



UPPSALA
UNIVERSITET

*Digital Comprehensive Summaries of Uppsala Dissertations
from the Faculty of Medicine 331*

Cancer During Adolescence: Psychosocial Consequenses and Methodological Issues

ELISABET MATTSSON



ACTA
UNIVERSITATIS
UPSALIENSIS
UPPSALA
2008

ISSN 1651-6206
ISBN 978-91-554-7160-6
urn:nbn:se:uu:diva-8643

Dissertation presented at Uppsala University to be publicly examined in Auditorium Minus, Gustavianum, Uppsala, Thursday, May 8, 2008 at 13:00 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract

Mattsson, E. 2008. Cancer During Adolescence: Psychosocial Consequences and Methodological Issues. Acta Universitatis Upsaliensis. *Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine* 331. 65 pp. Uppsala. ISBN 978-91-554-7160-6.

The overall aim of this thesis was to investigate psychosocial consequences of cancer during adolescence, using a longitudinal approach. An additional aim was to investigate if mode of administration has an influence on adolescents' and young adults' self-reported psychosocial function.

In Study I participants, aged 13-23 years, were randomised according to two modes of administration, telephone interview and postal questionnaire, and asked to complete the Hospital Anxiety and Depression Scale (HADS) and Short Form 36 (SF-36). The telephone mode resulted in a higher response rate, better self-rated psychosocial function (except for the youngest age group), overall lower Cronbach's alpha values, and a larger percentage of ceiling effects compared to the postal mode. A higher proportion of males than females chose not to participate in the postal mode. In Study II and III adolescents diagnosed with cancer completed the HADS and two sub-scales from the SF-36 (Mental Health and Vitality) 4-8 weeks, 6, 12, and 18 months after diagnosis. In Study II adolescents with cancer were compared to a reference group from the general population. Shortly after diagnosis the cancer group rated their psychosocial function as worse compared to the reference group. However, the differences gradually disappeared over time and were then reversed, resulting in the cancer group reporting better vitality and lower levels of anxiety and depression than the reference group eighteen months after diagnosis. In Study III five distinct psychosocial states were identified, characterised by: psychosocial dysfunction (state A), poor psychosocial function (state B), incomplete psychosocial function (state C), good psychosocial function (state D), and excellent psychosocial function (state E). Shortly after diagnosis more adolescents than expected by chance were found in states A and C and fewer were found in states D and E. Eighteen months after diagnosis a different pattern emerged, where more adolescents than expected were found in state E and fewer than expected in state C. In Study IV adolescents, two years after diagnosis, reported problems with physical impairment, intrusive thoughts, feelings of alienation, and problems catching up with school. However, a majority of the participants also reported positive consequences with regard to the cancer disease: a more positive view of life, good self-esteem, knowledge and experience with regard to disease and hospital care, good relations, broader perspectives, and material gains. Study V, a review of the literature, indicates that survivors of childhood/adolescent cancer do not differ from comparison groups with regard to relations to others and relation to self. However, some findings highlight that friendship and marital status are areas of concern, and parenthood and sexuality are areas of potential concern. In conclusion, mode of administration influences adolescents' and young adults' self-reported psychosocial function and is related to age. Psychosocial function increases with time from diagnosis for most adolescents diagnosed with cancer. However, some individuals remain in poor psychosocial states during the first eighteen months after diagnosis. Increased efforts should be taken to identify these individuals.

Keywords: adolescents, cancer, consequences, HADS, negative, positive, SF-36

Elisabet Mattsson, Department of Public Health and Caring Sciences, Uppsala Science Park, Uppsala University, SE-75183 Uppsala, Sweden

© Elisabet Mattsson 2008

ISSN 1651-6206

ISBN 978-91-554-7160-6

urn:nbn:se:uu:diva-8643 (<http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-8643>)

This thesis is dedicated to three people who are no longer with us:

My Mother, Sonja, to whom I owe everything,
Kurt Karlsson for endless support whenever I needed it and for never ever
doubting my ability to complete this doctoral thesis
and Edgar Engström for teaching me the power generated by human warmth,
humour and imagination.

List of papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:

- I Wettergren L, Mattsson E & von Essen L. Mode of administration has effect on self-reported health status among adolescents and young adults. Submitted.

- II Jörngården A, Mattsson E & von Essen L. (2007). Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: A prospective longitudinal study. *European Journal of Cancer* 43: 1952-1958.

- III Mattsson E, El-Khouri B, Ljungman G & von Essen L. Empirically derived psychosocial states among adolescents diagnosed with cancer. Submitted.

- IV Mattsson E, Ringnér A, Ljungman G & von Essen L. (2007). Positive and negative consequences with regard to cancer during adolescence: Experiences two years after diagnosis. *Psycho-Oncology* 16: 1003-1009.

- V Mattsson E, Lindgren B & von Essen L. (2008). Are there any positive consequences of childhood cancer? A review of the literature. *Acta Oncologica* 47: 199-206.

Papers II, IV and V have been reprinted with the kind permission of the Publishers.

Contents

Introduction.....	9
Cancer during adolescence.....	9
Measuring psychosocial function.....	10
Negative and positive consequences of cancer during adolescence.....	11
Acute phase.....	12
Extended phase.....	13
Permanent phase.....	14
Points of departure for this thesis.....	15
Aims.....	16
Methods.....	17
Design and sample.....	17
Participants.....	17
Reference group (Studies I-II).....	17
Adolescents diagnosed with cancer (Studies II-IV).....	19
Measures and data collection.....	21
Health-related quality of life (Studies I-III).....	21
Anxiety and depression (Study I-III).....	22
Positive and negative experiences of the cancer disease (Study IV).....	22
Positive consequences related to surviving cancer during childhood/adolescence (Study V).....	23
Procedure.....	24
Reference group (Studies I-II).....	24
Adolescents with cancer (Study II-IV).....	24
Data analysis.....	25
Study I.....	25
Study II.....	26
Study III.....	26
Study IV.....	27
Study V.....	28
RESULTS.....	29
Study I.....	29
Study II.....	33
Study III.....	35
Study IV.....	39

Study V.....	42
Life values	42
Relations to others	42
Relation to self.....	43
DISCUSSION	45
General discussion.....	45
Methodological discussion.....	50
Study I.....	50
Study II-IV.....	50
Study V.....	52
Conclusions and implications	53
Future perspectives.....	53
Acknowledgement	54
REFERENCES	56

Introduction

Cancer during adolescence

Adolescence is generally characterised as a time of great change for the individual. It involves establishing identity and self-image, becoming autonomous from parents and physical changes. Facing a life-threatening disease, such as cancer, during this period may be particularly challenging [1, 2]. The term adolescence generally refers to the developmental period between childhood and adulthood [3]. The period extends approximately from 12 to 19 years of age [1].

The mortality rates for childhood cancer have declined dramatically over the last decades and the current relative five-year survival rate for childhood and adolescent cancer is 75% [4, 5]. Increased survival rates have mainly resulted from expansive multimodal therapy, including combinations of surgery, radiation therapy, and/or chemotherapy [6]. Although improvements have resulted from all treatment modalities, chemotherapy has had the most dramatic effect on survival rates [7]. Nevertheless, cancer is one of the most critical events in a person's life and is likely to affect many functional, psychological, and social areas of life. Cancer and its treatment are associated with short- [8] and long-term physical side effects [9], prolonged hospitalisation and isolation [10], disrupted schooling [11], and social limitations [12].

Every year approximately 150 adolescents are diagnosed with cancer in Sweden [13]. Swedish paediatric oncology is organised in six centres. Each centre is responsible for the treatment of approximately 30-80 new cases of childhood/adolescent cancer yearly. Well-organised Nordic and international collaboration within paediatric oncology has resulted in standardised treatment protocols for almost all common childhood cancer diagnoses [14]. Central registers play an important part in the ongoing scientific development of paediatric oncology in Scandinavia [14]. So far, only medical variables, such as survival, have been registered. However, the increased survival rates have resulted in an increased interest in describing the psychosocial consequences of cancer during childhood/adolescence [15].

Reviews concerning the psychosocial consequences of childhood/adolescent cancer comment upon the difficulty of comparing different studies and of drawing definite conclusions due to the heterogeneity of the studies and to methodological weakness within studies

[9, 16]. Studies are often based on small sample sizes with different patient characteristics, for example with regard to age and time since diagnosis. Furthermore, there is a lack of longitudinal research within the field. In the research project “Psychosocial and health-economic consequences of cancer during adolescence”, which our research group started in 1999, we try to avoid these methodological shortcomings by following a group of adolescents diagnosed with cancer longitudinally, from four to eight weeks after diagnosis until at least 8 years after diagnosis.

Measuring psychosocial function

In the first thesis [17] from the project it was discussed whether, and if so, to what extent, mode of administration, i.e. the way data was collected, i.e. by telephone, has had any effect on the results. Various findings have shown that adults provide significantly more favourable responses with telephone interviews than with self-administrated questionnaires [18-21]. However, other findings indicate no difference between modes [22, 23]. Data from the few studies that have included participants younger than twenty years of age [18, 24] do not allow any conclusions about how adolescents respond to different modes of administration [25]. The effect of mode of administration is especially problematic if data collected by one mode is compared to data collected by another mode. In our case, telephone interview administrated results of psychosocial function were lower among adolescents with cancer shortly after diagnosis compared to postal administrated norm data [26]. It could, however, be hypothesised that differences between our data and norm data would have been greater if mode of administration had been the same for both samples. This issue became the starting point of a new study, investigating effects of mode of administration on self-reported psychosocial function among adolescents and young adults.

When addressing the psychosocial consequences of falling ill in and surviving childhood/adolescent cancer measures of health-related quality of life (HRQL) [9, 27, 28] and psychological distress are frequently used [16, 29]. HRQL is generally recognised as a multidimensional concept representing individual responses to the physical, mental, and social effects of illness on daily living, which influence the extent to which personal satisfaction with life circumstances can be achieved [30]. HRQL measures focus on individuals’ subjective perceptions of their health, as opposed to measures of psychological distress, which are often aimed specifically at detecting psychiatric disorders, anxiety, and depression [30]. In order to further explore psychosocial function measures of HRQL and psychological distress are often used simultaneously.

One question that needs to be addressed in psychosocial oncology is how to sort individuals’ responses to different psychosocial measures in a

clinically meaningful way. So far, most emphasis has been placed on analysing statistical trends across an entire sample, comparing groups, and/or relating psychosocial function to medical parameters [31]. Data from these studies do not provide meaningful information on how to help and support certain individuals. As a means towards this end, it needs to be explored how to sort individuals' responses to different psychosocial measures in a clinically meaningful way. Cluster analysis, a form of exploratory data analysis, aiming at sorting individuals according to similarity on one or more dimension/s, thereby producing groups that maximise within-group similarity and minimise between-group similarity may help in doing this [32, 33]. The method is referred to as "person-oriented" (in contrast to variable-oriented methods), as it identifies and describes groups of individual cases defined by similarities along multiple dimensions of interest [33]. This grouping can form the basis for understanding normal development, risk factors, or other outcomes. Furthermore, the stability of the identified clusters can be analysed over time and in relation to other patient characteristics. This may provide clinically meaningful information and possibilities of generating tailored supportive interventions. A very limited number of studies have used cluster analysis to explore clusters of psychosocial function among cancer patients, but there are some examples of studies from adult cancer patients [31, 34]. For instance, Trask and Griffith (2004) [31] used cluster analysis to determine whether there are subgroups of adult cancer patients who differ in coping, psychological, and quality of life measures, and to determine if these subgroups have a different course of distress and health following a cancer diagnosis. Four distinct clusters: psychologically unhealthy, physically unhealthy, combined psychologically and physically unhealthy, and healthy were identified. The course of distress and general health was distinct for each cluster during the nine months study period, with combined and psychologically unhealthy clusters reporting higher levels of distress and combined and physically unhealthy clusters reporting poorer overall health. In a study by Nagel and colleagues (2001) [34], a cluster analysis was performed to characterise breast cancer patients according to measures of HRQL and clinical and socio-demographic characteristics. Four clusters differing with regard to reported intrusiveness of disease and treatments, view of the future, age, body image, and sexual activity were identified.

Negative and positive consequences of cancer during adolescence

Cancer survivorship can be defined in various ways. In this research we adhere to the definition, widely used among cancer survivorship organisations, which implies that anyone diagnosed with cancer is a survivor, from the time of diagnosis until the end of life [35]. Cancer

survivorship has been described to consist of three phases: acute, extended, and permanent survival [36]. The acute phase ranges from diagnosis to the completion of initial treatment, the extended phase commences when initial treatment is completed and gradually evolves into permanent survival.

Acute phase

During the acute phase, extending from the diagnosis to the completion of initial treatment, adolescents with cancer may experience a number of physical as well as psychosocial aspects of distress. Physical aspects of distress commonly reported are: cough [8], drowsiness [8], fatigue [8, 26, 37, 38], lack of appetite [8], losing hair [26], mouth sores [26], nausea [8, 39], and pain [8, 40, 41]. Physical side effects of treatment are experienced as the worst aspects of the disease and are sometimes perceived as impossible to overcome [10, 42]. Symptoms reported to be associated with high distress are: difficulty swallowing [8], fatigue [26, 37], insomnia [8], losing hair [8], mouth sores [26], nausea [8, 26], pain [8], problems with urination [8], and skin changes [8]. The number of symptoms and level of distress generally decrease over time, it has however been reported that fatigue still causes high distress six months after initiation of treatment [37].

The physical side effects of treatment often restrict the adolescent in his/her daily life [42], which may lead to psychosocial problems. It has been reported that adolescents experience: disruption of relationships and plans for the future [43], missed leisure activities [26] and interruption of school [26, 43] during the acute phase. Altered self-image [37, 44], feelings of alienation [44], and lack of integrity [44] have also been described. Psychosocial aspects reported to be associated with high distress are: altered self-image [8], missed leisure activities [26], and worries about missing school [26]. The number and level of psychosocial aspects of distress generally decrease over time [37, 43]. It has, however, been reported that changed appearance still causes high distress six months after initiation of treatment [37].

