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Published online: 25 Oct 2013.

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ORIGINAL ARTICLE

Clinical significance in self-rated HRQoL among survivors after childhood cancer – demonstrated by anchor-based thresholds

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Abstract

Background. There is a need to establish clinically relevant thresholds (anchors) for identification of differences in health-related quality of life (HRQoL) and thereby provide stronger evidence regarding the HRQoL of childhood cancer survivors. *Aim.* To investigate HRQoL in childhood cancer survivors with a standardised instrument and to establish thresholds for clinically significant differences by using qualitative interviews as anchors. An additional aim was to investigate survivors' HRQoL in relation to an age-matched comparison group without cancer experience. *Material and methods.* Self-rated HRQoL (KIDSCREEN-27) was assessed in a national cohort of survivors (n = 63, aged 12–22) and a comparison group (n = 257, aged 11–23). Findings from qualitative interview data were also used (n = 61); three subgroups ("Feeling like anyone else"; "Feeling almost like others"; "Feeling different") were identified based on survivors own perception of influence on daily life. Effect size calculations based on means from the KIDSCREEN-27 dimensions were performed using the subgroups as anchors to indicate clinical importance. Furthermore, standard multiple regression analyses were performed. *Results.* Effect sizes between the subgroups "Feeling like anyone else" and "Feeling almost like others" and the group "Feeling different" were large for all dimensions (1.04–2.07). The multiple regression models showed that being a survivor was significantly associated with one of the dimensions, School Environment, where survivors scored higher HRQoL. Furthermore, female sex and older age (17–23 years) significantly contributed to lower self-rated HRQoL. *Conclusion.* In clinical practice the KIDSCREEN-27 could be a useful screening tool to identify survivors of childhood cancer in need of extra support, using KIDSCREEN dimension mean values of 45 or less as thresholds. Larger scale studies are recommended to identify and test thresholds with regard to different age groups and time since diagnosis.

The survival rates for children treated for childhood cancer have increased over the years and today the survival probability at 10 years is approximately 75% [1]. Results from large cohort studies show that long-term survivors are at high risk of developing serious health problems [2]. The focus of the present study is on health-related quality of life (HRQoL) where results from previous studies indicate ratings among survivors in parity or better compared to comparison groups [3–5]. To our knowledge, there is a lack of scientific reports that have combined quantitative and qualitative approaches when studying HRQoL in survivors after childhood cancer. Such an approach could be used to establish clinically relevant thresh-olds (anchors) for identification of differences in HRQoL and thereby provide stronger evidence regarding the HRQoL of childhood cancer survivors.

Essential areas of HRQoL are physical, emotional, social and cognitive in addition to body image and autonomy, the latter considered being especially important to young adults [6]. Ratings of physical domains of HRQoL have shown to display largest differences compared to peers [3] and being significantly lower for certain diagnoses and treatment regimens such as osteosarcoma or those treated with stem cell transplantation [7]. However, it has been shown that survivors rate psychological functioning

in parity with or even higher than comparison groups [3], still, being female, older age at follow-up, increased number of relapses and cranial irradiation have been identified as risk factors for emotional problems [8]. Regarding aspects such as development of autonomy (including paid job during secondary school, having been on vacation without adults), social development (social contacts with friends at school and during leisure time) and psycho-sexual development (love and sexual relations), survivors of childhood cancer including brain tumours, have been found to attain fewer milestones related to these aspects and/or they reach them later in life, compared to peers [9]. In contrast, results from a study excluding brain tumours, found that survivors had similar outcomes regarding social competence, self-concept, friendships and romantic relations compared to peers [10].

According to qualitative findings, young adult survivors (not including brain tumours) express that the cancer experience has changed them, has made them feel more mature compared to peers [11,12] and that they have achieved a different view on life [12]. Despite the feeling that the cancer experience has changed them compared to peers, they have also built stronger relationships with family or significant friends [11].

