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Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: A prospective longitudinal study

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ABSTRACT

The present study sets out to add to knowledge about the development over time of health-related quality of life (HRQL), anxiety and depression among survivors of adolescent cancer. The aim was to investigate if and how the HRQL, anxiety and depression of a group of adolescents with cancer differ from those of a reference group shortly after diagnosis, and subsequently at 6, 12 and 18 months after diagnosis.

Adolescents diagnosed with cancer and a reference group randomised from the general population completed the Hospital Anxiety and Depression Scale (HADS) and the two subscales Mental Health and Vitality in the Short Form 36 (SF-36) in telephone interviews.

The results indicate a steady increase in psychological well-being from the time of diagnosis, when the cancer patients' ratings were significantly worse than those of the general population, and onwards. The differences gradually disappeared and then were reversed, resulting in the cancer group reporting significantly better HRQL and lower levels of anxiety and depression than the reference group when 1.5 years had passed since diagnosis.

The adolescents faced with cancer show signs of adaptation to trauma, which can be understood in relation to the theoretical framework of posttraumatic growth as well as response shift. Future research should continue to follow this development over time, to investigate if the positive effects of the cancer experience will wear off, or if it has facilitated a permanent positive outcome.

1. Introduction

Recent advances in the treatment of childhood and adolescent cancer have led to improvements in the survival rate of these groups.[1–3] This increase has resulted in more attention being directed towards the psychosocial significance of being a survivor of childhood/adolescent cancer. Falling ill with a life-threatening disease is an experience, which may have a permanent effect on a person. Survival may alter the outlook on life in both negative and positive ways and could lead to an enhanced appraisal of life as well as an increased feeling of vulnerability, depending on how the individual reacts to and interprets the experience.[2]

Cancer survivorship as a concept can be defined in various ways. We adhere to the definition widely used among cancer survivorship organisations, which implies that anyone who has been diagnosed with cancer is a survivor, from the time of diagnosis until the end of life.[4] The survivorship experience has been described as including three phases: acute, extended and permanent. The acute phase ranges from diagnosis to the

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completion of initial treatment, the extended phase commences when initial treatment ends and then gradually evolves into permanent survival, as the risk of recurrence diminishes and the follow-up examinations thin out.[4,5] This article will follow a group of adolescents over time from the beginning of the acute phase of cancer survival and, for the majority, into the extended phase.

When addressing the psychosocial consequences of falling ill with and surviving cancer, studies frequently focus on measuring levels of health-related quality of life (HRQL).[3,6–9] There is no universally accepted definition of HRQL, and a multitude of different self-rating instruments exist. However, HRQL is generally seen as a multidimensional construct, encompassing physical, psychological, social and functional areas of life, and reflecting the impact of health and illness on these aspects.[6,10] Other common outcome measures used in this area of research are anxiety and depression.[11,12]

Reviews of the research concerning the quality of life and the psychological adjustment of survivors of childhood and adolescent cancer recurrently comment upon the difficulty of comparing different studies and of drawing definite conclusions, due to the heterogeneity of the studies and to methodological weaknesses.[2,12,13] among these, diverse patient groups with reference to diagnosis, treatment, age at diagnosis, time since diagnosis and a number of other characteristics can be mentioned. Furthermore, sample sizes are often small, different outcome measures and instruments are used, and different methods of comparison are employed. Especially noteworthy is the lack of longitudinal research. However, exceptions exist such as, for example, a study by Landolt and colleagues.[14]

Possibly due to the above-mentioned methodological limitations, research findings are somewhat inconsistent. The majority of the studies do not demonstrate any differences between survivors and population norms or control groups with respect to psychological and emotional functioning, leading to the conclusion that survivors generally are well adjusted.[2,12,15]

In contrast to this picture, where the experience of cancer leaves little or no effect, some studies report that survivors do indeed suffer from psychological consequences of cancer. Some evidence points to a considerable number of survivors suffering from PTSD, which is associated with lower levels of quality of life.[16] Furthermore, it has been reported that survivors of paediatric leukaemia, Hodgkin's disease and non-Hodgkin's lymphoma are approximately 1.6–1.7 times more likely to report symptoms of depression than a sibling control group.[17]