Facing a life-threatening disease, like cancer, during adolescence may raise existential uncertainty [45]. Feeling irritable, nervous, and sad [8] as well as fears of relapse and dying [44] are described. However, other findings demonstrate that during the acute phase adolescents report similar levels of anxiety [29, 46, 47] and depression [29, 46, 47] as those reported by healthy controls. On the other hand, other results show that adolescents on treatment report worse well-being than healthy controls [26].

Whether adolescents with cancer experience anything positive related to the disease and treatment during the acute phase has been investigated only to a very limited extent. However, in a previous study from our group [44] we investigated whether adolescents during different phases of survival, in retrospect, experienced anything positive with regard to being told the

diagnosis, getting treatment, and being admitted to the ward. The findings demonstrate the following positive experiences: good to have received a diagnosis, as opposed to uncertainty and secrets, gaining hope for the future, pain relief, positive relations with the staff, and being well cared for.

Extended phase

The extended phase, which starts when initial treatment ends, has been described as a time of crisis: unsettling feelings associated with cancer and its treatment may resurface causing stress, uncertainty, and fear [48].

Various physical aspects of distress may be experienced during the extended phase, for example: amputations [10], fatigue [49], hair loss [10], infertility [50], overweight [10], and shortness [10]. Physical side-effects of treatment are often regarded by adolescents as the worst aspects of disease even after completion of treatment [10]. Previous research pointed out that the worst aspects of distress experienced by adolescents during this phase are changes in appearance and physical impairments [10, 49, 51]. Although the number and level of physical side effects usually decrease after completion of treatment [8], adolescents have reported a more negative health status compared to healthy peers [50] during the extended phase.

During the extended phase adolescents report various aspects of psychosocial distress. Behavioural adjustment problems [52], problems catching up at school [11], decreased social activities [12, 50, 53], perceived lack of psychosocial support [54], and learning problems [52] have been described. Other aspects of psychosocial distress include alterations in self-image [10, 55], dependency on parents [12], and a negative body-image [10, 12, 56]. It has been reported that during the extended phase survivors participate in less than half as many social activities compared to healthy peers [53].

During this phase worries about long-term side-effects as well as the possibility of recurrence [10, 50, 54, 55] may be experienced. Other worries include sexual and reproduction issues [12, 50] and educational plans [11, 12]. Although survivors report fewer general worries about health than their peers, they report more worries with regard to fertility and being able to have healthy children [50] than their peers.

It has been concluded that adolescents off treatment report higher levels of anxiety and depression [46] compared to adolescents on treatment and that the time after treatment is related to low self-worth, social anxiety, and a negative body image [53]. Other findings suggest that adolescents are relatively well-adjusted with regard to psychosocial aspects, with the exception of social and sexual self-image [57].

When asked if something good has come out of the disease, adolescents off treatment have described that they experience a more positive outlook on life than before the disease [50] and feel that they have a purpose in life [50].

Others describe an increased involvement with their families [55] as well as experiencing special attention from parents [55]. Feeling stronger than before the disease [55] and being more mature than peers [50] have also been described.

Permanent phase

During the permanent phase of survival life is gradually getting back to normal. In recent reviews aiming at summarising the long-term consequences for survivors of childhood/adolescent cancer it is concluded that most survivors are equal to healthy controls with regard to physical and psychosocial function [9, 16]. However, survivors of brain tumours and acute lymphoblastic leukaemia are at risk of educational difficulties, whereas survivors of bone tumours are at risk of health problems and a less than optimal quality of life [9].

It has been concluded that most survivors experience a quality of life equal to that of healthy controls during the permanent phase [9]. However, a number of physical aspects of distress have been reported. Problems with amputation and deformities of limbs [58], being too short [59], change in hair colour and quality [58, 59], infertility [60], loss of condition [61], loss of muscles [59], overweight [59], restricted coordination [59], restricted mobility [62], and scars [59, 63] have been reported. These aspects of distress may restrict the survivor with regard to education and/or employment [61].

A number of psychosocial aspects of distress have been reported by survivors during the permanent phase, for example, with regard to employment [62, 64], family life [58, 59, 64], friendship [59], school performance [58, 59, 62-64], and social life [58, 59, 64]. Other aspects reported to be of concern during this phase are: body image [65], independence [59, 66], difficulties in relationships with the opposite sex [67], and self-development [63]. Some results indicate that survivors during this phase experience problems with social adjustment [65] and body image [68] whereas others indicate that they show less anti-social behaviour [69] and a more positive self-image [70] than healthy controls.

Survivors have reported worries about recurrence of the cancer [45], long-term treatment side-effects [45], infertility, not being able to have normal healthy children, and about their own children getting cancer [45, 58, 61] during this phase. Some findings point out that survivors experience more depression [71] than healthy controls and that a considerable number of survivors suffer from post traumatic stress disorder [72] during this phase. However, other results demonstrate that survivors report a better health-related quality of life [73], less anxiety [73, 74], and depression [73] compared to healthy controls.

In spite of the above-mentioned findings, it has been reported that during the permanent phase survivors experience that they know their own body better and are more aware of their body than before the disease [67]. It has also been reported that during this phase survivors experience that, as a result of the cancer disease, they have become more serious about school [67] and have been helped in planning their career [67].

During this phase survivors have described that they experience positive aspects regarding self-development. Experiences of being stronger [45, 59], more mature [59, 63, 67], more reflective [61, 67], more optimistic [45, 67], and having an increased empathy for other people [75] compared to before the disease have been described. It has also been described that survivors during this phase report having a stronger bond with friends [75], being more socially active and popular [67], and being more sensitive to friends' feelings [61] than before the disease. Positive changes with regard to family relations such as stronger bonds with family [75], more open communication within family [61], closer relations within family [61, 67], and that family members value each other more [61] have been described. Receiving special attention from parents' years after diagnosis has also been described as a positive experience [59, 61].

Points of departure for this thesis

Taken together, the above-mentioned findings indicate that cancer during adolescence may have negative as well as positive consequences. However, the noteworthy lack of studies with longitudinal designs makes it difficult to conclude how adolescents with cancer experience their psychosocial life-situation during the trajectory of the disease [9, 16]. Furthermore, in the literature there is a tendency to concentrate on childhood cancer, or not to differentiate between childhood and adolescent cancer [2]. Experiencing cancer during adolescence presents unique difficulties as the illness and/or its treatment may affect the transition from childhood to adulthood. Owing to this, there is a need for more research into the potential negative, as well as positive, psychosocial consequences of contracting cancer during adolescence.

Aims

The overall aim of this thesis was to investigate psychosocial consequences of cancer during adolescence, using a longitudinal approach. An additional aim was to investigate if mode of administration has an influence on adolescents' and young adults' self-reported psychosocial function.

The specific aims were:

- To investigate potential interaction effects of mode of administration, age, and gender on self-reports of health-related quality of life, anxiety, and depression in a randomly selected sample of Swedish adolescents and young adults. A further aim was to investigate whether mode of administration is related to response rate and data quality. (Study I)
- To investigate if and how health-related quality of life, anxiety, and depression among adolescents diagnosed with cancer differ from those of a reference group four to eight weeks, six, twelve, and eighteen months after diagnosis. (Study II)
- To identify psychosocial states, on the basis of self-reported health-related quality of life and anxiety, among adolescents diagnosed with cancer at four to eight weeks, six, twelve, and eighteen months after diagnosis and to analyse each state in relation to demographic and clinical characteristics and self-reported depression. (Study III)
- To explore potential negative and positive consequences of cancer during adolescence experienced two years after diagnosis. (Study IV)
- Through a review of the literature investigate whether there are any positive consequences related to surviving cancer during childhood/adolescence. (Study V)

Methods

Design and sample

Study I is based on data collected from a sample of 585 persons, aged 13-23 years, that was randomly chosen from the general Swedish population and stratified with regard to age, gender, and region. Participants were randomised according to two modes of administration: telephone interview and postal questionnaire.

Studies II-IV are based on data collected within the project: “Psychosocial and health-economic consequences of cancer during adolescence” in which sixty-one adolescents diagnosed with cancer have been included. Data has been/is collected at: 4-8 weeks (T1), 6 (T2), 12 (T3), and 18 (T4) months and 2 (T5), 3 (T6), 4 (T7), and 8 (T8) years after diagnosis. Findings based on data collected at T1-T5 (from June 1999 until December 2005) are presented in this thesis.

Study V is a review of the literature aiming to identify whether there are any positive consequences related to surviving cancer during childhood/adolescence. Descriptive (N=7) [45, 50, 58, 59, 61, 63, 75] and comparative (N=51) [11, 46, 53, 62-65, 68-70, 73, 76-115] studies published between 1990-2005 were reviewed.

Participants

Reference group (Studies I-II)

A simple random sample was drawn by Statistics Sweden (SCB) from their civil register of the total population. The target population (N=613 942) included all individuals covered by civil registration between 13 and 23 years of age, living in the three public healthcare regions containing the three paediatric oncology centres from which adolescents diagnosed with cancer were included in the project “Psychosocial and health-economic consequences of cancer during adolescence”: South (Lund), Middle (Uppsala/Örebro), and North (Umeå). The sample was stratified into 18 strata with regard to gender (an equal number of men and women), age

group (young adolescents: 13-15 years; older adolescents: 16-19 years; and young adults: 20-23 years), and public health-care region. One-way ANOVAs did not indicate any difference between regions, consequently, this variable was not considered in the statistical analyses performed in Study I. Within each stratum the participants were randomised according to two modes of administration, telephone interview and postal questionnaire. The selected eligible sample consisted of 840 individuals who were invited to participate, 391 of whom were approached through telephone interview and 449 by postal questionnaire.

The overall response rate was 69.6%: for the telephone interview mode 76.7% and for the postal questionnaire mode 63.5%. Only 0.8% of the addresses of those selected for the telephone interview and 0.7% of those selected for the postal questionnaire were impossible to find. It was only possible to record the reasons for non-participation among those randomised for the telephone interview. The reasons for non-participation in this mode were: hindered from participation due to illness or language difficulties (2.1%), impossible to reach (9.2%), and not wishing to participate (11.3%). Adolescents whose parents did not give their consent were categorised as not wanting to participate (n=7). See Table 1 for a presentation of response rate by mode, gender, age, and region. Data collection was performed between March and May 2005. In Study II persons participating in the telephone interview (N=300) formed a reference group and were compared to adolescents diagnosed with cancer.

Table 1. *Response rate by mode, gender, age, and region.*

	Telephone interview		Postal questionnaire	
	Participants (N=300) n (%)	Non-participants (N=91) n (%)	Participants (N=285) n (%)	Non-participants (N=164) n (%)
Gender				
Female	153 (51.0)	37 (40.7)	155 (54.4)	64 (39.0)
Male	147 (49.0)	54 (59.3)	130 (45.6)	100 (61.0)
Age				
13-15	89 (29.7)	28 (30.8)	91 (31.9)	43 (26.2)
16-19	119 (39.7)	26 (28.6)	110 (38.6)	58 (35.4)
20-23	92 (30.7)	37 (40.7)	84 (29.5)	63 (38.4)
Region				
South	98 (32.7)	35 (38.5)	99 (34.7)	55 (33.5)
Middle	138 (46.0)	39 (42.8)	126 (44.2)	75 (45.8)
North	64 (21.3)	17 (18.7)	60 (21.1)	34 (20.7)

Adolescents diagnosed with cancer (Studies II-IV)

Adolescents (13-19 years) newly diagnosed with cancer or with a recurrence of cancer were recruited between June 1999 and October 2003 from three of the six paediatric oncology centres in Sweden: Lund, Umeå, and Uppsala. To be eligible for inclusion, the adolescents had to be Swedish speaking, diagnosed with cancer for the first time or after having been disease-free and off treatment for at least one year, 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 physician, each adolescent's ability to participate. Of 90 adolescents diagnosed with cancer for the first time and of 10 diagnosed with a recurrence of cancer, 11 were not asked about participation as they did not speak Swedish well enough to participate and/or were considered too cognitively or physically affected by the disease or by a neurological comorbidity to participate. Of 89 eligible adolescents, 65 agreed to participate. Of these 4 did not participate as: 2 became too ill before they were interviewed for the first time and 2 were missed due to administrative reasons. Hence, 61 adolescents were included (56 newly diagnosed and 5 with a recurrence) in the project. Adolescents diagnosed with a recurrence were excluded in Study II.

See Table 2 for a presentation of demographic and clinical characteristics of adolescents included in the project and of those participating in Studies II-IV and Table 3 for a presentation of reasons for attrition at T2-T5 in Studies II-IV.

Table 2. A presentation of demographic and clinical characteristics of adolescents included in the project (same as in Study III) "Psychosocial and health-economic consequences of cancer during adolescence" and of those participating in Studies II and IV.

	Study II	Study III/Project				Study IV
	T1-T4 N=42	T1 N=61	T2 N=57	T3 N=50	T4 N=48	T5 N=38
Primary cancer/Recurrence of cancer	42/0	56/5	53/4	46/4	42/6	32/6
Study centre						
Lund	15	21	20	18	17	13
Umeå	11	18	16	13	12	13
Uppsala	16	22	21	19	19	12
Gender						
Male	23	37	35	29	28	22
Female	19	24	22	21	20	16
Age at diagnosis						
13-15 years		38				20
16-19 years		23				18
Mean (Sd)	15.7 (1.7)	16 (1.6)				16 (1.6)
Diagnosis						
CNS tumour	2	3	3	3	3	1
Leukaemia						
ALL ^a	6	16	13	10	9	8
AML ^b	3	4	4	3	3	3
CML ^c	1	1	1	1	1	1
Lymphoma						
Hodgkin	13	13	13	13	13	10
Non-Hodgkin	7	7	7	7	7	5
Other solid tumour						
Bone sarcoma	7	11	10	7	7	6
Nasopharyngeal carcinoma	1	1	1	1	1	1
Soft tissue sarcoma	2	4	4	4	4	3
Wilms' tumour		1	1	1	0	
On/Off treatment	8/34	61/0	43/14	14/36	11/37	9/29

^aAcute Lymphocytic Leukaemia

^bAcute Myelogenous Leukaemia

^cChronic Myelogenous Leukaemia

Table 3. *A presentation of reasons for attrition in Study II (T2-T4, n=19), Study III (T2, n=4; T3, n=8; T4, n=3), and Study IV (T2-T5, n=23).*

Reasons for attrition	Study II	Study III		Study IV	
	T2-T4 N=42	T2 N=57	T3 N=50	T4 N=48	T5 N=38
Chose to withdraw from the study	3	2			5
Chose not to participate at particular time		1	1	1	
Death	7	1	7	2	12
Missed due to administrative reasons					6
Recurrence at inclusion ^a	5				
Recurrence at T2-T4 ^a	4				

^aAdolescents diagnosed with a recurrence at inclusion or at T2-T4 were excluded in Study II but included in Study III and Study IV.

