Adolescent and young adult cancer survivors – body image and sexual health

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To all adolescent and young adult cancer patients

Adolescent and young adult cancer survivors – body image and sexual health

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ABSTRACT

Background

Adolescent and young adult cancer survivors constitute a group in society of which the numbers are increasing. To optimize rehabilitation efforts, we need to understand the possible physical and psychological consequences of cancer treatment for adolescent and young adult cancer survivors. The purpose of this study has been to identify the needs and topics that adolescents and young adults acknowledge as being important to them, and furthermore to explore possible physical and psychological complications post cancer treatment.

Methods

This thesis uses a combination of qualitative and quantitative methods. Eleven focus group interviews were conducted with adolescent and young adult cancer survivors aged 15-29. Subsequently, a study-specific web-based questionnaire was sent to a population-based cohort of adolescent and young adult cancer survivor and matched controls. 540 out of 721 (74%) eligible participants responded to the questionnaire. The topics covered in the questionnaire were psychosocial health, body image, sexuality, fertility, education, work and leisure.

Results

Adolescent and young adult cancer survivors reported in focus group interviews that they had unmet needs during and after cancer treatment, including age-appropriate information about sexuality. In the questionnaire study, they reported feeling less attractive than controls due to scars on their bodies, and they reported low satisfaction with their sexual function compared to controls. The participants did not find that questions addressing very personal and emotionally charged issues, like sexual activity, affected them negatively.

Conclusions

Adolescent and young adult cancer survivors perceived themselves as being unattractive due to scars on their bodies and were less satisfied with their sexual function than matched population-based controls. They also expressed the need for support to reintegrate into normal social life.

SAMMANFATTNING PÅ SVENSKA

I Sverige diagnostiseras årligen ca 800 tonåringar och unga vuxna, 15-29 år, med cancer. Att som tonåring eller ung vuxen genomgå cancerbehandling innebär stora påfrestningar för individen. Förutom de fysiska biverkningarna av cancer beskrivs även känslan av förlorad kontroll över sitt eget liv som enorm. Idag är den medicinska behandlingen god och flertalet tonåringar och unga vuxna överlever sin cancersjukdom, men vi vet lite om hur livet är efter behandlingen. För att dessa unga individer ska kunna återgå till ett normalt liv med arbete, socialt liv, samliv och fungera som människor kan det finnas behov av rehabilitering. Det är därför av stor vikt att fylla de kunskapsluckor som finns och få samlad kunskap kring möjliga följdtillstånd, följdsjukdomar och behov efter cancerbehandling för denna grupp. Forskning inom området har ökat under senare år och flera studier har visat att det finns obesvarade frågor kring livet efter behandling, som till exempel förekomst av symptom rörande kroppsuppfattning och sexualitet.

Denna studie hade som mål att ge tonåringar och unga vuxna som behandlas för cancer en röst, genom att belysa upplevda behov och fånga fysiska och psykiska följdtillstånd och följdsjukdomar relaterat till cancerbehandlingen.

I fokusgruppsintervjuer beskriver canceröverlevare i åldern 15-29 år, behov av en mer åldersanpassad vård, ett personligt möte i vården, psykosocialt stöd under och efter behandlingen samt kunskap och stöd i frågor kring sexualitet och fertilitet. I en web-baserad enkätstudie deltog 540 tonåringar och unga vuxna, varav 285 canceröverlevare och 255 i en kontrollgrupp (svarsfrekvens 74%). Deltagarna besvarade en enkät som innehöll frågor om självskattad mental hälsa, depression och ångest, livskvalitet, kroppsuppfattning, sexuella funktioner och fertilitet samt demografiska fakta såsom ålder, kön, utbildning och civilstånd. Avslutningsvis fick de frågor kring upplevelsen av att delta i undersökningen.

De tonåringar och unga vuxna som deltog i denna enkätstudie, innefattande frågor om sexualitet och självmord, upplevde inte dessa frågor som känsliga eller att det påverkade dem negativt. Det framkom

vidare att unga canceröverlevarna kände sig mindre attraktiva på grund av kroppsliga ärr jämfört med kontrollgruppen. En möjlig förklaring till detta kan vara att ärr associeras med cancerdiagnosen. De rapporterade också låg tillfredsställelse beträffande sexuell funktion jämfört med kontrollgruppen. Dessutom hade de en del fysiska symtom relaterat till sexuell funktion men inte i högre grad än kontrollgruppen. I en analys av förklaringar till missnöje med sexuell funktion var erektionsproblem bland de manliga och depression bland de kvinnliga canceröverlevarna, associerade faktorer. Vidare rapporterade de kvinnliga canceröverlevarna en lägre frekvens av orgasm och de manliga canceröverlevarna rapporterade mindre sexuell lust, än kontrollerna.

Resultaten i denna avhandling kan vara vägledande för planering av framtida studier kring känsliga frågor om exempelvis sexualitet, mental hälsa och självmord vad gäller etik, då deltagandet i denna studie upplevdes som något positivt. Vidare visar avhandlingens resultat att canceröverlevare behandlade vid 15-29 års ålder, har biverkningar i form av minskad attraktivitet på grund av ärr och låg tillfredställelse med sexuell funktion, samt att dessa huvudsakligen förklaras av psykologiska snarare än fysiologiska biverkningar till behandlingen. Om vi vill hjälpa unga canceröverlevare till ett bättre liv så visar resultaten från denna avhandling att bearbetande av de psykologiska reaktionerna på grund av ärr efter cancerbehandling kan vara en väg framåt. Vidare bör plastikkirurgisk kompetens konsulteras för att optimera förutsättningarna för så fina ärr som möjligt efter kirurgiska ingrepp. Jämfört med kontrollerna rapporterade de unga canceröverlevarna lägre tillfredställelse med sin sexuella funktion samt kvinnorna lägre frekvens av orgasm och männen mindre sexuell lust. En möjlighet att förbättra livskvaliteten för dessa patienter skulle kunna vara att erbjuda adekvata psykologiska stödinsatser. Dessutom kan framtida studier undersöka i vilken utsträckning cellgifter ger en nedsatt förmåga till orgasm.

LIST OF PUBLICATIONS I-VI

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I Olsson M, Jarfelt M. Pergert P & Enskär K. Experiences of Teenagers and Young Adults Treated for Cancer in Sweden. *J European Oncology Nursing 2015; 19(5):575-81.*

II Olsson M, Enskär K, Steineck G, Wilderäng U & Jarfelt M. Adolescent and young adult cancer survivors´ perceptions of participating in a survey – ethical and methodological considerations. Submitted

III Olsson M, Enskär K, Steineck G, Wilderäng U & Jarfelt M. Self-perceived physical attractiveness in relation to scars among adolescent and young adult cancer survivors – a population-based study. *J of Adolescent and Young Adult Oncology.* 2018 Jan 26. doi: 10.1089/jayao.2017.0089.

VI Olsson M, Steineck G, Enskär K, Wilderäng U & Jarfelt M. Sexual function among adolescent and young adult cancer survivors – a population-based study. *J of Cancer Survivorship.* 2018 Mar 5. https://doi.org/10.1007/s11764-018-0684-x.

CONTENTS

1. INTRODUCTION

In my clinical work as a paediatric oncology nurse, I have had the privilege to meet many wonderful adolescent cancer patients. During the years, they have taught me how cancer influences their lives. There have been many deep and serious discussions over the years and a lot of laughter. Together with colleagues we have organized support programmes in the form of social activities for the group. This experience pushed me into the research field, made me want to find out more systematically about the adolescent and young adult life experiences during the cancer journey. I wanted to find out what was really important for this group of patients and how cancer affected them physically and psychologically.