Adding further to the inconsistency of the research field, there are a number of articles that demonstrate that the survivors of childhood/adolescent cancer report better HRQL and less anxiety and depression. This is demonstrated in a study by Apajasalo and colleagues,[18] where the survivors report a better psychological adjustment with regard to, for example, vitality and depression than a control group of the general population. Similarly, Elkin and colleagues[19] find better evaluations of psychological functioning among young former cancer patients compared with normative values, one measure being anxiety. Moreover, a recent study predominantly reports better ratings of HRQL and lower levels of depression among adult long-term survivors of childhood cancer compared to population norms, but higher scores of trait-anxiety.[6]

There is a tendency in the literature to not differentiate between childhood and adolescent cancer.[20] Adolescence is a period generally characterised by change, when the individual is striving for autonomy and forming a mature self-image as well as relationships. Facing cancer during this time of life may be particularly challenging.[15,20,21] Owing to this, there is a need for more research into the potential psychosocial consequences of suffering from and battling against cancer during adolescence and young adulthood.

The present study sets out to add to knowledge about HRQL, anxiety and depression among survivors of adolescent cancer by following over time a group of individuals who probably will recover from their illness and be defined as permanent survivors, starting shortly after diagnosis. Taking age and gender into consideration, it will be investigated if and how their HRQL, anxiety and depression differ from those of a reference group shortly after diagnosis, and subsequently at 6, 12 and 18 months after diagnosis.

2. Methods

2.1. *Design*

This study is based on a longitudinal design and is part of a research project entitled 'How do adolescents with cancer cope with disease- and treatment-related aspects of distress?' Data were collected from two samples: adolescents diagnosed with cancer and a reference group randomised from the general population. The cancer group was asked to report levels of anxiety and depression as measured by the Hospital Anxiety and Depression Scale (HADS) and aspects of HRQL as measured by the two subscales Mental Health and Vitality in the Short Form 36 (SF-36) on four occasions: firstly shortly after diagnosis (T1), and subsequently at 6 (T2), 12 (T3) and 18 (T4) months after diagnosis. The reference group completed the same questionnaires, but was only asked to participate once. All data were collected by means of telephone interviews.

2.2. *Participants*

2.2.1. *Cancer group*

Adolescents (13–19 years) diagnosed with cancer were recruited between June 1999 and October 2003, from three of the six paediatric oncology centres in Sweden: Lund, Uppsala, and Umeå. Data were collected between June 1999 and April 2005. To be eligible for inclusion, the adolescents had to be Swedish speaking, diagnosed with cancer for the first time, treated with chemotherapy, and cognitively, emotionally and physically able to participate. A co-ordinating nurse at each centre was responsible for recruitment and assessed, in collaboration with a treating physician, each adolescent's ability to participate.

Ninety adolescents were diagnosed with cancer for the first time during the time of inclusion. Of these, nine were not eligible: two did not speak Swedish well enough to participate and seven were considered too cognitively or physically affected by the disease or neurological co-morbidity to participate. Of the remaining adolescents, 61 agreed to participate. However, two of these became too ill before they could be interviewed, two were overlooked due to administrative failure and one chose to withdraw from the study. Hence, 56 adolescents were included in the study. During the time of data collection, four of the participants were diagnosed with a recurrence of cancer (T3, $n = 1$, T4, $n = 3$), and were therefore excluded in an effort to keep the group homogenous in terms of survivorship, as a recurrence diminishes the chance of permanent survival. Also, seven participants died (T3), and their earlier responses were excluded for similar reasons. Additionally, three of those initially taking part in the study chose to withdraw (T2), leaving 42 adolescents with cancer that completed the study. See Table 1 for a presentation of the group's demographic and clinical characteristics and reasons for attrition.

2.2.2. *Reference group*

The sample was randomly chosen by Statistics Sweden from their civil register of the total population. The target population included all individuals covered by civil registration between 13 and 23 years of age, living in the three public healthcare regions where the three paediatric oncology centres studied are situated: South (Lund), Middle (Uppsala), and North (Umeå). The sample was stratified regarding gender (an equal amount of men and women), age group (young adolescents: 13–15 years; older adolescents: 16–19 years; and young adults: 20–23 years), and public healthcare region. The stratification regarding geographical area was included to be able to explore any possible occurrences of systematic differences regarding HRQL, anxiety, and depression due to the region. This was tested by a one-way ANOVA, which did not indicate any such differences, and therefore this variable was not taken into consideration in the following statistical analyses.