Measures and data collection

Health-related quality of life (Studies I-III)

The SF-36 is a generic instrument for assessment of HRQL that has been developed by an American research group, led by John Ware [116]. The questionnaire consists of 36 items, which measure eight dimensions of life quality: Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health. In addition, one single item determines perceived differences in state of health over the past year. Verbal response choices vary from two to six. Based upon the eight scales, two summary scales have been constructed for physical (Physical Component Summary) and mental health (Mental Component Summary) respectively [117]. The Physical Component Summary is primarily a comprehensive measure of Physical Functioning, Role Physical, Bodily Pain, and General Health, whereas the Mental Component Summary mainly encompasses Vitality, Social Functioning, Role Emotional, and Mental Health [118]. However, the Vitality, General Health, and Social Functioning scales have noteworthy correlations with both components [118]. 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 [118].

The SF-36 is described as adequate from early adolescence (14 years) [116]. Normative data collected by telephone interviews and postal questionnaires for the general Swedish population ages 13-23 have been published by our group [119]. Cronbach's alpha values for Vitality and Mental Health, in telephone interviews, were 0.81 and 0.82 respectively [119].

At T1-T4 the cancer group was asked to answer two SF-sub-scales mainly associated with mental health and well-being, namely Vitality (four items) and Mental Health (five items). The reason for this was twofold. Firstly, the participants were asked to answer a large number of questions apart from the ones forming the basis of Studies II and III, concerning for example disease- and treatment-related aspects of distress and coping-strategies. Therefore, efforts were made to simplify participation as much as possible. Secondly, the project has its emphasis on the psychosocial consequences of falling ill with and surviving cancer, and therefore the mental aspects of HRQL were perceived as the more determining sources of information. However, at T5-T7 the cancer group answered the entire SF-36, as did participants in Study I (including the reference group in Study II).

Anxiety and depression (Study I-III)

Anxiety and depression were measured by the Hospital Anxiety and Depression Scale (HADS). The HADS was developed by Zigmond and Snaith [120], and has been used extensively in a wide range of settings as a psychological screening instrument and in population-based surveys when studying aspects of distress. To lessen the possible effects of physical illness, no items relating to symptoms that might stem from a somatic condition, such as dizziness and loss of appetite, are included [120]. Anxiety and depression are measured on two separate sub-scales, each consisting of 7 items, rated from 0 to 3. Sub-scale scores range from 0 (no distress) to 21 (maximum distress). The HADS was originally developed to be answered by people aged between 16-65, but has been used with adolescents aged 12-16 years [121]. Normative data, collected by telephone interviews and postal questionnaires, for the general Swedish population ages 13-23 have been published by our group [119]. The Cronbach's alpha values for HADS Anxiety and HADS Depression, in telephone interviews, were 0.75 and 0.54 respectively [119].

Positive and negative experiences of the cancer disease (Study IV)

At T5 the participants were asked the following questions: "What, if anything, is bad for you due to the cancer disease?" and "What, if anything, is good for you due to the cancer disease?" Elisabet Mattsson (EM) conducted all interviews at T5. Participants were asked to answer according to their present situation. Follow-up questions were asked in order to help the respondents to elucidate their answers. The answers were tape-recorded and transcribed verbatim.

Positive consequences related to surviving cancer during childhood/adolescence (Study V)

A review of the literature was performed. In the first step, studies with a descriptive design, reporting survivors' descriptions of positive consequences of cancer during childhood/adolescence, were identified through a search in the databases CINAHL, PsycINFO, and PubMed. The keywords adolescence, cancer, childhood, consequence, experience, meaning, paediatric, positive, and survivors were used. Studies meeting the following criteria were included: descriptive design, sample of persons diagnosed with cancer during childhood/adolescence, off treatment and without any sign of recurrence, article written in English and published in a peer-reviewed journal 1990-2005. Seven studies met the criteria [45, 50, 58, 59, 61, 63, 75]. Reported positive consequences were inductively categorised into three themes by EM and an additional person, according to a manifest content analysis [122]. The three themes were life values, relations to others, and relation to self. Taking these as a starting point, a second search was conducted in the databases mentioned above. The purpose was to identify studies with a comparative design in which variables that could be assigned to the three themes were investigated. The keywords adjustment, adolescence, cancer, childhood, existential, existential psychology, faith, family relation, friend, infertility, life expectation, life value, marital, paediatric cancer, parent-child relation, parenthood, philosophy of life, psychological, psychosocial, religion, religious, religious beliefs, religious ethics, response shift, self-concept, self-esteem, self-image, self-perception, sexual, and spiritual were used. Identified articles were hand-searched for further references. Studies meeting the following criteria were included: comparative design, sample of persons diagnosed with cancer during childhood/adolescence, off treatment and without any sign of recurrence, a comparison group (healthy controls/population norms), and article written in English and published in a peer-reviewed journal 1990-2005.

There were 51 studies with a comparative design [11, 46, 53, 62-65, 68-70, 73, 76-115] in which variables related to the three themes were investigated for survivors of cancer during childhood/adolescence: life values [108], relations to others [11, 53, 62-65, 69, 70, 73, 77, 78, 80-112, 114, 115], and relation to self [46, 53, 63, 65, 68, 70, 76-79, 83, 88, 91, 97, 99, 103, 107, 109, 110, 113].

Procedure

Studies I-IV were approved by the local ethics committees at the Faculties of Medicine at the Universities of Lund, Umeå, and Uppsala.

Reference group (Studies I-II)

The data was collected by SCB between March and May 2005.

Telephone interview (Study I and Study II)

After completing an organised training program, five interviewers performed the telephone interviews. Potential participants received a letter containing information about the study. For those under 18 years, a separate information letter was addressed to the parents. Potential participants were contacted over the telephone by one of the interviewers within a week of the information letter being mailed. Provided that the respondent agreed to participate, and that parental consent was obtained for those under 18 years of age, a time was either booked for the interview or the interview was conducted directly. The interviewer read the two questionnaires (the SF-36 and the HADS) aloud to the respondent, and recorded the responses. All participants were asked the same questions in the same order. As a form of compensation, all participants received a cinema ticket by mail.

Postal questionnaire (Study I)

Potential participants received a letter containing the two questionnaires (the SF-36 and the HADS) and written information about the study, as well as a stamped and addressed envelope. In order to obtain parental consent, a separate information letter was addressed to the parents, if the potential participant was under 18 years of age. Those who did not return the questionnaires within two weeks were sent a reminder. Shortly after their participation, all participants received a cinema ticket by mail, as a form of compensation.

Adolescents with cancer (Study II-IV)

A co-ordinating nurse at each centre provided eligible adolescents and their parents with oral and written information about the study approximately three weeks after the diagnosis. A few days later the same nurse asked the adolescent whether he/she agreed to participate. If the adolescent was 17 years old or younger, parental consent was also obtained. Adolescents who agreed to participate were subsequently contacted by telephone by a doctoral

student from the Department of Public Health and Caring Sciences, Uppsala University. The author (EM) conducted the majority of the interviews in Studies II and III and all interviews in Study IV. In all assessments data were collected over the telephone. All participants were asked the same questions in the same order.

At T1-T4 (Studies II and III) a structured interview guide developed for the research project was used. The interview guide included background data, questions about prevalence and levels of disease- and treatment-related aspects of distress and coping strategies, two sub-scales of the SF-36 (Vitality and Mental Health), and the HADS.

At T5 (Study IV) the participants were first asked to report background data, then to answer the SF-36 and HADS, and finally to answer the following questions: “What, if anything, is bad for you due to the cancer disease?” and “What, if anything, is good for you due to the cancer disease?” The answers were tape-recorded and transcribed verbatim.

On each occasion, when data were collected, the interviewer read the questions aloud to the participant, and recorded the responses. When the open-ended questions were asked (T5), the interviewer asked follow-up questions in order to help the respondent to elucidate their answers.

At the end of the interviews (at T1-T5), the participant was asked whether he/she agreed to be contacted for another interview at the next assessment (T2-T6). Before each interview (at T2-T5), the interviewer contacted the coordinating nurse at the relevant centre to check whether the adolescent was alive and considered capable of participating. Each time they participated the adolescents received a small gift in appreciation of their participation.

Data about disease- and treatment-related aspects of distress and coping strategies are not presented in this thesis.

Data analysis

Study I

All statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 11.0 (SPSS Inc, Chicago, IL).

The SF-36 was 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 the standard SF-36 scoring algorithms [118]. The two summary scores for Physical Component Summary and Mental Component Summary are standardised to a mean of 50, with a score above 50 representing better than average function and below 50 poorer than average function. Missing values were substituted if half or more of the items within the scale were responded to; that is, a person-specific mean score was calculated based on the existing answers.

When a HADS questionnaire was partially incomplete, the scale values were estimated by assuming that the missing item(s) had a value equal to the average of those in existence, provided that no more than three items of a sub-scale were missing.

Descriptive statistics were used to present data from the two modes of administration and Chi-square analyses were conducted to assess differences in overall response rate between mode of administration, between participants and non-participants regarding distribution of gender and age, and in the percentage scoring scales at the floor (lowest possible level) and ceiling (highest possible level) by mode. Cronbach's alpha values were calculated to estimate the internal consistency of each SF-36 and HADS scale. According to the generally accepted standard, the alpha coefficient should not fall below .70 [123] for group comparisons. Two-way between-group ANOVAs were used to evaluate the potential interaction effects of mode of administration and age and gender on self-reported HRQL, anxiety, and depression. P-values $\leq .01$ were considered statistically significant.

Study II

All statistical analyses were conducted using the SPSS, version 14.0 (SPSS Inc, Chicago, IL). Descriptive statistics (means and standard deviations) for the HADS sub-scales Anxiety and Depression and the two SF-36 sub-scales, Vitality and Mental Health, were calculated for the cancer group at T1-T4 and for the reference group at the single time of measurement. As there were more boys than girls in the cancer group, and as the longitudinal design means that the participants' age during the study, the comparison between the estimated mean of the cancer group and the reference group was calculated using 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: $y = a + (b_1 \times \text{age}) + (b_2 \times \text{gender}) + (b_3 \times \text{group})$. P-values $\leq .05$ were considered statistically significant.

Study III

A "person-oriented" method called ISOA (I-States as Objectives of Analyses) [124, 125] was used to identify a finite set of psychosocial states based on three dimensions: vitality, mental health, and anxiety. Correlations between vitality, mental health, and anxiety based on data from T1-T4 were: vitality and mental health, $r=0.69$; vitality and anxiety, $r=-0.32$; mental health and anxiety, $r=-0.51$. The HADS Depression scale was used as an external validation variable to discriminate between the formed clusters (psychosocial states) [126]. When short-term development is in focus, an

individual may be described on a certain measurement occasion using one of a finite set of states. These states are based on vectors of related measures taken from the relevant time period. The available variable value profiles from all time points are used collectively to define a finite set of states, called i-states. Because each profile (belonging to a distinct individual and to a distinct time point) is included in the analysis, the individual can be characterised by a sequence of i-states which he/she may share with other individuals. Instead of the original repeated multivariate data set, a set of longitudinal profiles expressed in terms of state sequences is obtained for each individual.

In this study each individual contributed a number of data vectors, each corresponding to one measurement occasion. A total of 215 data vectors were obtained. One vector was substituted for missing values and one was excluded from the analysis as it was found to be an outlier. Cluster analysis was performed on the remaining set of 214 data vectors using Ward's method. The established rationale for obtaining a well-functioning [127, 128] and trustworthy classification was followed [126]. Validation by replication analysis was performed to ensure the stability of the clustering in the data [126] and the result was tested against a null hypothesis of no relationships in the data by simulation [129]. All of these analyses were conducted using procedures in SLEIPNER 2.1. [125].

Because each individual is characterised by one state on a given measurement occasion, this allows for an analysis of state frequencies per measurement occasion. For this type of analysis exact analyses of single cells in a contingency table using EXACON were performed [130]. EXACON was also used to compare the obtained states with regard to extraneous categorical variables (i.e. age at diagnosis, diagnosis, gender, and family situation).

One-way ANOVAs were used to compare the clusters with regard to the HADS Depression scale. Post-hoc tests were performed (Tamhane, Dunnett T3, Games-Howell, and Dunnett C). P-values <.05 were considered statistically significant.

Study IV

To ensure that all participants had an equal chance to describe negative and positive experiences of the cancer disease, semi-structured open-ended questions were asked. The answers were analysed using content analysis, a method that can be used to draw valid conclusions about a manifest message in a communication by systematic identification of specified communication characteristics [122]. The analysis was performed in the following steps [131]: 1. EM and an additional researcher read the transcribed text. Words and sentences (recording units) containing relevant information regarding

the interview question were identified. 2. EM and an additional researcher grouped recording units into exclusive categories reflecting central messages. Recording units in the same category are assumed to have a similar meaning, on the basis of either the precise meaning of the words or of words sharing the same connotations. 3. EM and two additional researchers defined the boundaries of each category and developed final descriptions of the central characteristics of each category. Even if a participant mentioned a certain recording unit several times, it was only counted once in the results.

Study V

In the first step of the review of the literature, seven descriptive studies [45, 50, 58, 59, 61, 63, 75] meeting the inclusion criterion i.e. reporting at least one positive consequence with regard to surviving childhood/adolescence cancer were identified. Reported positive consequences were, according to a manifest content analysis [122], categorised by EM and an additional researcher into three themes: Life values, Relations to others, and Relation to self. Fifty-one studies [11, 46, 53, 62-65, 68-70, 73, 76-115] with a comparative design, investigating variables referring to the three themes mentioned above, were identified. The variables identified were first assigned to categories and thereafter to themes.