2. BACKGROUND

2.1 Adolescent and young adult oncology

Adolescent and young adult (AYA) oncology is a relatively new clinical and research field. The development of this field started in United Kingdom with the first adolescent unit in 1990. This was followed by a Government document, guidance in quality standards and cancer services in 2015.[1, 2] Australia has had a comparable development followed by the United States and several European countries.[3-5] However, in in some European countries there is still no specialized care for AYA cancer patients and therefore room for improvement[6]. Clinical healthcare professionals and researchers in AYA oncology, have from the start formed a close collaboration with patient organizations in order to improve outcomes, highlight needs and spread information.[7] Research on AYA cancer patients followed the clinical development and at the beginning of the twenty-first century, the first research papers were published.[8-13]

2.2 Definition of the group

There are discussions both in the clinical and research fields on age definition of the AYA group with a cancer diagnosis. There seems to be a consensus on the lower age limit, and the age of 15 has been established in all countries. In Europe, the definition varies from 15 years old to 25 alternatively 29 years old.[14, 15] In the United States, the age range is 15 to 39 years old, in Australia the age range 15-25 years old is used.[16, 17] In the United States, the argument for including people up to 39 years old is that this group has had a poorer survival rate than elderly people. Those who argue for 25 years old as the upper limit talk about biological and psychosocial maturity, asserting that the differences between people aged 25 and 39 are too great. When the age group has been defined as 15-29, it has generally been motivated by the need to include a larger number of cancer patients. In a recent European publication, epidemiologists suggested defining the AYA age group as including 15-39 year olds.[6] The debate is ongoing and consensus has not been reached.[18]

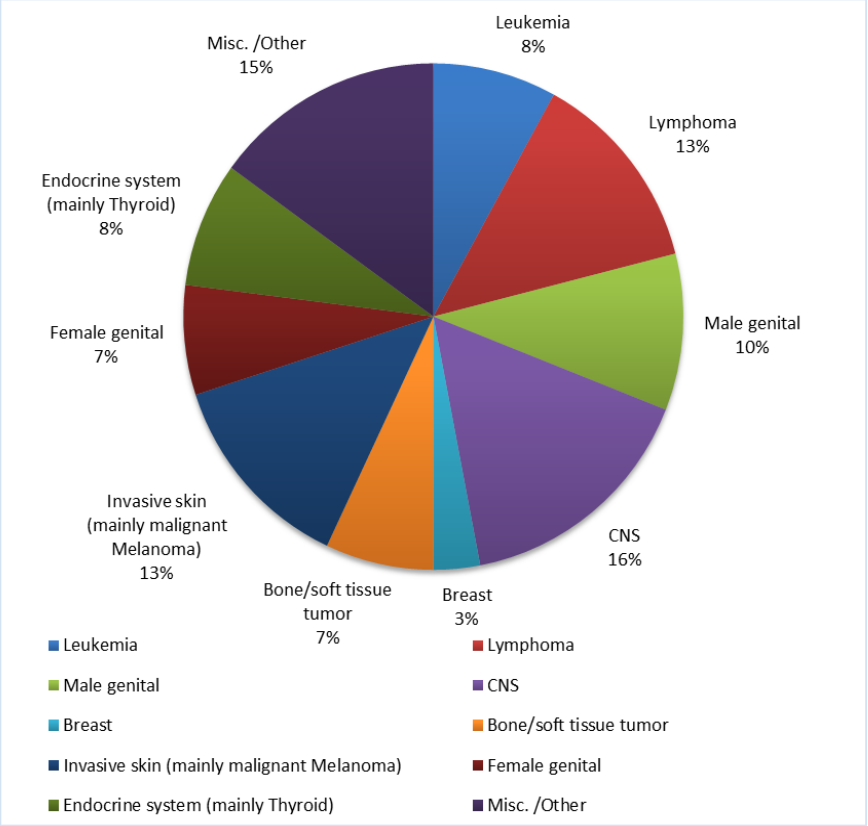
In this study, we decided on the inclusion of 15-29 year olds in the AYA age group, as was current in Europe at the start of this study.[14] Since AYA cancer is a new clinical and research field, this discussion is ongoing, as stated above.

2.3 Diagnosis and survival

Worldwide today there is an estimated number of one million new AYA (15-39 years) cancer cases annually.[19] The annual cancer incidence in Sweden in the AYA group aged 15-29 years old, is approximately 800.[20] Cancer diagnoses in the age-span 15-29 are different from children and older adults (Figurer 1). In children, there are higher incidences of leukaemia and brain tumours, whereas in adults there are higher incidences of e.g. prostate cancer, breast and gynaecological cancers. The main diagnoses in the AYA group are, in descending incidence, lymphomas, invasive skin cancer including malignant melanomas, male genital cancers, cancers in the endocrine system including thyroid cancer, female genital cancers followed by CNS tumours, leukaemia, sarcomas (bone and soft tissue) and miscellaneous (Figure 1).[21]

The overall 5-year survival rate in Europe for cancer among AYA patients (15-39 years) is 82%. This is a significant increase from 79 % 2000 to 82 % 2007.[22]

Figure 1. *Cancer in 15-29 year olds by primary site in Sweden 2010-2011, from the Swedish Cancer Registry.*



2.4 Treatment-related late complications

With the improvement in survival rate in the AYA group, the number of survivors with treatment-related complications has increased. Late complications after cancer treatment in the AYA group are dependent both on the cancer itself and the treatment and may include: cardiotoxicity, second primary cancer, cognitive deficits, fertility issues, dysfunctional sexual life and psychological issues.[23-26] For childhood cancer survivors there are several national guidelines for follow-up after cancer treatment, including long-term follow-up clinics in several countries.[27-29] There are guidelines for follow-up in adults cancer survivors too, but specific guidelines for follow-up of the AYA cancer group have to my knowledge, not yet been formulated.[23]

2.5 AYA psychosocial development and health

During the ages 15 -29 the psychological development is correlated to the maturing adolescent body. In adolescence, there is a transition from searching for one's identity to finding out more and more about who one actually is or wants to be.[30] From 15 to 18 years of age, the capacity for abstract thinking develops, including the ability to reason in terms of right and wrong. Even though the cognitive functions develop fast, there are gaps in the connection between them and the emotions, resulting in a lack of emotional coordination – all acceleration but no brakes. Emotions at this age are very intense and the adolescent at 15-18 years old is very experimental and sensation-seeking. Relationships at this age are serious and very emotional, and seemingly matters of life and death. Individuals at this stage have difficulty in seeing any other point of view than their own at one and the same time. They also keep asking themselves if they are good enough.[30, 31]

For 19-24 year olds, the body is now an adult body although parts of the brain are still going through changes. In the prefrontal cortex, the executive functions develop and in general, the connections between the regions in the brain increase, leading to more complex and critical thinking. The brain is now capable of calculating risks versus rewards and this may lead to the emotions being better regulated. These young adults are now able to think about and make plans for the future. Relationships are now based on mutual values and respect rather than on emotional self-centredness.[30, 32, 33]

At 25 years of age, the cognitive functions are even more developed, allowing for complex thinking, and thus the individual is more able to see the "big picture". AYA individuals are now more aware of their own role in decision-making. Their reasoning enables them to make self-corrections and they are more capable of both shaping and following rules. This is the age at which relationships may be committed and long-lasting.[30, 32]

AYA individuals in Sweden have shown a general increase in mental illnesses over recent years, mainly depression and anxiety disorders.[34] They have also reported high levels of stress, especially at the ages of

19-24, with women suffering more often from psychosomatic complaints than men.[35] There are mixed findings concerning trends in mental illness in the AYA group around the world.[36, 37] However, a recent publication from Britain reported an increase in mental illness in young women.[38]

2.6 AYA cancer and psychological impact

The impact of cancer during the AYA ages may result in negative psychological effects such as depression, anxiety and worries about relapse for a long time after treatment has been completed.[34, 39, 40] AYA cancer patients report a higher incidence of severe psychosocial problems than older cancer patients do.[41, 42]

In one study, AYA patients reported that at diagnosis, and during cancer treatment, thoughts of financial issues, body image, control over life, work plans, relationship with their partner, and plans for having children impacted on their lives in a negative way.[43] The changes in life caused by cancer may affect areas such as self-esteem and body perception. This in turn affected relationships with friends and also the desire for close relationships.

Many AYA cancer patients experienced a feeling of loss when it came to a normal life, having lost their health because of cancer. They also experienced losing control of their lives as enormously traumatic.[9, 44-46] AYA patients also reported worry as they approached the end of treatment, as well as an increase of anxiety and depression. About 29 percent of AYA cancer patients reported post-traumatic stress close to the end of treatment.[47] During cancer treatment, AYA patients may have suffered from treatment complications and therefore have had a limited social life. When these patients approached social life and met reality again, they reported difficulties concerning their expectations of life, since they were neither ill nor healthy.[48]

In this study, we use the term depression, meaning self-assessed depression. A previous study, in testicular cancer survivors, concluded that self-assessed depression may be used when screening for depression but it is not enough for clinical diagnosis.[49]

2.7 Body image

During the adolescent and young adult years, the focus on one's own body is very intense, and the view of the body is highly critical. Dissatisfaction with one's body and physical appearance is common.[50] Additionally, the importance of appearance is continually emphasized and attractive people are viewed as more successful, reliable and honest in Western society today.[51, 52] In many Western countries, dissatisfaction with one's appearances is however common in all age groups.[53, 54]

Free picture Pixabay, Internet

In the past few years, physical beauty treatments and cosmetic surgery have increased in frequency, which probably contributes to reinforcing negative perceptions in the AYA group of their physical appearance in general.[55, 56] According to the Cambridge Psychological Dictionary, there is a distinction between body image and self-image.

