



SAHLGRENKA ACADEMY

**Psychosocial, social and somatic late complications and concerns of disease
and treatment in adults that survived childhood cancer.**

Long term follow-up study at Sahlgrenska University Hospital, Gothenburg.

Degree Project in Medicine

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Abstract

Psychosocial, social and somatic late complications and concerns of disease and treatment in adults that survived childhood cancer.

Long term follow-up study at Sahlgrenska University Hospital, Gothenburg.

Background: Owing to medical progress, the survival rate of childhood cancer in Sweden is approximately 85 %. The risk of long-term complications is around 70-80 %. However, the knowledge about the medical history and the awareness of late complications and concerns among adult childhood cancer survivors varies within the group.

Aim: To study the most prevalent psychosocial, social and somatic concerns and needs, among adults that survived childhood cancer at long term follow up clinic, in Gothenburg (LTFU). Furthermore, to describe how patients perceive the visit at the LTFU clinic.

Methods: The descriptive retrospective cohort study included 322 individuals who completed the Psychosocial Survivorship Screening Tool. Data from the Psychosocial screening tool and medical journals were collected and analyzed. The interview-based study conducted through ZOOM included 15 individuals. Content analysis with an overall theme divided into categories and subcategories were used.

Results: The two most common patient reported concerns were trouble remembering things and not knowing fertility status, 40.4 % each. The ten most common concerns were further analyzed concerning relation to cancer treatment and sociodemographic data. The majority experienced no or low general distress. Moderate to severe distress was reported by 22 %. In the interview study patients' perception of the LTFU clinic were divided into three categories,

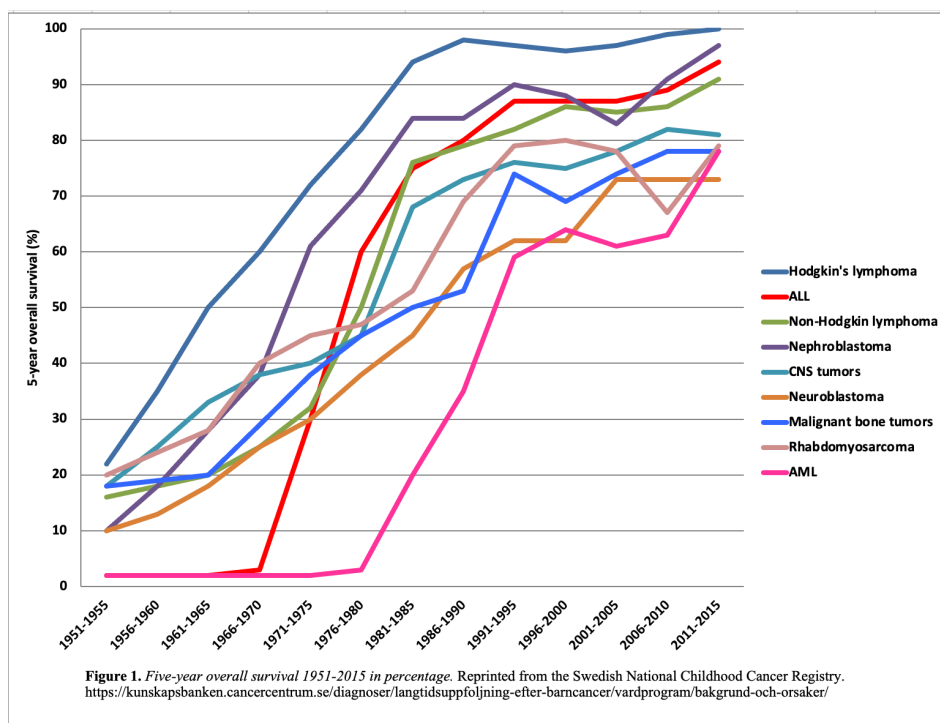
knowledge, security, and perceptiveness. Patients who received the Short term written care plan (STCP) described the visit at LTFU and short-term follow-up care more detailed than those who did not.

Conclusion: One of the most common concerns was Trouble remembering things, STCP may aid in enhancing the memory of the visit at the clinic and the arrangements decided at the LTFU. LTFU aids in increasing patient's health literacy and empowerment to take responsibility over their health situation in accordance with their capacity and needs. The study emphasizes the importance of a structured follow-up care after childhood cancer.