RESULTS

Study I

The response rate was significantly lower in the postal (63.5%) than in the telephone mode (76.7%) ($p \leq .001$). A higher proportion of males than females chose not to participate in the postal mode ($p \leq .01$). Age was not related to response rate in either mode.

Cronbach's alpha exceeded .70 for all scales in the postal mode, but in the telephone mode three sub-scales fell below .70: Bodily Pain (.62) and Social Functioning (.67) in the SF-36, and Depression (.54) in the HADS. The number of missing items was low for all SF-36 and HADS scales irrespective of mode (0-2.1%). The percentage of floor effects did not differ between the modes. For three scales: Physical Functioning ($p \leq .01$), Bodily Pain ($p \leq .01$), and Social Functioning ($p \leq .001$) the percentage of ceiling effects was significantly larger in the telephone mode.

See Table 4 for a presentation of mean values, standard deviations, and Cronbach's alpha coefficients for the SF-36 and HADS scales by mode and age. Cronbach's alpha for the SF-36 and HADS scales by mode and age revealed eleven coefficients that fell below .70. Seven of these were demonstrated for the youngest group (13-15 years) and nine in the telephone mode. Low values were demonstrated for HADS Depression for all age groups in the telephone mode and for Bodily Pain and Social Functioning in both modes for the youngest age group.

See Table 5 for a presentation of mean values, standard deviations, and Cronbach's alpha coefficients for the SF-36 and HADS scales by mode and gender. Cronbach's alpha for the SF-36 and HADS scales by mode and gender revealed eight coefficients that fell below .70. Seven of these were demonstrated in the telephone mode and five for males. Low values were demonstrated for HADS Depression in both genders in the telephone mode and for males in the postal mode. Low values were also found for Bodily Pain in the telephone mode for both genders.

The participants reported better Physical Functioning ($p \leq .001$), Vitality ($p \leq .01$), Social Functioning ($p \leq .001$), and Mental Health ($p \leq .01$) (all SF-36 scales) in the telephone mode than in the postal mode and a higher value was demonstrated for the Mental Component Summary in the telephone mode ($p \leq .01$).

Interaction effects by mode and age were demonstrated for three SF-36 scales: General Health ($p \leq .001$), Vitality ($p \leq .01$), and Mental Health ($p \leq .01$) and for the HADS Anxiety scale ($p \leq .001$). Young adolescents (13-15 years), in contrast to the older age groups, reported better health status and less anxiety when approached with a postal questionnaire versus a telephone interview. Only one interaction effect was found for mode of administration and gender, namely for the SF-36 scale Social Functioning ($p \leq .01$). When approached with a postal questionnaire, females reported worse Social Functioning than when approached with a telephone interview. A difference not demonstrated among men.

Table 4. A presentation of Cronbach's alpha coefficients (α), mean values, and standard deviations for the SF-36 and HADS scales by mode and age.

SF-36 and HADS scales	13-15 years			16-19 years			20-23 years		
	α	Mean ^a	Sd	α	Mean ^b	Sd	α	Mean ^c	Sd
Physical Functioning									
Telephone	Na	98.9	3.6	0.93	97.5	10.0	0.78	97.2	7.5
Postal	0.95	93.5	18.4	0.88	94.2	12.8	Na	96.8	7.8
Role-Physical									
Telephone	0.68	92.4	19.0	0.71	88.7	23.2	0.84	89.1	25.5
Postal	0.75	90.1	22.3	0.78	83.3	28.6	0.77	87.2	25.6
Bodily Pain									
Telephone	0.64	87.8	17.9	0.54	84.5	18.5	0.71	84.4	19.3
Postal	0.62	89.9	14.5	0.82	78.2	22.6	0.80	77.4	22.6
General Health									
Telephone	0.72	84.7	14.3	0.72	81.4	17.1	0.70	82.2	15.7
Postal	0.70	89.3	12.5	0.82	75.0	21.0	0.73	75.4	17.0
Vitality									
Telephone	0.72	74.3	14.8	0.84	67.9	20.0	0.80	66.6	18.9
Postal	0.80	76.4	16.7	0.82	58.7	22.0	0.81	58.8	20.5
Social Functioning									
Telephone	0.59	96.5	9.4	0.63	92.3	14.8	0.73	91.6	16.7
Postal	0.48	95.9	8.4	0.81	85.0	19.7	0.90	84.2	23.1
Role-Emotional									
Telephone	0.82	92.9	22.2	0.71	83.5	30.0	0.75	85.0	28.7
Postal	0.78	91.6	22.9	0.78	76.7	35.1	0.76	75.8	35.2
Mental Health									
Telephone	0.76	83.1	13.2	0.82	80.4	14.7	0.85	78.9	16.8
Postal	0.75	84.6	14.0	0.87	73.6	20.1	0.82	71.0	19.0
HADS-Anxiety									
Telephone	0.67	4.63	2.85	0.74	4.60	3.25	0.81	4.78	3.90
Postal	0.85	3.47	3.61	0.80	6.19	4.08	0.82	6.15	4.17
HADS-Depression									
Telephone	0.58	2.26	2.22	0.29	2.59	1.83	0.67	2.68	2.78
Postal	0.75	1.99	2.69	0.78	3.34	3.23	0.78	3.54	3.26

Na, not applicable due to no variance for two items.

^aTelephone mode n=89, postal mode, n=89-91; ^bTelephone mode n=119, postal mode, n=108-110; ^cTelephone mode n=92, postal mode, n=83-84.

Table 5. A presentation of Cronbach's alpha coefficients (α), mean values, and standard deviations for the SF-36 and HADS scales by mode and gender.

SF-36 and HADS scales	Males			Females		
	α	Mean ^a	Sd	α	Mean ^b	Sd
Physical Functioning						
Telephone	0.93	98.0	9.5	Na	97.7	5.7
Postal	0.92	95.4	13.7	0.91	94.3	13.8
Role-Physical						
Telephone	0.64	91.8	19.0	0.81	88.1	25.8
Postal	0.80	86.6	26.9	0.74	86.6	25.1
Bodily Pain						
Telephone	0.55	86.7	17.6	0.67	84.2	19.5
Postal	0.77	84.4	19.9	0.80	79.4	21.8
General Health						
Telephone	0.66	84.9	14.2	0.73	80.5	17.2
Postal	0.77	83.6	17.0	0.81	76.3	19.4
Vitality						
Telephone	0.79	74.1	17.2	0.80	65.0	18.6
Postal	0.77	68.5	19.1	0.87	60.7	22.9
Social Functioning						
Telephone	0.73	94.5	14.7	0.61	92.2	13.6
Postal	0.78	93.0	13.0	0.85	84.2	21.9
Role-Emotional						
Telephone	0.78	89.9	25.0	0.72	83.7	29.9
Postal	0.79	90.4	24.7	0.76	73.3	36.1
Mental Health						
Telephone	0.77	83.7	13.8	0.84	77.9	15.6
Postal	0.74	81.2	15.0	0.88	72.2	20.8
HADS-Anxiety						
Telephone	0.70	3.82	2.88	0.76	5.48	2.46
Postal	0.81	4.17	3.51	0.83	6.27	4.39
HADS-Depression						
Telephone	0.40	2.53	2.07	0.65	2.51	2.46
Postal	0.69	2.85	2.82	0.84	3.07	3.39

Na, not applicable due to no variance for two items.

^aTelephone mode n=147, postal mode, n=125-130; ^bTelephone mode n=153, postal mode, n=151-155.

Study II

Table 6 presents the means and standard deviations of the two HADS sub-scales and the two SF-36 sub-scales at T1-T4 for the cancer group, and at the single time of measurement for the reference group. The cancer group's ratings of all four variables differed significantly between T1 and T4. For Anxiety, the mean difference was 1.74 ($p \leq .05$), for Depression 2.76 ($p \leq .001$), for Vitality 30.7 ($p \leq .001$), and for Mental Health 18.7 ($p \leq .001$).

Table 7 presents the estimated mean differences between the cancer group and the reference group at T1-T4. Shortly after diagnosis, the estimated mean between adolescents with cancer and the reference group differed on the HADS subscale Depression ($p \leq .001$) and the SF-36 sub-scales Mental Health ($p \leq .001$) and Vitality ($p \leq .001$). Adolescents with cancer reported higher levels of depression and lower levels of the two aspects of HRQL compared to the reference group. No difference was found on the HADS sub-scale Anxiety. Six months after diagnosis, corresponding differences were identified regarding Mental Health and Vitality (both $p \leq .001$), but no differences on either of the two sub-scales of the HADS were discovered. Twelve months after diagnosis, no difference between the cancer group and the reference group were found for any of the investigated variables. Eighteen months after diagnosis, the estimated mean differed between adolescents with cancer and the reference group on the HADS sub-scales Anxiety ($p \leq .05$) and Depression ($p \leq .001$) as well as the SF-36 sub-scale Vitality ($p \leq .01$), whereas there was no difference regarding Mental Health. In a reverse situation shortly after diagnosis, the differences were that the adolescents with cancer reported lower levels of anxiety and depression and higher levels of well-being as measured by the SF-36 sub-scale Vitality.

Table 6. A presentation of HADS and SF-36 scores of the cancer group at T1-T4 and the reference group.

HADS and SF-36 sub-scales	T1		T2		T3		T4		Reference group	
	M (Sd)	M (Sd)	M (Sd)	M (Sd)	M (Sd)	M (Sd)				
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)					

Table 7. A presentation of the estimated mean difference^a between the HADS and the SF-36 scores of the cancer group and the reference group at T1-T4.

HADS and SF-36 subscales	T1		T2		T3		T4	
	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)

^a The estimate is based on the regression coefficient b₃, and is adjusted for age and gender.

*p≤.05, **p≤.01, ***p≤.001.

Study III

The cluster solutions are illustrated graphically in Figure 1 with the means z-transformed to expose for each cluster how the means of each dimension deviate from the mean of the total sample of states (N=214). One unit on the y-axis corresponds to one standard deviation. The mean values of the three dimensions in the total sample are presented as a straight line in the graphs for reference. A deviation of more than 1 standard deviation was considered large.

The characteristics of the cluster solutions including means, standard deviations, total number of individuals in each cluster, and number of individuals in each cluster at T1-T4 are presented in Table 8. Cluster A comprised a state with scores that were very low on mental health, very high on anxiety, and below average on vitality (psychosocial dysfunction); Cluster B scores were very low on vitality and mental health but average on anxiety (poor psychosocial function); Cluster C scores were below average on vitality and anxiety and around average on mental health (incomplete psychosocial function); Cluster D scores were above average on vitality and mental health and average on anxiety (good psychosocial function); Cluster E scores were very high on vitality and mental health and very low on anxiety (excellent psychosocial function).

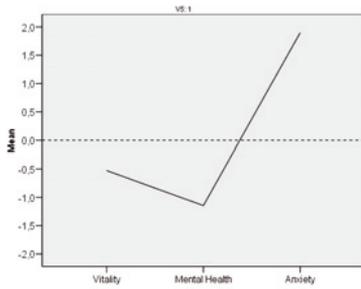
At T1 more adolescents than expected by chance were found in states A ($p<.05$) and C ($p<.01$) and fewer than expected in states D ($p<.05$) and E ($p<.001$). At T3 fewer adolescents than expected were found in state C ($p<.05$) and more were found in state D ($p<.05$). At T4 fewer adolescents than expected were found in state C ($p<.05$) and more were found in state E ($p<.001$).

Agglomerating over time, more girls and fewer boys than expected by chance were found in state A ($p<.05$) and more boys and fewer girls were found in state C ($p<.01$ and $p<.05$ respectively). In state B older adolescents (16-19 years at diagnosis) were more frequent than expected by chance ($p<.05$), whereas younger adolescents (13-15 years at diagnosis) were less frequent ($p<.05$).

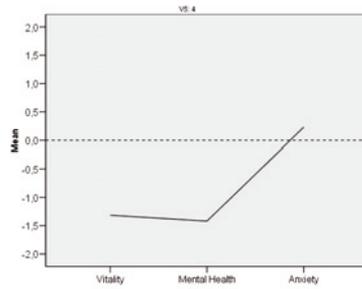
At T1 more girls than expected by chance were found in state A ($p<.05$) and fewer were found in state E ($p<.05$). At T3 fewer girls were found in state B ($p<.05$), whereas more were found in state D ($p<.05$). At T4 more girls were found in state E ($p<.05$). Boys were found more often than expected by chance in state C at T1 ($p<.01$) and less in state E ($p<.01$). At T3 and T4 fewer boys were found in state C ($p<.01$) whereas more boys were found in state E at T4 ($p<.05$).

States A-C all had higher scores on the HADS Depression scale than states D and E: A>D, $p<.001$; A>E, $p<.001$; B>D, $p<.001$; B>E, $p<.001$; C>D, $p<.01$; and C>E, $p<.001$. State D had higher scores on the HADS Depression scale than state E ($p<.01$).

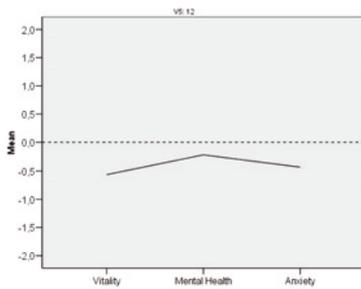
A. Psychosocial dysfunction



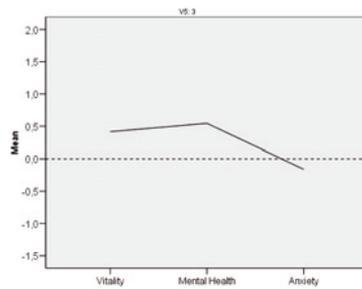
B. Poor psychosocial function



C. Incomplete psychosocial function



D. Good psychosocial function



E. Excellent psychosocial function

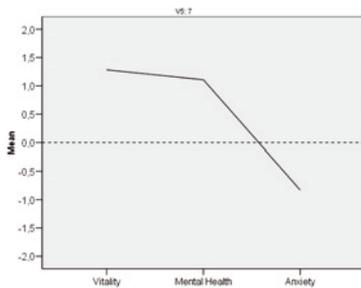


Figure 1. The cluster solution describing five psychosocial states.

