Cancer during Adolescence

Coping Shortly after Diagnosis and Psychosocial Function during the Acute and Extended Phase of Survival

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Abstract

In this thesis coping shortly after diagnosis and psychosocial function during the acute and extended phase of survival was investigated for individuals struck by cancer during adolescence. Thirty-one participants were recruited and data were collected from four to eight weeks (T1) up to four years (T7) after diagnosis. Study I: the aim was to describe how participants (n=36) cope with cancer-related distress in response to closed and open-ended questions. In response to closed-ended questions, the majority reported emotion-focused strategies, and in response to open-ended questions they reported meaning-based and problem-focused strategies. Study II: the aim was to investigate nurses’ and physicians’ ability to identify which coping strategies participants (n=48) use. Neither nurses nor physicians were successful in identifying which strategies participants used, although physicians were somewhat better. Study III: the aim was to identify participants’ (n=61) psychosocial states. Three states were identified: poor (A), average (B), and good (C). From 18 months after diagnosis more participants than expected by chance were in state C. At T7 77% were in State C and 15% in State A. Female gender, divorced parents, and using distracting to cope was related to State A and B. Study IV: the aim was to describe negative and positive cancer-related consequences reported (n=32) three and four years after diagnosis and to establish whether using certain strategies at T1 was related to reports of certain consequences at T7. The majority reported negative and positive consequences and a relation between using distracting to cope at T1 and reporting bodily concerns at T7 was established. In conclusion: it is difficult for nurses and physicians to identify how adolescents recently diagnosed with cancer cope with distress; the majority of individuals diagnosed with cancer during adolescence experience a state of good psychosocial function during the extended phase of survival, and distress and personal growth often go hand in hand after cancer during adolescence.

Keywords: adolescents, cancer, coping, psychosocial, consequences

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To adolescents struggling with adversity
This thesis is based on the following papers, referred to in the text by their Roman numerals.


IV Engvall, G., Cernvall, M., Larsson, G., von Essen, L., and Mattson, E. Cancer during adolescence: Negative and positive consequences reported three and four years after diagnosis. Submitted.

Study I and II: Reprints were made with kind permission of respective publishers.
Preface

Since 1983 when I became a paediatric nurse I have met children in different situations and health conditions in paediatric care, including four years in paediatric oncology care. Frequently, I have wondering, both as a nurse at the Children’s Hospital in Uppsala and as a teacher in the Nursing programme at Uppsala University, how to improve the care to the benefit of the children and their families. The step into research was for me a means to reach extended knowledge, by studying paediatric psychosocial oncology, through a scientific approach. In 2007 I became a PhD-student and joined the Psychosocial Oncology and Supportive Care research group and started to work with the research project Cancer during adolescence: psychosocial and health economic consequences.

An adolescent, struck by cancer, not only has to handle a serious disease but also frequent hospital visits, treatments, painful procedures, and side effects. To start with I would like to present some words expressed, shortly after diagnosis and four years later, by three individuals diagnosed with a cancer disease during adolescence.

“Well, I have talked a lot to my mates, that’s great ’cause they say that I’m the same person that I used to be even if I don’t have any hair... I can’t change these things. It’s going to be better later... It’s going to become as it was.” (Female, 13 years) Four years later: “I’m very tired, nothing is fun anymore... Maybe it’s now that I have sort of begun to understand that I’ve been ill... Well, I’ve grown, I’m probably more sensible too about what I should do and not do... It feels as if I have also become much more honest towards Mum and Dad ...”

“I try to live day by day, live as normally as possible. Do whatever I can manage... I try to think about other things, any stuff I can think of. I’m tired so I take it easy as much as possible...” (Male, 15 years) Four years later: “Distressing... yes, I can’t do those sports I used to do before... football and floorball. I can’t run because of the amputation...”

"I try to not think about it. I am looking ahead. There is going to be a life afterwards... a time when the treatment is finished. And I talk to Mum and Dad, asking questions and so on. They comfort me.” (Female, 17 years) Four years later: “I’ve got a new perspective. I appreciate everything more, the
people I have around and so on… I don’t take everything for granted any-
more. I live day by day... I’ve become more harmonious. I feel that I have
experienced so many hard things so it can’t become worse anyway.”

Each of these individuals has her/his own story and experiences. The overall
purpose of this thesis is to describe experiences in terms of coping and psy-
chosocial function reported during the acute and extended phase of survival
by individuals diagnosed with cancer during adolescence.
Introduction

Cancer during adolescence

Adolescence initiates the transition into adulthood [1], and is a period characterised by significant physical [2] and psychosocial changes [3] with great variation regarding physical and psychosocial development [1-2]. At the beginning of puberty the bodily growth and development of sexual characteristics accelerates ending up around 15-16 years for girls and 17-18 years for boys [2]. Puberty affects psychological development and relationships profoundly [1]. Adolescence is a time when strong positive and negative emotions abound. Most adolescents’ bonds to the family vary between being warm and being tense, revealing a process towards independence. Education, relations to peers, and belonging to a group are the main issues for adolescents. Abstract, systematic, and critical thinking, including the ability to reflect on one’s own thinking usually develops during adolescence [1]. However, the growth and maturation of the brain continues into the beginning of adulthood [4]. A cancer disease and subsequent treatment challenges the development during adolescence not only with regard to physical aspects but also aspects such as independence, gender role, and career plans [3, 5].

Approximately 100 Swedish adolescents are diagnosed annually with a cancer disease [6]. The main diagnostic groups are: Leukaemia, CNS tumours, Lymphoma, and bone tumours [7]. The treatment most often consists of chemo- and radiotherapy; surgery is often an option besides chemo- and/or radiotherapy for those with solid tumours [8]. Haematopoietic stem cell transplantation is used for patients with high-risk diseases [8]. The duration of treatment varies from a few months to two and a half years depending on the diagnosis, a relapse may extend the treatment period [8]. Swedish paediatric oncology care is organised by multi-professional teams at six centres: Gothenburg, Linköping, Lund, Stockholm, Uppsala, and Umeå [7].

Effective treatment programmes have improved the five year survival rate showing stabilization during the latest decades with approximately 75-80% five year survival rates [7, 9-10]. It has been proposed that an individual diagnosed with cancer should be considered as a survivor from the time of diagnosis [11]. Three phases of survival have been suggested: the acute phase which covers the time from diagnosis to completion of initial treat-
ment, the extended phase which starts after completion of treatment and gradually evolves into the third phase, permanent survival [12].

Responses to cancer

Negative experiences

A cancer disease and subsequent treatment causes distress during the acute phase of survival and adolescents have reported a range of physical concerns e.g. pain, nausea/vomiting, lack of appetite, hair-loss, and fatigue [13-22], emotional distress e.g. feeling sad, loss of control, changed body image, worries about treatment procedures [15-22], and social concerns e.g. feeling isolated, missing school and leisure activities [13, 15, 21]. Some concerns may persist into the extended phase of survival such as pain, fatigue, and worries about e.g. a relapse and missing school [13, 22]. The concerns may cause anxiety and depression [20, 23-25] and influence the individual’s perception of health, often described as health-related quality of life (HRQoL). HRQoL is a multidimensional concept representing individuals’ responses in physical, psychological, and social dimensions [26-27]. In the acute phase of survival, adolescents with cancer report lower levels of HRQoL than reference groups [20, 28]. After the acute phase the majority report normalised levels of HRQoL on a group level [20, 29-32]. Symptoms of posttraumatic stress (PTSS) may develop in response to a traumatic event such as cancer [33-35]. PTSS has been reported during the extended and permanent phase of survival [36-39]. PTSS includes symptoms of re-experiences, avoidance, and hyper-arousal [35, 40-41]. The diagnosis of cancer may also cause feelings of helplessness and intensive fear [42]. Cancer during adolescence may not only have an emotional impact on the individual struck by cancer but also on her/his family members [33].

Findings from our group show that individuals diagnosed with cancer during adolescence, on a group-level, report higher levels of anxiety and depression and lower levels of vitality and mental health than a reference group six months after diagnosis. Twelve months after diagnosis there were no differences between the groups for any of these variables [20]. However, a subgroup reports psychosocial dysfunction up to eighteen months after diagnosis [43]. The distress may become a barrier to physical recovery, shown among adults suffering from chronic posttraumatic stress, resulting in a vicious cycle of disability related to the onset of diseases, increased healthcare utilisation, and premature death [44].
Coping

Individuals use different strategies to handle distress e.g. caused by a serious disease such as cancer [45]. Coping can be both an automatic process which does not involve much cognitive capacity and a controlled process, regulated by higher-order cognitive functions [46]. The concept is described as a person’s constantly changing cognitive and behavioural efforts to manage external and/or internal demands appraised as taxing or exceeding the person’s resources [47].

The ability to cope with distress increases gradually through the development of language and abstract thinking [46]. Coping involves emotions, thoughts, and behaviours to resolve the sources of distress and to manage the reactions caused by them [45]. Strategies to cope have been categorised as problem or emotion-focused [45] and as approach or avoidance-focused [48-49]. Problem-focused strategies aim at solving and/or managing problems e.g. by seeking information and finding a solution, whereas emotion-focused strategies aim at regulating distress e.g. by seeking support and avoiding feelings and situations reminiscent of a trauma [47, 50-51]. In addition to these strategies, meaning-based strategies such as formulating new goals, making sense of what is happening, and appraising benefit where possible can be used [52].

