European Journal of Oncology Nursing 17 (2013) 711–719

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Self-reported psychosocial wellbeing of adolescent childhood cancer survivors

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Keywords:
Adolescent
Child
Neoplasms
New Zealand
Quality of life
Survivors
Comparative study
Questionnaires

A B S T R A C T

Purpose: To describe self-reported psychosocial wellbeing of adolescent childhood cancer survivors (CCS) compared with a control group of their peers.
Methods: In this case–control study, 170 CCS aged 12–18 years completed an internet survey. The survey was a modified version of the Youth'07 Health and Wellbeing Survey of Secondary School Students in New Zealand. The control group (historical comparison) were the 9107 Youth'07 survey participants. Psychosocial wellbeing was assessed by measures of a) wellbeing (WHO-5), b) anxiety (MASC-10), c) depression (RADS2-SF) and d) emotional and behavioural difficulties (SDQ).
Results: The majority of CCS scored within the normal range across all four measures: wellbeing (89%), anxiety (93%), depression (94%) and emotional and behavioural difficulties (82%), leaving a small but important minority of CCS reporting significant clinical issues. Compared to their peers, adolescent CCS were no more likely to have an abnormal score for any of the psychosocial measures, and less likely to report abnormal psychosocial wellbeing (OR = 0.44, $p = 0.0003$) and prosocial behaviour problems (OR = 0.53, $p = 0.009$). Survivors of central nervous system tumours, older age, older age at diagnosis, and lower socioeconomic status were associated with some psychosocial difficulty.
Conclusions: Following a diagnosis of childhood cancer, intensive therapy, and the subsequent risk of adverse health outcomes, one might expect CCS to be doing less well than their peers in terms of psychosocial wellbeing. The findings of this study, however, show that CCS are doing as well, and in some respects better, than their peers.

Introduction

The survival rates for children and young people who have had a childhood cancer have risen dramatically in the past 20–30 years with current estimates of a 5 year overall survival rate of greater than 80% (Howlader et al., 2011). Increased survival rates have been brought about by a combination of advances in treatment, improved supportive therapies, and collaborative multi-centred clinical trials (Weiner et al., 2003). It is now estimated that in developed countries about 1 in every 1000 adults reaching the age of 20 will be a long term survivor of cancer (Last et al., 2005). In New Zealand each year approximately 160 children 15 years of age or younger are diagnosed with a childhood malignancy, therefore with an estimated 80% or greater survival, every decade will see an additional 1200 survivors within our population. However, cure has come at a cost, as cancer survivors are at risk for physical or psychosocial late effects from their disease, chemotherapy, radiation therapy, and surgery (Diller et al., 2009; Hudson et al., 2003; Ishida et al., 2010). The North American Childhood Cancer Survivorship Study Group is one of the largest multi-centred research groups, following a cohort of 14,000 survivors diagnosed between 1970 and 1986 and more recently, a second cohort between 1987 and 1999. They concluded that two out of three childhood cancer survivors (CCS) are likely to experience at least one chronic health problem and one in every four survivors is likely to experience a severe late effect as a consequence of their treatment or malignancy (Mody et al., 2008; Oeffinger and Hudson, 2004; Oeffinger et al., 2006). In recognition of the prevalence of late effects in CCS and the need to provide long term follow-up care, the national Late Effects Assessment Programme (LEAP) became formalised in New Zealand in 2006. Survivors transition into the LEAP programme between three to five years from completion of treatment and continue to be

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http://dx.doi.org/10.1016/j.ejon.2013.06.007

seen in the multidisciplinary team (MDT) clinic until late adolescence or early adulthood, depending on treatment toxicity and existing chronic health issues. The MDT consists of a paediatric oncologist, nurse specialist and clinical psychologist. In addition to being seen annually at a LEAP clinic, the CCS can access services outside of the clinic setting as needed.

There is a sound body of knowledge around the medical late effects for CCS based on risk-related exposure to therapies, with evidence based guidelines established for follow-up surveillance (Children's Oncology Group, 2008; United Kingdom Children's Cancer Study Group, 2005). The risk of late effects for CCS is varied and dependant on the disease, type and intensity of treatment, and individual personal characteristics, with those at greatest risk for significant cognitive and endocrine late effects being survivors of brain tumours and central nervous system (CNS) directed therapies (Diller et al., 2009; Edgar et al., 2009; Shaw, 2009). The psychosocial consequences of living with medical late effects and the journey through cancer are less well understood. Several studies suggest adolescent survivors are at increased risk for adverse emotional, behavioural and social outcomes compared to healthy matched peers or siblings (Hobbie et al., 2000; Krull et al., 2010; Mody et al., 2008; Rourke et al., 2007; Speechley et al., 2006; Zebrack and Chesler, 2002). Zeltzer et al. (2009) have suggested a link between high rates of neurocognitive deficits and behavioural or emotional disorders among child cancer survivors. In a number of studies, however, CCS are generally reported having a positive quality of life with higher rates of happiness and better psychosocial adjustment than their peers (Parry and Chesler, 2005; Zebrack and Chesler, 2002; Zeltzer et al., 2008).