Table 8. A presentation of mean values, standard deviations, total number of individuals in each cluster, and number of individuals in each cluster at T1-T4.

Cluster	Vitality		Mental Health		Anxiety		T1		T2		T3		T4	
	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	n	N (%)	n	n	n	n	n	n
A: Psychosocial dysfunction	48.6 (19.5)	52.7 (14.9)	10.1 (3.0)	29 (14)	13	6	6	4						
B: Poor psychosocial function	30.0 (12.9)	47.7 (9.1)	4.9 (1.8)	26 (12)	10	9	4	3						
C: Incomplete psychosocial function	47.8 (17.9)	69.7 (9.7)	2.8 (1.6)	47 (22)	23	15	4	5						
D: Good psychosocial function	70.8 (11.6)	83.5 (7.5)	3.7 (1.6)	78 (36)	15	19	26	18						
E: Excellent psychosocial function	91.3 (8.1)	93.8 (6.7)	1.6 (1.1)	34 (16)	0	6	10	18						
All	61.1 (23.5)	73.5 (18.2)	4.1 (3.1)	214	61	55	50	48						

Study IV

See Table 9 for a presentation of categories, category content, examples of recording units, and number of recording units in response to the question: What, if anything, is bad for you due to the cancer disease? Seven respondents stated that at present nothing was bad due to the cancer disease. Four categories of negative experiences were identified: a problematic body, unpleasant thoughts and feelings, outside the circle of friends, and difficulties with schoolwork.

See Table 10 for a presentation of categories, category content, examples of recording units, and number of recording units in response to the question: What, if anything, is good for you due to the cancer disease? Two respondents stated that at present nothing was good for them due to the disease. Six categories of positive experiences were identified: a more positive view of life, good self-esteem, knowledge and experience with regard to disease and hospital care, good relations, broader perspectives, and material gains.

Table 9. A presentation of categories, category content, examples of recording units, and number of recording units in response to the question: *What, if anything, is bad for you due to the cancer disease?* (N=38)

Category	Content	Examples of recording units	n
A problematic body	Physical and appearance problems and the consequences of these	“I have had a muscle removed from my leg, so I have problems walking on uneven surfaces.” (male, 16 years)	25
Unpleasant thoughts and feelings	Unpleasant thoughts and feelings e.g. with regard to relapse and memories from hospital visits and in connection with questions about the disease	“It’s probably thoughts mainly...that it’s coming, that you can get it back.” (female, 17 years)	17
Outside the circle of friends	Being isolated or having lost touch with friends	“Yes, you kind of get a bit isolated...from people...so that you...mmm...think that they don’t kind of want to know about you any more like. That maybe they can’t handle knowing about it or something like that. So then you stay at home... They kind of disappear. They kind of look away when you come like.” (female, 18 years)	5
Difficulties with school work	School work takes a lot of effort and energy and extra work is necessary to catch up on missed time at school	“Well, some exams here and the odd course where I wasn’t, which I missed as I was away that term, like.” (male, 20 years)	4

Table 10. A presentation of categories, category content, examples of recording units, and number of recording units in response to the question: *What, if anything, is good for you due to the cancer disease?* (N=38)

Category	Content	Examples of recording units	n
A more positive view of life	Another view of life. An awareness of death means that problems assume other proportions and that the presents and day-to-day life are at the centre of things	"I think like more about positive things like, really appreciate day-to-day life...and that you appreciate all the small things more, I think that is definitely true." (male, 18 years)	19
Good self-esteem	An inner change with regard to maturity and development into a responsible person with good self-esteem, amongst other things regarding the person's own body	"I feel mentally stronger. It is kind of like nothing can stand in my way. I can manage everything..." (female, 17 years)	16
Knowledge and experience with regard to disease and hospital care	Knowledge and experience of disease and a secure relationship with hospital care	"So I like it when I can go in for check-ups, meet the children, the doctors and the nurses." (female, 17 years)	14
Good relations	Good ability to understand and thus help other people. Values close relations with friends and other people	"When I hear others say that: I have had such a terrible time, so I have learnt...But it is actually so that I, I don't really know how to put my finger on it, but I have so much more, so much more understanding or empathy for people who are in a bad...or worse way or whatever..." (male, 21 years)	11
Broader perspectives	New leisure-time activities and occupational plans	"It has made me think...that I maybe will become a doctor." (male, 17 years)	4
Material gains	New things, social insurance, etc.	"It's some consolation that I also get social insurance money." (male, 17 years)	2

Study V

Life values

Positive consequences with regard to existential aspects [50], a deeper appreciation of life [45, 61, 63, 75], enjoying life more [45], worrying less, and living more for today [45] than before the disease were reported in studies with a descriptive design and were assigned to the theme life values. Only one study [108] with a comparative design was identified with regard to this theme. No positive consequence was reported in this study.

Relations to others

Increased empathy [75] and a desire to help others [75], stronger bonds to the family [61, 75] and friends [75], and more positive relations to others [58] than before the disease were reported in studies with a descriptive design and were assigned to the theme relations to others. See Table 11 for a presentation of results in studies with a comparative design with regard to this theme. A more positive attitude towards the family [70], a preference for interacting with others [83], more positive emotions when interacting with others [83], better social relationships [70], and less anti-social behaviour [69] than for comparison groups were expressed by self-reports. Teachers reported less aggressive and disruptive behaviour for survivors than for a comparison group [112].

Table 11. *A presentation of results in studies with a comparative design, published 1990-2005 (n=45), investigating whether survivors of childhood cancer differ from comparison groups with regard to the theme relations to others.*

Category	Results ^a		
	+	=	-
Family function	[70]	[65, 88, 99, 104, 108]	[65, 83, 103, 104]
Social life	[69, 70, 83]	[53, 63, 65, 77, 83, 88, 91, 97, 101, 103, 106, 109, 110]	[11, 53, 65, 69, 77, 93, 95, 99, 103]
Relation to friends		[97, 111, 112]	[78, 83, 93, 109, 111, 112]
Behaviour in school	[112]	[97, 109, 111, 112]	[97, 111, 112]
Living with parents		[69, 80, 92]	[62, 89, 90]
Marital status/ Cohabiting		[63, 64, 80, 87, 96, 107]	[62, 69, 82, 84, 89-92, 94, 95, 98, 100, 105, 114, 115]
Sexuality		[65, 70, 73, 102]	[69, 83, 89, 93, 102]
Parenthood		[62, 64, 80, 81, 96]	[82, 85, 86, 90, 92, 98]

^a (+) = Significantly more positive ratings, indicating higher function, better well-being, and/or fewer symptoms for the cancer group compared to the comparison group; (=) = Non-significant result, indicating no difference between the cancer group and the comparison group; (-) = Significantly more negative ratings, indicating lower function, worse well-being, and/or more symptoms for the cancer group compared to the comparison group.

Relation to self

Findings from studies with a descriptive design demonstrate that survivors experience that their personality has changed for the better due to the cancer disease [50, 61, 63], that they feel more mature than others of the same age [59, 63], that the illness has given them strength [45, 59], and they experience positive differences with regard to developmental/personality aspects [50, 58]. In addition, they feel more positive [45, 59], confident [45], and independent than before the disease [45]. These consequences were assigned to the theme relation to self. See Table 12 for a presentation of results in studies with a comparative design with regard to this theme.

Table 12. *A presentation of results in studies with a comparative design, published 1990-2005 (n=21), investigating whether survivors of childhood cancer differ from comparison groups with regard to the theme relation to self.*

Category	Results ^a		
	+	=	-
Global self-esteem	[70]	[46, 63, 65, 76, 77, 79, 83, 88, 91, 97, 99, 103, 109, 110]	[46, 78, 107]
Self-esteem with regard to appearance	[70, 91, 113]	[53, 68, 76, 79, 88, 97, 103, 109, 110]	[65, 68]
Self-esteem with regard to emotional function	[76]	[76, 77, 79]	[46]
Self-esteem with regard to competence	[76]	[46, 77, 79, 88, 97, 103, 109, 110]	[46, 79, 103]
Self-esteem with regard to personality/behaviour	[76]	[79, 88, 97, 103, 109, 110]	[69]
Self-esteem with regard to relations		[46, 76, 77, 79, 88, 97, 103, 109, 110]	

^a (+) = Significantly more positive ratings, indicating higher function, better well-being, and/or fewer symptoms for the cancer group compared to the comparison group; (=) = Non-significant result, indicating no difference between the cancer group and the comparison group; (-) = Significantly more negative ratings, indicating lower function, worse well-being, and/or more symptoms for the cancer group compared to the comparison group.

According to self-reports, survivors experience better total self-esteem [70], a better body image [70], worry less about what their own body looks like [91, 113], experience higher levels of happiness and satisfaction [76], and have a better self-esteem with regard to intellectual and school status and behaviour [76] than comparison groups.

DISCUSSION

General discussion

The most striking finding in this thesis is the shift over time from poor to good, or even excellent, psychosocial function among adolescents with cancer, as demonstrated in Studies II and III.

In Study I the telephone mode resulted in a higher response rate, better self-rated psychosocial function, and a larger percentage of ceiling effects compared to the postal mode. In addition, a visual inspection of Cronbach's alpha values by mode of administration demonstrates overall lower values for scales in the telephone mode. In the postal mode a higher proportion of males than females chose not to participate. The youngest age group (13-15 years) responded to the two modes in a reverse pattern compared to the older age groups: they reported better psychosocial function when approached with a postal questionnaire versus with a telephone interview.

Shortly after diagnosis the cancer group rated their psychosocial function as worse compared with adolescents in the general population. However, the differences gradually disappeared over time and were then reversed, resulting in the cancer group reporting better vitality and lower levels of anxiety and depression than the reference group eighteen months after diagnosis.

During the first eighteen months after diagnosis five distinct psychosocial states were identified, characterised by: psychosocial dysfunction (state A), poor psychosocial function (state B), incomplete psychosocial function (state C), good psychosocial function (state D), and excellent psychosocial function (state E). Shortly after diagnosis more adolescents than expected by chance were found in states A and C and fewer found in states D and E. Eighteen months after diagnosis a different pattern emerged, where more adolescents than expected were found in state E and less than expected in state C.

Two years after diagnosis the adolescents reported problems with physical impairment, intrusive thoughts, feelings of alienation, and problems catching up at school. Despite these difficulties, a majority of the participants reported that something good had come out of the disease and its treatment: a more positive view of life, good self-esteem, knowledge and experience with regard to disease and hospital care, good relations, broader perspectives, and material gains.

Positive consequences experienced by survivors with regard to life values, relations to others, and relation to self related to having had cancer during childhood/adolescence were identified through a review of descriptive studies. However, only a small minority of findings from comparative studies indicate that childhood cancer has any positive consequences with regard to relations to others and relation to self. A majority of the results indicate that survivors do not differ from comparison groups, whereas some findings highlight that friendship and marital status are areas of concern, whereas parenthood and sexuality are areas of potential concern. No conclusions about positive consequences with regard to the theme life values can be drawn, as only one study was identified.

Based on findings from Study I, it was probably a wise choice to collect data from adolescents diagnosed with cancer by telephone interviews. The telephone mode resulted in an overall higher response rate compared to the postal mode. Furthermore, a higher proportion of males compared to females chose not to participate in the postal mode. These factors are of great importance especially when the target sample is relatively small. However, findings from Study I highlight that the telephone mode has methodological costs. Firstly, the percentage of ceiling effects was significantly larger for three sub-scales from the SF-36. Secondly, it resulted in overall lower Cronbach's alpha values. However, most importantly the findings illustrate that the telephone mode generally resulted in a higher self-reported psychosocial function than the postal mode. It is very important to bear this fact in mind when comparing data collected through different modes. It can be speculated whether the findings demonstrating better self-reported psychosocial function and a larger percentage of ceiling effects in the telephone mode are consequences of social desirability. Social desirability refers to a tendency to answer questions according to prevailing social norms [132]. The phenomena may more likely occur when respondents do not feel anonymous, for instance in a telephone interview [133]. This may, in turn, affect the internal reliability of the scales. However, the respondents' willingness to describe negative, as well as positive, experiences in Study IV pleads against the idea that social desirability has had an effect on the findings.

Little attention has been paid to potential interaction effects of mode of administration and age on self-reported psychosocial function. Consequently, the findings from Study I are important with regard to this issue. Young adolescents (13-15 years), in contrast to the older age groups, reported lower values on the HADS Anxiety scale and higher values on the SF-36 sub-scales General Health, Vitality, and Mental Health when approached with a postal questionnaire versus a telephone interview. These results are difficult to interpret. It could be argued that people in this group are too young to be influenced by socially desirable norms. It may even be speculated that young adolescents feel uncomfortable sharing personal

characteristics with an unknown adult interviewer. Regardless of why, findings from Study I show that studies aiming at comparing self-reported psychosocial function between different age groups during adolescence need to consider that the mode of administration may influence the results.

That adolescents diagnosed with cancer are initially over-represented in states indicating a less than optimal psychosocial function and report higher levels of depression, lower mental health and vitality than a reference group is hardly surprising. It is well known that the first period after a cancer diagnosis is stressful [8, 42] and all adolescents in the cancer group were treated with chemotherapy, which causes physical distress [8, 10]. However, in spite of this, previous findings have shown that adolescents on cancer treatment do not differ from healthy controls with regard to psychosocial distress [29, 46, 47]. A question that arises when attempting to summarise research within the field of paediatric psychosocial oncology is: Are persons who experience cancer during adolescence worse, comparably, or better psychosocially adjusted than persons of the same age not struck by cancer? Data from Study II suggest that psychosocial function among adolescents with cancer changes for the better over time in relation to population norms.