Keywords: Adult childhood cancer survivors, Late complications, General Distress, Health literacy

1. Background

In Sweden approximately 350 children each year below the age of 18 are diagnosed with cancer, adding up to about one child per day. The most common childhood cancer diagnoses are leukemia and lymphoma, together 35 %. Brain tumor represents 25 % and a third group of various childhood cancer tumors represented by 40 %. The survival rate has progressively increased and has reached a level of around 85 %. The 5-year survival among girls is 82 % and among boys 84 % (1). Childhood cancer five-year survival presented in Figure 1 (2).



Many individuals, around 60-80 % have a high risk of developing long-term complications (2-6) due to the intense oncology treatment protocols received as a child. These often arise decades after treatment (2, 3). The late complications can be manifested as hormonal disturbances (7), infertility (8), cardiovascular diseases (9, 10), second malignancies (11, 12) and cognitive impairments (13, 14). The adult life after childhood cancer in Scandinavia

(ALiCCS) study showed that childhood cancer survivors had twice as high risk of being hospitalized and being in-patients for a longer period, compared to a control group of the same age and sex. The five major reasons for hospital admissions were diseases linked to the connective system, endocrine system, digestive system, and respiratory system. The survivors of childhood cancer often suffer from severe and challenging diseases, hence the importance of a professional health care that can detect, prevent, and manage symptoms related to late complications (15). To increase knowledge about the late complications and provide national guidelines the *Swedish Guidelines for long term follow-up after childhood cancer*, was published 2016 and revised 2019 (2).

1.1. Long term follow-up clinic

The Long term follow up clinic, (LTFU) located at the Sahlgrenska University hospital, Gothenburg offers one or more visits for all childhood cancer survivors that have reached 18 years of age and live in the western part of Sweden. The main purpose is to screen and inform patients regarding possible complications or in other words late complications stemming from childhood cancer treatment, and when necessary, refer to caregivers for further care. Before the first visit, the patients receive a *Psychosocial Survivorship Screening Tool*, (16) to be completed before the visit, (Appendix 1), originally from Australia. This is used to facilitate the consultation with the patient in focus. The medical team at LTFU, consists of a pediatric oncologist, a nurse and a counselor. During the visit they are all present and can contribute with their diverse and unique competences and provide a more comprehensive care. If needed, a psychologist/neuropsychologist and a radiation oncologist are available for consultation. Since 2018, all childhood cancer survivors are referred to LTFU from the pediatric cancer center, for at least one visit at LTFU at the age of 25, or earlier depending on treatment. In

addition, older childhood cancer survivors are offered visits at LTFU. All patients and relevant caregivers receive a *Survivorship passport* (Appendix 3), acting as a long-term guidance for follow-up. It contains both a summary of the childhood cancer treatment and recommendations regarding long term follow up care. From October 2019 patients receive a short term written care plan (STCP) (Appendix 2), that summarizes the visit, and contains planned medical investigations, as well as distribution of tasks between caregiver and caretaker, in an attempt to attain greater clarification for both parties.

1.2. General distress and Psychosocial aspects

Cancer patients experience a significantly higher general distress level, 25–60 % at any level from being diagnosed into survivorship compared to seven percent in the general population. As a group, childhood cancer survivors have a higher risk of developing psychosocial difficulties as a secondary effect, due to previous cancer diagnosis, treatment and late complications. (17). Children as well as adolescent cancer survivors, have an increased risk of developing symptoms such as anxiety, depression, inattention disorders, antisocial behavior and reduced social competence, compared to their sisters and brothers. The symptoms can arise long time after receiving treatment (18, 19). Distress connected to depression is experienced by 58 % of cancer patients, whereas 34 % connect the distress to anxiety (20). Women consistently experience a higher degree of distress during treatment (21, 22). Patients with cognitive deficits and have an impaired executive function, scale a higher degree of distress (20). Individuals living alone experience distress at a higher rate than those being married. The risk of developing negative psychological symptoms among childhood cancer survivors include, being unmarried, having a low income, being female, having a low education and living with a disability. CNS tumors with its targeted therapies as well as

physical comorbidities i.e. physical late complications after childhood cancer are linked to low psychosocial outcomes (17). Low education i.e., not being able to graduate high school, is especially acknowledged among survivors of childhood CNS tumors, leukemia, non-Hodgkins lymphoma and neuroblastoma (17). Childhood cancer survivors are 50 % more likely to be unemployed compared to the general population (23).

1.3. Transition care

In Sweden the transition of care occurs during the adolescence period, to ultimately transfer the individual from pediatric care to adult health care at 18 years of age (24). It is important to consider both physical, social, and mental health aspects and offer an individualized health care that enables the patients to take a more active part in their health care, based on capacity and needs (25).