It has been suggested that the extent to which adolescents with cancer succeed in coping with the illness experiences influences their ability to master age-appropriate tasks and achieve long-term social goals [5]. However, findings on how adolescents with cancer cope with disease and treatment-related distress are disparate both with regard to which strategies they use [50-51, 53-58] and whether there is a relationship between using certain strategies and psychosocial function [50-51, 53-54]. Findings from studies using a quantitative research approach show that problem and emotion-focused strategies are used to the same extent [50] and that approach-focused strategies are used to a greater extent than avoidance-focused strategies [54]. Other findings show that avoidance [53] and emotion-focused [51] strategies are used to a greater extent by adolescents with cancer than healthy control groups. However, in these studies the stressors have not been specified [50-51, 54] or, when specified, not specifically related to disease or treatment [53]. Findings from studies using a qualitative, inductive research approach show that adolescents with cancer use a variety of strategies not investigated in studies using a quantitative design, for example maintaining or getting back to normal life, positive thinking (e.g. belief in recovery), and busyness [55-58]. These strategies fit into the concept of meaning-based coping as described by Folkman and co-workers [59].
Positive consequences after adversity

Reports of benefit finding as a consequence of a cancer disease have been described by children and adolescents [60-62] revealing positive consequences after adversity. The idea that a struggle with adversity can lead to posttraumatic growth i.e. personal growth, better relationships, and a deeper appreciation of life is well-established [63]. Although the investigation of this phenomenon is recent, descriptions of growth have been reported by people who have faced a variety of traumatic events [64-70]. Growth after adversity has been reported by children after traumatic events e.g. road traffic accidents and natural disasters [68-70]. Positive outcomes such as optimism [71-72], stronger bonds to family and friends, increased capacity for empathy [71, 73], good self-confidence [72-73], and a deepened appreciation for life [71-72] have been described by childhood cancer survivors.

Growth after adversity, posttraumatic growth, has been conceptualised as a transformation of the understanding of the world [74]. Calhoun and Tedeschi [63, 75] have proposed that a traumatic event may provide a seismic shattering of the assumptive world forcing a reconfiguration of the person’s cognitive schemata. The process is facilitated by personal characteristics such as extraversion, openness to experience, and optimism [63]. Early successful coping is hypothesised to be supporting adaptation, leading to a ruminative activity characterised by the development of a life narrative [63]. It has been shown that positive rumination, such as thinking actively about the circumstances and how to make sense of them facilitates growth among adults [66, 76-78]. The conceptualisation of posttraumatic growth by Calhoun and Tedeschi is on a cognitive level [75] while others describe the transformation on a meta-level as a reconstruction of meta-schemas [79-80] e.g. concepts of self, society, and nature integrating biological and psychosocial aspects [80].

Growth does not exclude distress and manageable distress can support growth [63]. It has been shown that greater perceived treatment severity [61], life threat [61], and intensity of cancer-related symptoms [60, 62] and symptoms of posttraumatic stress [61] are associated with growth among survivors of childhood cancer.

The findings from our group show that individuals struck by cancer during adolescence, as a group, from eighteen months up to four years after diagnosis report a better psychosocial function than a reference group [81]. The result illustrates a positive psychological change. Moreover, two years after diagnosis the majority report positive cancer-related consequences [82]. Better HRQoL among survivors than reference groups have also been reported by others after the acute phase of survival [73, 83-85].
A very limited number of studies have investigated whether the use of certain strategies to cope with a trauma can be related to posttraumatic growth. Existing findings show a relationship between problem-focused coping and growth among adults after a diagnosis of cancer [86-87] and that emotional support from family and friends is related to growth among adults diagnosed with cancer [66, 87-88] and college students [89], but not among children after a natural disaster [90].

Health professionals’ ability to assess adolescents’ responses to cancer

As mentioned above adolescents struck by cancer are not necessarily at risk for psychopathology during the acute or extended phases of survival [20, 43, 71-73, 81-82], however a minority [43] experiences a clinically relevant level of emotional distress. This is potentially problematic as, within the context of oncology, it has been shown that nurses and physicians demonstrate low sensitivity and specificity in detecting these patients [91-92]. This can have serious consequences since persistent distress may become a barrier to physical recovery, and result in psychosocial dysfunction [44].

Very few studies within the context of paediatric oncology have investigated the staff’s ability to detect patients’ physical and psychosocial distress. The literature shows that physicians overestimate the health status of survivors [93] and of children on and off treatment [94], nurses more accurately identify children’s somatic distress and activity than their mood disturbances, compliance with treatment, and quality of interactions [95], and nurses and physicians are reasonably accurate when identifying adolescents’ physical distress but less accurate when identifying their psychosocial distress [92].

Point of departure for this thesis

In short, previous findings from our group show that individuals diagnosed with cancer during adolescence report negative as well as positive consequences two years after diagnosis [82] and, on a group-level, a better psychosocial function than a reference group from eighteen months up to four years after diagnosis [81]. However, at all assessments from shortly after diagnosis until 18 months after diagnosis, one subgroup does report psychosocial dysfunction [43]. In this research we set out to describe individuals struck by cancer during adolescence according to similarity of psychosocial responses up to four years after diagnosis. We also set out to describe negative and positive cancer-related consequences reported by these individuals three and four years after diagnosis. It can be assumed that the
ability to cope with disease and treatment-related distress during the acute phase of survival is related to later psychosocial function. In this research, we set out to investigate which strategies adolescents diagnosed with cancer use to cope with disease and treatment-related distress during the acute phase of survival and whether nurses and physicians are able to identify which strategies a certain adolescent uses and does not use. We also set out to investigate whether using certain strategies shortly after diagnosis is related to psychosocial function later on during the disease trajectory.
Aims

The overall aim was to investigate coping shortly after diagnosis and psychosocial function during the acute and extended phase of survival among individuals struck by cancer during adolescence. The specific aims were:

Study I
To describe how adolescents recently diagnosed with cancer report that they cope with disease and treatment-related distress in response to closed and open-ended questions, respectively.

Study II
To investigate nurses’ and physicians’ ability to identify whether a certain adolescent, recently diagnosed with cancer, has used certain coping strategies since diagnosis to cope with certain aspects of distress, and if so, the extent to which s/he has used these strategies.

Study III
To identify psychosocial states among individuals diagnosed with cancer during adolescence, from shortly after diagnosis up to four years after diagnosis, and to analyse these in relation to demographic and clinical characteristics, coping strategies, and depression.

Study IV
To describe negative and positive cancer-related consequences reported by individuals diagnosed with cancer during adolescence, three and four years after diagnosis, to examine whether similar and/or different consequences are reported three and four years after diagnosis as those reported two years after diagnosis, and to explore whether reports of using certain coping strategies shortly after diagnosis are related to reports of certain consequences four years after diagnosis.
Methods

Designs

The studies are based on data collected within a research project aimed at investigating psychosocial and health-economic consequences of cancer during adolescence. Sixty-one adolescents, 13-19 years of age, were recruited between 1999 and 2003 and data were collected shortly after diagnosis (4-8 weeks) (T1), and at 6 (T2), 12 (T3), and 18 (T4) months and at 2 (T5), 3 (T6), and 4 (T7) years after diagnosis. Since 2010, data have been collected at 10 years after diagnosis (T8). Findings based on data collected at T1-T7 are presented in this thesis.

Studies I and II have a cross-sectional, descriptive design with data collected at T1. Study III has a longitudinal, comparative design with data collected at T1-T7. Study IV has a longitudinal, descriptive design with data collected at T1 and at T5-T7.

Participants

Adolescents newly diagnosed with cancer or a relapse of cancer, were recruited at three of the six paediatric oncology centres in Sweden: Lund, Umeå, and Uppsala. To be eligible, the adolescents had to be Swedish speaking, diagnosed with cancer for the first time or with a relapse after having been disease-free and off treatment for at least one year, treated with chemotherapy and cognitively, emotionally, and physically capable of participating. A coordinating nurse at each centre was responsible for recruitment and assessed, in collaboration with a physician, each adolescent’s ability to participate.

Of 90 adolescents newly diagnosed with cancer for the first time and of 10 diagnosed with a relapse, 11 were not invited to participate since they did not speak Swedish well enough to participate (4 persons) and/or were considered too cognitively or physically affected by the disease or by a neurological co-morbidity to participate (7 persons). Of the remaining 89 adolescents, 65 agreed to participate. Of these, two became too ill before they were interviewed at T1 and two were lost on account of administrative reasons. Hence
61 adolescents were included. Fifty-six of these were newly diagnosed whilst 5 were diagnosed with a relapse. Their mean age at diagnosis was 15.5 years. See Figure 1 for a presentation of the number of participants in Studies I-IV.