For adolescents, medical and psychosocial effects intersect with the already difficult transitions involved in normal young adult development (Zebrack and Isaacson, 2012). For young people living in New Zealand who have survived a childhood cancer, our knowledge of the consequences of living with late effects as they try to deal with the normal tasks of adolescence and adulthood is limited, and based on the experience of other cultures and countries. The opportunity to gather our own information was timely and appropriate.

Aim

The aim of this study was to describe self-reported psychosocial wellbeing of adolescent childhood cancer survivors aged between 12 and 18 years and to compare this with a control group of their peers.

Methods

Design

In this non-interventional case control study, participants completed an internet-based, computer administrated branching questionnaire using M-CASI (multimedia computer assisted self-interview programme). The childhood cancer survivor questionnaire was carried out in 2009–2010 as the Adolescent Cancer Survivor Impact Study (ACSIS). The historical comparison group were the 9107 students throughout New Zealand who completed the questionnaire for the Youth'07 health and wellbeing survey in 2007–2008. The Youth'07 questionnaire included 622 questions across 9 domains, including emotional wellbeing, and was completed, on average, in an hour and a quarter (Adolescent Health Research Group, 2008). Recognising that adolescents were unlikely to complete the full questionnaire independently in the home setting, the Youth'07 questionnaire was modified (reduced) to focus on key questions within the same domains. The final modified questionnaire included 250 questions and was completed on average in half an hour. In this manuscript we focus on the four standardised measures of psychosocial wellbeing included in the questionnaire: anxiety, depression, emotional wellbeing, and strengths and behavioural difficulties. Health and Disability Multiregional Ethical approval was granted by the Upper South B Regional Ethics Committee (URB/09/05/017). Support was also granted by the Auckland and Canterbury District Health Boards and their respective Māori (indigenous New Zealanders) Research Review Committees (MRRC).

Measures of psychosocial wellbeing

- The World Health Organisation-Five Wellbeing Index (WHO-5) is a positively worded scale designed to assess emotional wellbeing within the previous 2 weeks, covering positive mood, vitality, and general interest. The 5 items are scored on a 6-point Likert scale from 0 (not present) to 5 (constantly present) (Bech, 1999; Bech et al., 2003). The total score ranges from 0 (worst possible) to 25 (best possible), with cut-off raw scores for poor ($<$13), good (13–17), very good (18–21) and excellent (22–25). The WHO-5 has been found to have a good internal consistency (Lowe et al., 2004), reliability and validity (de Wit et al., 2007).
- The Reynolds Adolescent Depression Scale-Short Form (RADS2-SF) measures symptoms of depression in adolescence. It has 10 items with a five-factor structure that assesses generalised demoralisation, despondency and worry, externalised somatocism, anhedonia, and self-worth. Possible raw scores range from 10 to 40 with a suggested cut-off score $\geq$26 as indicative of depression (Reynolds, 2002). In a New Zealand sample, the RADS2-SF had good internal reliability and validity (Milfont et al., 2008). The depression cut-off score suggested by Milfont et al. (2008) of $\geq$28 was used for both the Youth'07 health and wellbeing survey (Adolescent Health Research Group, 2008) and for this study.
- The Strengths and Difficulties Questionnaire (SDQ) measures psychosocial functioning in 4–18 year olds. SDQ has four difficulties scales (emotional, conduct problems, hyperactivity-inattention, and peer problems) and one positive strength scale (prosocial). Each of the five scales is measured by five items with a possible score from 0 to 10. A total difficulties score is calculated by summing the four difficulties scales scores (Goodman, 1997, 2001; Klasen et al., 2000). The SDQ is widely used and has good internal reliability and validity (Koskelainen et al., 2000).
- The Multidimensional Anxiety Scale for Children–short form (MASC-10) is a ten item, 4-point Likert measure with four basic anxiety dimensions: physical symptoms, harm avoidance, social anxiety, and separation anxiety in children aged 8–18 years (March et al., 1997). Possible score ranges from 0 to 25 with $>$19 for females and $>$17 for males indicative of significant anxiety. The Scale has good reliability and internal consistency (Hocking et al., 2011; March and Sullivan, 1999).

Cases

Given the relatively small number of adolescent survivors in New Zealand and the individual variables of disease type, treatment therapies, and late effects, a whole population approach was utilized. Participants were recruited from the New Zealand Child Cancer Registry (NZCCR) and hospital records. Inclusion criteria were all survivors of a childhood disease that met the International Classification of Childhood Cancers 3rd Edition (ICCC-3), aged

between 12 years and 18 years inclusive at the commencement of the study and who were at least two years from completion of therapy and disease free. Participants had to have English language skills equivalent to year 6 (10 years of age), the same criteria as that set for the Youth'07 survey. In addition, participants needed to be able to physically and visually use a computer and understand instructions to competently interface with the computer and questionnaire. Three hundred and ninety six eligible CCS were invited to participate.

Controls (historical comparison)

The control sample was the 9107 students from 96 secondary schools throughout New Zealand who completed the questionnaire using hand held computers for the Youth'07 survey (Adolescent Health Research Group, 2008). The Youth'07 study provided a unique opportunity to use recent, comparative data from a large representative cohort of 12–18 year old New Zealand students. This control group is representative of the general adolescent population in school, irrespective of their physical health or psychosocial wellbeing.