Table 1 – Demographic and clinical characteristics at T1–T4 and reasons for attrition at T2-T4 among adolescents diagnosed with cancer

	T1, *n*	T2, *n*	T3, *n*	T4, *n*
Eligible	81	56	53	45
Participated	56	53	45	42
Attrition				
Chose to withdraw from the study		3		
Recurrence			1	3
Death			7	
Study centre				
Lund	19	18	16	15
Umeå	17	16	11	11
Uppsala	20	19	18	16
Sex				
Boy	32	31	26	23
Girl	24	22	19	19
Age at diagnosis				
13–15	35			
16–19	21			
Mean age	15.7			
Diagnosis				
CNS tumour	2	2	2	2
Ewing sarcoma	4	3	2	2
Leukaemia	18	16	11	10
Lymphoma	20	20	20	20
Osteosarcoma	8	8	6	5
Other	4	4	4	3
On/off treatment	56/0	40/13	11/34	8/34

The selected eligible sample consisted of 391 individuals who were invited to participate. The response rate was 76.7%, leaving 300 participants (147 boys and 153 girls, mean age 17.5 years). The reasons for non-participation were prevented from participating due to illness or language difficulties (2.1%), impossible to reach (9.2%), and not wishing to participate (11.3%). Teenagers whose parents did not give their consent were included among those not wanting to participate ($n = 7$). Only 0.8 % of the addresses were impossible to find.

2.3. Questionnaires

Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS) and aspects of HRQL were measured by the two subscales Mental Health and Vitality in the Short Form 36 (SF-36).

The HADS was developed by Zigmond and Snaith,[22] and has been used extensively in a wide range of settings as a psychological screening instrument and in population-based surveys, studying aspects of disease and quality of life. To lessen the possible effects of physical illnesses, no items relating to symptoms that might stem from a somatic condition, such as dizziness and loss of appetite, are included. Anxiety and depression are measured in two separate subscales, each consisting of seven items, rated from 0 to 3. Subscale scores therefore range from 0 (no distress) to 21 (maximum distress). The HADS was originally developed to be answered by people aged between 16 and 65, but has been found valid and adequate for use with adolescents (aged 12–16) in a study by White and colleagues.[23]

The SF-36 is a generic instrument for the assessment of HRQL developed by an American research group, led by John Ware.[24] The questionnaire consists of 36 items, which measure eight dimensions of life quality: physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH). In addition, one single item determines perceived differences in state of health over the past year. Verbal response choices vary from 2 to 6. The SF-36 is scored by coding raw scores for each question, and recalibrating, summing and transforming them into a scale from 0 (worst possible HRQL) to 100 (best possible HRQL), following standard scoring algorithms.[25] The SF-36 is described as adequate from early adolescence (14 years).[24]

For the purpose of this study, two SF-36 subscales mainly associated with mental health and well-being were used, namely Vitality (four items) and Mental Health (five items). The reason for this is twofold. Firstly, as the data collection was conducted within a larger project, the participants were asked to answer a large number of questions apart from the ones forming the basis of the present investigation, concerning, for example, cancer-specific symptoms and coping strategies. Therefore, efforts were made to simplify participation as much as possible. Secondly, this study has its emphasis on the psychosocial consequences of falling ill with and surviving cancer, and therefore the mental aspects of HRQL were perceived as more determining sources of information.

2.4. *Procedure*

Ethical approval was obtained from the local ethics committee at the Faculty of Medicine at the universities of Lund, Umeå, and Uppsala.

2.4.1. *Cancer group*

The co-ordinating nurse at each of the three centres provided potential participants and their parents with oral and written information about the study approximately three weeks after diagnosis. A few days later the same nurse asked for consent from the adolescent. If the adolescent was younger than 18, parents were asked to provide consent on his/her behalf. Adolescents who agreed to participate were then interviewed by telephone at T1–T4. The interviewer read the items included in the two questionnaires (the HADS and the subscales Mental Health and Vitality included in the SF-36) aloud to the respondent, and recorded his or her responses. The second author conducted the majority of the interviews, and the rest were conducted by three other doctoral students. At the end of each interview, the adolescent was asked whether he or she agreed to be contacted again for another interview. Before each interview at T2–T4, the co-ordinating nurse at each centre was contacted to ensure that the adolescent was still cognitively, emotionally and physically able to participate. The participants received a small gift in appreciation of their participation.

