

**Young adults after childhood cancer:
Health and psychosocial consequences
of treatment and illness**

Master thesis in Medicine

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Abstract

Introduction: Malignant disease during childhood is rare, age standardized incidence in Europe is 140 in 1 million children. In recent decades survival from childhood cancer has increased to over 80%, unfortunately with risk for long term complications. Sweden has 11000 individuals that have or have had cancer during childhood, of whom 6000-7000 are adults today. The number of complications increases with time after diagnosis up to a complication rate of 88% in survivors 20 years after treatment.

Aim: To summarize general distress, self-reported concerns and complications, and possible correlations between them, in a cohort of survivors of childhood cancer from the long-term follow-up clinic in Gothenburg.

Method: A retrospective descriptive study of individuals visiting a Long-term follow-up clinic. All participants were over 18 years, had survived childhood cancer with >5 years since last treatment. One hundred and six individuals (50 women and 56 men) fulfilled the criteria for inclusion and gave permission to use the data. Data was collected from medical journals and a questionnaire. Distress was measured using the Distress Thermometer.

Results: Complication was found in 86 individuals (81%). Mean number of complications was 2.29. Radiotherapy was associated to higher risk of complications ($p=0.001$). New complications were diagnosed in 30% of participants. Mean score of general distress was 2.52. There was a correlation between high amount of complications and higher score of general distress ($p=0.01$). Women scored significantly higher than men, 3.2 and 1.8 respectively ($p=0.005$). Women were more

likely to have moderate to severe distress (≥ 4) ($p=0.02$).

Conclusion: Many childhood cancer survivors develop complications. New complications were found in 30% of participants and higher levels of distress were found in women and individuals with previously known complications. The results indicate that specialized follow-up clinics are helpful for maintaining a good health among childhood cancer survivors.

Key words: Childhood cancer survivors, Complications, Distress

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Introduction

Survival rate now and then

The prognosis of childhood cancer has improved and nowadays more than 80% of individuals diagnosed with childhood cancer survive. The ACCIS project (The Automated Childhood Cancer Information System) is a part of the International Agency for Research on Cancer, a branch of the World Health Organization. Steliarova-Foucher et al showed a significant improvement in survival from only 44% in the 1970's to 73% in the 1990's within the ACCIS project(1). The reduction was due to the introduction of modern therapy with combinations of chemotherapy, radiation, surgery and supportive care. In 2009 Gatta et al showed that 5-year survival for children and adolescents had increased to 81% and 87% respectively (2). They also showed a significant reduction of relative risk of death by 8% in children, and by 13% in adolescents. Over the last decades a total increase in childhood cancer incidence can be seen, with an average annual percentage change of 1.1 % (1, 3). However this increased incidence has not been seen in Sweden (4). There is a discussion if the increase could be due to changed diagnostic procedures or registration artefacts (3, 5). Age standardized incidence is now 140 cases in 1 million children in Europe (1, 3) which gives a total number of 300 000-500 000 childhood cancer survivors.

Late effects and complications

For children who survive, the treatment often leaves permanent marks. In this report the word complications will be used, but there are several commonly used terms. There is no absolute definition for late complications. Anderson once described it as “Any chronic or late occurring physical or psychosocial outcome persisting or

developing well after diagnosis of the tumour” (6). In 2006 Oeffinger et al showed within the Childhood Cancer Survivor Study (CCSS) that 62% of long-term survivors displayed at least one complication, and an increase in the number of late complications with time (7). Geenen et al found complications in 75% in a similar study in the Netherlands, 2007 (8). In 2015 Phillips et al showed an increase of complications from 66% in ages 5-19, up to 88% for survivors between 40-49 years old.(9) Generally, morbidity seems to increase with age. The number of survivors with severe or life-threatening complications 17 years after diagnose is estimated from 27.5% to 40 %.(7, 8) Many survivors also suffer from multiple complications. In the Netherlands, Geenen et al showed that 24.6% had five or more adverse events (8), Oeffinger et al showed within the CCSS that 23.8% had three or more complications(7).

Late mortality

In a Nordic study Möller et al shows a late mortality number of 12,3% during extended follow-up of long-term survivors (10). Standardized mortality rate, (SMR) for survivors range from 8.3 to 10.8, mostly due to excess mortality from primary cancer (11, 12). Möller et al found in 2001 that SMR for second cancer was 4.9, and 3.1 non-cancer death (11). In 2010 Tukenova et al found SMR to be five times higher for cardiovascular diseases for survivors of childhood cancer than the general population (12). To reduce cancer-related morbidity and to increase quality of life, risk-based health care is one of the corner stones, but both health care providers and patients lack knowledge about risks and prevention methods (13). In a study from the CCSS, North America, only 31.5% received survivor-focused medical care, 17.8% reported discussing risk reduction or screening tests (14). Complications do not only impact health, but also factors as education, income and employment. Studies show that CNS cancer survivors have less education, lower income and lower employment

rate. Non-CNS cancer seemed to be able to reach the same achievements as the population in general (15).

Self-experienced health and quality of life

Self-experienced health is more complicated to measure in an objective manner. In a study by Sundberg et al 68% reported negative consequences, but 53% also reported positive consequences, describing a more positive view on life and of self (16). In a questionnaire regarding Health Related Quality of Life survivors scored lower than the corresponding general population, with women reporting a significantly greater burden of morbidity than men (17). Female sex, low household income and low educational attainment are factors associated with greater risk of adverse health status (7, 16, 18). Literature reviews indicates though that psychological adaptive style is more important than actual health status regarding psychosocial outcomes (19). A Swedish study of ALL-survivors (Acute Lymphatic Leukaemia) 20 years past treatment including CNS-radiation, showed lower neuropsychological function but still rated their quality of life as normal (20). General distress is a simple tool used for screening after depression, anxiety and psychological effects. Holland et al define distress in cancer as following in "Distress Management" in 2010:

" Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis." (21)

The Distress Thermometer has become one of the standard instruments for measuring distress among cancer patients and survivors from cancer. It is not yet fully validated

for use on young childhood cancer survivors, but is recommended as a complement to the multidisciplinary care. (22) See Appendix 2 to see the Distress Thermometer.

Sweden

Approximately 300 children are diagnosed with cancer in Sweden each year. The 5-year survival rates in the Nordic countries vary from 75% up to 90%. In an international comparison this is a very good result seen to represent the gold standard in cancer treatment (23). Despite the improved prognosis, childhood cancer is still the most common reason for death among children between 1 and 14 years of age.

At the moment approximately 11000 individuals in Sweden have or have had cancer during childhood, of who 6000-7000 are adult childhood cancer survivors (4, 24).

Swedish guidelines for follow-up were formed in 2007 by SALUB, Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (24). In November 2012, a long-term follow-up clinic was formed at Sahlgrenska University Hospital. So far, approximately 170 patients have visited the clinic. The future plan is to offer all childhood cancer survivors in the region of West Sweden a structured summarize of their cancer treatment at 18 years, and then a follow-up visit by the age of 24-25.

Since a structured follow-up clinic has not been available in this region before, patients treated in 1985 and later were the first to be invited. Prioritized were diagnoses where high rates of complications were expected, such as sarcoma, Hodgkin's lymphoma, and leukaemia. In addition, a few patients were referred from other clinics or contacted the clinic themselves. Before/during the visit all patients have been asked to fill out a questionnaire regarding cancer related distress, areas of concern and questions revealing their knowledge about risks and complications for their own diagnosis. This questionnaire was used in a clinical setting to identify areas of concern for the individual patient.