Given the growing number of survivors of childhood cancer reaching adolescence and young adulthood it is important to focus on patient reported outcomes (PROs) in this population to further understand their needs, identify individuals in need of interventions and develop the follow-up care especially since physical health is expected to deteriorate over time. Our research group has followed a national cohort of children diagnosed with cancer during school age (7–16 years) with data collections on several occasions using individual interviews and standardised instruments [13,14]. Initial results from this cohort showed that during initial cancer treatment (2.5 months and 5 months after start of treatment) females rated their HRQoL significantly lower than males in areas of Independence, Physical limitation, Emotion and Social Exclusion [15]. Since the sample of survivors was diagnosed during school age they were confronted with issues such as missing school, the ability of catching up with peers as well as feeling different from others. By following HRQoL over time, with both quantitative and qualitative approaches, and comparing them to persons without cancer experience, the knowledge about the impact and complexity of childhood cancer in relation to several aspects of HRQoL will increase. Furthermore, the identification of those in need of support will be facilitated. The reporting of p-values does not specify whether a certain finding carries a clinical significance in the sense that statistical significance is not necessarily equivalent to a meaningful difference or change in the measured variable [16]. Therefore effect size calculations (a distribution-based method) can be performed and relevant anchors can be used in order to highlight the clinical importance of potential mean value differences. According to Wyrwich et al. [16] the use of distribution-based methods are most appropriate when used in conjunction with meaningful anchors from an external source to the HRQoL instrument used [16]. The aim of this study was to investigate HRQoL in childhood cancer survivors with a standardised instrument and establish thresholds for clinically significant differences by using qualitative interviews as anchors. An additional aim was to investigate survivors' HRQoL in relation to an age-matched comparison group without cancer experience.

Material and methods

The present study has a cross sectional design including both quantitative and qualitative data.

Samples

Survivors. The present study reports on results from a cohort study including all school children (7–16 years) in Sweden that were diagnosed with cancer during a two-year period (2004–2006) [13].

For the current study 92 survivors were eligible and invited to participate. A total of 63 of the 92 (68%) eligible survivors median age 17 (range 12–22 years) accepted participation at the time for follow-up, a median time of 63 months (range 50–74) after diagnosis. They had been treated for acute lymphoblastic leukaemia (n = 21), skeletal and soft tissue sarcoma (n = 15), tumours of the central nervous system (CNS) (n = 10), Hodgkin's lymphoma (n = 6), non-Hodgkin's lymphoma (n = 6), acute myeloid leukaemia (n = 3), and for other diagnoses (n = 2) (one Sertoli/Leydig cell tumour and one germ cell tumour). Of the 63 participants, 12 had experienced an event: relapse (n = 11) or second malignancy neoplasm (n = 1).

Comparison group. An age-matched comparison sample of 500 individuals (50% females) was randomly selected from the Swedish population register (SPAR). Twenty-four persons were excluded for the following reasons: being abroad (n = 10), language difficulties (n = 5), cognitive impairment (n = 3), prior cancer experience (n = 1). Additionally, five persons were excluded due to unidentifiable addresses. Of the remaining 476 eligible participants, median age 16 (range 11–23 years), 257 (54%) accepted participation, and 219 declined.

Data collection

KIDSCREEN-27. The KIDSCREEN-27 was used to measure HRQoL in survivors and the comparison group. The instrument was chosen because of its generic character and the suitability for both chronically ill and healthy children and adolescents, aged 8–18 years [17]. The instrument measures HRQoL in five dimensions and contains 27 items. *Physical Well-being* (5 items) reflects aspects of general health and the ability to be physically active. *Psychological Well-being* (7 items) refers to the ability to enjoy life as well as aspects of loneliness and sadness. *Autonomy and Parent Relations* (7 items) includes items regarding having enough time for oneself, enough time from parents and the personal financial situation. *Social Support & Peers* (4 items) includes aspects of time spent with friends, having fun with friends as well as the ability to receive help from friends and rely on friends. *School Environment* (4 items) refers to cognitive and school functioning measuring happiness at school, the ability of getting along well, paying attention and getting along well with teachers. Each item is self-reported by the participant for the preceding week and the response alternatives follow a five-point scale: poor to excellent; not at all to extremely or never to always [17].