2.4.2. *Reference group*

All potential participants received a letter containing information about the study. A separate information letter was addressed to the parents of persons younger than 18. Potential participants were contacted by telephone by one of the interviewers within a week of the information letter being mailed. Five interviewers performed the telephone interviews, after completing an organised training programme. Provided that the respondent agreed to participate, and that parental consent was obtained for those under 18, a time was either booked for the interview, or in some cases the interview was conducted directly. The interviewer read the items included in the two questionnaires (the HADS and the two subscales of the SF-36) aloud to the respondent, and recorded his or her responses, in the same way as described above. Shortly afterwards, all participants received a cinema ticket by mail, in appreciation of their participation.

2.5. *Statistical analysis*

All statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 14.0 (SPSS Inc, Chicago, IL).

Descriptive statistics (means and standard deviations) for all the variables were computed at T1–T4 with regard to the cancer group and at the single time of measurement for the reference group. A comparison between the cancer group's ratings at T1 and T4 was calculated with dependent *t*-test. As there were more boys than girls in the cancer group, and as the longitudinal design means that they age during the study, the comparison between the estimated mean of the cancer group and the reference group was calculated using a linear regression, taking age and gender into account for each of the variables. The mean difference between the groups was estimated by the regression coefficient b_3 according to the following formula: $y = a + (b_1 \times \text{age}) + (b_2 \times \text{gender}) + (b_3 \times \text{group})$.

3. Results

Table 2 presents the means and standard deviations of the two HADS subscales and the two SF-36 subscales at the four times of measurement for the cancer group, and at the single time of measurement for the reference group. The development over time for each subscale can also be viewed in Figs. 1–4. The cancer group's ratings of all the four variables differed significantly between T1 and T4. For Anxiety, the mean difference was 1.74 ($t = 2.62$, $p < .05$), for Depression 2.76 ($t = 6.51$, $p < .001$), for Vitality 30.7 ($t = 5.76$, $p < 001$), and for Mental Health 18.7 ($t = 5.12$, $p < 001$).

Table 3 presents the estimated mean differences between the cancer group and the reference group at T1–T4. At diagnosis (T1), the estimated mean differed between the cancer group and the reference group on the HADS subscale Depression ($p \leqslant .001$) and the SF-36 subscales Vitality and Mental Health (both $p \leqslant .001$). The differences signify that the cancer group reported higher levels of depression and lower levels of the two aspects of HRQL. No difference was found on the HADS subscale Anxiety.

Six months after diagnosis (T2), corresponding differences were discovered regarding Vitality and Mental Health (both $p \leqslant .001$), but there were no differences on either of the two subscales of the HADS.

Twelve months after diagnosis (T3), there were no differences between the cancer group and the adolescents randomised from the general population in the estimated means of any of the variables.

Table 2 – HADS and SF-36 scores of the cancer patients at T1–T4 and of the reference group

HADS and SF-36 subscales	M (SD)				
	T1	T2	T3	T4	Reference group
Anxiety	5.05 (3.13)	4.60 (3.12)	3.79 (3.44)	3.31 (3.18)	4.66 (3.35)
Depression	3.95 (2.70)	3.07 (2.02)	1.88 (1.73)	1.19 (1.29)	2.52 (2.27)
Vitality	47.0 (24.6)	55.8 (23.2)	72.0 (19.1)	77.7 (20.2)	69.4 (18.5)
Mental Health	65.0 (18.9)	71.4 (18.0)	79.7 (16.5)	83.7 (14.4)	80.7 (15.0)

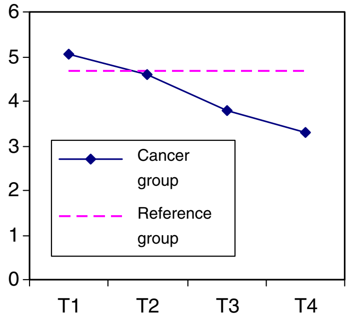

Fig. 1 – Changes over time for HADS Anxiety Scale.

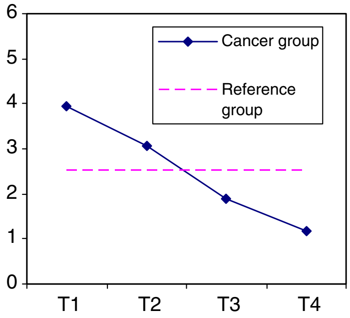

Fig. 2 – Changes over time for HADS Depression Scale.