Procedures

All eligible CCS were sent a pack inviting their participation. For those under the age of 16 years, the letter was addressed to the parent/caregiver with a request to pass the information to their child to complete if they agreed. Consent for those 16 years of age and over was implicit in logging on to the internet questionnaire using a unique identifier code. Participants were informed that we would provide headphones for privacy and assist in organising computer and internet access if needed. The data collection period was from August 2009 to January 2010. The Youth'07 research was conducted in secondary school facilities with a research team at hand with enrolment during 2007 and 2008.

Data analysis

Firstly, we described childhood cancer survivors and compared respondents and non-respondents; Secondly, we described the psychosocial wellbeing of adolescent CCS. Internal consistency of the psychosocial scales was tested by Cronbach's alpha coefficient. Thirdly, we tested whether demographics or type of childhood cancer diagnosis and treatment was associated with psychosocial wellbeing. Comparisons between respondents and non-respondents were made using the Fisher's exact test for categorical measures or the *t*-test for the three age related continuous measures and for socioeconomic status (SES). SES was measured by the New Zealand Deprivation 2006 index, a census based ordinal scale from one to ten with one being lowest deprivation (Crampton et al., 2007). While these continuous distributions were typically not strictly normally distributed, the use of non-parametric tests for analyses of these continuous measures made no material difference to the results or conclusions of this study. Due to the small number of respondents across cancer diagnoses, three diagnosis categories were used: (a) Leukaemia/Lymphoma, (b) Central Nervous System (CNS) tumour and (c) all others. Treatment types were categorised into (a) chemotherapy, (b) radiation, (c) Haemopoetic Stem Cell Transplant (HSCT) and (d) surgery.

Psychosocial measure scores were standardized and converted to categories as per instrument manuals. For the ease of presentation and analysis we have (where necessary) dichotomized and renamed categories as "Abnormal" (WHO-5 "poor" <13, RADS2-SF ≥ 28, MASC-10 "significant" >19 and >17 in females and males respectively, SDQ "Borderline/Abnormal") and "Normal" based on published cut-off scores. Comparisons between demographic and cancer characteristics of the CCS were tested by logistic regression using PROC LOGISTIC in SAS, with psychosocial wellbeing measure of interest as the categorical outcome, and weighting to correct for respondent ethnicity and SES. Odds ratios (OR) were calculated for the odds of an abnormal outcome. Confidence intervals (95% CI) and *p*-values were likelihood ratio based. Where the count in one group was zero, Fisher's exact test was used.

Finally, we compared wellbeing, depressive symptoms and strengths and difficulties of adolescent CCS with New Zealand secondary school students. Comparisons between CCS cases and Youth'07 controls were tested by multivariable logistic regression using PROC SURVEYLOGISTIC in SAS. For these analyses, the psychosocial wellbeing measure of interest was incorporated as the categorical outcome of a multivariable model which included as predictor co-variables: the study group (CCS or Youth'07), age, gender, ethnicity and socioeconomic status. The cancer survivor data were weighted (by ethnicity and SES) to match the New Zealand CCS sample, and the Youth'07 data were weighted and allowance made for the clustered sampling design as instructed by the providers of the Youth'07 data. Hence, the predictor effect (and associated *p*-value) of the study group co-variable (CCS vs. Youth'07) provided a comparison of the two groups, while controlling for differences in age, gender, ethnicity and SES. This method allowed for the complex study design of the Youth'07 data, and enabled use of the entire data from both study groups.

We define statistical significance as $p < 0.05$, but acknowledge because of the multiple factors examined, this definition may include results where the true study-wide probability of obtaining a greater test statistic when there is no true difference is > 0.05. Furthermore because the number of cases is relatively low, we considered effect sizes and determined some results as clinically interesting, even if $p > 0.05$.

Results

Characteristics of the study sample

A total of 396 CCS aged between 12 and 18 years and at least 2 years from the end of treatment were invited to complete the survey, 170 (43%) responded. As shown in Table 1, survey respondents were similar to non-respondents in gender and age, but Māori and Pacific ($p = 0.07$) and those living in higher deprivation areas ($p = 0.01$) were under-represented. The most common cancer diagnosis was Leukaemia, followed by Central Nervous System (CNS) disease and Lymphoma. In comparing respondents with non-respondents by cancer diagnosis, there was overall some difference ($p = 0.02$), although the percentage of cancer diagnoses of the respondents generally matched the percentage for the total CCS cohort. Respondents were slightly younger at age of cancer diagnosis (5.6 years) compared to non-respondents (6.5 years, $p = 0.02$) and similarly the time since diagnosis was slightly longer in respondents compared to non-respondents (9.7 years vs. 8.9 years respectively, $p = 0.02$).

Psychosocial wellbeing of childhood cancer survivors

The four primary psychosocial wellbeing tests had good internal consistency in this sample (Cronbach's $\alpha = 0.87, 0.89, 0.84$ and 0.76, for WHO-5, RADS-SF, Total SDQ and MASC-10 respectively). The distribution parameters of the scores from our CCS sample are given in Table 2. The vast majority ($\geq$89%) of CCS scored within the normal range across the measures of wellbeing, depressive symptoms, and anxiety symptoms. The proportion of CCS who scored within the normal range for strengths and difficulties (SDQ) measures, was slightly lower (79–87%).