Aim

To summarize general distress, self-reported concerns and complications, and possible correlations between them, in a cohort of survivors of childhood cancer, who visited a long-term follow-up clinic in Gothenburg. By assessing distress, areas of concern and complications among the survivors, we hope to get a better understanding of the needs of this group, but also define areas for improvement in the future childhood cancer survivor care and point directions for screening programs and future studies. Since this is the first structured follow-up in this region it gives an opportunity to survey problematic areas in a way that has not been done before.

Material and methods

The cohort was chosen from the late-effect follow-up clinic, Sahlgrenska University Hospital. A total of 149 individuals had a first doctor's appointment at the Follow-up clinic between November 2012 and April 2015, of them 129 fulfilled the inclusion criteria below. Twenty-three of them either rejected (n=8) or did not answer the request (n=15). Overall 106 individuals remained in the study, 50 women and 56 men. Materials were collected from medical journals and the questionnaire filled out in connection with the appointment, see below.

Inclusion criteria:

- Childhood cancer diagnosis before the age of 18
- Attained at least one doctor's appointment at the follow-up clinic.
- Age >18 for the time of the visit.
- >5 years since last treatment.
- No current relapse.
- Completed the questionnaire before the visit at the follow-up clinic

Questionnaire and study protocol

From the medical records we collected data about diagnosis, treatment, gender, year of birth/diagnosis and time since diagnosis/last treatment. Furthermore, we gathered anthropometric data, demographic data, complications sub grouped by organ systems and secondary malignancies. For each complication we documented whether the complication was previously known or newly discovered, and if any further intervention was made. For all variables see the Study protocol in Appendix 1.

The questionnaire *Psykosocial screening för unga vuxna som haft cancer före 18 års ålder* (Appendix 2) was created with an Australian questionnaire (22) as a model. The original consists of the distress thermometer, and the following multiple-choice questionnaire. For this study the questionnaire was translated and validated according to the forward- and back-translation procedure. According to international recommendations a cut-off score for Moderate to Severe Distress was set at a score

of >4. The recommendation has been questioned, but is still considered to be valid for research purpose, according to a study comparing the

Distress Thermometer with the Hospital Anxiety and Depression Scale. (25) A pilot version of the questionnaire was first tested on 63 patients. Since it was well accepted, and no greater changes were made these individuals were also invited to the study.

The questionnaire consists of the Distress Thermometer and a section with different statements, where the individuals were asked to mark areas of concerns for the last month. The questionnaires were first used in a clinical setting, and not primarily for

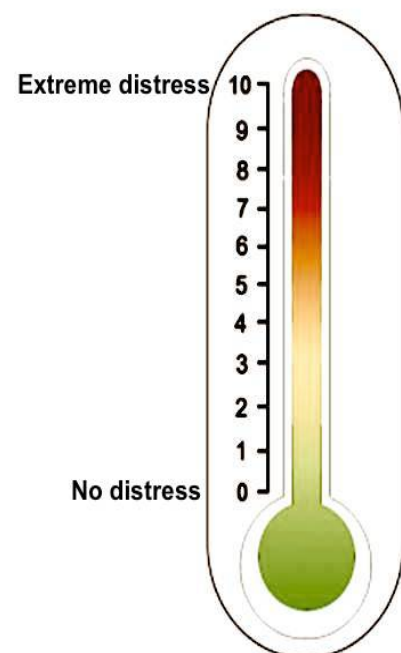


Figure 1:1. The Distress Thermometer. The patients were asked to evaluate their level of distress related to the previous cancer disease and/or treatment.

research. Therefore, requests for the permission to use the collected material were retrospectively sent out to the patients. The results from the questionnaires were subsequently registered and coded.

Ethics

Since the primary purpose of the questionnaires was purely clinical and private areas connected with personal issues and concerns of childhood cancer survivors in a relatively small population was investigated, the handling of the material has to be done with cautiousness. Therefore an application for an ethic approval was prepared. The study was approved by the Regional Ethical Review Board Gothenburg Sweden (Dnr: 161-15) March 23rd 2015.

Statistical methods

Statistical analyses were undertaken using the Statistical Package for the Social Sciences III version 22.0 (SPSS Inc., Chicago, Illinois, USA). Mean values, standard deviations and range were used to describe the distributions in the group.

Comparisons of all measurements were made with independent samples *t*-test and Pearson's chi-square test. Simple and multiple linear regression analysis determined all correlations. Multiple linear regression was performed with gender, age at follow-up, age at diagnose, complications before visit and radiation as independent variables, and general distress as dependent variable. Results were corrected for multiple comparisons by Bonferroni's method. The level of significance was set at $p < 0.05$.

Results

In total 106 individuals participated, 56 men and 50 women. Mean age for visiting the Follow-up clinic was 28.1 years (SD 5.9, range 19-42) and mean time since last treatment was 17.9 years (SD 5.9, range 5-33). The mean age at diagnose was 8.9

years (SD 5.3, range 0.3-18), and mean time since diagnose was 19.5 years (SD 5.8, range 7-36). After finished treatment 19 individuals had experienced a relapse during childhood, in those cases also the second treatment were registered. A total of 7 patients had been diagnosed with secondary malignancies. The treatment for secondary malignancies were not registered or analysed in our study. The secondary malignancies did not require any treatment other than surgery.

Demographic data, educational level and psychosocial support.

In total 43.4% (n=46) had either current or finished University studies and 50.9% (n=54) had either current or finished Swedish high school education as their highest level of education. For 1.9% (n=2) elementary school was the highest achieved education. Educational information was missing in 4 individuals. By the time of the visit 63.2% (n=67) had an employment, 20.8% (n=22) survivors were studying, 8.5% (n=9) were on a longer period of sick leave and 6.6% (n=7) were unemployed. The percentage of individuals living alone or with parents was 46.2% (n=49), whereas 51.9% (n=55) were living with partner and 22.6% (n=24) had biological children. Psychosocial support, including assistance for work/school/everyday life as well as counselling, was used by 21.7% (n=23) before the visit, and initiated for an additional 9.4% (n=10) after the visit. Smoking was reported by 12.3% (n=13).

Height and weight was measured in 98 (52 men, 48 women) of the participants. The mean body mass index of the men in the study was 25.8 (SD 6.2, range 18.0-49.8) and 23.9 (SD 5.8, range 15.6-45.0) for the women. Forty-two percent (n=22) of the men and twenty-one percent (n=10) of the women were defined as overweight (BMI \geq 25). Twenty-five percent (n=13) of the men and eight percent (n=4) of the women were defined as obese (BMI \geq 30).

Diagnoses

Totally 16 different diagnoses was included, (see Table 1:1). The three most common diagnoses were ALL, Mb Hodgkin and Sarcoma. Diagnoses were further divided into six diagnostic groups; Leukaemia (AML, ALL), Lymphoma, (Mb Hodgkin, Non-Hodgkin), Sarcoma (Rhabdomyosarcoma, Ewing's sarcoma, Osteogenous sarcoma, peripheral PNET), Wilm's tumour, Other (Angiofibroma, Retinoblastoma, Malignant melanoma, Germ cell tumour, Neuroblastoma, Carcinoma), Tumour Cerebri (PNET, Germ cell tumour, Ependymoma) (see Fig 1:1).

Table 1:1.