The shift over time, demonstrated in Studies II and III, from poor to good or even excellent psychosocial function together with reported positive experiences in Study IV indicate that there may exist some positive psychosocial consequences related to having had cancer during adolescence. The assumption that suffering and distress may cause a positive life change is thousands of years old [134]. However, it is not until the 1980s that research has focused on the possibility of growth from a struggle with a trauma [135]. Tedeschi and Calhoun (1996) have identified five categories of positive changes after a trauma, indicating posttraumatic growth: an increased appreciation of life; closer, more intimate, and more meaningful relationships with others; a general sense of increased personal strength; identification of new possibilities for one's life, and growth in the domain of spiritual and existential matters [135]. In this perspective, it is not unreasonable to assume that perceptions of one's psychosocial function may change for the better when faced with a serious illness. The assumption is supported by findings from a qualitative study of psychosocial thriving in childhood cancer survivors [136] in which the majority of the participants reported a variety of positive changes, all underscored by a metanarrative of psycho-spiritual growth. It may seem contradictory that at the same time as the participants described positive experiences two years after diagnosis, they also described various physical, as well as psychosocial, aspects of distress related to the cancer disease. However, the findings may be related to results by Barakat et al. (2006) demonstrating that posttraumatic growth is positively associated with perceived treatment severity and life threat among survivors of cancer during adolescence [15]. Furthermore, it has been concluded that the best predictor of positive psychosocial outcome after a

traumatic event is a balance between individuals' perceptions of positive changes and the recognition of negative sequelae [134].

The findings indicating positive consequences with regard to cancer during adolescence may also be explained by a response-shift involving changed internal standards, values, and the conceptualisation of e.g. psychosocial function [137]. Such a change may involve being satisfied with less and finding meaning in the ordinary.

The concepts of posttraumatic growth and response shift describe similar processes. They both lead to a change for the better in perceived quality of life, and may be hard 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 increased strength when faced with a difficult situation; new depths and other positive attributes are added to the personality [134]. Response shift, on the other hand, is focused on acceptance; an individual learns to adapt expectations and standards to a lower level [137]. 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 are more situational. Whether the identified positive consequences reported in this thesis persist at three, four, and eight years after diagnosis is at present being investigated within the project "Psychosocial and health-economic consequences of cancer during adolescence".

On the basis of findings from Studies II and III, as well as from previous studies [9, 138], it can be concluded that most adolescents diagnosed with cancer accommodate well. Several factors have been identified that contribute to good psychosocial function in the context of significant adversity, for example good cognitive abilities and self-esteem [139]. Close relationships with parents, other adults and peers, parents' education and socioeconomic status, effective schools and good public health care with high availability are other contributing factors [140]. An important aspect for paediatric oncology care is to identify individuals who lack these protective factors as well as individuals who will remain in poor psychosocial states over time. Routinely assessing protective factors as well as psychosocial distress could be an accessible way of identifying adolescents at risk. The findings from Studies II and III indicate that it is important that psychosocial interventions are planned carefully in order not to disrupt the natural recovery process that most adolescents experience. Interventions aiming at targeting psychosocial function also ought to provide support to enhance a positive outcome, for example offer parent education classes, provide a tutor, build self-esteem, and teach effective coping strategies for specific threatening situations [140]. In order to achieve the best psychosocial outcome it is necessary to explore at what point in the course of disease interventions should be provided.

Study V demonstrated that survivors report poorer function for friendship [93] as well as lower satisfaction with friendship [83] compared to healthy controls. Furthermore, reports by parents demonstrate that survivors less often use friends as confidants [78] and have fewer close friends [78] than healthy controls while reports by teachers demonstrate that survivors are less popular than peers [109] and reports by peers indicate that survivors less often than peers are selected as best friends [111, 112]. Other findings indicate that survivors are more sensitive and isolated in class compared to healthy controls [97, 111, 112]. These results are consistent with results from Study IV demonstrating that participants, two years after diagnosis, express concerns about catching up with school work as well as missing former friends. It is well known that cancer treatment often leads to interruption of schoolwork and relationships with others [10, 43, 51]. Research has mainly focused on school attendance [141], but there is a need to further explore the link between school absence and social isolation. For example more considerations need to be given to adolescent's other activities, e.g. participating in leisure activities.

Various findings indicate that fewer survivors of cancer during childhood or adolescence than healthy controls are married/cohabit [62, 69, 82, 84, 89-92, 94, 95, 98, 100, 105, 114, 115]. Concerns about sexuality, future fertility, and the health of future children [142, 143] may explain the findings. It has been concluded that cancer during childhood and adolescence and subsequent treatment in general do not have a significant impact on pregnancy outcomes and the health of offspring [144]. However, a number of studies show that survivors are uncertain about their fertility status [61, 90, 113, 115] and findings from one study show that almost 20% of young women who have survived cancer report high anxiety about pregnancy causing a recurrence and fear of birth defects [143]. On the other hand, findings from another study demonstrate that survivors report the same intentions as healthy controls with regard to having children [81]. Another factor that may influence intimate relationships is sexuality. It has been reported that survivors have delayed sexual development [69], report sexual dysfunction [93] as well as dissatisfaction with their sex lives [83]. It has been hypothesised that a perceived loss of opportunity for parenthood may be devastating for self-esteem and damaging to marital or other intimate relationships [60]. Taken together the findings indicate that psychosocial factors related to cancer may influence survivors' and their partners' decision about becoming parents. The relationship between worries about fertility issues, sexual function, marital status, and parenthood after childhood cancer may illustrate an important clinical problem and should be further explored.

Identified categories about positive consequences due to having had cancer in Study IV are consistent with reported positive consequences from survivors in descriptive studies reviewed in Study V. However, the identified

areas of concern in Study V highlight a need to further explore late psychosocial effects of cancer. This research should focus on psychosocial, as well as medical variables identifying risk and protective factors for cancer survivorship and consequences of survivorship [6]. Hopefully, the negative results identified in Study V will not hold true for those children and adolescents struck by cancer during the 21st century. To further illuminate the psychosocial consequences of cancer during adolescence interdisciplinary studies are needed and as a means towards clinically meaningful research, so-called psychosocial variables should be included in central registers of paediatric cancer.

Methodological discussion

Study I

In Study I the sample was randomly chosen and weighted in order to reflect the target population. Furthermore, the sample was stratified with regard to gender, age group, and region. The latter was important as the findings revealed an interaction effect between age and mode of administration.

Study II-IV

A methodological strength of Studies II-IV is the relative homogeneity of the sample with regard to age and time since diagnosis. The sample may, however, be considered small and heterogeneous with regard to diagnoses. This circumstance is difficult to overcome, as the Swedish adolescent population diagnosed with cancer is very small. It can be speculated that the findings would have revealed a more negative picture of the participants' psychosocial function if more adolescents diagnosed with CNS tumours had been included [9, 92, 145]. Whether the speculation holds true would be interesting to explore in a future study, focusing on adolescents diagnosed with a CNS tumour. In order to obtain a sample of the present size, adolescents with cancer were included for over four years at three of the six Swedish paediatric oncology centres and the sample together with the longitudinal design are methodological strengths, even in an international perspective.

Another methodological strength is that all data for the cancer group as well as for the reference group were collected by the same mode of administration, i.e. telephone interviews. This is of importance as Study I shows that mode of administration has a decisive influence on adolescents' self-reported psychosocial function.

When choosing instruments to be used in the project, "Psychosocial and health-economic consequences of cancer during adolescence", two main factors were considered. One of them was that the cancer group should be

followed for at least eight years resulting in an age range from 13 to at least 27. Another was that comparisons between adolescents and young adults diagnosed with cancer during adolescence and healthy controls should be made with regard to psychosocial function. Bearing these factors in mind, two extensively used instruments were chosen: the HADS and the SF-36. Both were considered adequate and valid for use with adolescents as well as young adults [116, 121]. The shift over time demonstrated in Studies II and III, from poor to good psychosocial function, highlights a need to acknowledge human functioning in terms of strengths and environmental resources in addition to deficiencies and stressors when struck by serious illness. Such a perspective, in psychosocial oncology, will teach us how to better prevent and treat psychosocial dysfunction.

It has been suggested [17] that the HADS Depression scale is not suitable for screening of depression among adolescents on cancer treatment. However, the scale discriminated between dysfunctional (A-C) as well as functional states (D and E). In addition to these findings, it is important to mention that the face validity [133] of the HADS was judged as good both by the interviewers in Study I (SCB) and II-III (the author). Taken together, despite a low alpha value, the HADS Depression scale seems to identify psychosocial distress among adolescents.

Studies on the psychosocial consequences of cancer during adolescence have most often investigated within-group differences over time, between-group differences, and associations between psychosocial function and medical parameters. Data from such studies do not provide meaningful information on how to help and support certain individuals. As a means towards this end, Study III tried to sort individuals' responses on different psychosocial measures in a clinically meaningful way. Special methodological efforts were taken to ensure the validity of the discovered classificatory structure and these verified the cluster solution.

Several circumstances may have contributed to detection of a large part of the investigated phenomena in Study IV. Among these it can be mentioned that the interviewer had an extensive experience of interviewing patients and participants in different studies and that the participants previously had been interviewed within the same project four times. These circumstances may have increased the participants' willingness to respond to the questions and thereby the credibility of the findings.

A number of studies have demonstrated that emotional disclosure can provide improvements in physical and psychological health for individuals with chronic diseases [146-148]. It can therefore be speculated whether the improvements in psychosocial function over time, as demonstrated in Studies II and III, at least partly depend on repeated assessments giving the participants an opportunity to disclose their concerns. Whether the findings in Studies II and III are related to this circumstance can not be concluded on the basis of the design of these studies. However, the possibility that

repeatedly answering questions about psychosocial function is related to a positive psychosocial outcome is presently investigated by our research group.

Study V

The aim of the review of the literature was not only to explore positive experiences related to childhood/adolescent cancer described by survivors, but also to try to verify to what extent the reported positive experiences were supported by findings from comparative studies investigating related variables. This approach is, to our knowledge, new and may add some knowledge to the debate about whether there are any positive and negative consequences after childhood/adolescence cancer, and if so, which these are.

Efforts were made to assess the scientific value of the reviewed studies and thereby the validity of the findings from the respective studies. Due to methodological shortcomings in the studies, we did not succeed in these efforts. Consequently, each result has been given equal importance in the presentation of the findings.

Conclusions and implications

- Mode of administration influences adolescents' and young adults' self-reported psychosocial function and is related to age. This is important to consider both when planning how to collect data within a study and when comparing data between studies.
- Psychosocial function increases with time from diagnosis for most adolescents diagnosed with cancer. However, some individuals remain in poor psychosocial states during the first eighteen months after diagnosis. Increased efforts should be taken to identify these individuals. As a means towards this end, identifying factors related to increased risk to remain in poor psychosocial states after a diagnosis of cancer during adolescence should be taken.
- Friendship and marital status are areas of concern for survivors of childhood and adolescent cancer.
- It is recommended that individuals struck by cancer during adolescence are followed up by multi-professional teams focusing not only on physical but also on psychological aspects. The follow-up and subsequent treatment and care should be planned and provided in order not to disrupt, but to support, the natural recovery process that most persons diagnosed with cancer during adolescence experience.

Future perspectives

The conclusions presented above are based on data collected during the first two years after a cancer diagnosis during adolescence. Data collected at three, four, and eight years after diagnosis will reveal whether the conclusions presented in this thesis will hold true and if the identified positive consequences will persist. Future studies from our group will also aim at revealing at what time during the disease trajectory it is most effective to provide psychological support to individuals diagnosed with cancer during adolescence, in order to prevent poor long-term psychosocial function.

Acknowledgement

Writing a thesis is definitely not a one-man job! I have been surrounded by people who have untiringly given me help and supported me, not only in the scientific work, but also through their friendship. My warm thanks to you all! I would especially like to thank the following people, without whose support this thesis would never have seen the light of day:

All study participants, who patiently answered all our questions and allowed us to share thoughts and experiences with regard to being struck by cancer as a teenager.

Louise von Essen, my supervisor, for getting me to aim even higher, when I thought it was impossible. You are the best supervisor I could ever have wished for!

Gustaf Ljungman, my co-supervisor. Thanks for always giving priority to our research in your tight schedule. Your clinical insight has been invaluable!

Katarina Steen-Karlsson, my co-supervisor at the Vårdal Institute, for your enthusiasm and support and for bringing in a health-economic perspective into our project.

Björn Lindgren, former Research Director at the Vårdal Institute and co-writer, for constructive criticism and the job satisfaction that you passed on to all of us in the working group at the Vårdal Institute.

Ingalill Rahm Hallberg, Head of the Vårdal Institute, for becoming an extraordinary role model for all doctoral students at the Vårdal Institute.

All members of our research team: **Johan Arvidsson**, for reading my thesis and providing constructive advice on how to improve it. **Gun Engvall**, for your ideas and enthusiasm for further developing the research project concerning adolescents struck by cancer. I look forward to continuing to work with you! **Camilla Fröjd**, for never-ending support and for having given me a new guiding star to follow: “Irrespective of whether you think you can do it or not, you will be right.” **Susanne Lorenz**, for all the warmth and consideration you show me and everyone else at the Department. **Ulrika Pöder**, for all the discussions about big and small research issues and other things of this world, and never-ending support. Thanks also to: **Therese Berglund**, **Kristina Haglund**, **Mariann Hedström**, **Lena Hedén**, and **Annika Lindahl Norberg**. You have all contributed to this thesis by advice,

constructive criticism, enthusiasm, hard work, inspiration, laughs, scientific discussions and support!

Anna Jörngården, Bassam El-Khoury, Anders Rignér, and Lena Wettergren for being the most brilliant co-writers I could ever wish for. It has been a pleasure working with you!

Coordinating nurses **Britt Fällman, Yvonne Håkansson, LizBeth Blennerup Persson, Lise-Lott Pettersson, and Lotta Öijen** for invaluable help with recruitment of study participants.

Thanks to **all colleagues at the Department of Public Health and Caring Sciences** for support and inspiration. Special thanks to **Per Lindberg and Maj-Britt Sundelin** for administrative support during the years.

The Vårdal Institute and its co-workers for support and inspiration.

Lars Holmberg, my former boss at the Regional Oncologic Center, for introducing me to the world of science and for always taking time to guide me through this complicated world.

Annette Eriksson, Gerd Rödahl, Katarina Schoning, Barbro Wadensten, Kerstin Wilbrand, and Ulla and Ian Zettersten for always being there and giving me a push up all the hills.