![Figure 1. Number of participants in Studies I-IV.](image)

Study I
The fifty-six adolescents who were newly diagnosed with cancer at the time of inclusion participated in Study I. There were 32 boys and 24 girls. Their diagnoses were: CNS tumour (2 persons); Ewing sarcoma (4); Leukaemia (18); Lymphoma (20); Osteosarcoma (8), the 4 remaining adolescents were diagnosed with other solid tumours.

Study II
Forty-eight adolescents, to whom a nurse and a physician could be matched, participated in Study II. There were 32 boys and 16 girls. Their diagnoses were: CNS tumour (2 persons); Ewing sarcoma (3); Leukaemia (16); Lymphoma (14); Osteosarcoma (8), the remaining 5 were diagnosed with other solid tumours. Forty-two nurses were interviewed about 48 adolescents, range 1-2 interviews per person (M 1.1, SD 0.4). Thirty-four were registered nurses, 8 nursing assistants (non-registered staff with two years of education). Nurses and nursing assistants are hereafter referred to as nurses. Their mean age was 37 years (range 25-59), 36 were women, 6 were men; they had worked in healthcare for a mean of 10 years (range 1-35) and with adolescents with cancer for a mean of 8 years (range 4 months-30 years). Twenty-six physicians were interviewed about 48 adolescents, range 1-7 interviews per physician (M 1.8, SD 1.5). Their mean age was 48 years (range 28-62), 9 were women, 17 were men, they had worked in healthcare for a mean of 19 years (range 4-35) and with adolescents with cancer for a mean of 8 years (range 2 months-31 years).
Study III

All adolescents who were included in the project participated in Study III. Their clinical and demographic characteristics at T1 are presented in Table 1. Additionally, the clinical and demographic characteristics of the subgroups of participants at T2-T7 and reasons for attrition at T2-T7 are presented in Table 1.

Table 1. Clinical and demographic characteristics of participants at T1-T7 and reasons for attrition at T2-T7.

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<td>n=48</td>
<td>n=38</td>
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<td>CNS tumour</td>
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<td>Ewing sarcoma</td>
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<td>Osteosarcoma</td>
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<tr>
<td>Other solid tumours</td>
<td>5</td>
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<td>5</td>
<td>4</td>
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<td>42/14</td>
<td>14/36</td>
<td>11/37</td>
<td>9/29</td>
<td>4/38</td>
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Study IV

The thirty-two adolescents who participated at T1 and T5-T7 participated in Study IV. There were 18 boys and 14 girls. Their diagnoses were: CNS tumour (1); Ewing sarcoma (1); Leukaemia (10); Lymphoma (13); Osteosarcoma (4), or other solid tumours (3).
Procedure and data collection

Approximately three weeks after diagnosis, a coordinating nurse at each centre provided potential participants and their parents (for those under 18 years of age) with oral and written information about the study. A few days later the adolescent was asked for oral consent by the coordinating nurse. If the adolescent was under 18 years of age, her/his parents were asked to provide oral consent on behalf of their child. A few days later, adolescents who had consented or on whose behalf a parent had consented were contacted by telephone by a doctoral student, most often Mariann Hedström (MH) or Elisabet Mattsson (EM), from the Department of Public Health and Caring Sciences at Uppsala University. At this time, a time for the first data collection (T1) was agreed upon. At the end of the interviews at T1-T6 the participant was asked whether s/he agreed to be contacted again for another interview. Before each interview the coordinating nurse at the respective centre where the participants were registered was contacted to ensure that the participant was cognitively, emotionally, and physically able to participate in the following interview. Shortly after each interview the participants received a small gift in return for their participation.

The questions were posed by telephone in the same order to all participants and at all assessments (T1-T7). The participants were first asked questions about their clinical and demographic characteristics (T1-T7). They were thereafter asked whether they had experienced any disease and/or treatment-related distress with regard to feelings of alienation, personal changes, physical concerns, and worries (T1-T4). Each area embraced five aspects. The areas and aspects were identified through interviews with adolescents on or off cancer treatment, their parents, and nurses [13-14]. The participants were asked to answer questions about whether they had experienced distress with regard to these aspects on six-grade scales ranging from not at all to very much (coded 0-5), except for four questions about personal changes with dichotomised answering alternatives. They were asked to answer the questions referring to the time since diagnosis at T1 and to the last four weeks at T2-T4.

If a participant reported distress with regard to at least one aspect within a specific area, s/he was asked open and closed-ended questions about how s/he had coped with that area (T1-T4). For each area the participant was first asked: “Try to describe what you do or think to handle feelings of: alienation, personal changes, physical concerns, and worries”. Follow-up questions were sometimes asked in order to help the respondent to elucidate or develop her/his answers. The participant was thereafter asked closed-ended questions about whether, and if so, to what extent s/he had used the following strategies, exemplified with statements, to handle each area: accepting, distracting,
fighting spirit, minimising, seeking information, and seeking support. Participants were asked to answer these questions on six-grade scales ranging from not at all to very much (coded 0-5) referring to their experiences since diagnosis at T1 and during the last four weeks at T2-T4. The strategies were chosen on the basis of the literature available at the time when the project was planned (1999) [47-48, 96], clinical experience of the members in the research group, and findings from pilot interviews with five healthy adolescents.

Participants were thereafter (T1-T7) asked questions about anxiety, depression, and HRQoL. Anxiety and depression was measured by the Hospital Anxiety and Depression Scale (HADS) embracing two subscales: Anxiety and Depression, each consisting of seven items (response range 0-3) [97]. The HADS was originally developed for people aged 16-65 years of age, but has been used among adolescents of 12-16 years of age [98]. HRQoL was measured by the SF-36 consisting of 36 items organised in eight subscales each measuring one dimension: Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, and Mental Health [99]. The SF-36 is described as adequate for use from early adolescence [100]. Participants were asked to answer the questions in the subscales Mental Health (MH, 5 items) and Vitality (VT, 4 items) at T1-T4 whereas they were asked to answer the questions in all the subscales at T5-T7. The reason for this was twofold. Firstly, the participants were asked to answer a large number of questions over and above the ones measuring HRQoL at T1-T4 and efforts were made to simplify participation as much as possible. Secondly, the emphasis of the project is on the psychosocial consequences of falling ill with and surviving cancer, and therefore the mental aspects of HRQoL were perceived as the more determining sources of information. Finally at T5-T7 the participants were asked open-ended questions about whether they experienced any negative and/or positive consequences of the cancer disease. Follow-up questions were sometimes asked in order to help the participant to elucidate or develop her/his answers.

At T1 a nurse (nurses and nursing assistants are referred to as nurses) and a physician who best knew the particular adolescent were matched to the adolescent by a coordinating nurse at the respective centre, and, as close in time to the adolescent’s interview as possible, they were asked to answer staff versions of the above mentioned questionnaires. These versions comprised questions directed to the staff, asking them what they thought their matched adolescent had experienced since diagnosis. For all the questions the staff had the possibility of answering “I do not know”.

22
Data analysis

Study I

A coping strategy from the closed-ended questions at T1 was conceptualised as used by a specific adolescent in the event of her/him answering that s/he had used the strategy moderately to very much (answers coded 3-5). The Statistical Package for the Social Sciences (SPSS) version 15.0 was used for the analysis.

Answers to the open-ended questions at T1 were audio taped, transcribed verbatim, and analysed by content analysis, which can be used to draw valid conclusions about a manifest message in a communication by the systematic identification of specified communication characteristics [101-103]. The analysis was performed in the following steps [104]: 1) Gunn Engvall (GE) read the transcribed text several times. 2) Words and sentences (recording units) containing information about how the participant coped with any of the four areas of distress were identified (by GE and an additional researcher). 3) GE and an additional researcher grouped recording units into categories reflecting central messages and defined the boundaries of each category. 4) GE and three additional researchers participated in the discussion of the boundaries and the labelling of the categories and in grouping strategies into dimensions. Recording units in the same category are assumed to share a similar meaning. Even if a participant mentioned a certain recording unit several times, it was only counted once in the result. In the event of the content in an identified category corresponding with the content of one of the coping strategies investigated by the closed-ended questions it was given the same name. However, open-ended data were not analysed with the intention of fitting into the strategies measured by closed-ended questions.

Study II

A coping strategy was assessed as used by an adolescent in the event of her/him answering that s/he had used the strategy moderately to very much (answers coded 3-5).

The nurses’ and physicians’ ability to identify whether a certain adolescent had or had not used a certain strategy to cope with a certain area of distress was assessed by sensitivity and specificity analyses. Sensitivity was calculated as the proportion of nurses/physicians able to detect a strategy as prevalent for a certain adolescent, i.e. answering moderately, quite a lot, or very much when the adolescent provided any of these answers. Specificity was calculated as the proportion of nurses/physicians able to detect a coping strategy as not prevalent for a certain adolescent, i.e. answering not at all,
just a little, or somewhat when the adolescent provided any of these answers. These calculations are based on an idea presented by Brunelli and co-workers [105] and were performed in accordance with a previous study from our research group [92]. Values at or above 60% are considered to indicate reasonable agreement. Potential associations between adolescent-nurse/physician answers were analysed using Pearson’s correlations and potential differences between adolescent-nurse/physician ratings with dependent t-tests. In these analyses the full range of answers were used. P-values \( \leq .05 \) were interpreted to indicate statistical significance in all analyses. SPSS version 17.0 was used to analyse data.

