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Long-Term Survivors of Childhood Cancer Report Quality of Life and Health Status in Parity with a Comparison Group

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Abstract

Background. There is a need for more knowledge about how survivors of childhood cancer perceive their lives and what influence current health status has on their quality of life. The purpose was to describe this among a group of long-term survivors and among a comparison group. **Procedure.** Telephone interviews were performed with a cohort of 246 long-term survivors and 296 randomly selected from the general population using the Schedule for the Evaluation of Individual Quality of Life- Direct Weighting (SEIQoL-DW). The participants nominated the areas they considered to be most important in life and rated the current status of each area on a seven-point category scale. An overall individual index score was calculated as a measure of quality of life. Self-reported health status was assessed using the Short Form Health Survey (SF-36). **Results**. Long-term survivors rated their overall quality of life and self-reported health status almost in parity with the comparison group. In both groups, family life, relations to other people, work and career, interests and leisure activities were the areas most frequently reported to influence quality of life. The survivors only differed from the comparison group on one of eight SF-36 scales reflecting problems with daily activities owing to physical health. **Conclusions.** Health status was not shown to have a major impact on overall quality of life, indicating that health and quality of life should be evaluated distinctively as different constructs. This should be taken in consideration in clinical care of children with childhood cancer and long-term survivors.

Introduction

Due to advances in medicine there has been a considerable improvement in childhood cancer survival rates. Today three out of four children who have been diagnosed with cancer are cured [1]. In the growing population of long-term survivors of childhood cancer treatment related health problems have been widely acknowledged [2-5]. Furthermore, the literature reveals negative impacts on close relationships and life goals such as education and work as well as worries about illness recurrence and uncertainty about the future [6,7]. However, other studies of survivors report the same or better quality of life [8,9] and psychological functioning [6,10] as that found in comparison groups. Nevertheless, the importance of following up health care needs after childhood cancer is highlighted owing to physical problems that may have negative consequences for the individual [11]. Health care providers' inability to meet such needs was reported in a Swedish study, where 30% of the long-term survivors of childhood cancer were dissatisfied with the follow-up visits they had been offered [12].

There is as yet no commonly accepted definition of what constitutes quality of life nor is there a 'gold standard' measure. Assessing quality of life generally includes the individual's appraisal of different dimensions, such as physical, emotional and social functioning [13]. Measures of quality of life are often health related and standardized and are designed to assess the impact of illness and treatment on a person's life [14]. An alternative approach to assessing quality of life is to use an individualized measure that enables identification and evaluation of aspects considered important in life [15]. Thus, using such an approach it may be possible to detect the individual's perspective on factors that influences quality of life-factors not necessarily detected with standardized measures.

It is clear that many survivors of childhood cancer experience ongoing physical health problems. However, there is less knowledge about how young adult survivors perceive their current lives and about what influence health status has on their quality of life. Accordingly, the present objective was to describe quality of life in relation to self-reported health status and socio-demographic characteristics among long-term survivors of childhood cancer as compared to that among a sample from the general population.

Methods

The present cohort study is part of a larger study investigating the current lives of young adult long-term survivors of childhood cancer.

Participants

Long-term survivors of childhood cancer (N =369) were recruited from a regional cohort identified from a medical register at the Karolinska University Hospital in Stockholm. They were all former patients diagnosed with cancer during the period 1985-1999, at least five years beyond cancer diagnosis and were at least 18 years of age at the time of the study. Twenty patients were excluded for the following reasons: they had undergone bone marrow transplantation (n=14), having a relapse or a second cancer in progress (n=2) or were suffering from Down syndrome or mental dysfunction (n=4). The remaining eligible 349 participants were invited to take part in the study, 246 (70%) were interviewed and 217 of the interviewees also returned a self-reported questionnaire.