2. Definitions

Psychosocial Survivorship Screening Tool is a screening tool given to the patients before the first visit at LTFU. It is designed to detect and address possible psychosocial and physical concerns stemming from childhood cancer treatment (16).

The ***written short term health care plan***, abbreviated STCP, summarizes the visit at LTFU. It acts as a short-term plan both for the patient and the caregivers at LTFU.

Survivorship passport summarizes the childhood or adolescent cancer treatment and acts as recommendation, and guide for long term follow up care, both for the patient and relevant health care providers.

General distress is cited by Deshields T.L. as; “*a multifactorial unpleasant emotional experience of a psychological (i.e. cognitive, behavioral, emotional), social, spiritual, and/or*

physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along the 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” (26).

Late complication is defined according to Anderson et. al. “*Any chronic or late occurring physical or psychosocial outcome persisting or developing well after diagnosis of the tumor” (27).*

Health literacy is defined according to Ratzan and Parker: “*The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (28).*

3. Research questions

Main research question: Can the use of a psychosocial screening tool in combination with individualized medical information, during the clinical visit at the Long term follow-up clinic, increase health literacy in adults that survived childhood cancer?

Underlying research questions, quantitative: Which are the most common patient reported, psychosocial and health related symptoms and concerns at the first visit at Long term follow-up clinic? Were these reported symptoms and concerns related to childhood cancer diagnosis and treatment?

Underlying research questions, qualitative: How do the patients perceive the visit at Long term follow-up clinic?

4. Methods

This study was conducted at LTFU, Sahlgrenska University Hospital, Sweden. A mixed method according to Creswell et. al. was used including both a qualitative and quantitative method (29). To answer the main research question, it was broken down into three underlying questions, thus aiding from different perspectives to help answering the main research question.

4.1 Method cohort study

A retrospective descriptive study of patient-reported, psychosocial and health related symptoms and needs before the first visit at the LTFU clinic, related to childhood cancer treatment and sociodemographic data.

4.1.1 Population

The participants were enrolled patients at LTFU between November 2012-December 2019, in total 322 individuals. Patients who had completed the psychosocial screening tool before the first visit at LTFU and who accepted it to be used in a study, were enrolled by signing the psychosocial screening tool. Inclusion criteria: Childhood cancer diagnosed before the age of 18 y, > 18 years old at study, more than five years since last oncology treatment and a completed Psychosocial screening tool. In total 449 patients visited the clinic, 337 completed the psychosocial screening tool. Of these 15 patients did not give their permission to include their psychosocial screening tool in this study. Inclusion rate 71.7 %.

4.1.2 Data collection and variables

The *Psychosocial survivorship screening tool* consists of the distress thermometer used as a tool to measure general distress. The distress thermometer is scaled 0-10, where 0 is “no distress” and 10 is considered as “high distress”. Patients are asked to scale their distress considering the past week (20). Furthermore, the Screening Tool contains questions divided into 11 subgroups (physical, emotional, social, concentration, fertility, impact of experience, family, lifestyle, survivorship, employment, education) (Appendix 1). It is in total designed to clinically detect and address possible psychosocial and physical concerns stemming from childhood cancer treatment. A level of general distress of four or more is considered as moderate to severe distress (30, 31). The distress thermometer has not been widely validated as a tool to detect general distress among young individuals, 15-25 years old, even though some studies have addressed it (16, 30). In the Netherlands, distress thermometer is validated and used among both adolescent and adult childhood cancer survivors as a screening tool, as an easy way to detect patients who experience high general distress and are in need of further psychological support (32).

Prior to the data collection a letter was sent to all patients at LTFU who had visited the clinic between November 2012-December 2019. The letter contained a description regarding the study and gave the participants the option to withdraw their consent. Data was collected from medical records and the Psychosocial survivorship screening tool. Clinical characteristics including age when diagnosed, diagnosis, gender, year since last given oncological treatment, surgery, chemotherapy, stem cell transplantation (SCT), radiation, and age at follow up were collected from medical records as well as sociodemographic data including occupation, children, highest level of education and marital status. All data extracted from the medical

journals and the psychosocial screening tool were collected, decoded and manually entered into SPSS version 27 by the author.