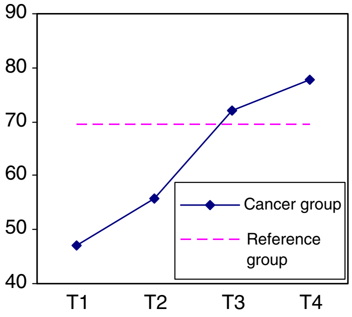

Fig. 3 – Changes over time for SF-36 subscale Vitality.

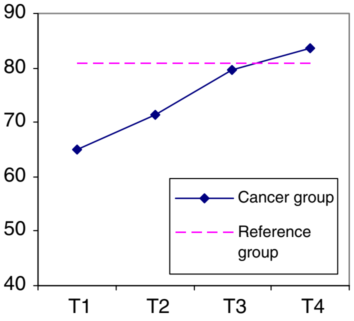

Fig. 4 – Changes over time for SF-36 subscale Mental Health.

Eighteen months after diagnosis (T4), the estimated means of the two groups of adolescents differed on the HADS measures Anxiety ($p \leqslant .05$) and Depression ($p \leqslant .001$) as well as the SF-36 scale Vitality ($p \leqslant .01$), whereas there was no difference regarding Mental Health. In a reverse situation from T1, the differences entail that the adolescents with cancer report lower levels of anxiety and depression and higher levels of well-being as measured by the HRQL subscale Vitality.

4. Discussion

This article presents findings on the difference at various times between how adolescents diagnosed with cancer and a reference group randomised from the general population assess their health-related quality of life and levels of anxiety and depression. The results indicate a steady increase in psychological well-being from the time of diagnosis, when the cancer patients' ratings were worse than those of the general population. The differences in aspects of quality of life and psychological adjustment gradually disappeared and then were reversed, resulting in the cancer group reporting better vitality and lower levels of anxiety and depression than the reference group when 1.5 years had passed since diagnosis.

The fact that the adolescents and young adults diagnosed with cancer initially felt psychologically worse than the reference group is hardly surprising. The highly stressful nature of the period immediately following a cancer diagnosis is supported by Eiser and colleagues[26] by a study of the quality of life in children newly diagnosed with cancer and their mothers. However, not all research into psychosocial status at the time of diagnosis agrees with the above mentioned study. In a study that focuses on anxiety and depression in adolescent cancer at the time of diagnosis, Allen and colleagues (1997) found no differences between the adolescents with cancer and a control population.[11]

The finding that the cancer groups' evaluations of HRQL, anxiety, and depression at 12 and 18 months match, and even surpass, those of the relatively healthy general population is noteworthy and requires further discussion in relation to different theoretical frameworks. It has been acknowledged throughout history that harrowing experiences may lead to positive outcome.[27] The potential for a positive psychological change, focusing on the concept of post traumatic growth,[27] defined as the 'experience of significant positive change arising from the struggle with a major life crisis' (p. 521),[28] has recently attracted much attention in the academic community. Examples are a sense of increased self-reliance, strengthened interpersonal relationships and altered life priorities.[29] It is feasible that the perception of aspects of health-related quality of life could also potentially change for the better when faced with a serious illness. The supposition that the cancer experience might lead to the perception of a higher quality of life than before cancer is strengthened by the results of a qualitative study of psychosocial thriving in childhood cancer survivors.[30] The majority of the participants reported a variety of positive changes, all underscored by a metanarrative of psychospiritual growth.

An alternative but related understanding of the reversal in the self-evaluations can be phrased in terms of human adaptation and the process of response shift, which has been described both in persons with cancer,[3,31] and in persons with other life-threatening or chronic diseases as well as other sources of stress.[32] Response shift means that the experience

Table 3 – The estimated mean difference[a] between the HADS and the SF-36 scores of the cancer patients and the reference group at T1–T4[a]