The definition of body image is a person’s mental representation of her/his own physical appearance, based on looking in mirrors or at photos and also based on the reactions of people around her/him. Self-image is more a person’s idea of who he/she actually is as a person, not only physically.[57]

2.8 Body image and cancer

Disturbed body image among adolescents after childhood cancer has earlier been reported.[58-61] In a recent study, childhood cancer survivors reported psychological distress due to treatment-related scars.[62]

Studies on body image among adults mainly deal with breast cancer patients and testicular or head and neck cancer patients.[63-67] These studies describe the negative impact of losing a breast, and the feeling among testicular cancer patients of being less masculine or being damaged goods. For head and neck patients the difficulty has mainly been to accept their altered appearance.

There are few qualitative studies on adolescent and young adult cancer survivors investigating body issues and describing this group’s difficulties in accepting and adapting to physical changes and feelings of being different from others.[68, 69]

2.9 Sexuality

According to the World Health Organization’s (WHO’s) current working definition, sexual health is:

> ”A state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.”[70]

Additionally, the WHO concludes that sexual health cannot be understood or become functional without a broad approach to sexuality, which is needed as a basis for behaviour related to sexual health. The working definition of sexuality is:

> "A central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors."[70]

In adolescence, at 15-18 years of age, an individual's psychosexual development is connected to the physical development of becoming an adult. Psychosexual development includes testing one's personal identity, exploring sexual identity, flirting, needing to feel socially accepted and testing an intimate relationship with someone.[30] In young adulthood, 19-29 years of age, when physical development is sooner or later completed, a person becomes more aware of her/his personality, competence and interests. An individual's psychosexual development may not be completed, there may still be a search for personal sexual identity, but he/she will have gained more sexual experience and now is the time for establishing longer relationships.[30, 71]

Sexual function may also be described in a broader way, including frequency of sexual activity, and it may furthermore be affected by physiological, psychological, social, religious and ethical factors.[72] According to ICD-10, (International Statistical Classification of Diseases and Related Health Problems – Tenth Revision), sexual dysfunction not caused by organic disorder or disease covers the various ways in which an individual is unable to participate in a sexual relationship as he or she would wish. Sexual dysfunction is a psychosomatic process and thus – as this adjective shows – both psychological and somatic processes are usually involved in the causation of sexual dysfunction.[73]

In this thesis, the term ‘sexual function’ is used and conceptualized in combined domains, consisting of desire, arousal/erection, lubrication (women), orgasm, ejaculation (men), satisfaction, and genital pain (women).[74]

“The Kiss” by G. Klimt (1908)

2.10 Sexuality and cancer

Cancer treatment during adolescence and young adulthood may affect the development of the affected individuals’ sexuality. When cancer and/or treatment hinder participation in social life, psychosexual development may be inhibited.[75, 76] Sexual function after cancer treatment has been studied among adult cancer survivors and common physical sexual problems after cancer treatment are low desire, genital pain, decreased lubrication, erection difficulties and arousal difficulties.[77-81]

Supplementary psychological effects of cancer treatment such as depression, anxiety, altered body image and poor self-image may influence sexual function.[82, 83] In AYA cancer survivors, mixed findings have resulted in studies investigating sexual function. Women treated for Hodgkin´s disease reported lower satisfaction with sexual function than controls, while no difference regarding satisfaction with sexual function was found between testicular cancer survivors and controls.[84] [85] Having cancer during these years may affect patients' possibilities of engaging socially, due to treatment-related peripheral complications or changes in physical appearance, and these factors may lead to delayed psychosexual development[75].

2.11 Cancer care

Cancer care in Sweden for the AYA group is organized according to age. The upper age limit for treatment in childhood cancer care is 18 years of age. Young patients over 18 years of age are treated in adult oncology units. Research has put forward the argument that specialized cancer care is needed for adolescents and young adults.[86, 87] AYA cancer patients have special needs, for example different coping strategies compared with adults and children. They also have special psychological issues due to their stages of development, such as compliance to treatment, the importance of peers, and planning for the future, education and work.[88-90] Adolescents treated in paediatric settings have reported feeling like strangers, and young adults treated in adult settings also reported unmet needs.[91, 92] There is a discussion on how and where to care for AYA cancer patients and that there is need for collaboration between paediatric and adult oncology to meet the needs of this population of patients.[93]

2.12 Cancer stigma – society and cancer

In high-income countries, knowledge about developments in cancer treatment and about increased survival is well spread in most groups in society. Despite this, cancer is still surrounded with fear, negative images and uncomfortable emotions.[94, 95] Cancer patients are sometimes defined as victims.[96] Adjusting to life after cancer treatment can be difficult on account of the stigma surrounding cancer, and in one study, 50% of AYA cancer survivors reported difficulties in returning to work or education.[97] It is still difficult for AYA cancer patients/survivors to disclose their cancer diagnosis to others, due to fear of reactions.[98] The fear of cancer in society may influence the process of returning to social life for AYA cancer survivors, since they often face a lack of understanding from people in educational institutions and work environments.[43]

3. AIMS

3.1 General aim

The general aim of this study has been to identify needs that adolescent and young adult cancer survivors stress as important to them and to explore possible physical and psychological conditions that may exist for an adolescent or young adult cancer survivor.

3.2 Specific aims

Paper I – to explore AYA patients' needs and problems during and after cancer treatment
Paper II – to study AYA´s perceptions of participating in a survey with sensitive questions
Paper III – to study the effects of cancer treatment on appearance and to compare possible symptoms/problems with a matched control group, thus exploring the possible extent of the problem
Paper IV – to investigate the incidence of physical symptoms affecting sexuality after cancer treatment, in AYA patients and to compare possible symptoms/problems with a matched control group, thus exploring the possible extent of the problem

4. MATERIAL AND METHODS

We started this study in a very broad manner, conducting focus group interviews in order to explore what AYA cancer survivors find important during their cancer journey (Paper I). After analyzing these interviews with a qualitative method, a few areas were highlighted by the AYA participants as being important but not properly addressed in the healthcare system. A study-specific questionnaire was constructed in order to include these areas and to study the incidence of physical and psychological symptoms after cancer treatment. Paper II described and analyzed the use of a study-specific questionnaire including sensitive questions. Papers III and IV reported the incidence of symptoms in AYA cancer survivors and compared the results with those of a matched control group. A summary of the papers is presented in Table 1.

Table 1. *Summary of the four studies, design, participants, time and type of data collection in Papers I-IV.*

Paper	Design	Participants	Time of data collection	Type of data collection
I	Qualitative, descriptive	Adolescent and young adult cancer survivors age at study 15-31 N= 44	3-48 months post treatment	Focus group interviews
II - IV	Quantitative, cohort study, with varying follow-up	Adolescent and young adult cancer survivors age at study 19-35 N= 285 Matched controls N= 255	9-69 months post treatment	Study-specific questionnaire

4.1 Focus group interview study – Paper I

4.1.1 *Data collection*

The study has a qualitative design and data was collected through focus group interviews. The focus group interview is a method used when researchers want to collect opinions on experiences, attitudes, feelings and values concerning specific topics.[99, 100] Furthermore, a focus group interview is used to take advantage of the interaction between participants and offers opportunities for reflection during the discussion. The focus group interviews were carefully planned and were conducted by a moderator and an assistant as described by Kreuger & Casey.[100] The moderator directed the discussions from a set of open questions about care needs and covered different areas by using an interview guide (Table 2). During the focus group interviews the moderator started by stimulating an open discussion, asking: What are your experiences of cancer care? What was important for you during your treatment? The assistant did not participate in the discussion but took notes during the discussion. At the end of each session, the assistant presented a summary for the participants to approve or add to and clarify their opinions. Digital audio recordings were made. Each focus group interview lasted 60-90 minutes. The focus group interviews were conducted in conference rooms at the respective clinics.

Table 2. Focus groups interview guide
Types of care
Environment
Decision-making
Family/significant other
Respect and integrity
Communication
Close relationships
Competence (among healthcare professionals)
Continuity

4.1.2 *Participants*

AYA survivors who had been treated for cancer and had completed their treatment at either paediatric or adult cancer units in one of two University hospitals in Sweden, in Stockholm and Gothenburg, received a written invitation to participate in the study. Individuals treated for cancer between the ages of 15 and 29 were eligible to participate in the study.

4.1.3 *Data analysis*

The digital recorded focus group interviews were transcribed and analyzed according to qualitative content analysis.[101, 102] Content analysis steps included preparation, organization and report writing.[102] Preparation included repeatedly reading the text of each focus group interview, selecting units of analysis, and collecting notes and headings.