Many specific diagnoses were included in the study. Below the number and percentage of each diagnose included are presented.

	n	%
ALL	30	28,3
Mb Hodgkin	29	27,4
Sarcoma	14	13,2
Wilm's tumour	9	8,5
Non-Hodgkin	7	6,6
Neuroblastoma	4	3,8
Rhabdomyosarcoma	3	2,8
PNET	2	1,9
TC	1	,9
Retinoblastoma	1	,9
Carcinoma	1	,9
Angiofibroma	1	,9
Malignant Melanoma	1	,9
Germ cells tumour	1	,9
AML	1	,9
Ependymoma	1	,9

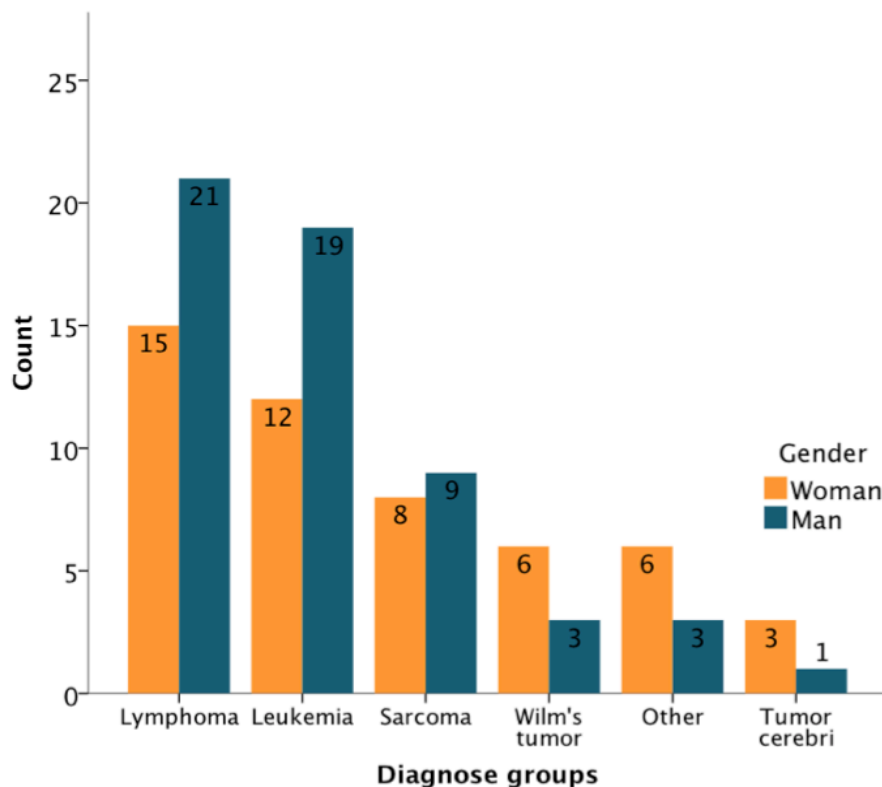


Figure 1:2. To enable more statistically accurate analyses the diagnoses were divided into 6 major groups, presented above with frequencies distributed between genders.

Treatment

There were four major treatment modalities (see Fig 1:2), and 8 combinations of them. Almost all patients 98.1%, received chemotherapy. The second most common treatment modality was radiotherapy (64.2%). Surgery had been performed in 42.4% of the patients and 8.5% (n=9) had been treated with stem cell transplantation (SCT), 2 of them autologous and 7 allogeneic. The most common combination was chemotherapy and radiotherapy. Most individuals were given combination therapies, 17 (16%) individuals received chemotherapy as only therapy.

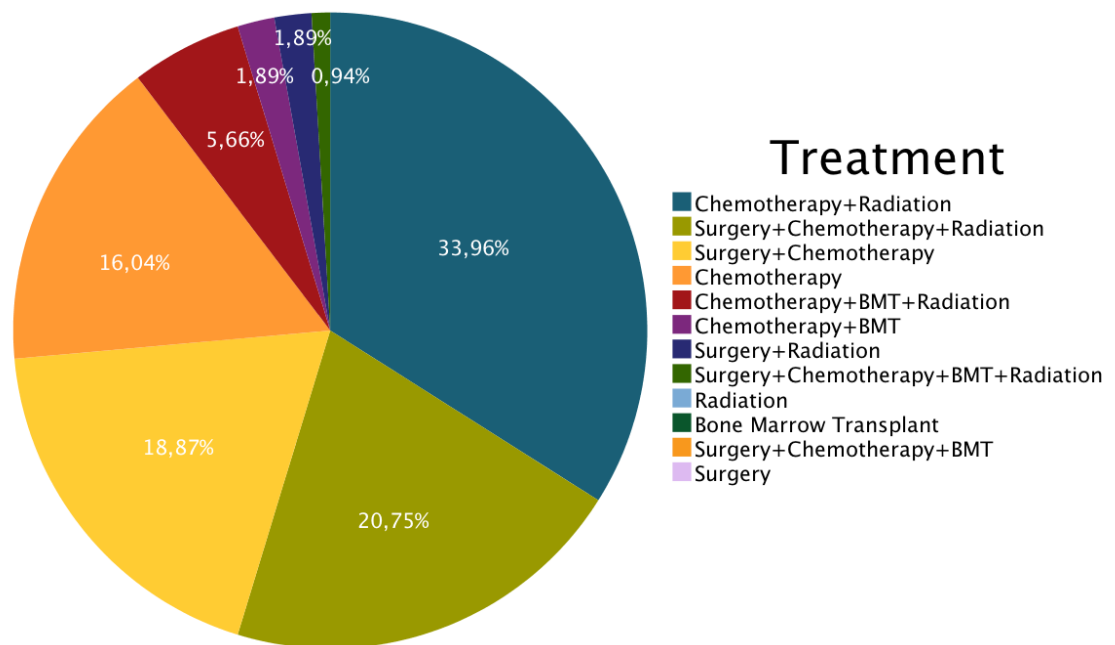


Figure 1:3. The patients could receive four different modalities of treatment, Chemotherapy, Radiation, Surgery and Bone Marrow Transplant. Most patients received a combination of different therapies. The percentage of the amount of patients receiving each combination is shown above.

General distress

Mean general distress was 2.52 (SD 2.38, range 0-9.5) (Fig 1:3). Women scored significantly higher than men, ((3.2 (SD 2.4) and 1.8 (SD 2.1), respectively)

($p < 0.005$). Moderate to severe distress, (score 4 or more) were found in 24% ($n=23$). Women were more likely to have moderate to severe distress, (17 women, 6 men) ($p=0.02$). The number of complications known before the visit correlated to a higher score of general distress ($p=0.01$). In a multiple regression analysis, higher general distress was significantly related to female sex ($B=1.26$, $p=0.03$), and to higher amount of complications known before the visit ($B=0.37$, $p=0.02$) but not to age at visit, age at diagnosis or radiotherapy. There was no difference in general distress between the diagnostic groups. Eleven individuals did not mark anything on the DT and were excluded from the analysis.