The comparison group came from a random sample of 600 persons living in the Stockholm region drawn from the Swedish population register. The sample was gender matched and stratified for age (43% 18-22 years, 50% 23-30 years and 7% 31-37 years) so as to resemble the participating survivors. Forty-two persons were excluded because they did not speak Swedish (n=7), no longer lived in the Stockholm region (n=34) or were suffering from Down syndrome (n=1). Of the remaining 558 eligible participants who were invited to take part in the study, 296 persons (53%) agreed to be interviewed and 264 of the interviewees also returned a self- reported questionnaire.

Data collection

Semi-structured telephone interviews were conducted based on the Schedule for the Evaluation of the Individual Quality of Life- Direct Weighting (SEIQoL-DW) developed to assess individual quality of life without using predetermined variables [15]. The instrument has shown to be feasible and valid [16] and has been translated to Swedish [17]. The measure allows respondents to nominate those areas in life they regard as the most important and to rate the level of current functioning or status with each area. The question asked is “If you think about your life as a whole, what are the most important areas - both good and bad - in your life presently that are crucial to your quality of life?” Subsequently the nominated areas are selected and rated separately on a seven-point category scale, with the verbal anchors “as bad as could possibly be” (scored 1) and “as good as could possibly be” (scored 7). An overall individual quality of life score (SEIQoL Index) can be calculated by summing the ratings and dividing the sum by the number of nominated areas.

The Short Form 36 Health Survey (SF-36) is a generic instrument for assessing health status [18]. The instrument groups 36 items into eight multi-item scales: Physical Function (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE) and Mental Health (MH). Verbal response choices vary from two to six. Raw scores for each question are coded, summed and transformed into a scale from 0 (worst possible health state) to 100 (best possible health state), following standard scoring algorithms. Based upon the eight scales, two summary index scores - Physical Component Summary (PCS) and Mental Component Summary (MCS) - are constructed for physical and mental health respectively. All scales influence the scores in the component summaries, although the PCS is primarily a measure of PF, RP, BP and GH scales, whereas the MCS mainly comprises the VT, SF, RE and MH scales. Support for validity and reliability has been provided for the Swedish version of SF-36 [19,20], as well as when using the instrument in populations of long-term survivors of childhood cancer [21].

Demographic data for the survivors and the comparison group were collected through interviews and questionnaires. For the survivors, data regarding age, gender, diagnosis, age at diagnosis, and type of treatment were obtained from the medical register. The study was considered unproblematic from an ethical point of view by the Regional Ethical Review Board in Uppsala.

Procedure

Prospective participants received an invitation letter providing study information and stressing that participation was voluntary and confidential. A telephone call requesting their participation followed shortly. Those who could not be reached by telephone were sent an additional letter requesting that they contact us if they wished to participate. The interviews were conducted over the telephone by the two first authors (ED, KS) and lasted for approximately 10 minutes. The SF-36 questionnaire was sent by post to the participants soon after the interview followed by a reminder if it was not returned within two weeks.

Analysis

Tape-recordings and documentation from the interviews were transcribed verbatim and the data was analysed according to manifest content analysis [22]. The interview data from the two study groups were analysed separately by the first and the second author. There were repeated meetings within the research group before a final agreement was reached regarding the created categories thought to reflect the areas considered to be important in life. One of the authors not previously involved in the categorization process was asked to validate the analysis which resulted in 96% agreement for the survival group and 95% for the comparison group. Finally, the categories from the two groups were merged as they were judged to be equivalent.

Chi-square statistics were performed to compare proportions of categorical variables between groups. The Student's *t*-test was used for comparison of means between groups. A one sample *t*-test was used to compare SF-36 mean scores with Swedish normative data on young adults [23]. In two forced steps, a hierarchical multiple regression analysis was employed to account for the variance in the scores of the dependent variable SEIQoL Index (overall quality of life). In the first step, the living situation 'living alone', which is known to differ between long-term survivors and the general population, was included together with age, sex and group (long-term survivor vs. comparison group). In the second step physical (PCS) and mental (MCS) health were forced into the model. Impact of other factors such as 'age at diagnosis', 'time since diagnosis', 'married/living with a partner' were tested in a first set of analyses but excluded from the final model as those predictors had negligible impact on the variance of quality of life (data not shown). A statistical significance level of $p<0.05$ was applied in all analyses.