Table 1
Socio-demographic and cancer characteristics of adolescent New Zealand childhood cancer survivors (CCS) and study respondents.

	Eligible CCS population ($n = 396$)		Study non-respondents ($n = 226$)		Study respondents ($n = 170$)		P[a]
	n	%	*n*	%	*n*	%	
Socio-demographic characteristics							
Gender							
Female	163	41	90	40	73	43	0.53
Male	233	59	136	60	97	57	
Ethnicity							
European	269	68	146	65	123	72	0.07
Māori	66	17	45	20	21	12	
Pacific	38	10	25	11	13	8	
Asian	23	6	10	4	13	8	
Deprivation Index[b]							
Mean	5.7		6.0		5.2		0.01
Range	1, 10		1, 10		1, 10		
Age at time of study (years)							
Mean	15.3		15.4		15.3		0.85
Range	12, 18		12, 18		12, 18		
Cancer Characteristics							
Diagnosis[c]							
I Leukaemia	159	40	92	42	65	38	0.02
II Lymphoma	47	12	28	12	19	11	
III Central nervous system	64	16	42	19	22	13	
IV Neuroblastoma	14	4	8	4	6	4	
V Retinoblastoma	8	2	1	0	7	4	
VI Renal Tumours	32	9	16	7	18	11	
VII Hepatic Tumours	9	2	2	1	7	4	
VIII Bone Tumours	22	6	11	5	11	6	
IX Soft Tissue sarcoma	20	5	15	7	5	3	
X Germ Cell/Gonadal Tumours	8	2	2	1	6	4	
XI Epithelial/Melanoma NOS	10	3	7	3	3	2	
XII Malignant neoplasm NOS	1	0	0	0	1	1	
Cancer diagnosis grouped							
Leukaemia/Lymphoma	206	52	122	54	84	49	0.06
Central nervous system	64	16	42	19	22	13	
Other	126	32	62	27	64	38	
Age at diagnosis (years)							
Mean	6.1		6.5		5.6		0.02
Range	0, 16		0, 16		0, 15		
Time since diagnosis (years)							
Mean	9.2		8.9		9.7		0.02
Cancer Treatments							
Surgery	208	53	126	54	82	48	0.14
Chemotherapy	351	89	202	89	149	88	0.59
Radiation	101	26	61	27	40	24	0.43
Haemopoetic Stem Cell Transplant	39	10	20	9	19	11	0.44

[a] Tests for differences between respondents and non-respondents. Chi-square was used for categorical characteristics and *t*-test for continuous characteristics.
[b] A ten point ordinal measure from one to ten, where one is lowest deprivation (see methods).
[c] Diagnosis is based on International Classification of Childhood Cancers–3rd Edition. NOS = not otherwise specified.

Table 2
Psychosocial measures scores in childhood cancer survivors ($n = 170$).

	Median score	Inter-quartile range	Range	Percentage classified as normal[a]
Wellbeing (WHO-5)	76	60, 88	8, 100	89
Depressive symptoms (RADs-SF)	42	36, 52	33, 75	94
Anxiety (MASC-10)	46	40, 55	29, 90	93
Difficulties (SDQ Total Diff)	9	6, 13	0, 27	82
SDQ sub-measures				
Emotional symptoms	2	1, 4	0, 9	86
Conduct problems	1	0, 2	0, 6	85
Hyperactivity	3	2, 5	0, 10	79
Peer problems	2	0, 3	0, 9	85
Prosocial difficulties (reverse score)	8	7, 9	1, 10	87

[a] As defined by the manuals (see Methods).

Demographic and cancer characteristic associations with psychosocial wellbeing of childhood cancer survivors

Associations with psychosocial wellbeing were investigated across the range of demographic and cancer characteristics. Tables 3 and 4 present the odds ratios for an abnormal measure compared between demographic and cancer characteristics. For ethnicity and diagnostic groups, comparisons with the most frequent sub-group (European and Leukaemia/Lymphoma respectively) only are presented. Because the number of Asians in this study was low ($n = 10$), Asian comparisons are not presented. Many of the sub-categories had small samples sizes and wide confidence intervals so findings should be considered tentative. Older age at time of survey and older age at time of diagnosis were associated with poorer reported wellbeing (WHO-5 OR = 1.4, $p = 0.02$ and OR = 1.1, $p = 0.05$ respectively; Table 3). The average age at diagnosis and average age at study of children who's reported wellbeing fell within the clinically abnormal range was 7.4 and 16.5 years respectively compared to 5.3 and 14.9 years for children whose

Table 3
Associations between demographic and cancer characteristics, and an abnormal[a] score on a psychosocial measure of wellbeing in childhood cancer survivors.