Study III
Cluster analysis using Ward’s method was used to identify a cluster solution based on the dimensions: Vitality (SF-36), Mental Health (SF-36), and Anxiety (HADS). Each individual contributed a number of data vectors, each corresponding to one occasion. A total of 334 vectors were obtained and a three cluster solution was selected. The explained error sum of squares was 59%. The clusters represent psychosocial states, labelled: A, poor; B, average; and C, good psychosocial function.

Each individual is characterised by one state on a given occasion, allowing an analysis of state frequencies per occasion. Cell frequencies were investigated with exact single-cell tests based on the hyper-geometric distribution using the EXACON module in SLEIPNER [106]. The same procedure was used to compare the states with regard to: gender, age at diagnosis, family situation, and diagnosis. A participant’s use of a coping strategy (T1) was calculated as the sum (range 0-20) of the scores reported for each strategy divided by the number of areas (range 1-4) for which the participant reported distress and how s/he had coped with the distress. The mean value for a certain strategy varied between 0 and 5. One-way ANOVAs were used to analyse coping strategies compared to the three states at T1-T4. At T5-T7 there were too few participants \( \leq 5 \) in each group to perform ANOVAs. Finally, one-way ANOVA with Hochberg’s post hoc test was used to discriminate between the three states with regard to the HADS Depression subscale (T1). P-values \( \leq .05 \) were interpreted to indicate statistical significance in all analyses.

Study IV
The open-ended data at T6-T7 were analysed by content analysis, see above under Study I for a description of how the analysis was performed. If the content in a category corresponded with the content of one of the categories identified at T5 [82], it was labelled with the same name. However, data
collected at T6-T7 were not analysed with the intention of fitting into the categories identified at T5. Four researchers participated in the discussion of the boundaries and the labelling of the categories. Even if a respondent mentioned a certain recording unit several times, it was only counted once in the result.

SPSS version 17.0 was used to explore whether there was a relation between using a certain coping strategy at T1 and reporting a certain consequence at T7. A participant’s use of a coping strategy was calculated as follows: the sum (range 0-20) of the scores reported for each strategy was divided with the number of areas (range 1-4) for which a participant had reported distress and how s/he had coped with the distress. The mean value for a certain strategy varied between 0 and 5. A strategy was conceptualised as used by a participant if the mean value of his use of the strategy varied from 2.6-5 and not used when the mean value ranged from 0-2.5. Percentages were used to explore potential relation between use of a certain coping strategy (used vs. not used) at T1 and a reported consequence at T7. Potential relations were calculated for those categories that included statements from ten or more participants. Values at or above 60% are considered to indicate reasonable agreement [105] and are reported.

Ethical considerations

Ethical approval was obtained from the local Ethics Committee at the Faculty of Medicine at the universities of Lund, Umeå, and Uppsala. Adolescents and her/his parents in the event of the adolescent being younger than 18 years of age, were provided with oral and written information about the study. Adolescents 18 years or older were asked for oral consent. If an adolescent was younger than 18 years, her/his parents were asked to provide oral consent on behalf of their child. Participants were informed that they could withdraw from participation at any time without giving any reason for this and that neither participation nor non-participation would have any effect on their care and treatment.
Results and comments

Coping with distress during the acute phase of survival – summary of Studies I and II

Adolescents’ reports of how they cope with distress

See Table 2 for a presentation of the rank order by which coping strategies were mentioned in response to closed and open-ended questions. In response to closed-ended questions, adolescents most often reported using emotion-focused strategies such as accepting and minimising. However, in response to open-ended questions these strategies were mentioned as number three and six respectively in rank order. When asked open-ended questions adolescents most often mentioned using meaning-based strategies such as positive thinking and problem-focused coping such as problem solving to cope with distress. These strategies were not investigated by the closed-ended questions.

Table 2. The rank order by which coping strategies were mentioned by participants (N=56) in response to closed and open-ended questions.

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Category</th>
<th>Closed-ended questions</th>
<th>Open-ended questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion-focused</td>
<td>Accepting</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Distracting</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Minimising</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Seeking support</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Problem-focused</td>
<td>Fighting spirit</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Problem solving</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Seeking information</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Meaning-based</td>
<td>Positive thinking</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>

The strategy that the adolescents most often mentioned in response to the open-ended questions, i.e. positive thinking, is not included in the predetermined strategies investigated by closed-ended questions. Interestingly the finding indicates that the process of positive reconstruction already starts shortly after diagnosis. Additionally, the findings show that the same strate-
gy e.g. minimising is high in ranking in response to closed-ended questions whereas it is low in ranking in response to open-ended questions. A possible explanation to this difference may be that in response to the open-ended questions the adolescents answered what first came to mind. However, in response to closed-ended answers they were probably provided with additional strategies than those they had previously reported and consequently responded to whether they had used them or not.

The coping-models most extensively described in the literature organise coping strategies in two dimensions: problem vs. emotion-focused [45] and approach vs. avoidance-focused [48-49]. Some authors have recommended organising strategies in four dimensions [107-108]. In the present study the strategies are organised in three dimensions: problem-focused, emotion-focused, and meaning-based, a dimension first described in 2000 by Folkman [52, 59]. The meaning-based dimension includes strategies such as a positive attitude, reconstruction, striving towards new goals which were earlier included in emotion-focused coping [45], benefit finding, reordering of priorities, infusing events with positive meaning [109], and hope [110] as proposed by Folkman [109-110]. In the present study the category positive thinking derived from answers to open-ended questions includes statements illustrating hope. Hope is probably necessary for adolescents to sustain the daily distress caused by the cancer disease [110-112]. In studies with a qualitative design, meaning-based coping has been described by e.g. positive thinking, belief in recovery [56], and shown to be associated with positive effects [57]. Differences between findings by others regarding which strategies adolescents use [50-51, 53-58] may be explained, at least partly, by methodological differences [113] such as type of design, characteristics of the sample, and how strategies are conceptualised into dimensions.

Nurses’ and physicians’ ability to assess how a certain adolescent copes with distress

Neither nurses nor physicians are successful in estimating how adolescents recently diagnosed with cancer cope with disease and treatment-related distress even though physicians are somewhat more successful. See Table 3 for a presentation of sensitivity and specificity values and significant associations and differences for adolescent nurse/physician ratings of adolescents’ use of coping strategies.
Table 3. Sensitivity and specificity values (percentages\(^a\)) and significant associations (r value) and differences (t value) for adolescent\(^b\) nurse\(^c\)/physician\(^d\) ratings of adolescents’ use of coping strategies (N=48).

<table>
<thead>
<tr>
<th></th>
<th>Nurses</th>
<th></th>
<th>Physicians</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensitivity/Specificity(^a)</td>
<td>r</td>
<td>t</td>
<td>Sensitivity/Specificity(^a)</td>
</tr>
<tr>
<td><strong>Accepting</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of alienation</td>
<td>79/</td>
<td>94/</td>
<td></td>
<td>93/</td>
</tr>
<tr>
<td>Personal changes</td>
<td>88/</td>
<td>95/</td>
<td></td>
<td>82/</td>
</tr>
<tr>
<td>Physical concerns</td>
<td>85/</td>
<td>82/</td>
<td></td>
<td>97/</td>
</tr>
<tr>
<td>Worries</td>
<td>77/</td>
<td>81/</td>
<td></td>
<td>100/</td>
</tr>
<tr>
<td><strong>Distracting</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of alienation</td>
<td>93/</td>
<td>*</td>
<td>69/</td>
<td></td>
</tr>
<tr>
<td>Personal changes</td>
<td>88/</td>
<td>80/</td>
<td></td>
<td>97/</td>
</tr>
<tr>
<td>Physical concerns</td>
<td>97/</td>
<td>*</td>
<td>89/</td>
<td></td>
</tr>
<tr>
<td>Worries</td>
<td>100/</td>
<td>**</td>
<td>76/</td>
<td></td>
</tr>
<tr>
<td><strong>Fighting spirit</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of alienation</td>
<td>88/</td>
<td>*</td>
<td>72/</td>
<td></td>
</tr>
<tr>
<td>Personal changes</td>
<td>88/</td>
<td>80/</td>
<td></td>
<td>87/</td>
</tr>
<tr>
<td>Physical concerns</td>
<td>87/</td>
<td>90/</td>
<td></td>
<td>83/</td>
</tr>
<tr>
<td>Worries</td>
<td>83/</td>
<td>67/</td>
<td></td>
<td>67/</td>
</tr>
<tr>
<td><strong>Minimising</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of alienation</td>
<td>73/</td>
<td>***</td>
<td>/86</td>
<td>*</td>
</tr>
<tr>
<td>Personal changes</td>
<td>/67</td>
<td>**</td>
<td>/67</td>
<td>*</td>
</tr>
<tr>
<td>Physical concerns</td>
<td>/67</td>
<td>**</td>
<td>/67</td>
<td>*</td>
</tr>
<tr>
<td>Worries</td>
<td>/</td>
<td>***</td>
<td>/91</td>
<td>***</td>
</tr>
<tr>
<td><strong>Seeking information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of alienation</td>
<td>73/</td>
<td>73/</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Personal changes</td>
<td>90/</td>
<td>82/</td>
<td></td>
<td>77/</td>
</tr>
<tr>
<td>Physical concerns</td>
<td>77/</td>
<td>82/</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Worries</td>
<td>84/</td>
<td>68/</td>
<td></td>
<td>73/</td>
</tr>
</tbody>
</table>