Results

Long-term survivors and comparison group

A total of 246 long-term survivors with a mean age of 24 years at the time of the study, and a mean age of nine years at diagnosis, were interviewed at a median time of 16 years after diagnosis. The distribution of cancer diagnoses among the survivors was: 24% central nervous system tumours, 23% leukaemia, 19% lymphoma, and 34% other tumours. Only one statistically significant difference was found between the participants and the nonparticipant survivors: a higher proportion of females (77%) than males (68%) chose to participate (p=0.04). In the comparison group, the mean age of the 296 participants was 25 years and did not differ from that of the non-participants. From the eligible sample, a higher proportion of females (62%) than males (52%) chose to participate (p=0.03). No statistically significant differences were found between the survivors and the comparison group with respect to age and gender. There were statistically significant differences between the two groups regarding living situation, education and occupation (Table I).

Quality of life

An overall quality of life mean score (SEIQoL Index) was calculated and there was no statistically significant difference between the score of the long-term survivors (M=5.5, SD 0.82, range 2.3-7.0) and that of the comparison group (M=5.4 SD 0.80, range 3.0-7.0). The reported important areas currently influencing quality of life were grouped into categories as shown in Table II. The most frequently reported areas -categorized as ‘Family life’, ‘Relations to other people’, ‘Work, career’ and ‘Interests, leisure activities’ - were the same for the survivors and the comparison group (Table III). In both groups, participants nominated an average of four important areas each (range 1-5). The survivors reported to a higher extent than the comparison group did that ‘Family life’ and ‘Relations to other people’ were important for quality of life. A lower proportion of survivors nominated areas categorized as ‘Own health’ and ‘Finances’, and the survivors reported being less satisfied with those areas than the comparison group did.

Health status

The long-term survivors reported worse health status than the comparison group did on one of the eight functional scales of the SF-36 (Table IV). The mean score for Role-Physical was significantly lower in the survivor group than in the comparison group. Health status and socio-demographic characteristics were weak predictors of overall quality of life (SEIQoL Index) shown in a hierarchical regression analysis (Table V). The influence of the socio-demographic variables included in the first step accounted for 6% of the variance in overall quality of life. Adding health status in the second step gave a model where 17% of the variance in overall quality of life was accounted for by the influence of the predictor variables.

Discussion

Quality of life and self-reported health-status in a representative cohort of long-term survivors of childhood cancer appear to be almost in parity with that in a comparison group from the general population. More similarities than dissimilarities were detected regarding what was considered to be important in life when comparing the long-term survivors and the comparison group, despite the supposed differences in childhood health experience. The five most frequently reported areas in life were the same in both groups and in concordance with findings from a study of long-term survivors of adult cancer [17]. Notably, the survivors more frequently considered relationships important than did the comparison group, which supports earlier findings on great importance placed on positive relations after a cancer experience [24]. Health status had a weak influence on the overall ratings of quality of life, although the influence of mental health (MCS) was larger than that of physical health (PCS). The influence of socio-demographic characteristics was also weak. Thus, we found no strong relation between quality of life and the investigated determinants confirming the complexity of the concept and the call for more than one methodological approach to assess quality of life.

The long-term survivors only differed from the comparison group on one of the eight SF-36 scales, reflecting problems with daily activities due to physical health, which also could be seen in other results we recently presented for the same cohort of survivors [25]. In response to open questions about perceived consequences of childhood cancer, 28% of the survivors reported limitations in activity and performance. Numerous studies [3,4,9,26,27] have reported on limitations in physical performance among long-term survivors of childhood cancer. The physical health status in this group of long-term survivors contrasts to the extent of problems reported in studies based on clinical assessment of adverse health outcomes [2,4,5].

Present findings regarding mental health status showed that the survivors did not differ significantly from the comparison group, which is in line with findings in the extant literature [8,9,27]. Interestingly, the mean scores for the SF-36 mental component summary reported by the present survivor and comparison groups are below the standardized mean of 50 [20], but in accordance with recent normative data on Swedish adolescents and young adults [23].