The organization phase included making matrices from the notes and headings collected. These notes and headings were freely grouped into preliminary categories. This step was followed by an abstraction phase creating subcategories, generic categories and a main category to generate the research description of the research topic. This was reviewed to confirm the accuracy of the contents, and to ensure that the data met the requirements of prescribed analytical methods.

The analysis continued until the descriptions of the generic categories and subcategories were close to the contents of the text.[102] Three of the authors were engaged in the data collection, data analysis and development of subcategories and categories, and these were discussed until a consensus was reached.[102]

The data from the focus group interviews with participants from paediatric units and data from adult care settings were analyzed separately. However, the results are presented jointly because the results from the paediatric and the adult care settings were mainly congruent.

4.2 Questionnaire study – Papers II-IV

The study design in Papers II to IV was developed based on a stepwise method established by the research group at the Division of Clinical Cancer Epidemiology in Stockholm and Gothenburg, and used in more than 20 data collections focusing on cancer and survivorship[103-106] (Figure 7; page 49). The questionnaire consists of seven areas: demographics; disease and treatment; wellbeing and quality of life; self-image and sexuality; treatment-related questions on sexuality and fertility; education, work and leisure; and questions on participation. The questionnaire addressed to the cancer survivors contained 146 questions with follow-up questions and space for free comments. The control group received a shorter questionnaire containing 95 questions, excluding questions on cancer treatment.

4.2.1 Q*uestionnaire development*

The study-specific questionnaire was developed based on the focus group interviews, in-depth interviews, clinical experience and literature studies. This method of questionnaire construction has been used in several previous investigations carried out by our research group, Clinical Cancer Epidemiolog.[106-110] The questionnaire was developed in collaboration with AYA cancer survivors. During the questionnaire development, expert validation by professionals from oncology units, midwives, epidemiologists and statisticians was obtained. Areas covered in the questionnaire were psychosocial health, body image and sexuality, fertility, education, work and leisure. Depression was measured using one question: “Are you depressed?” followed by response alternatives “yes, no, do not know”. This method to assess depression has earlier been used in a study by Skoogh et al.[49] The revised questionnaire was tested using face-to-face validation, i.e. answering the questions in the presence of the interviewer and discussing unclear questions. Ten AYA cancer survivors participated in the validation to ensure that the questions were relevant and understandable. Following the face-to-face interviews, the revision of the questionnaire was finalized. In collaboration with a web survey constructor, the questionnaire was transferred to a digital format.

4.2.2 *Pilot study of questionnaire*

A pilot study was conducted on 28 cancer survivors, more than 5 years post cancer treatment. In the pilot study, the web-based questionnaire was tested to assess questions and response rate. The overall participation rate in the pilot study was 71% and it resulted in minor refinement of the questionnaire.

4.2.3 *Main* q*uestionnaire study*

4.2.4 *Study population*

AYA cancer survivors were eligible for the study if they had been treated for cancer at ages 15-29 during 2010-2011, and were alive and at least one year post treatment at study. All malignant diagnoses were included based on ICD version 10, neoplasms.

Names and addresses of cancer survivors were obtained from the population-based Swedish National Cancer Registry, including four of the register holders, the north, west, southeast and central Regional Cancer Centres in Sweden. Controls were randomly identified from the Swedish National Population Registry, for the same four register holders. The controls were matched by age, gender and place of residence.

The identification of the cancer survivors and the matching with the controls was carried out by the register holders at each Regional

Cancer Centre. The research group thus did not know whether the participants were cancer survivors or not until they had completed the questionnaire.

Participants were eligible for the study if they: 1/ understood the Swedish language; 2/ were not under treatment for cancer; 3/ had a listed phone number; and 4/ were functionally/intellectually able to answer the questionnaire.

4.2.5 *Data collection*

An introductory letter was sent followed by a phone call 1-2 weeks later when an assistant contacted all potential participants. The procedure is described in Table 4. The introductory letter contained information about the study. Participants were informed that participation was voluntary and that they could end participation at any time without any explanation. Furthermore, they were informed that the research group did not know whether the participant was a cancer survivor or not. The researchers' names and contact details were listed in the introductory letter and participants were encouraged to contact us if they had any questions or if they needed support during the study. For ethical reasons it was made easy for them to decline participation before being contacted by phone, by giving the research group's contact details: e-mail and mobile phone number.

Fifty to seventy-five letters were sent at a time, enabling contact to be made with all participants within 1-2 weeks. Data collection could thus be stopped if there were signs that the research was at all harmful to participants. During the study, telephone contact was avoided on official holidays. Inclusion during the summertime was paused due to possible travelling and vacations.

Prior to the first phone call, a text message was sent, to inform about the nature of the call, and about the study. In Sweden today, people receive many advertising calls and might be reluctant to answer an unknown number. This population was easily reachable during weekday afternoons between 4-8 pm and possibly on Sunday afternoons. The phone calls were made by a research assistant or by the PhD student, both being registered nurses with many years of clinical experience.

Participants thus called were approached sensitively, starting with the question of whether they had received the letter about the study. A denial was accepted immediately without any persuasion to participate. Those giving informed oral consent to consider participation gave the interviewer their e-mail address. In an e-mail, participants then received a personal username, the password to the web questionnaire and information about an around-the-clock mobile phone number to the research team.

After two weeks, the participants received a thank-you e-mail to show appreciation for their participation and to serve as a reminder. After a few weeks, the interviewer phoned those who had not completed the questionnaire.

4.2.6 *Data management*

The web-based questionnaire was returned to a database, and each questionnaire was allotted an identification number to maintain confidentiality. A second tailor-made database was used to enable safe and systematic data collection to be implemented, where all events and comments from participants were registered.

4.2.7 *Statistical analyses*

Statistical analyses were carried out using the statistical software SAS version 23 and SAS 9.4 for Windows. Socio-demographic and descriptive characteristics were compared between the survivors and controls using the chi-2 test for categorical variables. The non-parametric Kruskal-Wallis test was used to test potential differences between groups in the paper.

Table 4. AYA cancer survivors and controls – a Swedish population-based survey: summary of ethical protocol for epidemiological surveys on AYA cancer survivors.

Preparation

Carefully plan the inclusion criteria

Same introductory letter to cancer survivors and controls

To meet requirements of the Swedish law of secrecy, the researcher did not receive information about participants' cancer diagnoses. The informants themselves revealed these, after they had completed the survey.

Make time; be prepared for long conversations with presumptive informants

Create a database for all communication and contact information

Introductory letter

Researchers' contact information, e.g. telephone number, available 24 h

Focus of the study and the questionnaire

Option to end participation at any time without explanation

Opportunity to decline contact or participation

Several ways to decline contact/participation, e.g. telephone, text message, e-mail

Information about coming telephone call – when and by whom

Consideration and decision about how many letters to send at a time in order to be able to consider and respond to informants

Telephone call

Telephone call by trained interviewer

Text message before first telephone call, providing information what the call is about

Careful sensitive "step-by-step" approach going from general questions to more detailed

Being responsive and prepared for questions and need of support

Providing support and help with referral if needed

Encouraging contact again if help or support is needed

Giving enough time for questions and support

Accepting denial directly without further probing

Repeating the option to end participation at any time without explanation

Asking for consent to send login to questionnaire

Obtaining participants' e-mail addresses for sending login to survey

During participation

Continuity throughout the study with the same trained interviewers

Interviewers being available and prepared for questions and support 24 h

Providing support and help with referral if needed

Giving enough time for questions and support

Giving enough time for participation, e.g. being able to complete the survey online with a generous time allotment

Sending an e-mail with a thank you note – and asking if there are any questions

With permission of author P. Omerov. The ethics of doing nothing. Suicide-bereavement and research: ethical and methodological considerations. Psychological Medicine (2014), 44, 3409–3420. A modification of the Summary of ethical protocol for epidemiological surveys on suicide-bereaved persons.

Outcome measures were presented as a relative risk and odds ratio in Papers III and IV. In Paper III, Spearman correlation analysis was undertaken to analyze the correlation between attractiveness and social activities such as seeing friends, going to the cinema or to the pub.

Before conducting a multiple regression analysis in Paper III, a DAG (directed acyclic graph) was drawn to identify possible confounding factors, mediators and effect-modifying factors for variables concerning attractiveness. In Paper IV, the analysis to identify possible predicting factors was conducted in a univariate regression analysis after which a multiple regression analysis was conducted. The level of significance was set at $p < 0.05$.

