating greater risk of mental disorders. A cut-off score of 16 is used to identify individuals at increased risk for anxiety or depression.<sup>26</sup> Cronbach’s  $\alpha$  for this study was 0.93.

### **Educational and vocational support**

To identify sources of support, AYAs were asked: “*If you experienced disruption to your education and/or employment during cancer treatment, who helped you with information and support about any changes that had to be made?*” Response options included “not applicable – no disruption”, “I mostly took care of finding information and making changes on my own”, “parents”, “friends”, “staff at main

*cancer treatment center*”, “*staff at place of education (e.g. teachers, lecturers)*” and “*staff at place of employment*”. Respondents were able to tick any that applied.

Access to and experiences of professional educational and/or vocational support, both during and after treatment, were measured using the following four questions: 1) “*Did you talk with an educational/vocational advisor about schooling/training/employment DURING treatment?*”; 2) “*Do you think this was or would have been helpful?*”; 3) “*Did you talk with an educational/vocational advisor about schooling/training/employment AFTER treatment?*”; and 4) “*Do you think this was or would have been helpful?*”. Response options for all questions were “*yes*” or “*no*”. Within this study, we defined an educational/vocational advisor as a professional capable of having a conversation with AYAs and parents around education and employment. Unmet need was defined as not receiving the service but believing it would have been helpful.

A final item assessed how supported AYAs felt in relation to any changes that had to be made to their education or employment commitments during treatment (“*not supported*”, “*supported to some extent*”, “*well supported*”).

### **Statistical analyses**

To describe categorical variables, percentages were calculated and compared using chi-squared tests. For continuous variables, means and standard deviations (SD) were calculated and groups were compared using two-tailed t-tests. PCL-S and K10 scores were skewed, thus log transformation was required to reach even distribution prior to analyses. Original scores are reported here due to their clinical relevance. Bivariate linear regression analyses were conducted to assess associations of the following variables with PedsQL school/work functioning: age, gender, new cancer diagnosis vs. relapse/recurrence, on vs. off treatment, PCL-S and K10 scores. Significant variables were utilized in a multiple regression model. Bivariate logistic regression analyses were conducted to assess the associations of age, gender, new cancer diagnosis vs. relapse/recurrence, on vs. off treatment, PCL-



S, K10 and PedsQL school/work functioning scores with being “back on track” with educational and work plans (binary outcome measure). Significant variables from initial analyses were included in a multiple regression model. Statistical analyses were performed using Stata 13 (Stata Corp, College Station, TX).

## **RESULTS**

Demographic characteristics are summarized in Table 1. The mean age at diagnosis was 19.9 (SD 3.2) years and mean age at time of study was 21.6 (3.1) years. Most AYAs (n=161, 82%) had completed treatment at the time of the survey. Cancer diagnoses were heterogeneous; approximately one third (31%) had a hematological malignancy. Of the total cohort, 86% were treated in an adult setting, including 60 of the 87 (69%) 15-19 year-olds.

### **Educational and vocational outcomes**

Fifty percent of AYAs were studying part- or full-time, 44% were working part- or full-time and 11% were unemployed. The self-rated impacts of cancer on education and work plans and how well AYAs felt “back on track” with their previous education and work plans are summarized in Table 2. When both education and work plans were combined, 57% of AYAs (106/186) were “back on track”.

The mean score for the complete PedsQL was 68.5 (SD=18.1) and the mean PedsQL education/work dimension score was 63.7 (SD=24.1).

### **Factors associated with educational and vocational outcomes**

Older AYAs (age 20-25 years) were more often “back on track” with education and work than younger AYAs (62% vs. 49%; p=0.011). Twenty-seven of the 35 patients still on active treatment reported they were “back on track”.

As previously reported, the mean PCL-S and K10 scores for AYAs were 32.6 (SD=13.6) and 19.2 (SD=8.2), respectively.<sup>27</sup> Younger age at survey, female gender, symptoms of PTSD and emotional distress were associated with poorer school/work functioning in linear regression analyses (Table 3). Male gender, lower PTSD symptoms and emotional distress and higher school/work functioning were associated with a greater likelihood of being “back on track” with education and work plans (Table 4). Only school/work functioning remained significant in multiple regression.