And last, but not least: my family! **Stefan**, my husband, for love and consideration through thick and thin. What would life be without you? Thank you for always being by my side. My children **Peter, Moa, and Julia** for always getting me to remember what it is that makes life worth living.

This thesis was supported by grants from **the Swedish Children Cancer Foundation** and the **Swedish Cancer Society**.

REFERENCES

1. Whyte F, Smith L. A literature review of adolescence and cancer. *Eur J Cancer Care (Engl)* 1997; **6**: 137-46.
2. Bleyer WA. Cancer in older adolescents and young adults: epidemiology, diagnosis, treatment, survival, and importance of clinical trials. *Med Pediatr Oncol* 2002; **38**: 1-10.
3. Fabes R, Martin CL. *Exploring child development*. Needham Heights, MA; 2003.
4. Ries L, Eisner M, Kosary C, et al. *SEER Cancer Statistic Review, 1973-1999*. Bethesda: MD: National Cancer Institute; 2002.
5. Jemal A, Clegg LX, Ward E, et al. Annual report to the nation on the status of cancer, 1975-2001, with a special feature regarding survival. *Cancer* 2004; **101**: 3-27.
6. Reaman GH. Pediatric cancer research from past successes through collaboration to future transdisciplinary research. *J Pediatr Oncol Nurs* 2004; **21**: 123-7.
7. Balis FM, Holcenberg JS, Blaney SM. *General principles of chemotherapy, in Pizz, PA., Poplack DG. (eds): Principles and practice of pediatric oncology, pp 237-308*. Philadelphia: Lippincott Williams & Wilkins; 2002.
8. Collins JJ, Byrnes ME, Dunkel IJ, et al. The measurement of symptoms in children with cancer. *J Pain Symptom Manage* 2000; **19**: 363-77.
9. Langeveld NE, Stam H, Grootenhuis MA, Last BF. Quality of life in young adult survivors of childhood cancer. *Support Care Cancer* 2002; **10**: 579-600.
10. Enskär K, Carlsson M, Golsäter M, Hamrin E. Symptom distress and life situation in adolescents with cancer. *Cancer Nurs* 1997; **20**: 23-33.
11. Eiser C, Cool P, Grimer RJ, et al. Quality of life in children following treatment for a malignant primary bone tumour around the knee. *Sarcoma* 1997; **1**: 39-45.
12. Elad P, Yagil Y, Cohen L, Meller I. A jeep trip with young adult cancer survivors: lessons to be learned. *Support Care Cancer* 2003; **11**: 201-6.
13. Centre for Epidemiology NBoHaW, Sweden. *Cancer Incidence in Sweden 2005. Official Statistics of Sweden. Health and Diseases*

2007:3 <http://www.socialstyrelsen.se/Publicerat/2007/9514/2007-42-3.htm>, PDF.

14. Kreuger A, Berglund G, Garwicz S, et al. Acute lymphatic leukemia in Swedish children 1968-2001. The marked improvement of the survival can be ascribed to successful treatment. *Läkartidningen* 2004; **101**: 3890, 3-4, 7-8.
15. Barakat LP, Alderfer MA, Kazak AE. Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *J Pediatr Psychol* 2006; **31**: 413-9.
16. Eiser C, Hill JJ, Vance YH. Examining the psychological consequences of surviving childhood cancer: systematic review as a research method in pediatric psychology. *J Pediatr Psychol* 2000; **25**: 449-60.
17. Hedström M, *Distress among Adolescents with Cancer, Faculty of Medicine*. 2005, Uppsala University: Uppsala.
18. Perkins JJ, Sanson-Fisher RW. An examination of self- and telephone-administered modes of administration for the Australian SF-36. *J Clin Epidemiol* 1998; **51**: 969-73.
19. Lyons RA, Wareham K, Lucas M, Price D, Williams J, Hutchings HA. SF-36 scores vary by method of administration: implications for study design. *J Public Health Med* 1999; **21**: 41-5.
20. McHorney CA, Ware JE, Lu JF, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Med Care* 1994; **32**: 40-66.
21. Cheung YB, Goh C, Thumboo J, Khoo KS, Wee J. Quality of life scores differed according to mode of administration in a review of three major oncology questionnaires. *J Clin Epidemiol* 2006; **59**: 185-91.
22. Wu AW, Jacobson DL, Berzon RA, et al. The effect of mode of administration on medical outcomes study health ratings and EuroQol scores in AIDS. *Qual Life Res* 1997; **6**: 3-10.
23. Garcia M, Rohlfs I, Vila J, et al. Comparison between telephone and self-administration of Short Form Health Survey Questionnaire (SF-36). *Gac Sanit* 2005; **19**: 433-9.
24. Bowling A, Bond M, Jenkinson C, Lamping DL. Short Form 36 (SF-36) Health Survey questionnaire: which normative data should be used? Comparisons between the norms provided by the Omnibus Survey in Britain, the Health Survey for England and the Oxford Healthy Life Survey. *J Public Health Med* 1999; **21**: 255-70.
25. Huebner ES, Valois RF, Suldo SM, et al. Perceived quality of life: a neglected component of adolescent health assessment and intervention. *J Adolesc Health* 2004; **34**: 270-8.
26. Hedström M, Ljungman G, von Essen L. Perceptions of distress among adolescents recently diagnosed with cancer. *J Pediatr Hematol Oncol* 2005; **27**: 15-22.

27. Stam H, Grootenhuis MA, Caron HN, Last BF. Quality of life and current coping in young adult survivors of childhood cancer: positive expectations about the further course of the disease were correlated with better quality of life. *Psychooncology* 2006; **15**: 31-43.
28. Grant J, Cranston A, Horsman J, et al. Health status and health-related quality of life in adolescent survivors of cancer in childhood. *J Adolesc Health* 2006; **38**: 504-10.
29. Allen R, Newman SP, Souhami RL. Anxiety and depression in adolescent cancer: findings in patients and parents at the time of diagnosis. *Eur J Cancer* 1997; **33**: 1250-5.
30. Bowling A. *Measuring Health*. Buckingham: Open University Press; 2005.
31. Trask PC, Griffith KA. The identification of empirically derived cancer patient subgroups using psychosocial variables. *J Psychosom Res* 2004; **57**: 287-95.
32. Henry DB, Tolan PH, Gorman-Smith D. Cluster analysis in family psychology research. *J Fam Psychol* 2005; **19**: 121-32.
33. Bergman LR, Magnusson D. A person-oriented approach in research on developmental psychopathology. *Dev Psychopathol* 1997; **9**: 291-319.
34. Nagel GC, Schmidt S, Strauss BM, Katenkamp D. Quality of life in breast cancer patients: a cluster analytic approach. Empirically derived subgroups of the EORTC-QLQ BR 23--a clinically oriented assessment. *Breast Cancer Res Treat* 2001; **68**: 75-87.
35. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol* 2003; **13**: 248-66.
36. Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med* 1985; **313**: 270-3.
37. Hinds PS, Quargnenti AG, Wentz TJ. Measuring symptom distress in adolescents with cancer. *J Pediatr Oncol Nurs* 1992; **9**: 84-6.
38. Hockenberry-Eaton M, Hinds PS, Alcoser P, et al. Fatigue in children and adolescents with cancer. *J Pediatr Oncol Nurs* 1998; **15**: 172-82.
39. Hedström M, Haglund K, Skolin I, von Essen L. Distressing events for children and adolescents with cancer: child, parent, and nurse perceptions. *J Pediatr Oncol Nurs* 2003; **20**: 120-32.
40. Ljungman G, Gordh T, Sörensen S, Kreuger A. Pain in paediatric oncology: interviews with children, adolescents and their parents. *Acta Paediatr* 1999; **88**: 623-30.
41. Varni JW, Burwinkle TM, Katz ER. The PedsQL in pediatric cancer pain: a prospective longitudinal analysis of pain and emotional distress. *J Dev Behav Pediatr* 2004; **25**: 239-46.
42. Docherty SL, Sandelowski M, Preisser JS. Three months in the symptom life of a teenage girl undergoing treatment for cancer. *Res Nurs Health* 2006; **29**: 294-310.

43. Cavusoglu H. Problems related to the diagnosis and treatment of adolescents with leukemia. *Issues Compr Pediatr Nurs* 2000; **23**: 15-26.
44. Hedström M, Skolin I, von Essen L. Distressing and positive experiences and important aspects of care for adolescents treated for cancer. Adolescent and nurse perceptions. *Eur J Oncol Nurs* 2004; **8**: 6-17; discussion 8-9.
45. Parry C. Embracing uncertainty: an exploration of the experiences of childhood cancer survivors. *Qual Health Res* 2003; **13**: 227-46.
46. von Essen L, Enskär K, Kreuger A, Larsson B, Sjöden PO. Self-esteem, depression and anxiety among Swedish children and adolescents on and off cancer treatment. *Acta Paediatr* 2000; **89**: 229-36.
47. Neville K. Psychological distress in adolescents with cancer. *J Pediatr Nurs* 1996; **11**: 243-51.
48. Arnold EM. The cessation of cancer treatment as a crisis. *Soc Work Health Care* 1999; **29**: 21-38.
49. Ream E, Gibson F, Edwards J, Seption B, Mulhall A, Richardson A. Experience of fatigue in adolescents living with cancer. *Cancer Nurs* 2006; **29**: 317-26.
50. Lozowski SL. Views of childhood cancer survivors. Selected perspectives. *Cancer* 1993; **71**: 3354-7.
51. Hokkanen H, Eriksson E, Ahonen O, Salanterä S. Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nurs* 2004; **27**: 325-35.
52. Moore IM, Challinor J, Pasvogel A, Matthay K, Hutter J, Kaemingk K. Online exclusive: behavioral adjustment of children and adolescents with cancer: teacher, parent, and self-report. *Oncol Nurs Forum* 2003; **30**: E84-91.
53. Pendley JS, Dahlquist LM, Dreyer Z. Body image and psychosocial adjustment in adolescent cancer survivors. *J Pediatr Psychol* 1997; **22**: 29-43.
54. Duffey-Lind EC, O'Holleran E, Healey M, Vettese M, Diller L, Park ER. Transitioning to survivorship: a pilot study. *J Pediatr Oncol Nurs* 2006; **23**: 335-43.
55. Smith K, Ostroff J, Tan C, Lesko L. Alterations in self-perceptions among adolescent cancer survivors. *Cancer Invest* 1991; **9**: 581-8.
56. Larouche SS, Chin-Peuckert L. Changes in body image experienced by adolescents with cancer. *J Pediatr Oncol Nurs* 2006; **23**: 200-9.
57. Stern M, Norman SL, Zevon MA. Adolescents with cancer. Self-image and perceived social support as indexes of adaptation. *Journal of Adolescent Research* 1993; **8**: 124-42.
58. Novakovic B, Fears TR, Wexler LH, et al. Experiences of cancer in children and adolescents. *Cancer Nurs* 1996; **19**: 54-9.
59. Greenberg H, Meadows A. Psychosocial impact of cancer survival on schoolage children and their parents. *J Psychosoc Oncol* 1991; **9**: 43-56.

60. Zebrack BJ, Casillas J, Nohr L, Adams H, Zeltzer LK. Fertility issues for young adult survivors of childhood cancer. *Psychooncology* 2004; **13**: 689-99.
61. Gray RE, Doan BD, Shermer P, et al. Surviving childhood cancer: A descriptive approach to understanding the impact of life-threatening illness. *Psychooncology* 1992; **1**: 235-45.
62. Felder-Puig R, Formann AK, Mildner A, et al. Quality of life and psychosocial adjustment of young patients after treatment of bone cancer. *Cancer* 1998; **83**: 69-75.
63. Evans SE, Radford M. Current lifestyle of young adults treated for cancer in childhood. *Arch Dis Child* 1995; **72**: 423-6.
64. Dolgin MJ, Somer E, Buchvald E, Zaizov R. Quality of life in adult survivors of childhood cancer. *Soc Work Health Care* 1999; **28**: 31-43.
65. Madan-Swain A, Brown RT, Sexson SB, Baldwin K, Pais R, Ragab A. Adolescent cancer survivors. Psychosocial and familial adaptation. *Psychosomatics* 1994; **35**: 453-9.
66. Chang PN. Psychosocial needs of long-term childhood cancer survivors: a review of literature. *Pediatrician* 1991; **18**: 20-4.
67. Fritz GK, Williams JR. Issues of adolescent development for survivors of childhood cancer. *J Am Acad Child Adolesc Psychiatry* 1988; **27**: 712-5.
68. Puukko LR, Hirvonen E, Aalberg V, Hovi L, Rautonen J, Siimes MA. Impaired body image of young female survivors of childhood leukemia. *Psychosomatics* 1997; **38**: 54-62.
69. Stam H, Grootenhuis MA, Last BF. The course of life of survivors of childhood cancer. *Psychooncology* 2005; **14**: 227-38.
70. Maggiolini A, Grassi R, Adamoli L, et al. Self-image of adolescent survivors of long-term childhood leukemia. *J Pediatr Hematol Oncol* 2000; **22**: 417-21.
71. Zebrack BJ, Zeltzer LK, Whitton J, et al. Psychological outcomes in long-term survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma: a report from the Childhood Cancer Survivor Study. *Pediatrics* 2002; **110**: 42-52.
72. Meeske KA, Ruccione K, Globe DR, Stuber ML. Posttraumatic stress, quality of life, and psychological distress in young adult survivors of childhood cancer. *Oncol Nurs Forum* 2001; **28**: 481-9.
73. Apajasalo M, Sintonen H, Siimes MA, et al. Health-related quality of life of adults surviving malignancies in childhood. *Eur J Cancer* 1996; **32A**: 1354-8.
74. Elkin TD, Phipps S, Mulhern RK, Fairclough D. Psychological functioning of adolescent and young adult survivors of pediatric malignancy. *Med Pediatr Oncol* 1997; **29**: 582-8.
75. Karian VE, Jankowski SM, Beal JA. Exploring the lived-experience of childhood cancer survivors. *J Pediatr Oncol Nurs* 1998; **15**: 153-62.