4.3 Ethical considerations

There are a number of ethical considerations to take into account when planning a study like this. The scientific benefits must be carefully weighed against the possible burden laid on the shoulders of the participants. Ethical principles such as autonomy, informed consent, confidentiality and respect for integrity have been addressed. When planning and conducting research on sensitive or trauma-related events it is important to have a strong research design including a control group.[111]

The participants need to be approached carefully. If the method presented in this study is employed, this burden may be reduced to being very light or even non-existent, despite its addressing very personal and emotionally charged issues like sexual activity, suicide and death.[107, 112, 113] The participants in this study were approached in a sensitive way, all of them receiving a letter with information in both of the studies with notice of an upcoming phone call. They had the possibility to decline participation before the phone call by sending an e-mail or text message to the research team. Further discussion on ethics will follow in the Results section (Paper II).

Ethical approval for Study I has been obtained from the Regional Ethical Review Board in Gothenburg, Sweden, with reference number 753-09, and for Studies II-IV from the Regional Ethical Review Board in Gothenburg, Sweden, with reference number 691-13 and amendment 944-14.

5. RESULTS

5.1 Participants and characteristics – Paper I

Fifty-eight AYA survivors agreed to participate in focus group interviews. The majority of the patients were recruited from five adult cancer clinics and two paediatric cancer centres at the university hospitals in the two main cities in Sweden, Stockholm and Gothenburg. Further information on demographics can be found in Table 5. There were five focus groups with a total of twenty-one participants treated at paediatric cancer centres at the age of 15-18 and six focus groups with a total of twenty-three participants treated at adult healthcare facilities at the age of 19-29.

The number of participants in each group ranged from two to seven. In some of the focus groups, there were one or two dropouts on the day of the focus group interview, due to reported illness or with no reason given. The focus group interviews were conducted despite missing participants, out of respect for those who showed up.

Table 5. Demographics –Focus group interviews

Characteristics	**Range**	**Median (IQR)**
Age at interview, y	15-31	21 (7)
Age at diagnosis, y	14-28	17,5 (8)
Months since completed treatment	3-48	16,5(26)
		n (%)
Eligible Participants N= 125		
Participants consenting to participate		58 (46)
Participants in all focus group interviews		44 (76)
Drop outs		14 (24)
Male		16 (36)
Female		28 (64)
Leukaemia		12 (27)
Lymphoma		11 (25)
Sarcoma		12 (27)
Brain tumour		2(5)
Testicular cancer		5 (11)
Gynaecological cancer		2(5)

5.2 Paper I

In Paper I, the results are presented of the focus group interviews with AYA cancer survivors concerning their needs and important aspects of care. The analyses of the transcribed interviews resulted in four generic categories: personal professional interaction, knowledge and participation, age-appropriate environment and support (Table 6). Personal professional interaction illustrates the importance for AYA participants of being seen as a person during treatment.

Table 6. Generic categories and Subcategories of Needs for AYA treated for Cancer.

Generic Categories	**Subcategories**
Personal Professional Interaction	Personal healthcare professionals Healthcare professionals who listen Competent healthcare professionals
Knowledge and Participation	Being in control Knowledge of new situation Knowledge of sexuality and fertility Healthcare professionals ability to convey knowledge
Age-appropriate Environment	Interior design Activity Same-age environment Health care professionals ability for age-appropriate communication/interaction
Support	Family and significant other involved in care Psychosocial support- including financial Educational and counseling Counselling after treatment

The subcategories were: Personal and competent healthcare professionals who listen (Table 4). Personal and competent healthcare professionals were an important factor for building trust:

> "*It is a good feeling not to be seen just as a patient…but…when you can talk to the staff and feel that they are human and so…it feels pretty good…and that they can still be professional…because if you walk around here and get a feeling no one sees you…you don't believe these people have the capacity to help you.…*" (Female, 28 years old).

Knowledge and participation are two aspects of AYA cancer survivors’ needs for being informed and involved in the care. Healthcare professionals need to check on what each individual wants to know and to make sure he/she has fully understood the information:

> “*...so that they can transfer the knowledge to us...just because they have knowledge doesn´t make us feel safe…they need to transfer the knowledge to us…*” (Male, 24 years old).

One area in which AYA cancer survivors considered that they lacked knowledge and information concerned sexual issues. They pointed out the need for healthcare professionals to raise this question during and after treatment:

> *“One thing I have thought about after my treatment is that I was never informed about...I had testicular cancer…was never informed about how it could affect my sexual ability and so on…that is weird.*” (Male, 17 years old).
>
> “*…And no one asks about it…if I want information and so on, and I think that it is really very important, about your sex life and that. I do not understand why they don´t bring it up.*” (Female, 22 years old).

Age-appropriate environment was another issue addressed by the study. AYA survivors described their need to meet patients of their own age in a physical and social environment suited to their age group:

> “*…there are only old people…so when I was there…young…I thought…what am I doing here? You get sad…it is hard to relate...*” (Female, 20 years old).
>
> *“It was like…now let’s do some painting, and only the small children came out of their rooms, the teenagers stayed in their rooms…so we never met.”* (Female, 17 years old).

An age-appropriate environment also includes the need for HCP skills of communication with the AYA group:

> "*It was very different among the nurses…some treated you really well and some talked to you as if you were a small child and yes…it was so wrong."* (Female, 17 years old).

The fourth category was support. The AYA group described needing a different kind of support from the support they actually received. They said that they needed close relatives to be present and participate in their care, and that they wanted psychosocial support with counselling, generally after the end of treatment. Having close relatives participating in their care was most important:

> "*Mum and Dad lived there [at the hospital] a lot…it felt good to have them there..."* (Female, 26 years old).

The AYA group also expressed the need for psychological support during the life-after-treatment phase, to help them deal with what they had gone through, and to provide them with assistance to move on with their lives:

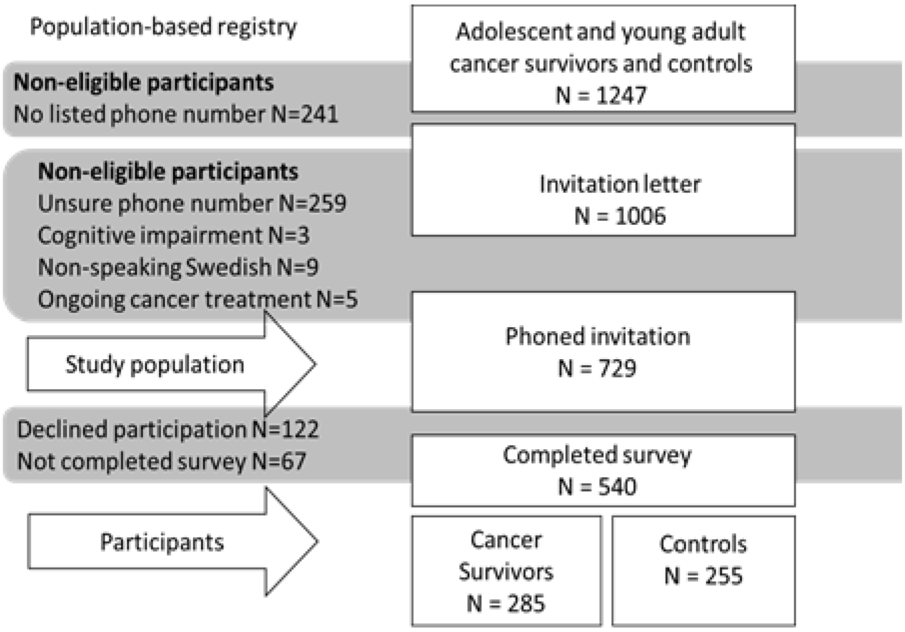
> "*...After all this you get back to school…it is then that you need to talk to someone. When you go to your parents it is like, you are alive...be happy…Yes, I am alive, but I feel bad. Yes... I survived...I am alive...but I'm not really living!…you should be grateful...*" (Female, 18 years old).
> "*Just get back to life...get some help...when you are out of the healthcare system.*" (Male, 26 years old).

Overall, in the focus group interviews, the topics discussed were similar whether the participants were treated at a paediatric unit or an adult cancer unit.

5.3 Participants and characteristics – Papers II-IV

From November 2014 to June 2016, 729 eligible cancer survivors and controls were included in the study. A total number of 540 participants completed the questionnaire, which gives a total response rate of 74%.

Figure 2. Flow chart of participation rate.



The study group consisted of 285 AYA cancer survivors, with the mean, age of 28 years old (range 19-35) and the control group contained 255 participants with the mean age of 28 years old (range 19-36), at study. For further information on participation, see Figure 2.

There were no differences between the groups, except regarding education, where the controls had a significantly higher educational level than the cancer survivors. For further information on demographics, see Table 5. The representation of cancer diagnoses in the study is comparable to previously published incidence rates (Figure 3).