		Wellbeing (WHO-5)		Depressive (RADs-SF)		Anxiety (MASC-10)		Difficulties (SDQ total diff)	
		OR (95%CI)	P[b]	OR (95%CI)	P[b]	OR (95%CI)	P[b]	OR (95%CI)	P[b]
Socio-demographic characteristics									
Gender	Female vs. male	1.8 (0.7, 5.1)	0.22	0.9 (0.2, 3.2)	0.82	0.9 (0.2, 2.8)	0.81	0.9 (0.4, 2.1)	0.87
Ethnicity	Māori vs. European	0.6 (0.09, 2.6)	0.57	0.5 (0.03, 3.0)	0.53	0.9 (0.1, 4.0)	0.85	2.4 (0.9, 6.2)	0.09
	Pacific vs. European	0.7 (0.06, 3.7)	0.75	n/a[c]	0.59	2.4 (0.4, 10.0)	0.28	0.5 (0.04, 2.2)	0.36
Deprivation index[d]	1 decile increase	1.0 (0.8, 1.1)	0.55	1.0 (0.8, 1.3)	0.71	1.1 (0.9, 1.3)	0.47	1.1 (0.9, 1.3)	0.28
Age at time of study (y)		1.4 (1.1, 1.8)	0.02	1.2 (0.8, 1.6)	0.39	0.9 (0.7, 1.3)	0.61	0.9 (0.8, 1.2)	0.57
Cancer characteristics									
Diagnosis group	CNS vs. Leukaemia/ Lymphoma	2.0 (0.4, 7.4)	0.36	0.8 (0.03, 5.9)	0.86	2.7 (0.5, 12.7)	0.24	2.0 (0.7, 5.7)	0.22
	Other vs. Leukaemia/ Lymphoma	1.4 (0.5, 4.2)	0.52	1.5 (0.4, 6.0)	0.55	1.6 (0.4, 6.3)	0.47	0.6 (0.2, 1.5)	0.25
Age at diagnosis (y)		1.1 (1.0, 1.3)	0.05	1.1 (0.9, 1.3)	0.39	1.0 (0.9, 1.2)	0.62	1.0 (0.9, 1.1)	0.61
Time since diagnosis (y)		0.9 (0.8, 1.1)	0.37	1.0 (0.8, 1.2)	0.64	0.9 (0.8, 1.1)	0.40	1.0 (0.8, 1.1)	0.37
Cancer treatments									
Surgery		0.6 (0.2, 1.7)	0.36	0.8 (0.2, 3.0)	0.77	0.9 (0.3, 2.9)	0.87	0.6 (0.3, 1.3)	0.20
Chemotherapy		2.8 (0.5, 50.0)	0.30	1.4 (0.2, 33.3)	0.75	0.8 (0.2, 5.9)	0.77	1.3 (0.4, 6.3)	0.68
Radiation		1.0 (0.3, 2.8)	0.94	0.3 (0.0, 1.6)	0.17	1.1 (0.3, 4.0)	0.84	0.8 (0.3, 2.1)	0.74
Haemopoetic Stem Cell Transplant		1.6 (0.4, 5.6)	0.48	0.8 (0.1, 4.5)	0.85	n/a[c]	0.37	1.1 (0.3, 3.6)	0.82

[a] As defined by the manuals (see Methods).
[b] Tests are likelihood ratio based (except see c.).
[c] Count of abnormal children in one group was zero so odds ratio (OR) could not be calculated. In these instances p value is for Fisher's exact test.
[d] A ten point ordinal measure from one to ten, where one is lowest deprivation (see Methods).

reported wellbeing was classified 'excellent'. There were no statistically significant associations between either depressive symptoms (RADS2-SF), or anxiety (MASC-10), and any demographic or cancer characteristic. Increasing deprivation was associated with conduct problems (OR = 1.2, $p = 0.04$; Table 4), but not with any of the other psychosocial measures. The likelihood of peer problems was greatest in the CNS diagnosis group (OR = 4.0, $p = 0.02$; Table 4), with 36% of CNS survivors whose responses fell within the clinically abnormal range compared to 12% in the other diagnostic groups. Younger age at time of study and less time since diagnosis were less likely to have prosocial difficulties and hyperactivity respectively (OR = 0.7, $p = 0.01$ and OR = 0.9, $p = 0.05$; Table 4). Cancer survivors who had received radiation therapy were less likely to endorse symptoms of hyperactivity (OR = 0.4, $p = 0.05$) and prosocial difficulties (OR = 0.3, $p = 0.05$) than children who had received other treatments (10% abnormal vs. 24% abnormal, and 5% abnormal vs. 16% abnormal, respectively). Cancer survivors who had received HSCT were less likely to endorse symptoms of hyperactivity (OR = 0.2, $p = 0.05$; Table 4) than children who had received other treatments (6% abnormal vs. 23% abnormal). Of potential importance, Māori were more likely than Europeans to report symptoms of conduct problems, hyperactivity, peer problems, and prosocial difficulties but none of these were statistically significant (Table 4).

The psychosocial wellbeing of childhood cancer survivors compared with a representative group of NZ adolescent students