KIDSCREEN-27 has shown satisfactory psychometric properties [18,19] and has previously been used in cancer populations [20]. A Rasch-analysis recently performed on the KIDSCREEN-27 [21] indicated satisfactory unidimensionality for four of the five dimensions. The dimension Autonomy & Parent Relations displayed non-satisfactory unidimensionality why the dimension was excluded in the present study.

The self-reported data from KIDSCREEN-27 was scored and analysed according to standard scoring algorithms. The different syntax steps performed, including transforming Rasch person parameter estimates into z-values, result in T-values with means of 50, standard deviation of 10 and higher values indicate better HRQoL [17].

Qualitative data. Qualitative data was obtained through individual interviews (n = 61) performed with the cohort of survivors. An interview guide was used covering the areas of current life situation, school situation and/or occupation, leisure and relation to friends. The interviews were audio recorded, transcribed verbatim and analysed using content analysis. The analysis resulted in the interviews being divided into three groups according to how the cancer experience influenced the daily lives of the survivors: "Feeling like anyone else"; "Feeling almost like others" and "Feeling different". Subsequently, the meaning units (words or sentences containing similar aspects) from the three identified groups were compared and four categories emerged displaying the differences between the three groups; thoughts around the cancer experience, presence of complications in daily life, ability to handle complications and view of life [14]. The group "Feeling like anyone else" described that they rarely thought about the experience, experienced minor or no complications, and if they had complications, handled those easily and expressed almost no influence on view of life. Regarding the group "Feeling almost like others" they described that they sometimes thought about the cancer experience, had complications that to a small degree influenced, but not hampered, daily life and often expressed that the experience influenced view on life. The group "Feeling different" described that they often thought of the experience, had complications that largely influenced and hampered daily life and expressed that the experience often influenced their view on life.

Background variables. Selected socio-demographic and clinical characteristics, from medical records as well as study specific, were used for the analyses.

Procedure

Data was collected through telephone interviews, with both survivors and the comparison group, during 2010 and 2011.

Survivors. An information letter was sent to all eligible participants, including detailed information of the study. Confidentiality and the possibility to withdraw from the study were stressed in the invitation letter as well as immediately before the interview. For those aged 11–15 years, the letter was sent to a parent; for those aged 16–17 years, the letter was addressed to the adolescent including a letter to the parent/parents; and for those aged 18 years and above, the letter was addressed directly to the eligible participants. Written informed consent was obtained from participants and parents for participants below 18 years of age and from participants aged 18 years and over. All participants received a cinema ticket as a form of compensation. Potential participants, or parents, were contacted by telephone within two weeks after the information letter was sent and for participants who agreed to participate, a suitable time was agreed upon for the telephone-administered interviews including both questionnaire data (KIDSCREEN-27) and qualitative interview data. Reminders were sent to participants who were difficult to reach.

Comparison group. The procedure for the comparison group was similar to the survivor group. Written

consent was obtained from participants and parents for participants below 18 years of age, while for those aged 18 years and above consent was recorded orally directly before the interview.

Two persons from the group of survivors and 27 from the comparison group chose to receive the questionnaires by mail instead, for self-administration.

Ethical considerations

Ethical approval for the study conducted during initial cancer treatment was obtained from the Regional Ethical Review Boards in Umeå, Uppsala, Stockholm, Linköping, Gothenburg and Lund. Ethical approval for this follow-up study was obtained from the Regional Ethical Review Board in Stockholm.