HADS and SF-36 subscales	T1		T2		T3		T4	
	Estimated difference	95% CI	Estimated difference	95% CI	Estimated difference	95% CI	Estimated difference	95% CI
Anxiety	–0.49	(–1.6 to 0.6)	–0.05	(–1.1 to 1.0)	0.79	(–0.3 to 1.9)	1.29*	(0.2–2.3)
Depression	–1.54***	(–2.3 to 0.8)	0.61	(–1.3 to 0.1)	0.60	(0.1–1.3)	1.32***	(0.6–2.0)
Vitality	24.89***	(18.7–31.1)	15.42***	(9.4–21.4)	–1.47	(–7.3 to 4.4)	–7.72**	(–13.6 to –1.9)
Mental Health	17.00***	(12.0–22.1)	10.37***	(5.5–15.3)	1.74	(–3.1 to 6.6)	–2.61	(–7.4 to 2.1)

* $p \leqslant 0.05$.
** $p \leqslant 0.01$.
*** $p \leqslant 0.001$.
a The estimate is based on the regression coefficient b_3, and is adjusted for age and gender.

of hardship changes a person's internal standards, values, and conceptualisation of the quality of life.[31] This new way of viewing life may involve being satisfied with less and finding meaning in the ordinary. Therefore, the causes of psychosocial health problems among the "normal" adolescents and young adults may seem of little consequence to those battling with cancer. This is supported by the finding that patients in poor physical and mental health tend to downplay current personal problems.[33]

These two theories describe similar processes of adaptation to trauma. They both lead to a change for the better in perceived quality of life, and may be difficult to distinguish from each other. Nonetheless, they differ in the conceptualisation of what this transformation entails. Posttraumatic growth puts the emphasis on the experience of an increased strength when faced with a difficult situation; new depths and other positive attributes are added to the personality by the reflection upon basic beliefs. Response shift, on the other hand, has the focus on acceptance; an individual learns to adapt expectations and standards to a lower level as a coping strategy. Because of this difference, it can be hypothesised that changes as a result of posttraumatic growth are more stable, while alterations owing to response shift should be more situational.

In the present study, efforts have been made to address many of the methodological limitations mentioned in the introduction. Instead of relying on a cross-sectional work, this study explores the development of HRQL, anxiety, and depression over time, starting at diagnosis. All participants have been included in the study at the same time in the course of their disease, avoiding the influence of variations in time elapsed since diagnosis. In addition, the time of inclusion lasted a relatively short period of time, avoiding discrepancies due to the developments in care and possible generational differences. Furthermore, the study focuses on one specific age group: persons falling ill with cancer in adolescence (13–19 years). Most of the research has focused on extended/permanent survivors of childhood cancer, often mixing ages liberally and expanding 'childhood' to 18 years. We believe that it cannot be assumed that experiencing cancer in childhood and adolescence are directly comparable, due to differences in developmental stages and the capacity for understanding the situation and reacting to it.

In addition, in our study, comparisons were made with data from a large reference group, collected during the same time using the same method of administration as for the cancer patients. The effects of age and gender were also considered. This is of importance, as it has been reported that all these three factors – age, gender, and survey mode – may have a decisive influence on the self-evaluation of HRQL, anxiety, and depression.[34]

However, not all methodological limitations could be avoided. The sample size may be considered small, and includes heterogeneous cancer diagnoses. This is difficult to circumvent, as the Swedish adolescent population diagnosed with cancer for natural reasons is small. When interpreting the results, it should also be considered that in an effort to keep the group as homogenous as possible with regard to survival probability, those diagnosed with a recurrence were excluded from the study, as were the ratings of patients that died at some point later on during data collection. This means that the study sample only consists of patients who are likely to become permanent survivors.

The present study addresses many of the questions that arise when attempting to summarise and survey the field of research in question. Are persons who experience a cancer diagnosis in adolescence worse, comparable with, or better psychologically adjusted than the normal population of the same age? Our data suggests that psychosocial adjustment in adolescent cancer survivors changes over time, in relation to population norms, and that sensitive longitudinal design is necessary to identify these changes. In addition, future research is necessary to determine whether the self-reported high psychosocial quality of life and low levels of anxiety and depression persist or are temporary. It is possible that the positive effects of the cancer experience will wear off as time passes by, with response gradually shifting to levels found in the general population. It is also conceivable that adverse late effects of both the illness and the treatment may become apparent, resulting in a diminished perceived well-being. However, the struggle with cancer, particularly at such a formative age, may well facilitate permanent positive changes, including personal growth and increased appreciation of life.

Conflict of interest statement

None declared.

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