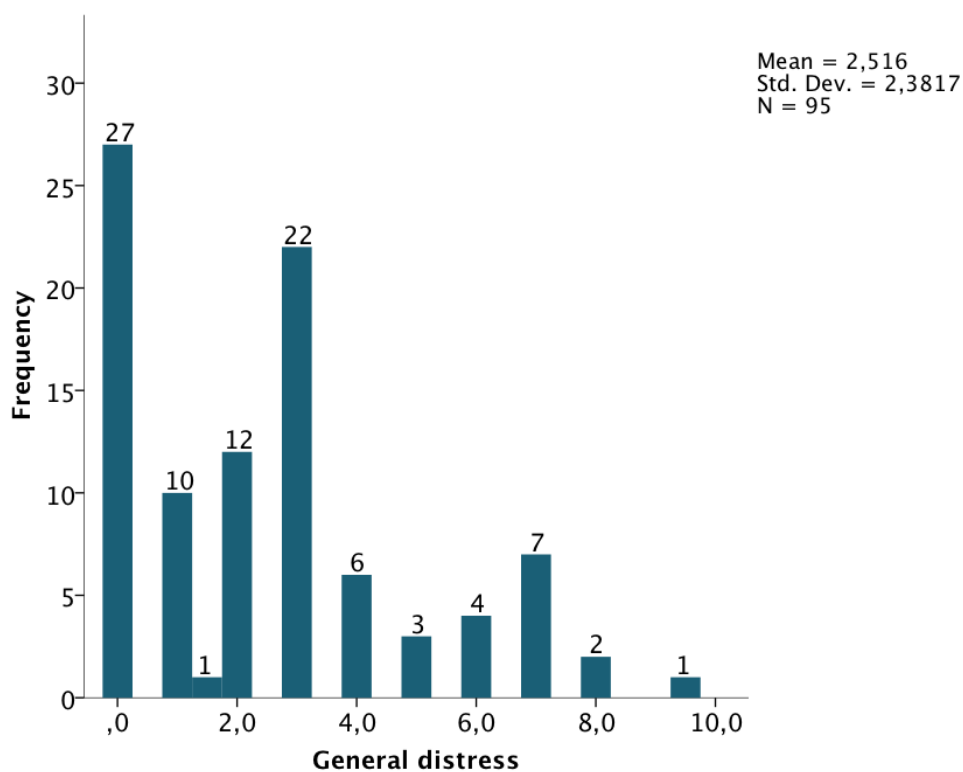


Figure 1:4. The patients were asked to evaluate the distress level for the last week. A score above 4 is considered as moderate to severe distress. The bars represent the number of patients marking each distress level on the scale.

Self-reported areas of concern

The survivors were asked to mark areas of concern for the last month, se Appendix 2.

The mean total reported areas of concerns were 11.2 (SD 8.9, range 0-43). The percentage of participants reporting different amounts of concerns is shown in Fig

2:1. The most commonly marked statement, 44.3% was "Not knowing fertility status". The second most common concern with 35.5% was "Worry about having long-term effects of treatment". Two of the Emotional statements "Sadness" and "Anxiety or fear" got 34% each. Another common area of concern was Concentration, where 34% and 28.3% respectively marked the statements "Trouble remembering things" and "Short attention span or concentration" respectively. A total of 33% respectively 31.1% marked the Physical statements "Problems with sleeping" and "Pain" respectively and 30.2% responded positive to the statement of "Feeling responsible to have a meaningful life". The remaining statements were marked by less than 30% of the patients. In one of the later editions of the questionnaire the statement "Feeling stronger as a person" was added. Among the 16 individuals that got the new edition 50% percent of them responded positively. For the 20 most common areas of concern see Figure 2:2.

Complications

Of individuals visiting the clinic, 86 survivors (81%), (44 women, 43 men) out of 106 were found to have at least one complication. Thirty per cent of the survivors were diagnosed with new complications as a result from the visit at the clinic (19 women, 13 men). The mean number of complications after the visit was 2.3 per patient (SD 2.2, range 0-12). Three or more complications were found in 38.7% (n=41) of survivors, and five or more were found in 10.4% (n=11). For frequencies of total number of complications see table 1:2. Individuals treated with radiotherapy had significantly higher risk for having at

Table 1:2.
The total number of complications was summarized for each patient. Below the distribution of complications within the group is presented in absolute numbers and percentages.

	n	%
None	20	18,9
1	26	24,5
2	19	17,9
3	18	17,0
4	12	11,3
5	5	4,7
6	1	,9
7	2	1,9
8	1	,9
12	2	1,9
Total	106	100,0

least one complication compared with those not treated with radiotherapy ($p=0.001$). Radiotherapy was also correlated to endocrine problems ($p=0.001$). No correlation was found between radiation and any other specific complication.

Screening, investigations and newly discovered complications

Further endocrine investigation was initiated for 19% ($n=20$) individuals and 6% ($n=6$) were discovered to have endocrine disturbances demanding substitution therapy. Among the women 26% ($n=13$) were referred for breast cancer screening, but no suspect cases have yet been found. Screening programs for heart problems (mainly echocardiogram every 5th year) were arranged for 63.2 % ($n=67$). Regular palpation of thyroid gland and levels of thyroid hormones in blood was initiated for 36.8% ($n=39$). Referral to a general practitioner or dermatologist for check-up of skin lesions was made for 53.8% ($n=57$). For frequencies of each complication see Figure 2:3.

Infertility included both complete infertility and partially reduced fertility where medical assistance was needed to achieve pregnancy. All survivors with known fertility-affecting treatment were offered further investigation and 20 individuals were referred to the Reproduction Clinic. Nine of them have yet been found to be infertile. Twenty-one persons had been diagnosed with infertility before the visit.

Hypertension was found in 6% ($n=6$) of individuals. Musculoskeletal and/or connective tissue affecting complications were found in 6% ($n=6$). Complications in mouth and throat were found in 3% ($n=3$). Neurologic disturbances and hearing impairment were discovered in 2% ($n=2$) each and pulmonary diseases, urinary tract- and gastrointestinal complications were found in 1% ($n=1$) each.

Discussion

In this study we found a high rate of physical complications. General distress was higher in those patients that already had at least one complication before the visit and especially in women. We found high numbers of concerns regarding possible complications as infertility, but many also marked statements as "Sadness", "Anxiety or fear" and "Trouble remembering things". Because of the short amount of time, there was no possibility to compare these childhood cancer survivors to a control group without a previous history of cancer. The question is if these levels of distress and areas of concern would differ so much from a cancer-free population of the same age. The transition from adolescence to adulthood is a time of change and challenges for most human beings. A time of big decisions and new responsibilities, which tests the ability to cope with stress and new situations.

General distress

The Distress Thermometer, DT is becoming more and more recognized within in the cancer care internationally, but there is still an on-going process of validation when screening adult survivors after childhood cancer. When using the DT, a score over 4 is generally considered as moderate to severe distress. (22) In this study the mean level of distress was significantly higher for women than men and they were also more likely to score 4 or more. There was also a significant correlation between amount of complications before the visit and general distress, but no difference in complications between men and women. It is questionable if the females de facto did experience a higher level of distress, or if it is an expression of different ways of valuing and expressing distress. Earlier studies show higher level of distress in female haematological patients than in men (26), but also higher frequencies of depression in female cancer survivors than in women not previously diagnosed with cancer (27). A

study on outpatients affected with anxiety disorders (without a previous history of cancer) showed a higher prevalence of anxiety disorders in women, but also showed that women scored higher on self-rated scales, but not on observer-rated scales (28). A study investigating distress in oncology patients, comparing the Hospital Anxiety and Depression Scale (HADS) and a classic thorough clinical assessment showed less agreement between the methods among males than females (29), and a similar situation cannot be ruled out also regarding the Distress Thermometer. Further validation should pay attention to possible difference in approach between genders.

Self-reported concerns

The two most common concerns "Not knowing fertility status" and "Worry about having long-term effects of treatment" covers areas that can be dealt with through investigations and screening programs. Earlier studies show that the risk of infertility varies with therapy modality, sex, tumour site and age at diagnose (30, 31). To educate the survivors about what risks they actually do have due to their disease and treatment reduces "unnecessary" anxiety. A very high percentage (44.3%) worried about fertility, but of those referred for investigations only 9 were found to be infertile. Several individuals expressed that the follow-up brought up worries about what complications they might be at risk for, but also that it was better to know than not to. A substantial part of the anxiety could be reduced already at the clinic since the given treatment did not increase the risk for that specific subject. A few asked for a new visit some months after the first because of new thoughts and worries. In the future it would be interesting to measure the general distress also after the follow-up.