Data analysis

The statistical calculations were conducted using SPSS version 20.0. Means and standard deviations (SD) are presented for continuous variables. χ^2 statistics were used to compare proportions for categorical variables between groups.

To establish thresholds for clinically significant differences the self-reported HRQoL from the group of survivors was elucidated by the findings from the qualitative analysis of the interview data (findings reported elsewhere) [14]. Mean values, standard deviations and effect sizes (ES) were calculated and compared to relevant anchors (the survivors own expression of influence on daily life) by each identified subgroup ("Feeling like anyone else", "Feeling almost like others", "Feeling different"). Effect sizes of d = 0.2 were considered small; d = 0.5 moderate and d = 0.8 large [22].

To explore potential influences of demographic variables on HRQoL, the independent variables sex (female vs. male), age (11–16 vs. 17–23 years) and group (survivors vs. comparison group) were included in the final multiple regression analyses, one for each KIDSCREEN-dimension, i.e. four regression models. A statistical significance level of $p < 0.05$ was applied in all analyses.

Results

Background characteristics for both groups are shown in Table I. Mean values and standard deviations (SDs) of the KIDSCREEN-27 for survivors and the comparison group are presented in Table II.

According to qualitative analysis of interview data from the same data assessment occasion [14] the majority of the interviewed survivors were categorised into the groups "Feeling like anyone else" (n = 29), and "Feeling almost like others" (n = 26) and a

Table I. Demographic characteristics of participating survivors and comparison group.

	Survivors n = 63	Comparison group n = 257	df	p[a]
Age, median (range)	17 (12–22)	16 (11–23)	1	0.050
Age ≤ 16, n (%)	27 (43)	148 (58)		
Age ≥ 17, n (%)	36 (57)	109 (42)		
Sex, n (%)			1	0.092
Female	26 (41)	139 (54)		
Male	37 (59)	118 (46)		
Living situation, n (%)				
With parent/parents	56 (89)	214 (83)	1	0.364[b]
Alone	4 (6)	18 (7)		
With partner	1 (2)	14 (6)		
Other constellation[e]	2 (3)	11 (4)		
Main occupation, n (%)				
Student[f]	52 (82)	206 (80)	1	0.802[c]
Employee[g]	6 (10)	41 (16)	1	0.274[d]
Unemployed	3 (5)	10 (4)		
Sick leave	2 (3)	0		

[a]Tested for differences in proportions by χ^2-test; [b]Tested between those living with one or two parents versus those reporting other living arrangements; [c]Tested between those in education versus those not in education; [d]Tested between those working versus those not working; [e]Other constellation: includes living with friends, other relatives or combined living, e.g. parents/student apartment; [f]In education: includes those both studying and working and those having study leave; [g]Work: includes those attending military service and those having parental leave.

minority into the group "Feeling different" (n = 6) (Table III). As follows are three quotes illustrating one participant in each group; "Feeling like anyone else": *You feel okay and everything is kind of good. I have no side effects from chemotherapy, everything went well, it's nothing really bothering me.*; "Feeling almost like others": *My immune system is not perfect you know but I don't think of that very much, I try to do what I want and live a normal life. Maybe something will come up later and then I'll have to deal with it.*; "Feeling different": *You are reminded about it often, when it comes to what's left after the tumour and the radiation... and because I have to take medication and explain to people why I can't manage the same pace.* When comparing the KIDSCREEN-27 scores for the groups "Feeling like

Table II. Descriptive statistics of KIDSCREEN-27.

KIDSCREEN-27[a]	Survivors n = 63 Mean (SD)	Comparison group n = 257 Mean (SD)
Physical Well-being	48.0 (8.6)	46.9 (8.9)
Psychological Well-being	53.3 (8.5)	51.5 (9.1)
Social Support & Peers[b]	51.4 (9.1)	51.3 (8.7)
School Environment[c]	54.9 (9.0)	52.3 (7.7)

[a]Possible range for each dimension: Physical Well-being 12.1–73.2; Psychological Well-being 4.5–73.5; Social Support & Peers 11.2–66.3; School Environment 16.3–71.0; [b]Comparison group: n = 253; [c]Survivors: n = 49; comparison group: n = 188 due to not all attending school the previous week.