4.1.3 Statistical methods

Median, range and interquartile range were used to describe the distribution in the population. Frequency and percentage were used to describe subgroups of childhood cancer diagnosis, self-reported areas of concern and treatment modalities. Chi-square test was used to compare groups. Kruskal-Wallis was used to compare results of more than two subgroups and in statistically significant results a pairwise comparison was performed, and the results were adjusted for Bonferroni correction. The level of significance was set to <0.05 . General distress was described as a mean and standard deviation. To facilitate data analysis, general distress was dichotomized into low distress (0-3) and moderate/high distress (4-10). Occupation was dichotomized into unemployed/sick leave and employed/students. Subgroups of the variables age at follow-up, age at diagnose and diagnosis were formed as follows: age at diagnose (0-5 y, 6-12 y and 13-18 y), age at follow-up (18-24 y, 25-30 y and >30 y) and diagnosis (leukemia, lymphoma, CNS-tumors and other). The groups and interval ranges chosen, were done so to facilitate as well as process large data. Caution was naturally taken to prevent losing crucial insights and/or data discrimination. SPSS version 27 was used for all analyses of the data. Excel version 16.49 was used to create figures and tables.

4.2 Method Interview study

4.2.1 Population

In total, 60 individuals were offered an interview, 15 individuals consented to participate. Of these eight (age 20-36 y) had received a STCP and seven (age 36-52 y) had not. The patients were divided in two groups based on whether they had received a STCP that summarized their visit (LTFU visits November 2019 – October 2020) or not (LTFU visits June 2019 – September 2019). Inclusion criteria; Childhood cancer diagnoses before the age of 18 y, > 18 years old at study and more than five years since last oncology treatment. Exclusion criteria: patients with communication barriers or could not communicate in Swedish.

4.2.2 Data collection and variables

Prior to conducting interviews, a letter was sent to patients at LTFU both containing a description of the study and a request of participation. For participants who gave their consent, the letter was followed-up with a phone call. The collected data was based on individual interviews conducted via ZOOM and/or telephone by the author, of patients who visited LTFU between 2019 – 2020, using strategic sampling. The interview was based on predefined interview questions (Table 1) and lasted approximately 30 minutes.

Table 1. Interview guide

How was the appointment at LTFU*?
What was good about the appointment at LTFU?
What areas could improve regarding the appointment at LTFU
Did someone accompany you to the appointment at LTFU?
What were the discuss topics at the meeting at LTFU?
Can you recall what was discussed and the plan going forward?
How did you experience have a group discussion with the medical team at LTFU?
Have you received the Survival Passport?

*LTFU = Long Term Follow-up clinic

4.2.3 Method analysis

The interviews were transcribed and analyzed according to Elo and Kyngäs qualitative content analysis (33). The text of each interview was repeatedly reviewed to confirm the accuracy of the content, and to ensure that the data met the requirements of prescribed analytical methods. The author and one of the supervisors reviewed the material separately and discussed the result until consensus was reached (33). The analysis continued until the descriptions of the categories and subcategories were close to the contents of the text (33). An overall theme was constructed that decipher the essence of the interviews (34). Excel version 16.49 was used to create tables.

5. Ethics

Interviews, psychosocial screening tool and data extracted from medical journals hold delicate information. All procedures performed in studies involving human participants followed the regional ethics review board's ethical standards in Gothenburg (D 686-10) and with the 1964 Helsinki declaration and its later amendments informed, consent was obtained from all individual participants included in the study. Before entering data from the psychosocial screening tool and medical journals into SPSS, it was de-identified. The interviews were decoded prior to transcription to ensure confidentiality. Only accredited personnel could access the study material. The outcome from the psychosocial screening tool, medical journals and the interviews aim to facilitate rehabilitation care succeeding childhood cancer at LTFU, for currently enrolled and future patients. Both the psychosocial screening tool and interviews may give rise to anxiety linked to previous treatment, present health situation and future treatment. Counseling would have been offered if/or needed at LTFU. The data

connected to the psychosocial screening tool will be used in a future scientific article.

Participants were informed that they may, at any time, for any reason end their enrollment in the study without affecting their future care at LTFU. The study was approved by the Ethical Committee (EPN), Dnr 161-15. To add results from patients who visited LTFU from 2015-2019 a supplemental ethical application was submitted, which was approved, Dnr 2021-00548. No application for ethical approval was performed for the interview study since this was a part of the LTFUs organizational development evaluation.

6. Results cohort study

The study population consisted of 322 childhood cancer survivors. Of these 157 (48.8 %) were men and 165 (51.2 %) were women. The median age at diagnosis was 8 years (Range 0-17, IQR 3-13), median time since last given treatment was 19 years (Range 1-47, IQR 13-24) and the median age at follow-up was 27 years (Range 18-52, IQR 23.75-33).