While it is possible that the SF-36 does not fully capture the specific health impairments that may follow after childhood cancer treatment, there may also be a time aspect involved explaining the paucity of reported impairments. Physical health status and late effects have been reported to be substantially worse among those diagnosed more than 20 years ago than among those diagnosed more recently [27,28]. The median time of sixteen years from diagnosis in the present cohort of survivors may not be long enough to entirely reflect the negative effects treatment has on health [5]. Another potential explanation of the present findings on health status is the psychological adjustment and possible changes in outlook on life that may follow the cancer experience. Indications that individuals adapt to a traumatic situation such as a cancer diagnosis or a chronic disease and add a positive meaning to their experience have been seen in a growing body of literature [29-32]. This was also reflected in statements about positive changes in outlook on life and the self made by a majority of the survivors in the present cohort in the context of our previous study [25]. While survivors in the present study reported less satisfaction with their own health (SEIQoL-DW) than did the comparison group, they also less frequently reported that health is important to their quality of life. This is in agreement with the assumption that an individual may adapt to a loss by decreasing his or her perception of the importance of those aspects of life affected by the loss [33]. Overall our results showed that the survivors perceived their quality of life to be good, which is in parity with the general population and could be seen as an expression of positive adaption.

As reported in earlier studies [34-36], a significantly lower percentage among long-term survivors than among the comparison group was married or living with a partner. Parenthood was just as common among the survivors as in the comparison group. It has previously been reported that long-term survivors are less likely than their peers to become a parent [6]. However, in this study the relatively low mean age of the participants in both groups could explain this finding as the trend in Sweden shows that parenthood comes later and later. The survivors in the present study were more likely to be students, but less likely to have graduated from higher education than were members of the comparison group. A lower rate of engagement in higher education has previously been found among survivors of childhood cancer [37,38]. While unemployment rates were the same in both groups, the survivors showed a considerably lower frequency of employment than did the comparison group, which has been reported previously [35]. In line with earlier findings [36] the present results suggest a delay in life goals indicating that important social and occupational aspects of life are affected by childhood cancer.

The high non-response rate in the comparison group should be regarded as a risk for selection bias. In relation to official statistics for the general population in Stockholm County participants in the comparison group seemed to be better educated and more “socially stable” than average. Thus, selection bias may account for some of the differences between the present survivor and comparison groups, which call for caution when drawing conclusions. However, when comparing health status between the survivors and recent Swedish normative data in one age group (age 20-23) [23] we found no discrepancies with our present results. Another limitation of the study is the difficulty in determining the health status of the 30% of survivors who did not participate. Nevertheless, the fact that no clinical differences were detected between the participating and the non-participating survivors indicates that health status should be the same in both groups.

The present study shows that young adult long-term survivors of childhood cancer and a matched sample drawn from the general population rate their overall quality of life and self-reported health status similarly. Self-reported health status was not shown to have a major impact on the ratings on overall quality of life among the survivors suggesting that health and quality of life should be evaluated distinctively as different constructs. Taking this into consideration may have both research and clinical implications. There are many methodological challenges in research assessing quality of life why diverse approaches could be beneficial. Furthermore, late effects and morbidity can aggravate over time which may influence the survivor’s life situation. However, the finding of a positive situation 16 years (median) after diagnosis can be useful information in clinical care both for the newly diagnosed and during follow-up. When shortcomings due to disease and treatment are irreversible it may be easier to cope if you hear that most patients find life as good as their peers in a longer perspective. Studies have shown that health care providers in cancer care appear to be poor judges of their patients’ general quality of life [39,40]. Clinicians must be aware that long-term survivors of childhood cancer may have other expectations and goals with respect to their current health status than clinicians do, and that specific questions may need to be asked to elicit important issues. In addition to assessment of health, questions with focus on consequences and problems as well as what is perceived important in life should be posed to establish the individual's priorities for the achievement of a good quality of life.

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Conflict of interest statement

None declared by all authors.

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