Figure 3. Diagnosis in Studies II-IV compared to cancer incidence in Sweden 2010-2011according to the Swedish Cancer Registry.

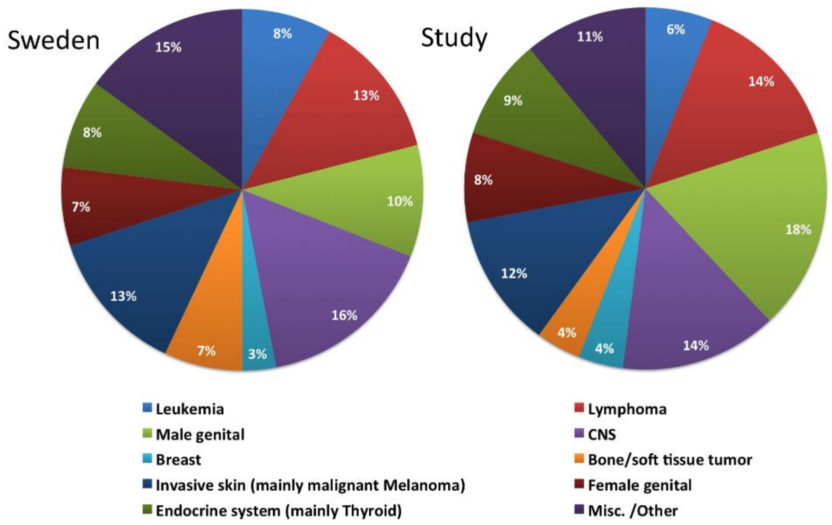


Table 5. Socio-demographics and self-reported clinical characteristics

Characteristics	**Survivors** N=285 (52.8 %)	**Controls** N = 255 (47.2 %)	*P value**
	n (%)	n (%)	
Age at study, years			
< 24	59 (21.5)	55 (22.0)	
25-30	124 (44.8)	108 (42.7)	
> 31	93 (33.7)	89 (35.2)	0.900*
Gender			
Male	138 (48.4)	106 (41.6)	
Female	147 (51.6)	149 (58.4)	0.111*
Relationship status			
Married/co-habit	152 (54.9)	148 (59.2)	
In relationship	44 (15.9)	36 (14.4)	
Single	81 (29.2)	66 (26.4)	0.606*
Sexual orientation			
Heterosexual	268 (97.1)	237 (95.2)	
Homosexual	1 (0.4)	2 (0.8)	
Bisexual	1 (0.4)	7 (2.8)	
Other	1 (0.4)	1 (0.4)	
Do not know	5 (1.8)	2 (0.8)	0.096**
Form of housing			
Parents	28 (10.1)	22 (8.8)	
Independent living	248 (89.5)	227 (90.8)	
Other	1 (0.4)	1 (0.4)	0.876*

Living environment			
Rural area	51 (18.4)	38 (15.3)	
Small town	173 (62.5)	162 (65.1)	
Larger city	53 (19.1)	47 (18.9)	0.371*
Education			
Elementary school	11 (4.0)	7 (2.8)	
High school/College	154 (55.8)	116 (46.0)	
University/College	111 (40.2)	129 (51.2)	0.039*
Age at diagnosis, years			
15-18	39 (13.7)		
19-24	119 (41.8)		
25-30	116 (40.7)		
Time from diagnosis to survey			
Median months (range)	49 (9-69)		
Primary diagnosis (self-reported)			
Leukaemia	17 (6.0)		
Lymphoma	39 (14.0)		
Testicular cancer	52 (18.6)		
Brain tumour	40 (14.3)		
Breast cancer	10 (3.6)		
Bone/soft tissue tumour	10 (3.6)		
Gynaecological cancer	22 (7.9)		
Skin cancer	35 (12.5)		
Thyroid cancer	24 (8.6)		
Misc. /Other	30 (6.0)		
Treatment (self-reported)			
Chemotherapy	122		
Radiation abdomen/pelvic	24		
Other radiation	67		
Surgery	221		
Stem cell transplantation	19		

Numbers may not reach column totals due to missing values

**The difference between young cancer survivors and controls analysed by Chi2-test.*

*** The difference between young cancer survivors and controls analysed by Fisher´s exact test. Note that the numbers in each column are few which may have affected the result. When selecting the variables hetero, homo and bisexual in an analysis, the result was P value=0.032.*

5.4 Paper II

In Paper II, no participant responded that the survey had a very negative impact on her/him and only four out of the 540 (0.7%) answered that they were moderately negatively affected by participation in the study. There was no significant difference between patients and controls regarding the negative effect of the participation. Positive experiences were widely expressed. Most of the participating adolescent and young adult cancer survivors and most of the controls

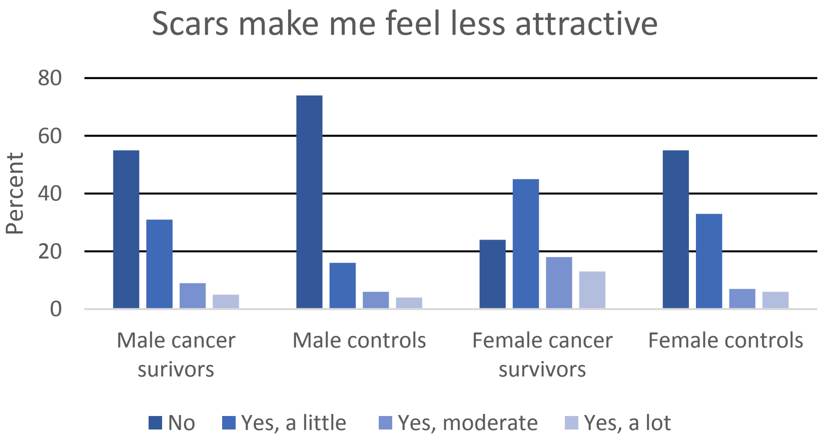
(98.8% totally) found participation in this study valuable. The adolescent and young adult cancer survivors found participation in this study more valuable than the controls did (p=0.008).

A total of 49 participants out of 521 (9.4%) reported that questions in the survey caused them distress. Out of the 49 reporting distress, 30 made comments on which questions they felt caused distress, the major causes being fertility and possible recurrence of cancer among the cancer survivors.

5.5 Paper III

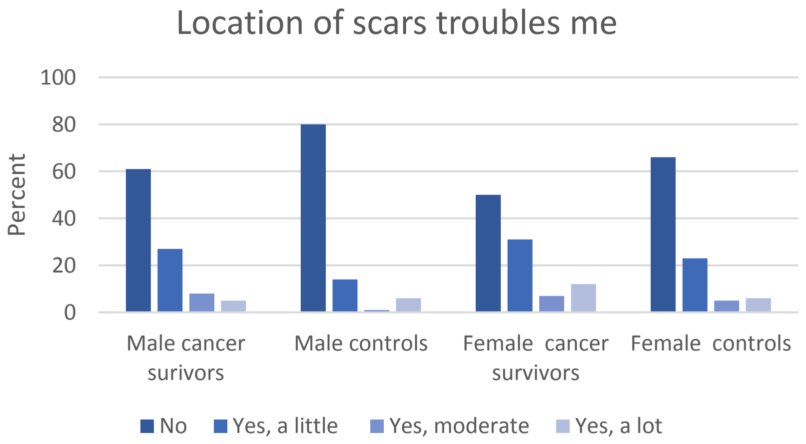
In this study both female and male cancer survivors reported that having scars on the body affected them negatively. The impact of scars was significantly higher in terms of feeling unattractive for cancer survivors compared to controls *(P<0.01).*

Figure 4. Low feeling of attractiveness due to scars on the body, cancer survivors compared to controls.



The location of the scars bothered cancer survivors significantly more compared to controls *(P<0.001).* Furthermore, the women in the cancer survivor group felt less attractive compared to women in the control group, regardless of scars *(P<0.001).*

Figure 5.The location of scars considred troublesome, cancer survivors compared to controls.

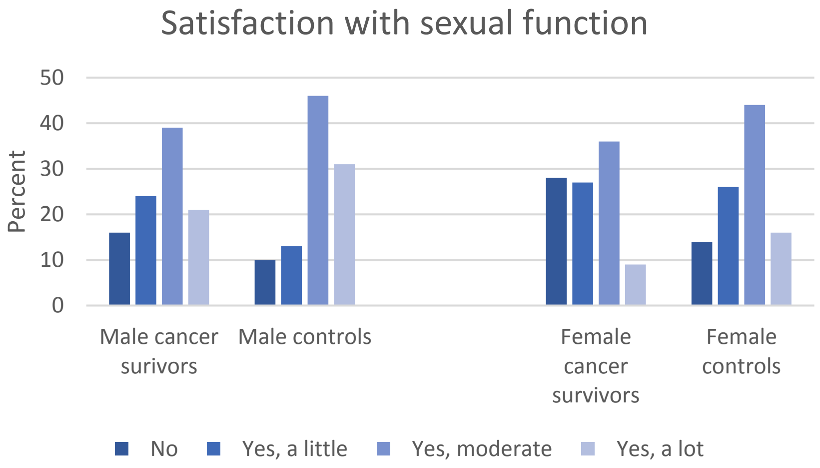


In a logistic regression analysis, statistically significant associations were found in the group of cancer survivors between the feeling of unattractiveness due to scars and lower education, depression and frequent exercise.