### **Educational and vocational support**

Nearly two thirds (63%, 122/193) of AYAs felt well supported in relation to the changes required to their education and/or employment commitments during treatment (Table 5). AYAs nominated their parents as the most frequent source of information and support. Support from parents was important for both younger and older AYAs (47% (41/87) among 15-19 year-olds vs. 39% (42/107) among 20-25 year-olds;  $p=0.34$ ). AYAs who felt well supported more frequently reported receiving support from professional sources (cancer center, place of education and place of employment) than those who felt less supported. AYAs who felt well supported also received assistance from more sources than AYAs who felt less supported (mean number of sources of support: well supported 1.7, to some extent 1.2, not supported 0.7;  $p=0.003$  and  $p<0.001$ , respectively, for difference between well supported and other two groups).

Half of AYAs (52%, 62/119) who felt well supported regarding necessary changes to education and/or employment had talked to an educational/vocational advisor compared to 31% (21/67) of those who felt less supported or not supported at all ( $p=0.006$ ). Less than half (45%, 84/188 with data available) had talked with an educational/vocational advisor during treatment. Sixty percent (107/173) considered this was or would have been helpful; seven (7/173, 4%) found it unhelpful. After treatment, 32% of respondents (48 of 148 who responded) had met with an educational/vocational advisor, although 56% (77/138) still considered it would have been helpful. Thirty-four AYAs (23% of 146 with data available) met with an educational/vocational advisor both

during and after treatment and 76% (26/34) found it helpful both times. Unmet need of talking with an educational/vocational advisor was more common among females than males both during treatment (49% (20/41) vs. 21% (9/43);  $p=0.002$ ) and after treatment (53% (26/49) vs. 29% (15/51);  $p=0.035$ ) and more frequent in adult than pediatric services (42% (70/168) vs. 17% (5/28);  $p=0.024$ ).

## **DISCUSSION**

In this nationally representative cross-sectional study, almost half of AYAs had not managed to get “back on track” with their previous education or employment six to 24 months after the diagnosis despite the majority having completed cancer treatment. Post-traumatic stress and emotional symptoms were associated with poorer education/work functioning. Education/work functioning was associated with being “back on track” with previous education and work plans. AYAs who felt well supported regarding changes to education and work plans more frequently reported receiving support from professional sources and from more sources than those who felt less supported. Unmet need of meeting with an educational/vocational advisor was significantly more frequent in adult than in pediatric services. Support from parents was important for both younger and older AYAs.

Cancer appears to have had a more negative impact on Australian AYAs’ education and employment plans than their American peers.<sup>5</sup> The mean educational/work functioning score was also lower in this study than in the US (63.7 vs. 72.7, respectively). These differences may be explained by differences in participants’ age (all AYAs in our study were 15-25 at diagnosis compared with only 31% in the US study) and time from diagnosis (6-24 months in our study versus 15-35 months in the US sample), as well as differences in cancer type and treatment. Although educational and vocational outcomes may improve over time as suggested by the US sample above, AYA cancer survivors from both countries experience disruption to education and employment.

A recent systematic review identified three studies of American educational reintegration programs which targeted 5-19 year old children and adolescents.<sup>28</sup> A meta-analysis confirmed that reintegration programs enhanced academic achievement and decreased rates of depression. Unfortunately no separate analyses were provided for adolescents. The Association of Pediatric Hematology Oncology Education Specialists and the Psychosocial Standards of Care Project for Childhood Cancer have published recommendations for managing the educational needs of young cancer patients, some of which are also relevant for AYA survivors.<sup>29,30</sup> These highlight that collaboration with the child's school should start at diagnosis, include a systematic study plan and continue until the end of education. However, most AYAs undergo treatment in adult care settings which are less accustomed to working with education providers and rarely offer educational support services.<sup>31</sup> AYAs who are only entering or have recently entered the workforce may lack the necessary skills to navigate support systems on their own and require more support than older adults. An American study revealed promising results from interventions: more than 50% of unemployed AYAs (age 18-25 years) who received vocational rehabilitation services became employed.<sup>32</sup> In our study, being "back on track" with education and employment showed no association with treatment status which suggests a need for individualized support. Support for students could mean as little as longer rest breaks during examinations, while a temporary shift from full-time to part-time work may be required for employees.