\(^a\)Only values at or above 60% are presented; \(^b\)n=46-48; \(^c\)n=31-48; \(^d\)n=28-47

\(*p \leq .05; \,**p \leq .01; \,***p \leq .001

Nurses and physicians are more able to identify when a certain adolescent has rather than has not used a strategy. Overall, nurses are more successful than physicians in this regard whereas physicians are more successful than nurses in identifying when an adolescent had not used a strategy. From a clinical point of view the absence of coping strategies appears more important to identify than the presence of coping strategies as absence could be a sign of less ability to cope and thereby indicate a potential need for support and help.
Associations between physicians’ and adolescents’ ratings were found for minimising in order to cope with feelings of alienation, personal changes, and worries and for seeking information to cope with feelings of alienation and physical concerns. Only one association, for seeking support to cope with physical concerns, was shown between nurses’ and adolescents’ reports.

A number of differences were evident between on the one hand adolescents’ and on the other hand nurses’ and physicians’ ratings. Most concern differences between nurses’ and adolescents’ ratings. In most cases, nurses reported that the adolescents had used the strategies to a greater extent than the adolescents reported. Contrary to this, nurses as well as physicians reported that the adolescents had used minimising to a lesser extent than the adolescents reported.

These findings support previous findings demonstrating difficulties for health professionals to accurately assess paediatric patients’ distress [92-95]. Findings from other contexts show that adult patients in acute care identified several severe physical, emotional, and spiritual problems not identified by nurses [114] and that nurses had a tendency to overestimate adult patient’ willingness to take an active role in the clinical decision-making regarding their care [115]. Other findings show that nurses’ assessments of adult medical patients’ depression were not related to the patients’ assessments [116]. Findings from another study show that nurses in home care for elderly patients identified less patients with depression than were identified when clinical interviews were used [117]. Recent findings from oncology care show that nurses report providing comfort more frequently to patients experiencing a high level of emotional distress, than was reported by the patients themselves [118]. To the best of our knowledge there are no previous studies where professionals have assessed adolescents’ coping strategies. However, findings from a paediatric setting where triage nurses, children, and parents assessed children’s pain establish that the nurses reported that the children experienced less pain than the children and their parents reported [119]. Findings from another study show that paediatric oncologists reported that adolescents on cancer treatment experienced more anxiety than the adolescents reported [24].

Combined, the findings show that physicians are somewhat more successful than nurses in identifying how adolescents with cancer cope with disease and treatment-related distress. Some possible explanations to this result are suggested below.

The typical physician-patient encounter is most often scheduled. Time and privacy increases the possibility to question, discuss personal matters, and
express emotions. The typical nurse-patient encounter most often takes place in the presence of others, is brief, and allows few possibilities to question, discuss, and express emotions. On the other hand nurses, in general, meet the patients more often than physicians which could provide opportunities to collect information. However, other responsibilities tend to interrupt and may limit nurses’ opportunities to adequately assess patients’ needs and provide personalised care and support.

Physicians are responsible for providing patients with the best possible treatment. As a means towards this end decisions are made based on data collected through interviews, observations, and examinations. Nurses are responsible for providing patients with the best possible nursing care e.g. providing prescriptions and treatments, being accessible, explaining and facilitating, comforting, and managing equipments. This care is often performed according to standardised care plans which, contrary to intention, may restrain the possibility to provide personalised care and instead support stereotyped care patterns. Involving patients in their care through open communication may increase the possibility to provide individualised care [114-115]. It has been established that patients are more satisfied with their care when nurses use both standardised and individualised care plans compared to when nurses do not use these care plans [120] which indicates that individualised care-plans are of importance.

Findings by others [91] show that nurses, within oncology care, with an education level higher than that of registered nurse more frequently agree with a certain patient concerning his level of distress. It has also emerged that nurses’ education is related to critical thinking and that critical thinking is related to accuracy in assessing female patients’ depression [116]. Combined, these findings indicate that education and critical thinking has an impact on the ability to assess a person’s psychosocial situation. With higher education more critical thinking may emerge. Other findings show that clinical experience is not related to accuracy when making risk assessments based on simulation scenarios in acute care [121]. The potential influence of education and critical thinking on accuracy when assessing the use of coping strategies has, to the best of our knowledge, not been investigated in the paediatric care context nor was it investigated in this research. Further studies are needed to explore the role of health professionals’ experience and education when assessing patients’ psychosocial function.

Caring is a process involving several steps, starting with the collection of information. Understanding a patient’s needs is a prerequisite for good caring and empathy forms the foundation of this understanding [122]. Empathy includes a capacity to communicate this understanding [123] and it has been reported that nurses and physicians show similar levels of empathy [123].
Furthermore, it has been established that health professionals do not show sufficient empathy towards patients [124]. However, education through experiential learning may improve nursing students’ and nurses’ empathy [125] and in the paediatric oncology context it has been shown that interprofessional narrative training seminars promote empathy [126]. Somatic care is often highly technical and physical and technical issues are more often in focus than psychological and emotional aspects [127]. It has been shown that nurse-patient interactions during medication activities are based on routines rather than on assessments of patients’ needs [128]. In the same study it was shown that even though the interactions were based on the nurses’ perceptions they nevertheless perceived that they worked according to a person-oriented approach [128]. Findings from another study show both caring (being open to and perceptive of others, morally responsible, truly present, and dedicated and having the courage to be involved) and uncaring (showing disinterest, insensitivity, coldness, inhumanity) encounters in adult somatic care [129]. Unfortunately there are no corresponding studies from paediatric settings and there is a need for research regarding health professionals’ understanding of patients’ needs in paediatric care.

Efforts to promote scientific, critical thinking in health professionals’ education programmes seem important in order to achieve a more empathic and critical caring approach in clinical care. Time for reflection through process-oriented group supervision [130-131] has shown promising results with regard to professional development especially for female nursing students [131]. Combined, the findings indicate that the accuracy with which health professionals assess patients’ psychosocial function, including coping strategies, could be enhanced through increased education in scientific skills, critical thinking, and supervision supporting reflection. However, in order to maximise the possibility to provide certain individuals, e.g. individuals struck with cancer during adolescence, with individually-tailored support and care professionals’ assessments should be complemented with patients’ self-reports.
Psychosocial function during the acute and extended phase of survival – summary of Studies III and IV

Psychosocial states

The cluster analysis identified three states, see Figure 2. The mean values for Vitality, Mental Health, and Anxiety were z-transformed to show potential deviations from the mean value of the total sample of vectors (N=334). The mean values for the three variables in the total sample of states are presented as a straight line in the graphs. A deviation of ≤ 0.5 SD from the line is conceptualised as indicating an average score, a deviation of > 0.5-1.0 SD as an above/below average score, whereas a deviation of >1.0 SD is conceptualised as a low/high score.

![Figure 2. The cluster solution describing poor, average, and good psychosocial function. One unit on the y-axis corresponds to one standard deviation (SD).](image)

Poor psychosocial function (State A), is characterised by a below average score on Vitality, a low score on Mental Health, and a high score on Anxiety; Average psychosocial function (State B) by a below average score on Vitality, an average score on Mental Health and Anxiety; and Good psychosocial function (State C) by an above average score on Vitality and Mental Health and an average score on Anxiety.

The characteristics of the states, including mean values and SDs, and the number of individuals in each state at T1-T7, are presented in Table 4.
Table 4. Mean values, standard deviations, and number of participants in each state at T1-T7.

<table>
<thead>
<tr>
<th>Psychosocial states</th>
<th>Vitality Mean (SD)</th>
<th>Mental Health Mean (SD)</th>
<th>Anxiety Mean (SD)</th>
<th>n (%)</th>
<th>T1 n</th>
<th>T2 n</th>
<th>T3 n</th>
<th>T4 n</th>
<th>T5 n</th>
<th>T6 n</th>
<th>T7 n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor</td>
<td>42.2 (19.0)</td>
<td>52.5 (13.3)</td>
<td>7.6 (3.6)</td>
<td>79 (24)</td>
<td>25</td>
<td>18</td>
<td>10</td>
<td>7</td>
<td>4</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Average</td>
<td>48.8 (16.2)</td>
<td>72.1 (8.3)</td>
<td>2.5 (1.4)</td>
<td>68 (20)</td>
<td>25</td>
<td>17</td>
<td>8</td>
<td>5</td>
<td>6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Good</td>
<td>81.6 (12.6)</td>
<td>89.3 (8.0)</td>
<td>2.7 (1.9)</td>
<td>187 (56)</td>
<td>11</td>
<td>21</td>
<td>32</td>
<td>36</td>
<td>28</td>
<td>29</td>
<td>30</td>
</tr>
<tr>
<td>All</td>
<td>65.6 (23.6)</td>
<td>77.1 (18.0)</td>
<td>3.8 (3.2)</td>
<td>334</td>
<td>61</td>
<td>56</td>
<td>50</td>
<td>48</td>
<td>38</td>
<td>42</td>
<td>39</td>
</tr>
</tbody>
</table>
Shortly after diagnosis more individuals than expected by chance are found in states A and B and fewer in state C (p ≤ .001). Over time more individuals are found in state C at T4 (p ≤ .01), T5 (p ≤ .05), T6 (p ≤ .05), and T7 (p ≤ .01), and fewer than expected by chance in state B at T4, T6, and T7 and in state A at T5 (p ≤ .05). Four years after diagnosis, 77% are found in state C, 8% in state B, and 15% in state A.