5.6 Paper IV

AYA cancer survivors reported lower satisfaction with their sexual function than controls (*P*<0.01).

Figure 6.Satisfaction with sexual function, cancer survivors compared to controls.



Female AYA cancer survivors had a statistically significant lower frequency of orgasm during sexual activity than controls ($P<0.01$) and female AYA cancer survivors who had a partner reported less confidence in their partner as a supportive friend than the controls ($P=0.03$). Male AYA cancer survivors had statistically significant lower sexual desire than controls ($P=0.04$).

There were no statistically significant differences regarding reported sexual physical problems between the cancer survivors and controls.

In a multivariable logistic regression model, depression (OR 3.5; 95% CI 1.4-8.9) was the only factor predicting low feeling of satisfaction with sexual function for female AYA cancer survivors. Among male AYA cancer survivors, erectile problems (OR 20.7; 95% CI 2.8-152.7) constituted the only factor predicting low feeling of satisfaction with sexual function.

6 DISCUSSION

6.1 Methodological considerations

6.1.1 *Paper I Validity – Trustworthiness*

Focus group interviews may be an efficient method to explore opinions among young people.[99] Validity, or **trustworthiness** as it is called in qualitative research, is about being able to describe that one has collected and processed data systematically and honestly. Focus group interviews have been described as a useful method for research on different aspects of healthcare in adolescents.[99] However, focus group interviews may also be inadequate if the participants have difficulties in expressing themselves in a group situation.[114] Therefore, it is important that the moderator has the knowledge and ability to lead the group discussion so that everyone can have her or his say. In this study, both the moderator and the assistant had experience and knowledge of working with AYA survivors, which Krueger and Casey (2009) described as being crucial for good results, and for **credibility**.

To establish **credibility**, a member-check was conducted when the focus group interview ended. This included a summary of the discussion by the assistant that made it possible for the participants to clarify their points and to approve the content of the interview. Additionally, peer debriefing was undertaken: three researchers read the transcribed focus group interviews separately and met afterwards for discussion of the analysis and categorization.[115]

Regarding the **dependability** of the process of planning the focus group interviews, knowledge was acquired on the subject and structured to serve as a framework for our discussions. An interview guide was used, which was the same in every interview. During each focus group interview, follow-up questions were developed during the process, depending on each discussion. After each focus group interview, the moderator and assistant discussed the subjects and decided whether new follow-up questions should be added to the next interview, which means that not every focus group interview was the same. This can be considered to have generated a richer study with each focus group contributing to a more comprehensive result[116]. Digital audio recordings and transcriptions were also made during the interviews, to avoid missing information.

Concerning **transferability**, the number of participants in the focus group discussions in the study was small and therefore did not represent all cancer diagnoses in the 15-29 age group. This affects the transferability of the results. However, the relevance of the results is strengthened by the fact that they are congruent with the results from previous studies on AYA cancer survivors in other contexts.[117-119]

6.1.2 *Papers II to IV – Validity*

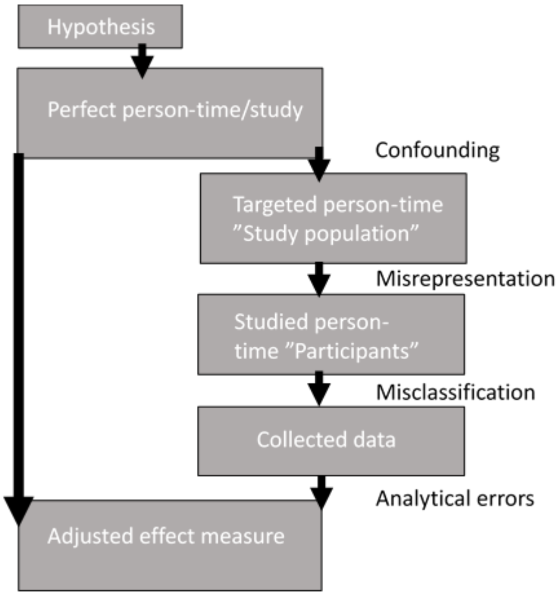
Researchers would always like to conduct the perfect study, but the perfect study exists only in theory. Any study is liable to be affected by randomly (chance) or systematically (bias) induced errors. A large, randomized, blinded study with no dropouts may reduce the risk for errors. To carry out a randomized, controlled study with AYA cancer survivors has not been possible in the present study.

We used the hierarchical step-model, a method developed by researchers at Clinical Cancer Epidemiology to identify possible threats to validity throughout the process (Figure 7).[120, 121] Even so, the study design can never be protected from the risk of systematic errors such as confounding factors, misrepresentation, misclassification and analytic alteration. The response rate in the current study is high, 74 percent. To the best of our knowledge, this is the only population-based long-term follow-up of AYA cancer survivors, using a matched control group from the normal population as a reference.

6.1.2.1 Confounding

In a perfect study, there would be no differences in outcome between two groups that have been studied, except for the studied factor, exposure. Confounding factors are associated with both the exposure and the outcome and they affect the true association between exposure and outcome. This could be a problem when there is imbalance in the groups studied, e.g. difference in age, gender and region of residence. Concerning confounding factors regarding these variables, in the present study the non-cancer survivors and controls were matched by age, gender and region of residence. Information on several potential confounding factors was collected in the web survey and adjusted for in statistical analysis. There were no differences between AYA cancer survivor and controls, except regarding education, where the controls had a significantly higher educational level than the cancer survivors. This may either be explained by delayed education due to cancer treatment and complications or in some cases due to cognitive complications later, creating obstacles for higher education.[67]

Figure 7. Hierarchical step-model – different stages in a clinical study for causation of bias.



6.1.2.2 Misrepresentation

When there is a loss of individuals (non-participants) between targeted person-time (study-population) and studied person-time (participants), misrepresentation occurs. Since the Swedish population-based register covers close to 100 percent of the eligible AYA cancer survivors, the risk of selection problems in the study was low. A high participation rate reduces the risk of misrepresentation. In the present study, the participation rate was 74 percent in both study and control group. This is an unusually high participation rate considering the study population and study design. For ethical reasons, the non-participants were not actively asked about their reasons for not participating, although a few stated it was too painful to think about their cancer treatment, and others stated that they never participate in surveys. However, the main reason stated was lack of time. Non-participation in AYA cancer survivors might have been due to not having any problems or on the other hand to having many problems and finding it too painful to think about them.

6.1.2.3 Misclassification

Misclassification (bias) occurs when the information collected in a study is incorrect. Therefore, the development of the questionnaire is important. When questions are misunderstood the sensitivity and specificity are reduced in relation to the truth. There is always a risk of misunderstanding, and no study has a 100 percent sensitivity and specificity. Efforts have been made in this study to reduce some the risks of misclassification by developing the questionnaire in cooperation with AYA cancer survivors through in-depth interviews and by face-to-face validation. The use of a self-administered anonymous web questionnaire may have reduced the risk of interview bias. Using a digital web questionnaire reduces the risk of technical errors related to data being entered from a paper questionnaire by researchers.

6.1.2.4 Analytical errors

During the analytical process, efforts have been made to reduce some of the errors during the previous processes due to confounding factors, misrepresentation and misclassification. A statistician/epidemiologist, co-writer has been involved during the whole process. Stratification and regression modelling have been used to reduce possible errors in the study, presenting the results in relative risk or odds ratio. Dichotomizing the data instead of using all the variables may lead to much information being lost, so the statistical power to detect a relation between the variable and patient outcome has been reduced. We therefore used the Kruskal-Wallis test to test the association between the level of exposure and outcomes (Papers III and IV).

6.2 General discussion

In the field of cancer research, adolescent and young adult cancer patients constitute a novel group. In this study, we highlight some of the reported problems and needs of adolescent and young adult cancer survivors.