Childhood cancer survivors (cases) and Youth'07 students (controls) were similar in gender and age. Males accounted for 57% of CCS and 54% of Youth'07 ($p = 0.58$). Mean age at time of survey was 15 years for both groups ($p = 0.76$). Overall there was some difference in ethnicity between groups ($p < 0.001$), with Europeans more prevalent in the CCS group (68%) than Youth'07 (53%) and Asians less prevalent in the CCS group (6%) than Youth'07 (18%). There was a minor difference in SES between groups with the average deprivation index in the CCS group slightly higher than Youth'07 (5.7 vs. 5.1, $p = 0.13$). Adolescents in the CCS group were less likely to report poor emotional wellbeing than those in the Youth'07 group ($p = 0.0003$; Table 5). The proportion of adolescents with 'excellent' emotional wellbeing (WHO-5) was 29% among CCS compared to 19% among Youth '07. Conversely, the proportion of adolescents with 'poor' psychosocial wellbeing was 11% among CCS compared to 22% among Youth'07. There was a lower rate of depressive symptoms in the CCS group (6% vs. 11%; OR = 0.58, $p = 0.09$) and fewer CCS were in the abnormal range on the conduct scale compared with the Youth'07 (15% vs. 22%; OR = 0.64, $p = 0.06$) but these were not statistically significant. In the prosocial scale, fewer CCS reached criterion for social difficulties than the Youth'07 group (14% vs. 22%; OR = 0.53. $p = 0.009$). The MASC-10 anxiety scale was not included in the Youth'07 survey, but the earlier Youth 2000 survey reported an abnormal proportion of 5%. The proportion in the CCS group was slightly greater at 7%, but with a 95% confidence interval of 4%–12%, the difference was not statistically significant. Seventeen percent of the Youth'07 group reported "chronic" (in the survey described as "long-term lasting 6 months or more") health problems or conditions and/or disabilities. These respondents were significantly more likely to meet criteria for abnormal wellbeing, depressive symptoms, and all the difficulties measures, compared to the rest of the Youth'07 group (ORs ranging from 1.4 for hyperactivity to 2.0 for emotional symptoms; $p < 0.0001$).

Table 4
Associations between demographic and cancer characteristics and an abnormal[a] score on a scale of the strength and difficulties questionnaire (SDQ) in childhood cancer survivors.

		Emotional symptoms		Conduct problems		Hyperactivity		Peer problems		Prosocial difficulties	
		OR (95%CI)	P^b	OR (95%CI)	P^b	OR (95%CI)	P^b	OR (95%CI)	P^b	OR (95%CI)	P^b
Socio-demographic characteristics											
Gender	Female vs. male	1.6 (0.6, 4.0)	0.32	0.7 (0.3, 1.7)	0.45	0.9 (0.4, 1.9)	0.71	1.3 (0.6, 3.1)	0.55	0.5 (0.2, 1.3)	0.17
Ethnicity	Māori vs. European	0.7 (0.1, 2.5)	0.62	2.2 (0.7, 5.9)	0.16	1.1 (0.4, 2.8)	0.90	1.4 (0.5, 4.0)	0.53	1.4 (0.4, 4.1)	0.56
	Pacific vs. European	0.5 (0.05, 2.6)	0.49	0.6 (0.05, 2.7)	0.52	0.3 (0.03, 1.5)	0.16	n/a[c]	0.13	n/a[c]	0.22
Deprivation Index[d]	1 decile increase	1.0 (0.9, 1.2)	0.92	1.2 (1.0, 1.4)	0.04	1.0 (0.9, 1.1)	0.82	1.0 (0.9, 1.2)	0.67	1.0 (0.9, 1.2)	0.79
Age at time of study (y)		1.0 (0.8, 1.2)	0.86	0.9 (0.7, 1.2)	0.52	1.0 (0.8, 1.2)	0.96	1.1 (0.8, 1.3)	0.70	0.7 (0.5, 0.9)	0.01
Cancer characteristics											
Diagnosis Group	CNS vs. Leukaemia/ Lymphoma	2.9 (0.9, 8.9)	0.08	1.4 (0.3, 4.6)	0.63	1.1 (0.3, 3.2)	0.88	4.0 (1.2, 13.0)	0.02	0.5 (0.08, 2.0)	0.37
	Other vs. Leukaemia/ Lymphoma	0.8 (0.2, 2.2)	0.59	1.1 (0.4, 3.0)	0.78	0.8 (0.4, 1.9)	0.66	1.0 (0.4, 2.9)	0.95	0.6 (0.2, 1.5)	0.24
Age at diagnosis (y)		1.0 (0.9, 1.2)	0.47	1.0 (0.9, 1.1)	0.99	1.1 (1.0, 1.2)	0.09	1.0 (0.9, 1.1)	0.75	0.9 (0.8, 1.0)	0.07
Time since diagnosis (y)		0.9 (0.8, 1.1)	0.36	1.0 (0.9, 1.1)	0.71	0.9 (0.8, 1.0)	0.05	1.0 (0.9, 1.2)	0.56	1.0 (0.9, 1.2)	0.66
Cancer treatments											
Surgery		0.7 (0.3, 1.6)	0.37	0.9 (0.4, 2.2)	0.84	1.1 (0.5, 2.4)	0.82	1.3 (0.5, 3.1)	0.58	0.8 (0.3, 1.9)	0.55
Chemotherapy		3.7 (0.7, 99.9)	0.16	1.0 (0.3, 4.8)	0.98	1.0 (0.3, 3.8)	0.96	0.7 (0.2, 2.9)	0.62	0.6 (0.2, 2.2)	0.38
Radiation		0.8 (0.2, 2.1)	0.63	0.9 (0.3, 2.5)	0.91	0.4 (0.1, 1.0)	0.05	2.1 (0.8, 5.3)	0.12	0.3 (0.04, 1.0)	0.05
Haemopoetic Stem Cell Transplant		1.8 (0.5, 5.6)	0.38	1.5 (0.4, 4.5)	0.54	0.2 (0.01, 1.0)	0.05	1.4 (0.4, 4.3)	0.59	0.3 (0.02, 1.8)	0.23

[a] As defined by the manuals (see Methods).
[b] Tests are likelihood ratio based (except see c.).
[c] Count of abnormal children in one group was zero so odds ratio (OR) could not be calculated. In these instances p value is for Fisher's exact test.
[d] A ten point ordinal measure from one to ten, where one is lowest deprivation (see Methods).