Questionnaire

In this study we focused mainly on problems and negative effects. When filling out the questionnaires several patients pointed at the lack of "positive effects". Sixteen

individuals got a later edition where the statement "Feeling stronger as a person" was added, among them 50% percent responded positively. Future studies could benefit from looking for factors connected with better self-reported health, as a way of helping survivors to a better life. To reach out to parents/relatives that was present during the years of disease and treatment could also give a wider perspective as many of the survivors were diagnosed as young children. A study within the CCSS focused on Positive Perceived Impact (PPI), which showed that women, non-White and patients exposed for intense therapy, relapse or second malignancy actually endorsed greater PPI than others (32). This does not automatically contradict distress, but contributes to a sense of meaning to life, which supposedly helps tackling complications.

Complications

Childhood cancer is a heterogeneous group when it comes to cancer diagnoses and with a great variety of treatment modalities. In this cohort there was a wide variation of diagnoses, and a relatively high number of individuals treated with radiotherapy. Previous studies have pointed out radiation as a risk factor both for physical(33) and psychological complications (34). The patient cohort in this study is selected since a high number of complications were suspected for the diagnoses of the majority of patients who visited the clinic. This might contribute to a higher number of complications in our group than expected. We also had a wide time range since diagnosis and finished treatment.

Relatively many complications were discovered at follow-up compared with earlier studies(7-9), and presumably additional late effects will be diagnosed since not all patients have yet been investigated due to long waiting periods. For the complications that were found, the most frequent complications had no overt symptoms, such as infertility and hypertension. Endocrine disturbances have unspecific but still very

affecting symptoms, such as fatigue, depression and weight gain. Other complications (such as musculoskeletal pain) were not completely unknown, but were not until the visit at the clinic confirmed to be a complication to their previous cancer and/or treatment. This might have prevented the survivors from getting the proper treatment and support from school, social services or other instances. Some of the elder survivors might have benefitted from discovering some of the complications earlier in life, to be able to take that in account when making life-decisions and to get proper support with studies and work. For those affected with infertility, preventive actions or spontaneous pregnancy may have been possible if discovered in an earlier stage. However, the methods for fertility preservation appropriate for this patient group have only been available during the most recent years. Since our main focus in this study was distress and areas of concern, we did not grade the severity of the complications. The number of survivors having three or more complications was slightly higher than what Oeffinger showed within the CCSS (7), but the number of individuals with five or more was slightly lower than in Geenen's study(8). This might be explained by the small number of brain tumour survivors in our study.

Strengths and weaknesses

The study was performed on a patient cohort who had been invited to the long-term follow up clinic in Gothenburg. Since the data was collected from already existing material it did not ask for any further effort from the participants, and a high percentage (82%) approved to our request. All patients included was examined by the same doctor.

External loss and limitations

The selection of patients invited to participate in the study was based on patients that had already visited the clinic. Some of the patients had contacted the clinic

themselves, but a big majority received an invitation from the clinic. Invitations were sent to specific diagnose groups based on expected complication rate. Since the participants only were picked from patients that actually chose to visit the clinic, we also excluded some patients that possibly did not experience any effects from their cancer and therefore felt no need for a follow-up. However, some of the most cognitive affected individuals could not participate in our study, which excludes one group with presumably high levels of distress and complications. An important group of patients not sufficiently represented in this study is survivors from brain tumours. This is a group known for having the highest rate of complications, but has not yet been invited to the follow-up clinic.

Internal loss

Eleven patients did not mark anything at the Distress Thermometer. This might be because they did not understand the term, they did not understand that they were supposed to mark it, or they did not experience any distress and "marked" that by not marking anything. Those answers were excluded from the analyses. Furthermore 2 individuals marked two numbers, which was registered as the mean value of them. They were included in the mean values, but not in the Chi-square tests. Some patients had marked alternatives among the self-reported concerns in a way that made it uncertain if they meant to mark it. Those statements were excluded from the analysis.

Conclusion

Many childhood cancer survivors have developed complications as a result of treatment or disease. In this study, new complications were found in 30% of the participants and higher levels of distress were found in women and individuals with previously known complications. The results indicate that the general health care fails

to meet the needs for childhood cancer survivors when it comes to finding new complications, establishing screening programs and educating the survivors about what risks they might be at stake for. Therefore, increased knowledge and organization for this growing patient group in the health-care system is needed.

Acknowledgement

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Populärvetenskaplig sammanfattning på svenska

Unga vuxna efter barncancer- hälsomässiga och psykosociala konsekvenser av behandling och sjukdom

Bakgrund: Barncancer är en ovanlig sjukdom, cirka 140 av 1 miljon barn drabbas. Överlevnaden efter barncancer har ökat de senaste årtiondena. Idag överlever mer än 80 % en barncancerdiagnos. Detta gör att antalet personer i samhället som haft cancer som barn ökar. I Sverige finns ungefär 11 000 personer som har eller har haft barncancer, av dessa är 6000-7000 vuxna idag. Tidigare forskning visar att upp till 88 % av överlevare har komplikationer 20 år efter sjukdom och behandling. I undersökningar uttrycker många icke-barncancerspecialister en osäkerhet kring eventuella risker och behandling av före detta barncancerpatienter. I november 2012 startades på Jubileumskliniken Sahlgrenska, en Uppföljningsmottagning för unga vuxna. Det är en mottagning för överlevare efter barncancer.

Syfte och metod: Att sammanställa oro/distress, egenupplevda bekymmer och komplikationer hos barncanceröverlevare som har besökt Uppföljningsmottagningen på Sahlgrenska Universitetssjukhuset. Material hämtades från journaler och enkäter som patienterna fick fylla i själva. Enkäten innehöll en Distress Termometer där oro skattades från 0-10, och en lista med olika områden för bekymmer.

Resultat: Totalt 106 personer deltog i vår studie, 50 kvinnor och 56 män. Alla hade fått en barncancerdiagnos innan 18 års ålder, och minst 5 år hade gått sedan senaste behandlingen. Av alla deltagare hade 81 % minst en komplikation. I snitt hade varje deltagare drygt två komplikationer. Strålbehandling gav högre risk för komplikationer och nya komplikationer hittades hos 30 % av deltagarna. De tre vanligaste

komplikationerna var smärta/stelhet/förtvining i muskler och leder, infertilitet (svårigheter att få barn) och nedsatt produktion av sköldkörtelhormon, Kvinnor och personer med tidigare kända komplikationer skattade en högre generell oro/distress. De vanligaste områdena för bekymmer var "Vet ej om jag kan få barn" och "Oro för sen-effekter pga. cancerbehandlingen".

Slutsats: Många överlevare har komplikationer och oro kopplat till sin tidigare barncancer. För de barn som överlever en cancerdiagnos återstår många år av livet. Det är viktigt att dessa år ges så god kvalitet som möjligt. Många unga överlevare har i media belyst brister i uppföljningen inom vuxenvården. För att möta deras behov behövs specialiserade center för uppföljning, med kunskap om risker och komplikationer för olika behandlingar och sjukdomar. Detta möjliggör riskförebyggande insatser och screeningprogram för till exempel hjärtfel och nya cancersjukdomar.