In the first study, AYA cancer survivors reported the lack of information and discussion on sexual issues during treatment. AYA survivors asserted how important it was for healthcare professionals to take the initiative to conversations on sex and to create comfortable settings for talking about sex. The reason for this lack of information and discussion may be that healthcare professionals are inadequately trained or have a feeling of uncertainty when it comes to initiating discussions on sex. Furthermore, sexual issues are perceived as personal and sensitive. To clarify this, the second study states that AYA cancer survivors do not find sex and sexuality as issues too sensitive to be taken up. The study shows that AYA cancer survivors found the study valuable and the issues brought up in the study important for them.

Scars on the body are inevitable after most cancer treatments. In AYA cancer survivors, scars on the body affected them to the extent that they led to perceptions of low attractiveness. Having an altered body image after cancer treatment has previously been described as affecting an individual's perception of attractiveness.[122, 123] In most studies, scars have been described as one of many factors leading to feelings of unattractiveness after cancer treatment. Negative body image has mainly been found in breast cancer patients, bone tumour patients and head and neck cancer patients.[66, 124, 125]. In Paper III, we found that scars constitute the single most important factor causing AYA survivors to feel less attractive. It has earlier been shown that young adults' self-perception of sexual attractiveness has far-reaching effects on sexual experience.[126] Feeling unattractive has in adult cancer survivors been described as affecting sexual activity and causing less frequent sexual activity post cancer treatment.[127]

In Study IV, AYA cancer survivors were shown to experience less satisfaction than controls with their sexual function, mainly for psychological rather than physiological reasons. We did not find any differences in physical symptoms between female AYA cancer survivors and controls, such as dyspareunia or lubrication problems, except for a lower frequency of orgasm. Physical problems affecting sexual function have earlier been described in female AYA cancer survivors mainly after breast cancer treatment.[128] Low orgasm frequency has been reported in previous research in AYA cancer patients, after surgery for diffuse low-grade glioma.[129] Having a lower frequency of orgasm may result in feeling less satisfied with sexual function. In studies on adult cancer survivors, one late complication is peripheral neuropathy in the extremities. In female adult diabetes patients, who have vascular damage and neuropathy this may result in decreased genital blood flow and cause decreased genital arousal and fewer orgasms.[130, 131]

Further research is required to establish whether difficulties with lower frequency of orgasm are due to physical or psychological effects, including more detailed information on cancer treatment. In this study, the only association for lower satisfaction with sexual function in female cancer survivors was depression. Low satisfaction with sexual function could be a cause of depression or vice versa. However, since depression according to previous studies is common post cancer treatment, it is not sufficient to connect low satisfaction with sexual function as a cause for depression.[132-134] The self-assessed measure of depression used in this study has in a previous study been shown to have a certain sensitivity for depression but a high sensitivity for non-depression.[49] The self-assessed depression in female cancer survivors needs to be addressed, in order to diagnose a possible clinical depression. Female cancer survivors who had a partner reported less confidence than the controls in their partner as a supportive friend. This has been described previously in adult cancer survivors but not in AYA cancer survivors. Maybe this is due to difficulties in communication, described by Bober et al. as the elephant in the room.[135]

In this study, male AYA cancer survivors reported statistically significant lower sexual desire than the controls. In previous studies there have been mixed findings regarding desire.[85, 136] In a study on testicular cancer survivors and controls there was no significant difference in desire between the groups [85]. Another study reported on low desire in male cancer survivors with low-grade glioma.[129] In this study, the only association for lower satisfaction with sexual function in male cancer survivors was erectile problems. This is contrary to previous research on testicular cancer survivors where no differences between AYA survivors and controls were found.[85] However, male AYA survivors of childhood cancer have been reported to have a higher risk of erectile dysfunction compared to controls.[137] Furthermore, low testosterone levels have been found in male childhood cancer survivors who have received radiation on any part of the body combined with chemotherapy.[138] Further studies are needed on AYA cancer survivors since this could affect sexual desire and function. Additionally, a study on adult (30-50 years) lymphoma survivors, reported erectile dysfunction.[139]

In order to address the needs described by AYA cancer patients and survivors in the first study, the requirement of an age-appropriate environment must be fulfilled. One example of this is the need for age-appropriate treatment, support and information on sexuality and sexual health during and after cancer treatment. AYA cancer survivors pointed out the lack of information on sexuality in relation to cancer treatment and they wanted healthcare professionals to initiate conversations on the subject. Our study found that AYA cancer survivors feel less attractive due to scars on their bodies and that they are less satisfied with their sexual function, which indicates the need for support interventions. This is not only an issue among AYA cancer patients but seems to be an issue for every age group undergoing cancer care, as has been described previously.[140, 141]

According to previous studies from Sweden, the UK and the US, AYA cancer survivors needed more pronounced support to get life back to normal after treatment.[88, 89, 97, 142, 143] Regarding psychological side effects, there is a call for support in the transition back to life after the cancer experience.[9, 44, 144] Several studies have found that cancer survivors need information and support, as has also been described in the AYA group.[140, 145] The AYA group in the first study described the need for after-treatment support in the form of counselling, as well as the need to receive a written summary of their treatment details, as has been described earlier.[146, 147]

In all research on human beings we need to consider the ethical principles of the Helsinki Declaration.[148] The benefits for the individual participating in research must outweigh the harm, and the participant's autonomy must be considered. In our study, the respondents, both AYA cancer patients and controls, found participation in the study valuable. Four out of the 540 (0.7%) answered that they were moderately negatively affected by participation in the study. There was no significant difference between patients and controls regarding the negative effects of participation. Our study is congruent with previous research in that it has been found acceptable to ask sensitive questions such as questions on sex, death and suicide without this causing harm to research participants.[107, 112, 113] It may even be beneficial for participants to be asked questions about sensitive subjects since this may help individuals to see their own problems, with assistance being provided through contact with the healthcare provider. Additionally, it may be beneficial for participants to be able to express feelings and describe experiences after a traumatic event in writing, since this may even promote these individuals' psychological wellbeing.[149, 150] Comments from the participants stated that questions in the survey normalized some of the physical and emotional conditions they were in and let them know that they were not alone. This kind of survey could benefit cancer survivors by shedding light on feelings and psychological states they might feel alone with and by creating a sense of coherence, as has earlier been stated.[151]

Thus when making an ethical assessment of future studies, the scientific benefits must be carefully weighed against the possible burden laid on the shoulders of the participants. However, if the method that we have presented here is employed, our results suggest that this burden may be reduced to being very light or even non-existent, despite its addressing very personal and emotionally charged issues like sexual activity, suicide and death.

7. CONCLUSIONS

- Cancer during adolescence and young adulthood affected the lives of the patients and the healthcare profession did not meet all their needs.

- Scars on the body made adolescent and young adult cancer survivors feel less attractive compared to controls.

- Lower satisfaction with sexual function was reported in adolescent and young adult cancer survivors compared to controls. Female adolescent and young adult cancer survivors reported lower frequency of orgasm than controls. Male adolescent and young adult cancer survivors reported lower desire for sex than controls.

- Erectile problems were associated with low satisfaction with sexual function in male adolescent and young adult cancer survivors. Depression was associated with low satisfaction with sexual function in female adolescent and young adult cancer survivors.

- The burden on participants was shown to be almost non-existent when using this sensitive approach, despite addressing very sensitive issues like sexual activity, suicide and death.

8. FUTURE PERSPECTIVES

The knowledge gathered in this study leads to the conclusion that there is room for improvement in the care of adolescent and young adult cancer patients. This should lead to both clinical improvements and further research.

AYA cancer survivors reported feelings of low attractiveness due to scars. Future studies could explore if there are suture techniques used by plastic surgeons that could be applied to AYA patients to reduce the size of scars or if there are any additional techniques when caring for a healing wound.

Female AYA cancer survivors reported low orgasm frequency, and a future study could investigate whether lower orgasm frequency is due to physical late complications such as neuropathy.

Male AYA cancer reported erection problems and a future study could investigate further causes for erection problems, related to treatment; chemotherapy and/or radiation.

With regard to future research, we have now shown that population-based studies including sensitive issues such as sexuality, death and suicide do not necessarily cause significant harm in the AYA population.

Additionally, research is needed, including an intervention study, on targeted psychosocial rehabilitation starting during treatment, continuing through treatment and follow-up.

In the clinical setting of oncology, specialized education on the AYA group is needed for healthcare professionals to be able to give individualized care. One way to deliver knowledge to healthcare professionals would be to develop online courses. These courses should include physical and psychosocial development and disease-specific knowledge for the AYA population, and also communication tools as well as education on sexuality and fertility. A further essential step is to formulate national guidelines for cancer care and follow-up for the AYA group. Specialist clinics for follow-up for AYA cancer survivors may be one way forward. Specialist clinics for AYA cancer survivors may generate new knowledge though experiences and research of benefit to both patients and healthcare professionals.

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