Table III. Mean values and effect sizes for survivors by subgroups (anchors).

KIDSCREEN-27	Feeling like anyone else; n = 29; 47% Mean (SD)	Feeling almost like others; n = 26; 43% Mean (SD)	Feeling different; n = 6; 10% Mean (SD)	ES[a]	ES[b]	ES[c]
Age median, (range)	14 (12–21)	17.50 (12–21)	20 (12–22)			
Physical Well-being	51.3 (5.8)	47.6 (8.1)	36.4 (9.6)	1.88	1.26	0.53
Psychological Well-being	54.7 (5.5)	54.7 (7.4)	39.6 (8.7)	2.07	1.87	n/a[d]
Social Support & Peers	52.7 (5.6)	52.7 (8.2)	44.1 (8.4)	1.20	1.04	n/a[d]
School Environment[e]	53.7 (9.3)	57.6 (7.3)	45.0 (5.5)	1.14	1.95	0.47

[a]Effect size: Calculated between "Feeling like anyone else" and "Feeling different"; [b]Effect size: Calculated between "Feeling almost like others" and "Feeling different"; [c]Effect size: Calculated between "Feeling like anyone else" and "Feeling almost like others"; [d]n/a: not applicable; [e]Different n, by group, due to not attending school in the previous week: n = 24; n = 20; n = 3.

anyone else" and "Feeling almost like others" to the group "Feeling different", effect sizes were large for all dimensions (1.04–2.07). Moderate effect sizes were identified for two of the dimensions (*Physical Well-being* and *School Environment*) when comparing the groups "Feeling like anyone else" to "Feeling almost like others" (0.47–0.53) (Table III) while no differences were seen for the remaining two dimensions.

The results of the four multiple regression models showed that being a survivor was significantly associated with one of the dimensions, *School Environment*, where the survivors scored higher HRQoL (Table IV). Overall the models, when adjusted for age and group (survivor or comparison group), showed that female sex (in *Physical Well-being* and *Psychological Well-being*) was significantly associated with lower self-rated HRQoL. The variable age (all dimensions), when adjusted for sex and group (survivors or comparison group) was significantly associated with self-rated HRQoL, older age (17–23 years) at the time of interview was associated with lower self-rated HRQoL.

Discussion

In the present study HRQoL was investigated in survivors of childhood cancer a median time of five years after diagnosis by quantitative and qualitative methods. Effect sizes based on anchors (experiences expressed in qualitative interviews) made it possible to establish clinically relevant thresholds regarding HRQoL scores and thereby provide stronger evidence regarding HRQoL of childhood cancer survivors. Based on the results (Table III) it is recommended that those rating the KIDSCREEN dimension *Physical Well-being* as 37 or lower at follow-up should merit concern. For *Psychological Well-being* the threshold is suggested to be 40 and for *Social Support & Peers* and *School Environment* 45 or lower. The lower threshold chosen for *Physical Well-being* is reflected in previous research [3] and in the mean values for this dimension from both survivors (48.0) and the comparison group (46.9), indicating that this dimension is rated lower regardless of a cancer experience. In addition the multiple regression model showed that the experience of a cancer diagnosis did not have any statistical association to self-rated *Physical Well-being* (Table IV). This study illustrates the situation five years after diagnosis but in a longer perspective the situation is not clear and continued follow-up is warranted.

Self-rated HRQoL in this representative national cohort of childhood cancer survivors was generally not impaired compared to an age-matched comparison

Table IV. Multiple regression analysis by KIDSCREEN dimension (survivors and comparison group, n = 320).