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Figures

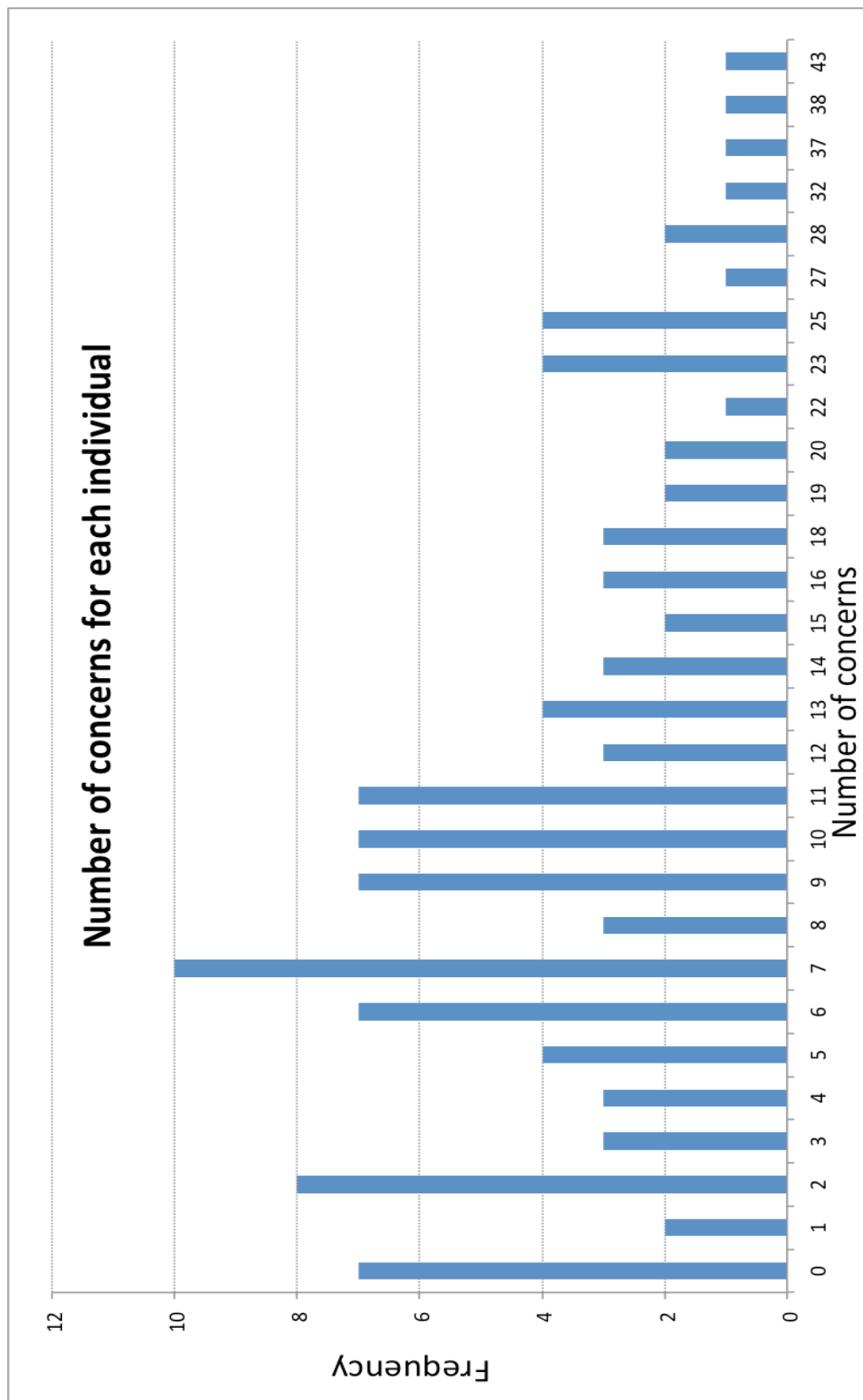


Figure 2:1. The patients were given a list of statements and were asked to mark areas of concern for the past month. The total number of concerns marked by each individual was summarized and presented above.

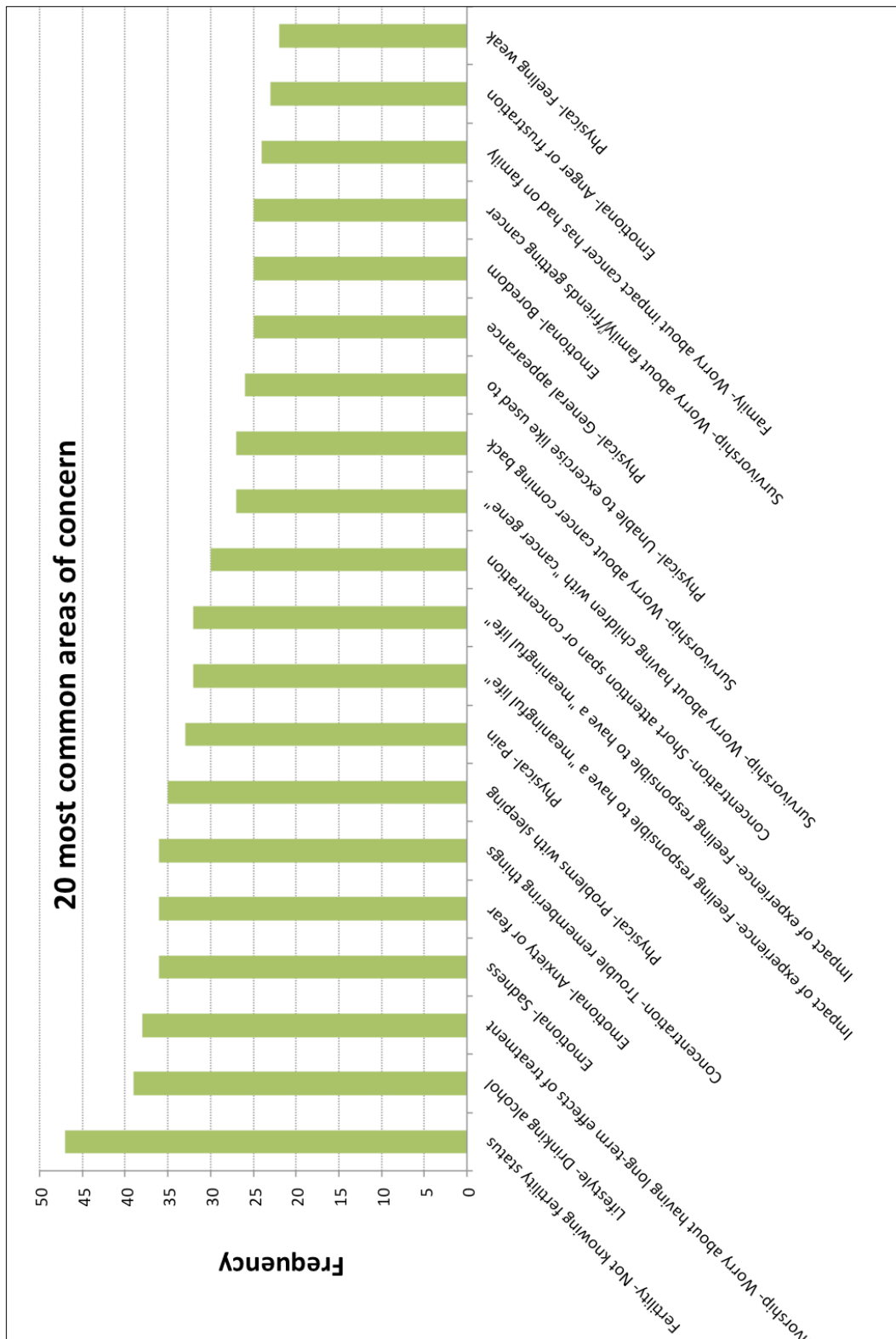


Figure 2:2. The patients were given a list of 81 statements, and were asked to mark areas of concern for the past month. Above is shown the 20 most commonly marked areas of concern, presented in decreasing order.