More females and fewer males than expected by chance are found in a state of poor psychosocial function at T1 (p ≤ .05) and more males and fewer females than expected by chance are found in a state of average psychosocial function at T1 (p ≤ .001) and T2 (p ≤ .05). More males and fewer females than expected by chance are found in a state of poor psychosocial function at T7 (p ≤ .05). More individuals with Lymphoma than expected by chance are in a state of good psychosocial function at T3 (p ≤ .01), T4 (p ≤ .05), and T6 (p ≤ .05) and fewer in a state of poor psychosocial function at T3 (p ≤ .05). At T2 more individuals with divorced and fewer whose parents are not divorced than expected by chance are in a state of poor psychosocial function (p ≤ .05), whereas fewer with divorced and more whose parents are not divorced are in a state of average psychosocial function (p ≤ .05).

Individuals found in a state of poor psychosocial function at T3 reported using distracting to a greater extent (p ≤ .05) at T1 (M 3.8, SD 0.9) compared to those found in a state of good psychosocial function at T3 (M 2.6, SD 1.2).

The HADS Depression subscale discriminates between the different states at T1 (p ≤ .001). Those in state A report more depression than those in states B and C (p ≤ .01).

As previously shown [13-21, 24-25, 28, 132] the findings reveal that the period immediately after a cancer diagnosis is extremely stressful for most adolescents. More females than expected by chance were in poor psychosocial function, supporting previous findings [27, 84-85, 133]. It has been reported that girls from the age of eight years report more distress than boys [134]. The fact that more individuals with divorced parents than expected by chance displayed poor psychosocial function six months after diagnosis supports findings showing that survivors’ distress is associated with poor family functioning [135].

Those with poor psychosocial function twelve months after diagnosis report more use of the distracting strategy to cope with distress shortly after diagnosis compared to those displaying good psychosocial function. This is in line with previous findings [136]. According to contemporary learning
theory, avoidance, a concept partly overlapping with distracting, prevents the elaboration of a trauma and thus the extinction of emotional responses [137]. Avoidance is associated with an elevated level of psychological distress among parents of children with cancer [138-139] and other traumatised populations [140].

Only a few participants were in a state of poor or average psychosocial function during the extended phase of survival. This limits the possibility to detect potential relationships between risk factors for poor or average psychosocial function during this phase. Only one diagnosis was related to psychosocial function, more individuals with Lymphoma than expected by chance were found in a state of good psychosocial function. Considering this it should be taken in account that if the sample had been larger and if more adolescents with CNS and solid tumours had been included, the findings could have been different. Among the four participants four years after diagnosis who were diagnosed with a relapse none was in a state of poor psychosocial function. Findings by others show that in the long term survivors of CNS and solid tumours during childhood and those with severe cancer-related late effects [27, 30, 85, 133, 141-143] are at risk of poor psychosocial function.

A visual inspection of the data shows that individuals move between states over time. One could speculate that those who died during the study period were physically and/or medically worse off compared to those who were alive four years after diagnosis. However, previous findings for this sample [81] as well as the distribution of participants in the states presented in this study do not support this assumption. All individuals who died (n=15) during the study period, except for two who were dead at T3, moved between states during the study period, see Figure 3. A visual inspection of the data does not show any difference with regard to the number of participants in the states at T1-T2 for those who had died at T3.
The fact that approximately three quarters of the participants are found in a state of good psychosocial function four years after diagnosis indicates the existence of a basic human protective system consisting of e.g. cognitive ability, self-esteem, relationships with peers and parents, effective schools, and good health care [144] and this supports previous findings [27, 30, 32, 73, 81, 83, 85, 141]. However, 15% of the participants are in a state of poor psychosocial function four years after diagnosis. A visual inspection of the data shows that approximately a third of those in a state of poor or average function shortly after diagnosis are still in one of these states four years after diagnosis. Only one of those who are in a state of good psychosocial function shortly after diagnosis is in a state of poorer psychosocial function four years after diagnosis. Early identification of risk factors such as gender and family situation is needed [145-146]. However further research to identify additional risk factors and on how to identify these risk factors is needed.
Negative and positive consequences

See Table 5 for a presentation of categories and category content for negative and positive cancer-related consequences identified three (T6) and four (T7) years after diagnosis.

Table 5. Categories and category content for negative and positive cancer-related consequences identified three and four years after diagnosis (N=32).

<table>
<thead>
<tr>
<th>Categories</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negative consequences</strong></td>
<td></td>
</tr>
<tr>
<td>Bodily concerns</td>
<td>Physical and appearance problems, and the consequences of these.</td>
</tr>
<tr>
<td>Unpleasant thoughts and feelings</td>
<td>Unpleasant thoughts and feelings, e.g. with regard to memories from the hospital visits, and in connection with questions about the disease. “Feeling blue”, depression, and sorrow over lost years.</td>
</tr>
<tr>
<td>Outside the circle of friends</td>
<td>Being isolated or having lost touch with friends.</td>
</tr>
<tr>
<td>Difficulties with schoolwork/work</td>
<td>Schoolwork takes a lot of effort and energy and extra work is necessary to catch up on missed time at school. Missed days at work.</td>
</tr>
<tr>
<td>Negative self-esteem</td>
<td>Increased shyness and insecurity, more withdrawn, which negatively affects self-confidence and self-image.</td>
</tr>
<tr>
<td>Time consumption and financial issues</td>
<td>Extra time, expenses, and loss of study grants due to disease and follow-up.</td>
</tr>
<tr>
<td><strong>Positive consequences</strong></td>
<td></td>
</tr>
<tr>
<td>A more positive view of life</td>
<td>Another view of life. An awareness of death means that problems assume other proportions and that the present and day-to-day life are at the centre of things.</td>
</tr>
<tr>
<td>Good relations</td>
<td>Good ability to understand and therefore help other people. Values close relations with family members, friends, and other people.</td>
</tr>
<tr>
<td>Good self-esteem</td>
<td>An inner change with regard to maturity and development into a responsible person with good self-esteem, among other things regarding their own body.</td>
</tr>
<tr>
<td>Knowledge and experience with regard to disease and hospital care</td>
<td>Knowledge and experience of disease and hospital care and a secure relationship with hospital care.</td>
</tr>
<tr>
<td>Broader perspectives</td>
<td>New leisure-time activities and occupational plans.</td>
</tr>
<tr>
<td>Material gains</td>
<td>New things, social insurance etc.</td>
</tr>
</tbody>
</table>

Two categories of negative consequences which were not reported two years after diagnosis [82] were identified: negative self-esteem (T6) and time consumption and financial issues (T6 and T7).

Most participants described how the cancer disease had caused a change including both negative and positive consequences. Only one person at T6 and two persons at T7 reported only negative consequences whereas only
three persons at T6 and T7 reported only positive consequences. One person did not report any negative or positive consequence at T6 and T7. Some examples of participants’ descriptions of negative as well as positive experiences four years after diagnosis are presented below.

A young man, 20 years old, described unpleasant thoughts and feelings and bodily concerns as well as a more positive view of life and good self-esteem. “It’s the worry that it will come back. That’s what bothers you... I’ve had lumps on my throat on and off. Often when I get a cold I get, I react quite strongly because my immune defence is so low... When you are a little more depressed, that’s when you start to think a bit more... It’s always there in your body. You’re always afraid.” He continued: “Yes, you see everything from another angle and get a different view of everything. And then I appreciate everything much more than I did before. The small things that mean so much, like feeling well, for example... I think I’ve grown as a person, actually. It feels as if I now have more self-confidence and yes, you believe in yourself in another way .... Loads of people are really curious when you say that you have been ill with cancer. Personally I think that it’s really nice to talk about it, so it doesn’t bother me a bit. Friends and colleagues at work and so on, everyone is curious. I usually say I’m open about it so just ask if anyone wonders.”

A boy, 16 years old, described unpleasant thoughts and feelings as well as good relations. “If I see a computer game, for example, and it says “cancel”, then I think a lot about it sounding almost like cancer and things like that and then I get the shivers, OK, if I see a book about things like that or see a small child with a shaved head or who has lost his hair and things like that, I think a lot about it... Thoughts come and go.” He continued: “Yes, and Dad has been there for me and so on, yes... We have grown closer.”