However, excluding respondents with 'chronic' health issues, made little difference to our comparison of CCS to Youth'07 (Table 5).

Twenty four percent of Youth'07 respondents were born overseas. However being born overseas had little effect on the odds of any of the psychosocial measures in the Youth'07 group (data not shown) and consequently removing respondents born overseas did not materially alter the results of our comparison with CCS (e.g., WHO-5 OR = 0.44, $p = 0.0009$; Conduct OR = 0.63, $p = 0.05$; Prosocial OR = 0.52, $p = 0.008$).

Discussion

The results of this study indicate that childhood cancer survivors are, overall, doing as well psychosocially, and in some cases better, than their general population peers. Among the CCS, some demographic and cancer characteristics were found to predict poorer psychosocial wellbeing. CNS disease was shown to have a stronger association with peer problems and though not statistically significant, more likelihood for emotional problems. Treatment modalities, specifically CNS directed chemotherapy and CNS

Table 5
Psychosocial wellbeing among childhood cancer survivors (CCS) compared to normative peers (Youth'07), and to the same peer group without children with chronic illness (Youth '07 excl. chronic illness).

	CCS ($n = 170$)	Youth'07 ($n = 9107$)	Odds ratio CCS vs. Youth'07 (95% CI)	P^b	Youth'07 excl. chronic illness ($n = 7479$)	Odds ratio CCS vs. Youth'07 excl. chronic illness (95% CI)	P^b
	Abnormal[a] % (95% CI)				Abnormal[a] % (95% CI)		
Wellbeing (WHO-5)	11% (6, 15)	21% (20, 23)	0.44 (0.27, 0.71)	0.0003	20% (19, 21)	0.50 (0.31, 0.80)	0.002
Depressive symptoms (RADS-SF)	6% (3, 10)	11% (10, 11)	0.58 (0.31, 1.09)	0.09	9% (9, 10)	0.68 (0.36, 1.28)	0.23
Strength and difficulties (SDQ)							
Emotional Symptoms	14% (8, 19)	13% (12, 14)	1.04 (0.65, 1.68)	0.86	12% (11, 13)	1.23 (0.76, 1.99)	0.39
Conduct Problems	15% (9, 21)	22% (20, 23)	0.64 (0.40, 1.01)	0.06	21% (19, 22)	0.69 (0.43, 1.09)	0.11
Hyperactivity	21% (14, 27)	23% (22, 24)	0.85 (0.58, 1.26)	0.43	22% (20, 23)	0.91 (0.62, 1.35)	0.65
Peer Problems	15% (10, 21)	15% (14, 16)	1.01 (0.65, 1.59)	0.95	14% (13, 15)	1.18 (0.75, 1.85)	0.47
Total Difficulties	18% (12, 24)	20% (19, 22)	0.86 (0.56, 1.31)	0.48	18% (17, 20)	0.98 (0.64, 1.50)	0.93
Prosocial Difficulties (reverse score)	14% (8, 19)	22% (20, 23)	0.53 (0.33, 0.85)	0.009	22% (21, 23)	0.52 (0.33, 0.84)	0.007
Anxiety (MASC-10)	7% (4, 12)	Not reported			Not reported		

[a] As defined by the manuals (see Methods).
[b] Analysis adjusted for age, gender, deprivation index, ethnicity and Y'07 clusters.

radiation are identified in the literature as being significant contributing factors to poorer psychosocial outcomes for CCS (Schultz et al., 2007; Zeltzer et al., 2009). However, in our study neither chemotherapy nor radiation was significantly associated with poor psychosocial wellbeing, and radiation was actually associated with a lower risk of prosocial difficulties and hyperactivity. But, the relatively weak evidence of association with treatment, and the use of relatively imprecise treatment categories (due to the small numbers in our study who had received more specific treatments) limits our interpretation. Based on the existing literature and our knowledge of the medical and neurological late effects that many of the survivors of CNS disease have, we expected the difficulties to be greater across the measures of wellbeing, reaching a much higher level of significance. One explanation that may account in part for this was suggested by Vannatta et al. (2007), who reported that while children who received CNS therapy with neurotoxic late effects had more peer problems and were more socially isolated, they did not report problems with social functioning to the same degree as parents or teachers and suggested that limited self-awareness of social difficulties may be a factor.