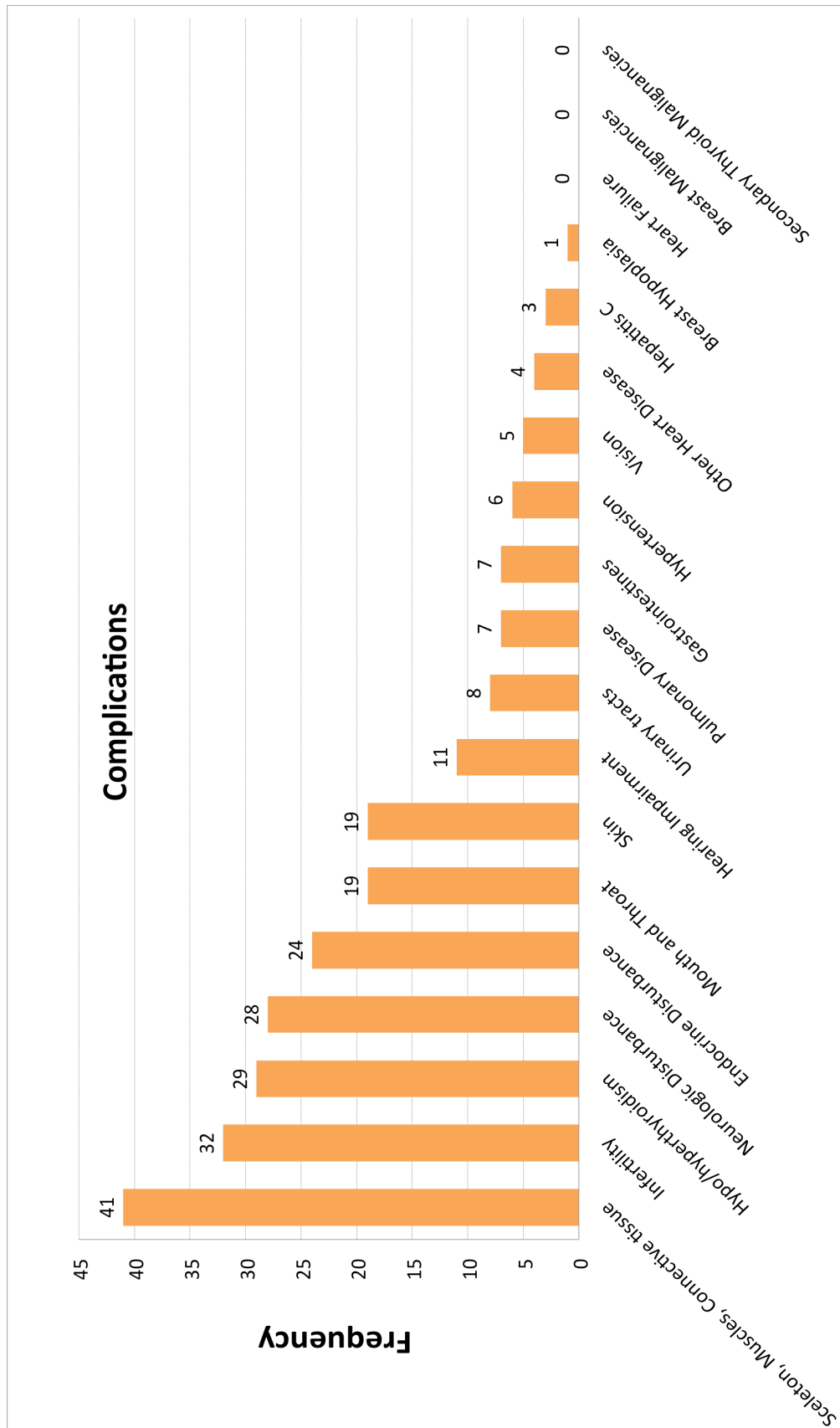


Figure 2:3. Complications of 19 different categories were summarized for each patient. Frequencies for each category are presented above in decreasing order.

Appendices

Study Protocol

Number

Year of birth

Gender 1 Woman 2 Man

Length WeightBMI

Year of diagnosis

Age of diagnosis

Years since last oncologic treatment

Year since diagnosis

Kind of tumour

Mb Hodgkin	1			
Sarcoma	2	TC	6	neuroblastoma 10
Wilm's	3	retinoblastoma	7	
PNET	4	carcinoma	8	
ALL	5	angiofibroma	9	

Relapse

Treatment

Surgery

Chemotherapy

Kind of chemotherapy

Anthracyclines	1
Alkylating agents	2
Platinum compounds	3
Vinca Alkaloids	4
Other	5

Localization for radiation None 0 1 Brain 2 Head and neck 3 Thorax 4

Abdomen

5 Extremities

Dosage

Civil status Missing 0

Living alone/with parents 1

Married/living as married 2

Partner, but not living together 3

Children no 1 yes 1

Highest level of education

Missing 0 Elementary school 1

College 2 University 3

Occupation

Missing 0 Working 1

Studying 2 Sick leave 3 Unemployed 4

Psychosocial support

None 0 Already in contact 1

Contacted initiated after the visit 2

Late complications

Hypertension

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2
Intervention Yes 1 No 0

Heart failure

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Other heart disease

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Intervention

Hypo/hyperthyroidism

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Secondary Malignant Thyroid Disease

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Intervention Yes 1 No 0

Breast Malignancy

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Breast hypoplasia

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Intervention Yes 1 No 0

Pulmonary diseases

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Intervention Yes 1 No 0

Reduced fertility or complete infertility

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Intervention Yes 1 No 0

Endocrine disturbance

None 0 Yes- already known complication 1
Complication discovered/started investigation during the visit 2

Kind of disturbance

None 0
 Thyroid hormones 1 Other 5
 Sex hormones 2
 Growth hormones 3
 Diabetes 4
 Intervention Yes 1 No 0

Neurologic disturbances
 None 0 Yes- already known complication 1
 Complication discovered/started investigation during the visit 2
 Kind of disturbance
 None 0
 Neuropathies 1
 Other 2
 Neurocognitive 3
 Intervention Yes 1 No 0

Urinary Tracts
 None 0 Yes- already known complication 1
 Complication discovered/started investigation during the visit 2
 Intervention Yes 1 No 0

Gastrointestinal complications
 None 0 Yes- already known complication 1
 Complication discovered/started investigation during the visit 2
 Intervention Yes 1 No 0

Mouth, Throat and Teeth
 None 0 Yes- already known complication 1
 Complication discovered/started investigation during the visit 2
 Intervention Yes 1 No 0

Hearing Impairment
 None 0 Yes- already known complication 1
 Complication discovered/started investigation during the visit 2
 Intervention Yes 1 No 0

Impaired vision
 None 0 Yes- already known complication 1
 Complication discovered/started investigation during the visit 2
 Intervention Yes 1 No 0