76. Anholt UV, Fritz GK, Keener M. Self-concept in survivors of childhood and adolescent cancer. *J Psychosoc Oncol* 1993; **11**: 1-16.
77. Arvidson J, Larsson B, Lönnerholm G. A long-term follow-up study of psychosocial functioning after autologous bone marrow transplantation in childhood. *Psychooncology* 1999; **8**: 123-34.
78. Barrera M, Shaw AK, Speechley KN, Maunsell E, Pogany L. Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. *Cancer* 2005; **104**: 1751-60.
79. Bauld C, Anderson V, Arnold J. Psychosocial aspects of adolescent cancer survival. *J Paediatr Child Health* 1998; **34**: 120-6.
80. Boman KK, Bodegård G. Life after cancer in childhood: social adjustment and educational and vocational status of young-adult survivors. *J Pediatr Hematol Oncol* 2004; **26**: 354-62.
81. Byrne J, Fears TR, Mills JL, et al. Fertility of long-term male survivors of acute lymphoblastic leukemia diagnosed during childhood. *Pediatr Blood Cancer* 2004; **42**: 364-72.
82. Byrne J, Fears TR, Mills JL, et al. Fertility in women treated with cranial radiotherapy for childhood acute lymphoblastic leukemia. *Pediatr Blood Cancer* 2004; **42**: 589-97.
83. Gray RE, Doan BD, Shermer P, et al. Psychologic adaptation of survivors of childhood cancer. *Cancer* 1992; **70**: 2713-21.
84. Green DM, Zevon MA, Hall B. Achievement of life goals by adult survivors of modern treatment for childhood cancer. *Cancer* 1991; **67**: 206-13.
85. Green DM, Whitton JA, Stovall M, et al. Pregnancy outcome of female survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *Am J Obstet Gynecol* 2002; **187**: 1070-80.
86. Green DM, Whitton JA, Stovall M, et al. Pregnancy outcome of partners of male survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *J Clin Oncol* 2003; **21**: 716-21.
87. Hays DM, Landsverk J, Sallan SE, et al. Educational, occupational, and insurance status of childhood cancer survivors in their fourth and fifth decades of life. *J Clin Oncol* 1992; **10**: 1397-406.
88. Kazak AE, Chritakis D, Alderfer M, Coiro MJ. Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. *Journal of Family Psychology* 1994; **8**: 74-84.
89. Kokkonen J, Vainionpää L, Winqvist S, Lanning M. Physical and psychosocial outcome for young adults with treated malignancy. *Pediatr Hematol Oncol* 1997; **14**: 223-32.
90. Langeveld NE, Ubbink MC, Last BF, Grootenhuis MA, Voute PA, De Haan RJ. Educational achievement, employment and living situation in long-term young adult survivors of childhood cancer in the Netherlands. *Psychooncology* 2003; **12**: 213-25.
91. Langeveld NE, Grootenhuis MA, Voute PA, de Haan RJ, van den Bos C. Quality of life, self-esteem and worries in young adult survivors of childhood cancer. *Psychooncology* 2004; **13**: 867-81.

92. Lannering B, Marky I, Lundberg A, Olsson E. Long-term sequelae after pediatric brain tumors: their effect on disability and quality of life. *Med Pediatr Oncol* 1990; **18**: 304-10.
93. Mackie E, Hill J, Kondryn H, McNally R. Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukaemia and Wilms' tumour: a controlled study. *Lancet* 2000; **355**: 1310-4.
94. Nagarajan R, Neglia JP, Clohisey DR, et al. Education, employment, insurance, and marital status among 694 survivors of pediatric lower extremity bone tumors: a report from the childhood cancer survivor study. *Cancer* 2003; **97**: 2554-64.
95. Ness KK, Bhatia S, Baker KS, et al. Performance limitations and participation restrictions among childhood cancer survivors treated with hematopoietic stem cell transplantation: the bone marrow transplant survivor study. *Arch Pediatr Adolesc Med* 2005; **159**: 706-13.
96. Nicholson HS, Mulvihill JJ, Byrne J. Late effects of therapy in adult survivors of osteosarcoma and Ewing's sarcoma. *Med Pediatr Oncol* 1992; **20**: 6-12.
97. Noll RB, Bukowski WM, Davies WH, Koontz K, Kulkarni R. Adjustment in the peer system of adolescents with cancer: a two-year study. *J Pediatr Psychol* 1993; **18**: 351-64.
98. Novakovic B, Fears TR, Horowitz ME, Tucker MA, Wexler LH. Late effects of therapy in survivors of Ewing's sarcoma family tumors. *J Pediatr Hematol Oncol* 1997; **19**: 220-5.
99. Olson AL, Boyle WE, Evans MW, Zug LA. Overall function in rural childhood cancer survivors. The role of social competence and emotional health. *Clin Pediatr (Phila)* 1993; **32**: 334-42.
100. Pastore G, Mosso ML, Magnani C, Luzzatto L, Bianchi M, Terracini B. Physical impairment and social life goals among adult long-term survivors of childhood cancer: a population-based study from the childhood cancer registry of Piedmont, Italy. *Tumori* 2001; **87**: 372-8.
101. Pemberger S, Jagsch R, Frey E, et al. Quality of life in long-term childhood cancer survivors and the relation of late effects and subjective well-being. *Support Care Cancer* 2005; **13**: 49-56.
102. Puukko LR, Hirvonen E, Aalberg V, Hovi L, Rautonen J, Siimes MA. Sexuality of young women surviving leukaemia. *Arch Dis Child* 1997; **76**: 197-202.
103. Radcliffe J, Bennett D, Kazak AE, Foley B, Phillips PC. Adjustment in childhood brain tumor survival: child, mother, and teacher report. *J Pediatr Psychol* 1996; **21**: 529-39.
104. Rait DS, Ostroff JS, Smith K, Cella DF, Tan C, Lesko LM. Lives in a balance: perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. *Fam Process* 1992; **31**: 383-97.
105. Rauck AM, Green DM, Yasui Y, Mertens A, Robison LL. Marriage in the survivors of childhood cancer: a preliminary description from

- the Childhood Cancer Survivor Study. *Med Pediatr Oncol* 1999; **33**: 60-3.
106. Recklitis C, O'Leary T, Diller L. Utility of routine psychological screening in the childhood cancer survivor clinic. *J Clin Oncol* 2003; **21**: 787-92.
 107. Seitzman RL, Glover DA, Meadows AT, et al. Self-concept in adult survivors of childhood acute lymphoblastic leukemia: a cooperative Children's Cancer Group and National Institutes of Health study. *Pediatr Blood Cancer* 2004; **42**: 230-40.
 108. Shankar S, Robison L, Jenney ME, et al. Health-related quality of life in young survivors of childhood cancer using the Minneapolis-Manchester Quality of Life-Youth Form. *Pediatrics* 2005; **115**: 435-42.
 109. Sloper T, Larcombe IJ, Charlton A. Psychosocial adjustment of five-year survivors of childhood cancer. *J Cancer Educ* 1994; **9**: 163-9.
 110. Spirito A, Stark LJ, Cobiella C, Drigan R, Androkites A, Hewett K. Social adjustment of children successfully treated for cancer. *J Pediatr Psychol* 1990; **15**: 359-71.
 111. Vannatta K, Gartstein MA, Short A, Noll RB. A controlled study of peer relationships of children surviving brain tumors: teacher, peer, and self ratings. *J Pediatr Psychol* 1998; **23**: 279-87.
 112. Vannatta K, Zeller M, Noll RB, Koontz K. Social functioning of children surviving bone marrow transplantation. *J Pediatr Psychol* 1998; **23**: 169-78.
 113. Weigers ME, Chesler M-A, Zebrack B-J, Goldman S. Self-reported worries among long-term survivors of childhood cancer and their peers. *J Psychosoc Oncol* 1998; **16**: 1-23.
 114. Zebrack BJ, Gurney JG, Oeffinger K, et al. Psychological outcomes in long-term survivors of childhood brain cancer: a report from the childhood cancer survivor study. *J Clin Oncol* 2004; **22**: 999-1006.
 115. Zevon MA, Neubauer NA, Green DM. Adjustment and vocational satisfaction of patients treated during childhood or adolescence for acute lymphoblastic leukemia. *Am J Pediatr Hematol Oncol* 1990; **12**: 454-61.
 116. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992; **30**: 473-83.
 117. Ware JE, Kosinski M. Interpreting SF-36 summary health measures: a response. *Qual Life Res* 2001; **10**: 405-13; discussion 15-20.
 118. Ware JE, Snow K, Kosinski M, Gandek B. *SF-36 Health Survey Manual and Interpretation Guide*. Boston: New England Medical Centre, The Health Institute; 1993.
 119. Jörngården A, Wettergen L, von Essen L. Measuring health-related quality of life in adolescents and young adults: Swedish normative data for the SF-36 and the HADS, and the influence of age, gender, and method of administration. *Health Qual Life Outcomes* 2006; **4**: 91.

120. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression scale. *Acta Psychiatr Scand* 1983; **67**: 361-70.
121. White D, Leach C, Sims R, Atkinson M, Cottrell D. Validation of the Hospital Anxiety and Depression Scale for use with adolescents. *Br J Psychiatry* 1999; **175**: 452-4.
122. Weber R. *Basic Content Analysis*. London: Sage Publications; 1990.
123. Streiner D,GR. N. *Health Measurement Scales. A practical guide to their development and use. 2nd ed.* New York: Oxford University Press; 1995.
124. Bergman LR, El-Khoury BM. Studying individual patterns of development using I-States as objects analysis (ISOA). *Biometrical Journal* 1999; **41**: 753-70.
125. Bergman LR, El-Khoury BM. *Studying individual development in an interindividual context: a person-oriented approach*. London: LEA, Lawrence Earlbaum Associates; 2003.
126. Milligan GW. *Clustering validation: Results and implications for applied analyses, in Arabie P, Hubert L, De Soete G. (eds.): Clustering and classification*. River Edge, NJ: World Scientific Press Publishers Co.; 1996.
127. Bergman LR. You can't classify all of the people all the time. *Multivariate Behavioral Research* 1988; **23**: 425-41.
128. Bergman LR. A pattern-oriented approach to studying individual development: Snapshots and processes, in Cairns RB, Bergman LR., Kagan J. (eds): *Methods and Models for Studying the Individual*. Thousand Oaks, CA: Sage; 1998.
129. Bergman LR, El-Khoury BM, *SLEIPNER. A statistical package for pattern-oriented analyses (Version 2.1)*. 2001, Department of Psychology, Stockholm University, Stockholm, Sweden, computer software.
130. Bergman LR, El-Khoury BM. EXACON - A fortran 77 program for the exact analysis of single cells in a contingency table. *Educ Psychol Meas* 1987; **47**: 155-61.
131. von Essen L, Enskär K, Haglund K, Hedström M, Skolin I. Important aspects of care and assistance for children 0-7 years of age being treated for cancer. Parent and nurse perceptions. *Support Care Cancer* 2002; **10**: 601-12.
132. Kazdin AE. *Research design in clinical psychology*. Boston, MA: Allyn and Bacon; 2003.
133. Polit DF, Hungler BP. *Nursing research: principles and methods* Philadelphia: Lippincott Williams & Wilkins; 1999.
134. Tedeschi RG, Calhoun LG. Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychol Inq* 2004; **15**: 1-18.
135. Tedeschi RG, Calhoun LG. The posttraumatic growth inventory: measuring the positive legacy of trauma. *J Trauma Stress* 1996; **9**: 455-71.
136. Parry C, Chesler MA. Thematic evidence of psychosocial thriving in childhood cancer survivors. *Qual Health Res* 2005; **15**: 1055-73.

137. Sprangers MA, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* 1999; **48**: 1507-15.
138. Servitzoglou M, Papadatou D, Tsiantis I, Vasilatou-Kosmidis H. Psychosocial functioning of young adolescent and adult survivors of childhood cancer. *Support Care Cancer* 2007; **16**: 29-36.
139. Masten AS, Hubbard JJ, Gest SD, Tellegen A, Garmezy N, Ramirez M. Competence in the context of adversity: pathways to resilience and maladaptation from childhood to late adolescence. *Dev Psychopathol* 1999; **11**: 143-69.
140. Masten AS, Reed MG. Resilience in development, in Snyder CR., Lopez SJ. (eds): *Handbook of Positive Psychology*. New York: Oxford University Press, Inc.; 2005.
141. Vance YH, Eiser C. The school experience of the child with cancer. *Child Care Health Dev* 2002; **28**: 5-19.
142. Schover LR. Sexuality and fertility after cancer. *Hematology (Am Soc Hematol Educ Program)* 2005: 523-7.
143. Schover LR. Motivation for parenthood after cancer: a review. *J Natl Cancer Inst Monogr* 2005: 2-5.
144. Nagarajan R, Robison LL. Pregnancy outcomes in survivors of childhood cancer. *J Natl Cancer Inst Monogr* 2005: 72-6.
145. Mostow EN, Byrne J, Connelly RR, Mulvihill JJ. Quality of life in long-term survivors of CNS tumors of childhood and adolescence. *J Clin Oncol* 1991; **9**: 592-9.
146. Smyth JM, Stone AA, Hurewitz A, Kaell A. Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis: a randomized trial. *JAMA* 1999; **281**: 1304-9.
147. Kelley JE, Lumley MA, Leisen JC. Health effects of emotional disclosure in rheumatoid arthritis patients. *Health Psychol* 1997; **16**: 331-40.
148. Stanton AL, Danoff-Burg S, Sworowski LA, et al. Randomized, controlled trial of written emotional expression and benefit finding in breast cancer patients. *J Clin Oncol* 2002; **20**: 4160-8.

Acta Universitatis Upsaliensis

*Digital Comprehensive Summaries of Uppsala Dissertations
from the Faculty of Medicine 331*

Editor: The Dean of the Faculty of Medicine

A doctoral dissertation from the Faculty of Medicine, Uppsala University, is usually a summary of a number of papers. A few copies of the complete dissertation are kept at major Swedish research libraries, while the summary alone is distributed internationally through the series Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine. (Prior to January, 2005, the series was published under the title “Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine”.)

Distribution: publications.uu.se
urn:nbn:se:uu:diva-8643



ACTA
UNIVERSITATIS
UPSALIENSIS
UPPSALA
2008