The strengths of this study include the measurement of stress and emotional symptoms as well as support regarding changes in education and employment. Validated measures were used to assess both outcomes and risk and protective factors which promotes international comparisons. The findings of our study are limited by the cross-sectional study design. Further limitations, common to this field,<sup>18</sup> include the low response rate (26%) which may cause selection bias. However, the demographic characteristics are fairly similar to data from the Australian Cancer Database<sup>19</sup> and recruitment of participants from multiple sites and States enhances the generalizability of the results.

This study highlights the connection between mental health and school/work functioning and the importance of holistic patient care and support. At a population level, stress and anxiety are known to impair attention and memory;<sup>13,33</sup> these may also contribute to the poor experiences of AYA cancer survivors. This would partly explain why female gender is a risk factor for low educational attainment after cancer because females are also at increased risk for emotional symptoms during these years. Impaired neurocognitive capabilities may also cause challenges at school and at work which, in turn, cause stress and anxiety.<sup>34</sup> Due to the cross-sectional nature of our data, we were unable to assess the causality of these findings.

Within the study, the role of an educational advisor was framed as based at the cancer facility but without necessarily reflecting a single discipline. AYAs considered this professional educational and vocational support was helpful, which suggests the value of making such professional support more consistently available than it was to the participants of this study. A subset is also likely to benefit from more intensive educational and vocational rehabilitation as described by Strauser et al.<sup>32</sup> However, satisfaction with vocational choices is also important, as cancer can indelibly shape a young person's identity. For example, in a qualitative French study, young female cancer survivors had lower educational attainment than expected but often chose occupations in child care or healthcare, which fulfilled their desire to reciprocate the care they had received.<sup>35</sup> Future longitudinal studies should aim to acquire more holistic understanding of the issues influencing educational and vocational pathways, the transition from education to employment after cancer during the AYA years, and effective interventions that facilitate the return to school and work after cancer treatment.

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## **AUTHOR DISCLOSURE STATEMENT**

No competing financial interests exist.

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**TABLE 1 Descriptive characteristics of the AYA sample (n=196).**

<b>Demographic</b>	
Gender male, n (%)	99 (51)
Age at survey, mean (SD)	21.6 (3.1)
Age at diagnosis, mean (SD)	19.9 (3.2)
Age group at diagnosis, n (%)	
15-19 years	87 (45)
20-25 years	107 (55)
<b>Social and economic factors</b>	
Resides with, n (%)	
Parents	141 (72)
Partner	23 (12)
Other <sup>a</sup>	32 (16)
Education/employment, n (%) <sup>b</sup>	
Full-time student	76 (39)
Full-time work	44 (22)
Part-time student	21 (11)
Part-time work	44 (22)
Unemployed	21 (11)
Other <sup>c</sup>	12 (6)
<b>Cancer-related factors</b>	
Cancer type, n (%)	
Malignant hematological	60 (31)
Hodgkin disease	48 (25)
Sarcoma	29 (15)
Brain tumor	17 (9)
Germ cell tumor	14 (7)
Melanoma	7 (4)
Thyroid	5 (3)
Other	13 (7)
Treatment type, n (%) <sup>d</sup>	
Chemotherapy	178 (44)
Radiotherapy	83 (21)
Surgery	97 (24)
Bone marrow transplant	28 (7)
Patients still on treatment, n (%)	35 (18)
Relapse or recurrence, n (%) <sup>e</sup>	31 (16)

<sup>a</sup> The 'other' group includes living alone or with friends; <sup>b</sup> Education/employment percentages do not add up to 100 because individuals may belong in more than one group (e.g. full-time student and part-time work);

<sup>c</sup> The 'other' group includes patients still on sick leave, taking a gap year after high school and homemakers;

<sup>d</sup> Respondents were allowed to tick more than one option.

<sup>e</sup> Mean age at first diagnosis 18.4 years.