There are themes emerging from the more recent studies that a large majority of CCS do not show elevated levels of anxiety, or depression, or lower self-esteem than their peers and may have a greater sense of wellbeing (Kazak et al., 2010; Parry and Chesler, 2005; Phipps et al., 2009; Williams et al., 2010). Newer therapies and advancing knowledge of the mechanisms of these diseases mean that the intensity of many treatment protocols have been modified, reducing the potential for the late effects of treatment reported in earlier studies. It is also very possible that with the comparatively small number of childhood cancer diagnoses and subsequent survivors in New Zealand, there is a health protective effect as most are still involved in a long term follow-up programme with multi-disciplinary health professional support and few are lost to follow-up in this age bracket. Parry and Chesler (2005) note that many childhood cancer survivors thrive, reporting that the cancer experience made them stronger, more self-reliant and better able to deal with problems, and "more mature" than others their age. This is congruent with the sense we get from working with these young people in a clinical setting. By necessity, many young survivors form a close bond with their family during the period of diagnosis, treatment and follow-up care which often spans a number of years including the time when most of their peers are becoming increasingly independent. In addition, the age for participation in this survey was 12–18 years, when the protective factors of family, targeted health care, school, and friends are still predominant and may have a positive impact on their psychosocial wellbeing. As suggested by Zebrack and Chesler (2002), at this age they have not yet had to deal with significant changes to home, employment, financial status or sexuality as a result of the cancer they had. One of the goals of this study was to survey adolescent CCS in the context of a New Zealand culture and determine whether our findings differed from published research. New Zealand has a national framework for child and adolescent cancer services that offers a comprehensive service for the diagnosis and treatment of childhood cancer, providing a free, equitable service, regardless of ethnicity or socioeconomic status. It could be argued that these are all protective factors that have a positive effect on the cancer experience for many survivors and may have contributed to the positive findings of this survey. While the number of survivors reporting significant depressive symptoms, anxiety and poor emotional wellbeing were low in this survey, it is important to acknowledge that for those that did so, it is clinically important.

Strengths and limitations of the study

This study is the first survey of the effects of a childhood cancer diagnosis and subsequent treatment on the wellbeing of adolescent CCS in New Zealand. The use of a nationally representative sample of New Zealand secondary school students as the control group provides a strong and valid comparison. Both groups used the same survey tool and overall the participants in both studies were similar for age, and gender. There was a lower proportion of Asians in the CCS group which could be the result of a recent rise in immigration and student visa holders from Asian countries being more highly represented in the Youth'07 survey (a healthy migrant effect). The distribution of SES was also somewhat different between the two groups. However, we employed an analysis technique that adjusted for any differences in age, gender, ethnicity and SES. We chose to compare to the control group as a whole irrespective of their physical health, psychosocial wellbeing, or any other factor, but in any case, excluding children who reported "chronic" illness or who were born overseas made little difference to the results. The use of self-reported measures, self selection and small sample size limits the generalisability of the findings. However as these were the same measures used in Youth'07 it was important to use these for comparison. Regardless, as Schwartz (2003) noted, "critical information for understanding the psychological and behavioural responses to survival is revealed by self-report" (p 1641). The CCS sample size was limited by the small number of childhood cancer diagnoses in New Zealand each year. Although a number of ways of accessing the questionnaire were offered, the use of an internet-based survey tool may still have been a barrier. Childhood cancer survivors with significant late effects affecting cognitive ability or vision impairment for example, were excluded, and such young people may have reported greater psychosocial distress that those who responded. In addition, it is acknowledged that this study does not address the issues of older adolescent and young adult survivors.

Implications for practice

While it is reassuring that a majority of childhood cancer survivors appear socially and emotionally well adjusted, there is a small but significant subgroup of young survivors who remain at risk for difficulties with psychosocial functioning. As a group, survivors of CNS tumours have been shown to have the greatest difficulties in this survey, and the results likely underestimate the true effect on the entire CNS group, many of whom were ineligible to participate. Adolescence is a time of transition and adjustment, and as these young survivors enter adulthood health problems may become worse with age. Many will certainly have to deal with significant long term morbidity and mortality that increases long after treatment is completed. There is clear evidence that they are more likely to get a second cancer, be infertile, and be at greater risk of developing a chronic health condition than the general population (Armstrong et al., 2009; Meadows et al., 2009; Oeffinger et al., 2006). In translating the findings of this study into the clinical setting it is important for health care practitioners to remember that these young survivors are individuals and assumptions cannot be made that they will all thrive.

Key implications for practice include a) continue to develop and strengthen the multidisciplinary model of care for survivors of childhood cancer incorporating medical surveillance, psychosocial support, and health education based on individual risk-related health outcomes; and b) develop strategies to ensure that the follow-up care continues to engage young survivors by maintaining relevance to their age, developmental stage, and changing needs.

Conclusion

This study provides valuable information on the self-perceived emotional wellbeing of adolescent childhood cancer survivors in New Zealand. Of the young survivors who took part in this survey, a greater number report themselves to be well adjusted young people than in the population sample. The dedicated long term follow-up programme for survivors of childhood cancer is an integral component of the continuum of childhood cancer care in New Zealand. The multidisciplinary support provided through the Late Effects Assessment Programme (LEAP), family support, and treatment advances may contribute to the majority of these young people doing so well to date.

Funding

Funding for the childhood cancer survivor survey was provided by the Newmarket Rotary Club Inc and CanTeen New Zealand.

Conflict of interest statement

None declared.

Acknowledgements

We acknowledge Simon Denny and the Youth'07 research team for access to survey data and valuable advice. A very special thank you to the childhood cancer survivors who gave their time to complete the survey, you are amazing young people who inspire us constantly with your courage and resilience.

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