A girl, 17 years old, described unpleasant thoughts and feelings as well as good self-esteem. “Maybe it’s now that I have sort of begun to understand that I’ve been ill... I’m sure that I go around and think so much, even though I’m not aware of it, and that I, I dream nightmares every night about all kinds of things and then I sleep very badly as well and that, if anything, is a sign that you’re worried or something like that ...., but I don’t know what it is, and it’s a bit tough....” “I lost those years... and even so they’re quite important years... yes, it feels as if I lost two of my teenage years, they’re just gone and you can’t do anything about it.” She continued: “Yes, I’ve grown, I’m probably more sensible too about what I should do and not do. I don’t think smoking is so cool anymore ... I’ve become terribly goal-oriented. It’s also something that I’ve found hard to do, like that, set goals, but I think I’ve become better at it... by just knowing what I want.”
A young woman, 20 years old, described a negative self-image as well as a more positive view of life and good relations “I’ve become shy. I’ve become this withdrawn and shy because I think that people can see that I’m different”. She continued: “You appreciate slightly different things that people usually do not think about, like how it smells at home…sitting and having a cup of tea, you can get this feeling that this is really good… Maybe my contact with my family is a little better, a little bit more open, like.”

The findings indicate some associations between reporting using compared with not using certain coping strategies shortly after diagnosis and reports of certain cancer-related consequence four years after diagnosis, see Table 6. Reports of using the strategies of fighting spirit, minimising, and seeking information relate to reports of a more positive view of life whereas reports of not using these strategies relate to reports of bodily concerns. Conversely, reports of using distracting and accepting are related to bodily concerns whereas reports of not using distracting are related to a more positive view of life. Reports of not seeking support are related to reports of bodily concerns as well as a more positive view of life.

The vast majority described both negative and positive cancer-related consequences three and four years after diagnosis within physical, emotional, social, cognitive, and financial domains. The findings support previous results illustrating positive life changes after struggling with a trauma [51, 63, 73, 147] and agree with results from our group for this sample showing better psychosocial function than for a reference group from 18 months up to four years after diagnosis [81].
Table 6. A presentation of the number of participants\(^a\) reporting using and not using a certain coping strategy shortly after diagnosis (T1) and a certain cancer-related consequence\(^b\) four years after diagnosis (T7) (N=32).

<table>
<thead>
<tr>
<th>Coping strategies</th>
<th>Negative consequence</th>
<th>Positive consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Bodily concerns (n=20)</td>
<td>A more positive view of life (n=19)</td>
</tr>
<tr>
<td></td>
<td>(%)</td>
<td>(%)</td>
</tr>
<tr>
<td>Accepting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used</td>
<td>(28)</td>
<td>64</td>
</tr>
<tr>
<td>Not used</td>
<td>(4)</td>
<td></td>
</tr>
<tr>
<td>Distracting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used</td>
<td>(16)</td>
<td>69</td>
</tr>
<tr>
<td>Not used</td>
<td>(16)</td>
<td>69</td>
</tr>
<tr>
<td>Fighting spirit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used</td>
<td>(17)</td>
<td>71</td>
</tr>
<tr>
<td>Not used</td>
<td>(15)</td>
<td>65</td>
</tr>
<tr>
<td>Minimising</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used</td>
<td>(20)</td>
<td>60</td>
</tr>
<tr>
<td>Not used</td>
<td>(12)</td>
<td>75</td>
</tr>
<tr>
<td>Seeking information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used</td>
<td>(20)</td>
<td>70</td>
</tr>
<tr>
<td>Not used</td>
<td>(12)</td>
<td></td>
</tr>
<tr>
<td>Seeking support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used</td>
<td>(17)</td>
<td>87</td>
</tr>
<tr>
<td>Not used</td>
<td>(15)</td>
<td>67</td>
</tr>
</tbody>
</table>

\(^a\) Percentages are presented when ≥ 60%
\(^b\) Findings are presented for consequences reported by ≥ 10 persons
Using fighting spirit, minimising, and seeking information to cope with cancer-related distress shortly after diagnosis is associated with positive consequences four years after diagnosis. The findings support previous results showing a relation between problem-focused coping and growth among adults after a diagnosis of cancer [86-87]. The reverse pattern was found for distracting; not using distracting is related to a positive consequence whereas using distracting is related to a negative consequence. Distracting has been reported as effective in reducing procedure-related pain in children and adolescents [148-151]. However, using avoidance to handle emotional distress may have long-term negative effects on mental health among adolescents and adults [152-153]. Other findings show that using problem-focused coping strategies is associated with better adjustment over time from diagnosis [136] supporting the view that problem-focused coping promotes adjustment in the extended phase of survival.

An additional analysis of the data shows that among those who four years after diagnosis reported a positive view of life more than expected by chance were in a state of good psychosocial function one year after diagnosis whereas, fewer of those who did not report a more positive view of life at that same time were in a state of good psychosocial function one year after diagnosis (p < .05). Among those who reported bodily concerns four years after diagnosis fewer than expected by chance were in a state of good psychosocial function two years after diagnosis whereas, among those who did not report bodily concerns at that same time more were in a state of good psychosocial function two years after diagnosis (p < .05). These results show a tentative relation between psychosocial states and consequences.

In order to support individuals who need help to cope with disease and treatment-related distress, interventions of psychosocial care and psychological treatments aiming at preventing development and/or maintenance of distress should be developed. These could e.g. include problem-solving strategies, imaginable exposure methods, and cognitive reappraisal. Acceptance-based interventions, a form of cognitive behaviour therapy [154] with a balance between acceptance and change aiming at helping individuals to act in accordance with personal values in the presence of interfering thoughts, emotions, and bodily sensations are viable options.
Methodological discussion

Perspectives
As nurses and physicians are involved in medical treatment, decision-making, and prioritising care and use of health care resources, we thought it imperative to investigate the accuracy with which they assess how a certain adolescent copes or does not cope with disease and treatment-related distress. We have chosen the adolescents’ self-ratings as the gold standard although these may be affected by mood, personality, and a more or less realistic perspective of which strategies that have been used or not used. In order to maximise nurses’ and physicians’ possibilities to identify which strategies a certain adolescent had or had not used we took great care to identify the nurse and the physician who best knew a certain adolescent and asked these persons to assess the adolescent’s use of coping strategies. This fact as well as the circumstance that the nurses and physicians had been informed about the aim of the study may have resulted in inflated values of sensitivity and overestimation of the use of coping strategies.

Design and Sample
Strengths of this research are the prospective, longitudinal design and the homogeneity of the sample with regard to age and time since diagnosis. Data were collected at seven assessments from shortly after diagnosis up to four years after diagnosis and at the first assessment there were no differences between participants and eligible non-participants regarding sex, age, estimated prognosis, and time since diagnosis [21].

Information about the study was provided to potential participants approximately three weeks after diagnosis, a time at which the diagnosis of a CNS tumour has not always been verified by a pathological examination. Moreover, treatment with chemotherapy was a criterion for inclusion. For these reasons few participants with a CNS tumour were included. It is known that patients with a CNS tumour report more distress and lower levels of HRQoL in comparison with patients with other cancer diagnoses as well as reference groups [30, 84, 141-143]. This should be taken in account when evaluating the results.
The original idea was to include participants from all six Swedish centres for paediatric oncology. However, only three agreed to participate and in order to get a sample of the present size adolescents were included for four years. In spite of great efforts to include a sample of the present size the number of participants limits the possibility of subgroup analyses e.g. in Study II regarding comparisons between nurses and nursing assistants, between registered nurses and paediatric nurses, and between physicians and paediatricians, as well as the power in the statistical analyses in Study II and III. National or even international efforts are necessary to improve the quality of future research with regard to sample sizes within the paediatric oncology context.

In this research attrition is mainly caused by death. Twenty-five percent of those included were dead four years after diagnosis. This gives a four-year survival rate of 75%, comparable to the five-year overall national survival rate of 75% at the time of inclusion [2] and a more recent figure of 80% [7, 9-10]. We therefore assume that the sample is reasonably representative for Swedish individuals diagnosed with cancer during adolescence, except for those diagnosed with a CNS tumour.

It can be questioned whether those participants who died during the study period were psychosocially worse off compared to those who were alive four years after diagnosis. However, previous findings for the participants up to four years after diagnosis [81] do not show such a difference. Of the four participants four years after diagnosis who were diagnosed with a relapse none was in a state of poor psychosocial function.

Data collection

Data were collected by telephone interviews, as for practical reasons face-to-face interviews could not be performed. We assume that the procedure to collect data via telephone, resulted in a higher response-rate and a lower internal drop-out than self-administered questionnaires would have [155], this is considered to be a strength of the research. Telephone interviews may be particularly suitable for adolescents. Our impression is that most adolescents appreciated the relative anonymity of the telephone contact. Some expressed appreciation that they had been contacted and asked about their experiences via telephone. The fact that they were posed orally and not in writing may, especially for those 15 years or older, have resulted in expressions of somewhat better psychosocial function than would have been the case if they had been asked to answer the same questions on their own. Findings by our group and others show that self-reports of health and distress vary dependent on mode of administration, with ratings being more favoura-
ble for telephone than postal administration [155-157]. However, self-preservation motives should always be taken into consideration when analysing data collected via self-reports [158-159] and alternative hypotheses, such as time [88], denial, defensiveness, social desirability, self-deception, and impression management [53, 132] should be considered. It can be speculated that adolescents are especially reluctant to express emotional problems and that they may have felt obliged to present themselves as “feeling good” in the aftermath of the disease.