**TABLE 2 AYAs’ self-report of the impact of cancer on education and work plans and how well they managed to get “back on track” with their previous education and work plans.**

	Education, n (%)	Work, n (%)
<b>Impact of cancer</b>		
positive	49 (25)	54 (28)
no impact	69 (36)	53 (27)
negative	76 (39)	88 (45)
<b>Back on track</b>		
yes	94 (49)	86 (45)
to some extent	47 (24)	57 (30)
no	29 (15)	29 (15)
does not apply	23 (12)	19 (10)

Group sizes vary due to missing data: Impact of cancer on education (n = 194), Impact of cancer on work (195), Back on track: education (193), Back on track: work (191).

**TABLE 3 Association of clinical factors, post-traumatic stress and psychological distress with PedsQL school/work functioning (n=183).**

Variable	Bivariate regression				Multiple regression			
	$\beta$	95% CI	t	p-value	$\beta$	95% CI	t	p-value
Age group	7.64	0.68 to 14.59	2.17	<b>0.002</b>	1.28	0.13 to 2.43	2.21	<b>0.029</b>
Gender	12.50	5.29 to 18.80	3.52	<b>&lt;0.001</b>	8.96	1.98 to 15.93	2.55	<b>0.012</b>
On vs. off treatment	7.04	-16.97 to 2.89	1.42	0.160				
New diagnosis vs. relapse/recurrence	0.15	-9.34 to 9.64	0.03	0.975				
PCL-S	-0.95	-1.33 to -0.56	-2.63	<b>0.009</b>	-0.63	-1.12 to -0.14	-2.58	<b>0.012</b>
K10	-1.27	-2.06 to -0.49	-3.54	<b>0.001</b>	-0.86	-1.48 to -0.24	-2.75	<b>0.007</b>

CI = confidence interval; PCL-S = Post-traumatic Stress Disorder Checklist specific version; K10 = Kessler Psychological Distress Scale

Age, PCL-S and K10 analyzed as continuous variables, others as dichotomous variables.

Multiple regression only included variables that were significant in bivariate analyses.

**Respective reference groups: age 15-19 years, female gender, off treatment, new diagnosis; for PCL-S and K10, each increasing unit in the respective scores.**

**TABLE 4 Association of clinical factors, post-traumatic stress, psychological distress and PedsQL school/work functioning with being “back on track” with education and work plans (n = 182).**

Variable	Bivariate regression				Multiple regression			
	OR	95% CI	z	p-value	OR	95% CI	z	p-value
Age group	1.50	0.83, 2.69	1.34	0.18				
Gender	2.11	1.17, 3.82	2.48	<b>0.013</b>	0.67	0.34, 1.32	-1.16	0.24
On vs. off treatment	1.33	0.62, 2.85	0.74	0.48				
Relapse/recurrence vs. new diagnosis	1.98	0.90, 4.38	1.69	0.09				
PCL-S	0.94	0.91, 0.96	-4.73	<b>&lt;0.001</b>	0.98	0.94, 1.02	-1.00	0.32
K10	0.91	0.87, 0.94	-4.44	<b>&lt;0.001</b>	0.96	0.90, 1.03	-1.07	0.28
PedsQL school/work functioning	1.04	1.02, 1.06	5.36	<b>&lt;0.001</b>	1.03	1.01, 1.05	3.18	<b>0.001</b>

OR = odds ratio; PCL-S = Post-traumatic Stress Disorder Checklist specific version; K10 = Kessler Psychological Distress Scale  
PCL-S, K10 and PedsQL school/work functioning analyzed as continuous variables, others as dichotomous variables.

**Respective reference groups: age 15-19 years, female gender, off treatment, new diagnosis; for PCL-S, K10 and PedsQL school/work functioning, each increasing unit in the respective scores.**

**TABLE 5 Sources of support, according to how supported AYAs felt regarding necessary changes to their education and/or employment (n [%] of those in each respective group\*).**

<b>Source of support</b>	<b>Level of support</b>		
	<b>Well supported (n=122)</b>	<b>To some extent (n=53)</b>	<b>Not supported (n=18)</b>
Cancer center	40 (33)	14 (26)	1 (6)
Place of education	41 (34)	8 (15)	1 (6)
Place of work	44 (36)	12 (23)	1 (6)
Parents	56 (46)	21 (40)	3 (18)
Friends	20 (16)	6 (11)	6 (33)

\*Percentages in columns do not add up to 100 because AYAs were allowed to tick one or more sources of support.