Independent variables	Physical Well-being Std β	Psychological Well-being Std β	Social Support & Peers[a] Std β	School Environment[b] Std β
Sex[c]	0.208***	0.277***	0.001	−0.003
Age at interview[d]	−0.183**	−0.200***	−0.133*	−0.159*
Group[e]	−0.048	−0.073	−0.022	−0.150*
R²	7.4%	11.6%	1.8%	4.2%
F	8.476***	13.804***	1.854	3.411*

P-value: *< 0.05, **< 0.01, ***< 0.001. [a]n = 316; [b]Lower number (n = 237) due to not all attending school the previous week; [c]Female = 1, Male = 2; [d]Age: 11–16 years = 1, 17–23 years = 2; [e]Survivors = 1, Comparison group = 2.

group. This is also supported by the qualitative findings for the same cohort [14] where the majority described that the cancer experience only had a small influence on daily life, i.e. they felt like others ("Feeling like anyone else" or "Feeling almost like others"). An explanation often discussed is that cancer survivors may appreciate their lives to a greater extent, in spite of impairments, and develop new values due to their cancer experience [3]. Nevertheless, the group "Feeling different", which rated lowest HRQoL in the present study, indicating a need for extra support.

There were significant differences between the sexes, with females reporting lower HRQoL than males in two dimensions (Table IV). This is supported by national- [23] as well as WHO-reports [24]. A Swedish national systematic literature review [23] regarding mental health in children and adolescents (0–19 years) reported that mental well-being generally was on a high level but appeared to have deteriorated during the end of last century. Self-rated well-being was lower among females than males and older individuals reported worse well-being than younger [23]. Existing societal structures including different expectations for females and males might contribute to this situation. It may be that normal development, including challenges related to shifting one's own identity from being a child into becoming an adolescent and finally a young adult, contributes to lower HRQoL among older participants (17–23 years).

The multiple regression model showed that the survivors scored the dimension *School Environment* (questions included happy at school, getting along well at school, able to pay attention and able to get along well with teachers) statistically significantly higher than the comparison group (Table IV). This is promising, despite existing evidence of difficulties among survivors in terms of cognitive functions such as memory and processing speed [25].

Strengths and limitations

The main strength of the present study is that it constitutes a follow-up of a national cohort of all school children in Sweden, diagnosed with cancer during a two-year period, investigated approximately five years after diagnosis. By combining quantitative and qualitative data it has been possible to present a comprehensive picture of the participants self-reported HRQoL and to identify clinically relevant thresholds for HRQoL dimensions.

However, low power due to small samples increase the risk of type II errors and may have contributed to non-significant findings in the regression analyses. The relatively low response rate in the comparison group could be considered as a risk for selection bias and therefore not suggested to be used as normative data. In addition, the R^2-values were generally small, especially for the dimension *Social Support & Peers*, indicating that the included independent variables did not explain much of the variance in the ratings by the participants, for the dependent variables.

The recommended age limit of 18 years for KID-SCREEN-27 was exceeded by some participants but no particular reservations were expressed by those individuals during the interviews.

Conclusion

Clinically important mean value differences in self-rated HRQoL were identified using effect size calculations and relevant anchors (experiences expressed in qualitative interviews). In clinical practice the KIDSCREEN-27 could be a useful screening tool for identifying survivors after childhood cancer in need of extra support, using KIDSCREEN dimension mean values of 45 or less as thresholds. The results regarding HRQoL in the present study are promising with regard to survivors, approximately five years after a childhood cancer diagnosis. However a small group considered the cancer experience to influence daily life in that they feel different from others, reflected in lower ratings of HRQoL.

Since it is known that health problems in survivors of childhood cancer increases with time continued research is of importance to understand the impact of the cancer experience in an even longer perspective. Larger scale studies aiming to identify and test thresholds with regard to different age groups and time since diagnosis, including childhood cancer survivors and comparison groups, are recommended.

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