Data analyses

In Studies I and IV data were collected by open-ended questions and analysed by content analysis [101-103]. The trustworthiness of the data analysis is supported by the facts that the interviewer took part in the data analysis, and avoided leading questions, that some, but not all, of the researchers taking part in the data analysis had experience of research within the field of paediatric oncology, and that the researchers taking part in the analysis had extensive experience of analysing data from open-ended questions with content analysis. The fittingness of the results is supported as the individuals diagnosed with cancer during adolescence have recognised the inductively derived aspects of coping and consequences related to having had cancer during adolescence.

The choice of coping strategies investigated by closed-ended questions in Studies I and II was based on the available literature at the time when the project was planned (1999) [47-48, 96], the clinical experience of the members in the research group, and findings from pilot interviews with five healthy adolescents. Psychometric properties for the coping questions are lacking. Each strategy was measured by one item, consequently Chronbach alpha values could not be calculated, nor has the test-retest reliability or the construct validity of the measure been investigated.

In Study I answers from closed-ended questions are presented in relation to answers from open-ended questions. Open-ended data, to a larger extent than data from closed-ended questions, rely on respondents’ ability to remember and verbalise [160]. It has been reported that children and adolescents, when answering open-ended questions about how they cope, report using one to three strategies to cope [161]. In Study I the participants reported one to four strategies in response to the open-ended questions. The relatively small number of reported strategies indicates a potential limitation with regard to the amount of new information that can be derived when open-ended questions are used to investigate a phenomenon. Nevertheless answers from open-ended questions may generate new aspects of an investigated pheno-
menon, complement findings from closed-ended questions, and generate new questions and hypotheses for further research.

There are no absolute cut-off points for what is considered good sensitivity and specificity for a test as this is highly dependent on the clinical situation in which the test is used. In general, both sensitivity and specificity should be satisfactory as high sensitivity alone may indicate a systematic overestimation whereas, high specificity alone may indicate a systematic underestimation. Sensitivity and specificity values can be expected to be 50% by chance. As a basis for discussing the accuracy of nurses’ and physicians’ ratings in Study II we used a value at 60% or higher as indicating reasonable agreement [105]. The choice to express the accuracy of health professionals’ ratings in terms of sensitivity and specificity has the advantage of making it possible to discuss their ratings in terms of properties of many tests used in health care. A value of 60% indicates a relatively low level of agreement. An additional analysis revealed that using 70% as the threshold provided a reasonably comparable sensitivity agreement except for four strategies for nurses and eight strategies for physicians. However, for specificity all values for nurses and physicians were below 70% except one value for nurses and two for physicians. For an explorative purpose we in Study IV used the same value i.e. 60% to indicate reasonable agreement when discussing potential associations between reports of using certain coping strategies and experiencing certain consequences.

In this research the psychosocial function of individuals diagnosed with cancer during adolescence was explored in a longitudinal perspective and cluster analysis was used to identify subgroups of individuals with regard to psychosocial function. Efforts were made to ensure the validity of the classificatory structure by discriminating between the three identified states using the HADS Depression subscale and these analyses verified the selected cluster solution.

A significance level of ≤ .05 was chosen in this research and as a large number of calculations were done there is a risk of mass significance. However a post-hoc power analysis for study II reveals that the t-tests were performed with a .68 power with an effect size of .50 and a significant level of ≤ .05.
Conclusions and Implications

Answers to open and closed-ended questions about which strategies adolescents recently diagnosed with cancer use to cope with distress during the acute phase of survival provide somewhat different impressions of which strategies the adolescents use. Together the answers provide a more complete description of how the adolescents cope than either open or closed-ended questions would have provided. This should be considered when investigating psychosocial phenomena not only in a paediatric context but also in other contexts.

Nurses and physicians have difficulties assessing how adolescents recently diagnosed with cancer cope with disease and treatment-related distress. Using their ratings to guide provision of psychosocial care, seems inaccurate. Considering that the accuracy of health professionals’ ratings is probably lower outside a research study than the values presented in this research, actions to support adolescents’ coping need to rely on direct communication. In order to increase health professionals’ possibilities to assess patients’ e.g. individuals struck with cancer during adolescence, psychosocial function including coping strategies, increased attention needs to be paid to promote their education in scientific, critical thinking. In addition, reflection through supervision should be promoted within education programmes and clinical care.

A relation between on the one hand the use of distracting to cope with distress during the acute phase of survival and on the other hand poor psychosocial function and negative consequences later on during the disease trajectory was revealed. Within the paediatric context as well as other contexts, efforts should be taken to investigate whether, and if so how, coping with distress by distracting influences psychosocial function.

Four years after diagnosis, a vast majority of those diagnosed with cancer during adolescence are in a state of good psychosocial function and report positive cancer-related consequences. These findings illustrate the existence of a basic human protective system and that distress and personal growth go hand in hand after a trauma such as cancer during adolescence. However, a subgroup is in a state of poor psychosocial function four years after diagnosis indicating that efforts to prevent and treat cancer-related distress and
promote good psychosocial function among individuals struck by cancer during adolescence are needed. These efforts could e.g. comprise programmes consisting of interactive support and cognitive behavioural therapy. Using the Internet to provide this kind of care would increase the possibility to reach those who due to limited healthcare resources, time, and distance do not have access to psychosocial health care. It may also help individuals struck by cancer during adolescence to overcome barriers to psychosocial care, and increase the possibility for them to get psychosocial help when they need it the most.
Svensk sammanfattning

Denna avhandling presenterar resultat från ett pågående projekt ”Att drabbas av cancer under tonåren. Psykosociala och hälsoekonomiska konsekvenser”. Det övergripande syftet var att undersöka hur tonåringar som drabbats av cancer hanterar sjukdoms- och behandlingsrelaterade besvär i samband med diagnos och hur de mår i psykosocialt avseende upp till fyra år efter diagnos.


Som svar på slutna frågor angav flest deltagare att de använt emotionsfokuserade strategier för att handskas med besvär medan flest, som svar på öppna frågor, angav att de använt problemfokuserade och meningsskapande strategier. Sjuksköterskor och läkare hade svårt att identifiera vilka strategier en viss tonåring använt respektive inte använt och sjuksköterskor överskattade i vilken utsträckning deltagarna använt olika strategier.

Deltagarna indelades i tre undergrupper vad gäller psykosocial funktion: dålig, medel och bra psykosocial funktion. Vid fyra till åtta veckor samt sex månader efter diagnos fanns fler än förväntat i gruppen med dålig eller medel psykosocial funktion. Från arton månader t.o.m. fyra år efter diagnos fanns fler än förväntat i gruppen med bra psykosocial funktion. Att vara flicka, ha skilda föräldrar och att använda sig av distraktion för att handskas med besvär var relatert till dålig psykosocial funktion upp till ett år efter diagnos. Fyra år efter diagnos återfanns 77% i gruppen med bra psykosocial funktion medan 15% återfanns i gruppen med dålig psykosocial funktion. Vid tre och fyra år efter diagnos rapporterade deltagarna negativa såväl som positiva cancerrelaterade konsekvenser. Bland dessa kan nämnas kroppsliga besvär, oroande tankar och känslor, utanförskap samt en mer positiv syn på livet, förbättrad självkänsla och förbättrade relationer.
Att skriva den här avhandlingen har varit mycket intressant, inspirerande och intensivt. Det är många personer som har bidragit på olika sätt under arbetets gång och som jag minns med tacksamhet men enbart några kan omnämnas här.

**Ett stort TACK till:**

*Tonåringarna* som har deltagit i projektet och svarat på frågor och berättat om sina erfarenheter av att drabbas av cancer.

*Louise von Essen*, huvudhandledare och guide i forskningens labyrint, som med sin stora forskningserfarenhet, kunskap och tålmod, med fokus på de psykosociala frågorna har fört avhandlingsarbetet framåt under hela processen.

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*Elisabet Mattsson*, biträdande handledare, vägvisare och mentor där ingen fråga är för stor eller för liten, som sporrar till att höja ribban med uttalanden som: varje gång vi skriver en artikel ska den vara bättre än den förra.

*Mariann Hedström, Inger Skolin och Gunnel Larsson*, medförfattare och seniorkollegor, som har granskat databearbetning och manus till artiklar och väglett utifrån sitt kunnskapsomfattande.


Medarbetare i forskargruppen psykosocial onkologi och stödjande vård som har inspirerat genom diskussioner på seminarier men också på fikapauser. Bland dessa finns *Martin Cernvall*, medförfattare och doktorandkollega, *Ulrika Pöder, Erik Olsson, Malin Ander och Ellen Skogseid* som har granskat manus och delar av avhandlingen och gett värdefulla infällsvinklar och
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