Musculoskeletal complications
 None 0 Yes- already known complication 1

Complication discovered/started investigation during the visit 2

Kind of complication

Atrophy 1

Scoliosis/kyphosis 2

Other 3

Intervention Yes 1 No 0

Skin

None 0 Yes- already known complication 1

Complication discovered/started investigation during the visit 2

Kind of skin lesion

None 0

Malignant lesion 1

Benign lesion 2

Other 3

Intervention Yes 1 No 0

Spleen/Immunology

None 0 Yes- already known complication 1

Complication discovered/started investigation during the visit 2

Intervention Yes 1 No 0

Hepatitis C

Other

Secondary malignancies

Complications in total

Psykosocial screening för unga vuxna som haft cancer före 18 års ålder

Uppföljningsmott. Unga Vuxna/Väst

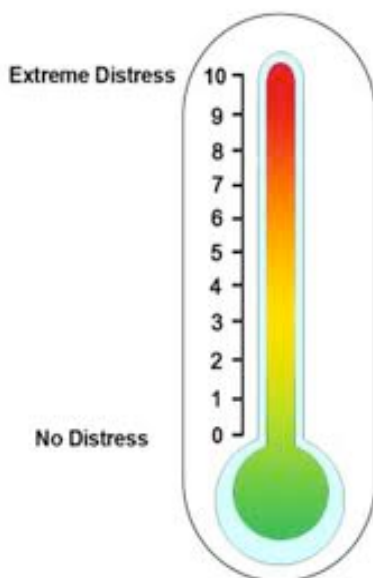
Namn:

Datum för ifyllande:

140310

1. Distress allmänt

Ringa in den siffra (0-10) som bäst beskriver hur mycket distress (bekymmer/besvär) du upplevt den senaste veckan inklusive idag som är kopplat till din tidigare cancerdiagnos/behandling



Distress är svåröversatt, men kan beskrivas som en obehaglig och ofta komplex upplevelse som kan ta sig uttryck i fysiska, psykiska, social och/eller existentiella symtom. Man kan säga att det handlar om upplevda bekymmer och besvär. Här ska upplevelsen vara kopplad till din cancerdiagnos och/eller den cancerbehandling du fått.

2 Specifika områden för bekymmer/besvär eller anpassningsförmåga?

Var snäll och kryssa för de områden som har varit ett problem för dig under den senaste månaden inklusive idag (behöver inte vara direkt relaterat till din cancerdiagnos):

Fysiskt

- Allmänt tillstånd
- Ätande eller aptit
- Förstoppning eller diarré
- Sexuella bekymmer
- Smärta/värk
- Anpassning till ny funktionsnivå
- Mindre ork än före cancer
- Lägre kapacitet för "normala" aktiviteter
- Oförmögen att träna som jag brukade
- Känner mig svag
- Sömnpromblem
- Biverkningar av behandlingen

Konsekvenser av min cancer-erfarenhet

- Avsaknad av trygg framtid
- Identitets förändring
- Förlust av livsmening/mål med livet
- Förlust av ekonomisk självständighet
- Ifrågasättande av tro eller andlighet
- Sorg över andra patienters död
- Skuld över andra patienters död ("överlevnads skuld")
- Känner ansvar för att leva ett "meningsfullt liv"

Känslomässigt

- Nedstämd/ledsen
- Känner mig ensam eller isolerad
- Oro/ångest eller rädsla
- Skuld känslor
- Uttråkad
- Ilska eller frustration
- Extremt negativa känslor
- Känns som allting kräver en ansträngning
- Känsla av hopplöshet eller hjälplöshet
- Känsla av förvirring
- Livet känns meningslöst
- Självmordstankar

Koncentration

- Kort uppmärksamhetsfokus eller koncentrationsförmåga
- Problem att komma ihåg saker
- Tar längre tid att slutföra saker än tidigare

Fertilitet/fortplantning

- Vet inte om jag kan få barn
- Känner inte till vilken hjälp som finns att få för att få barn
- Oro för kostnader för fertilitetsbehandling
- Oro över att diskutera fertilitet med partner/framtida partner
- Sorg över barnlöshet

Livsstil

- Röker cigaretter
- Dricker alkohol
- Använder droger
- Gör andra saker som riskerar livet
- Har oskyddad sex
- Har en ohälsosam livsstil
- Sköter inte bokade möten (bla medicinska)

Arbetsmarknad

- Att få ett jobb
- Återgång i arbetet
- Stöd från arbetsgivare
- Diskriminering på arbetet
- Problem med arbetskamrater
- Ändrade karriär strävanden

Familjen

- Upplever att familjen inte förstår
- Brist på stöd från familjen
- Känner ansvar för att "skydda" familjen från sanningen
- Behov av mer hjälp/stöd än familjen kan ge
- Oro för vilken påverkan cancer haft på familjen
- Oro för familjemedlemmar

Socialt

- Känner mig isolerad från vänner
- Vill/kan inte göra "normala saker" med mina vänner
- Mina vänner förstår mig inte
- Känner mig annorlunda jämfört med mina vänner
- Vill/kan inte träffa nya människor
- Oro för flick-/pojkvän/partner
- Kris i relationen med partner

Survivorship/överlevnad

- Vill inte berätta för andra att jag haft cancer
- Döljer "äkta" känslor för andra
- Håller "skenet uppe" inför kompisar
- Upplever att jag gått miste om livet pga cancer
- Svårt att acceptera ändrade omständigheter pga cancer
- Oro för att familj/vänner ska få cancer
- Oro för att familjen har "cancerigen"
- Oro för att få barn med "cancerigen"
- Oro för sen-effekter pga cancer-behandlingen
- Oro för att cancer ska komma tillbaka
- Orostankar om död och döende

Utbildning

- Återgång till utbildning
- Komma ikapp med studier
- Problem med studiekamrater
- Problem med lärare/föreläsningar/personal
- Behov av speciella åtgärder

Andra saker jag vill ta upp...

Vilka är dina mål för framtiden?

1. _____

2. _____

3. _____

4. _____

Var snäll och markera vilken ytterligare information som du anser skulle vara användbar:

Din cancerdiagnos	<input type="checkbox"/>	Långtidsuppföljning	<input type="checkbox"/>	Studievägledning	<input type="checkbox"/>
Genomförd behandling	<input type="checkbox"/>	Ekonomisk rådgivning	<input type="checkbox"/>	Arbetsmarknadsrådgivning	<input type="checkbox"/>
Psykosocialt stöd	<input type="checkbox"/>	Fertilitetsrådgivning	<input type="checkbox"/>	Vägar till förbättra hälsa	<input type="checkbox"/>
Stöd grupper	<input type="checkbox"/>	Ärftlig cancer	<input type="checkbox"/>	Fritidssysselsättningar	<input type="checkbox"/>

Här nedan följer ett antal frågor som är mycket värdefulla för vårt fortsatta omhändertagande av dig och vår fortsatta verksamhet (använd gärna baksidan vb)

Vilken tumörsjukdom har du fått behandling för: _____

Hur gammal var du när du fick din diagnos? _____

Vad fick du för behandling (sätt kryss för det som är aktuellt):

Cytostatika Strålbehandling Kirurgi(operation) Transplantation

Vet du idag om du har något problem som du kopplar till din tidigare cancersjukdom eller behandling?

Ja Nej

Om ja, vilket/vilka? _____

Vet du idag om du på grund av din tidigare cancersjukdom/behandling har någon ökad risk för biverkningar i framtiden?

Ja Nej

Om ja, vilket/vilka? _____

Aktuella sjukvårdskontakter: _____

Aktuella läkemedel: _____

Övriga uppgifter av värde: _____

Jag godkänner att ovanstående information får användas av mitt team på Uppföljningsmottagningen för mitt fortsatta omhändertagande.

Underskrift/patient:	Datum:
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