In the study population (54.3 %) were either living alone or with parents and (44.7 %) were married or living with a partner. The majority (57.2 %) did not have children. Among the study population it was most common to be either a college graduate (56.5 %) or having a university degree (32.3 %). The majority were employed (64.6 %) or students (17 %) at the time of the follow-up visit at LTFU. Furthermore, (6.5 %) were on sick leave, (4.3 %) were on permanent sick leave and (6.8 %) were unemployed. Sociodemographic data timepoints, gender, marital status, children, highest level of education and occupation (Table 2).

Table 2. Sociodemographic

Characteristics	Median (Range) (IQR)*	N=322 n (%)
Time points		
Age when diagnosed	8 y (0-17) (3-13)	
Age at follow up	27 y (18-52) (23.75-33)	
Year since last given treatment	19 y (1-43) (13-24)	
Gender		
Men		157 (48.8)
Woman		165 (51.2)
Marital status		
Living alone/with parents		175 (54.3)
Living with partner/married		144 (44.7)
Children		
Yes		79 (24.5)
No		242 (75.2)
Highest level of education		
Elementary**		32 (9.9)
College***		182 (56.5)
University ****		104 (32.3)
Occupation		
Employed		208 (64.6)
Student		55 (17.0)
Unemployed		22 (6.8)
Sick leave*****		21 (6.5)
Permanent sick leave*****		14 (4.3)

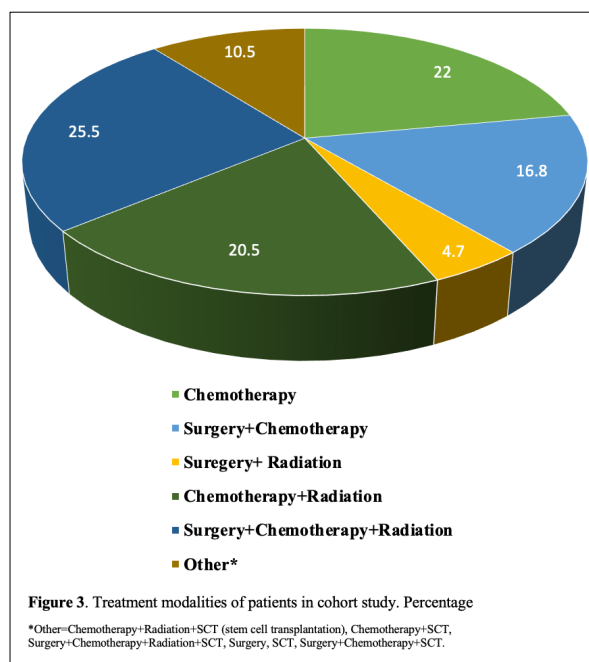
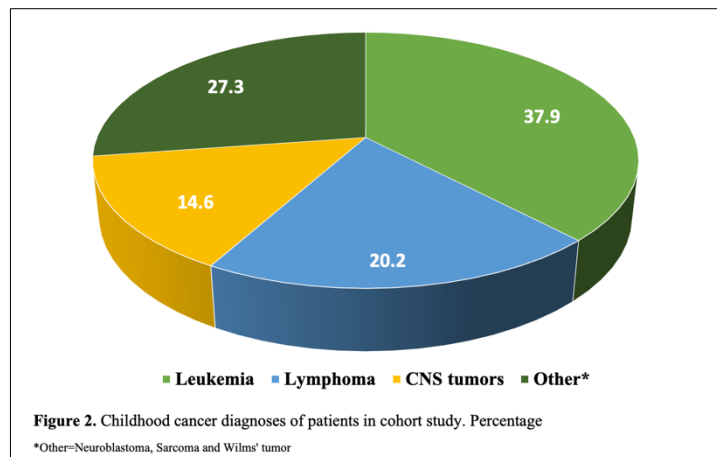
*IQR, interquartile range. Numbers may not reach column totals due to missing values.

Elementary school= Grade 1-9 according with Swedish standards. *Collage=Grade 10-12 according with Swedish standards plus vocational education and training plus folk high school. **** University= Completed studies on university level. ***** Sick leave is defined according to Swedish standards. All levels (25, 50, 75 %) of sick leave were included *****Permanent sick leave defined as never returning to employment.

6.1 Clinical characteristics

The childhood cancer diagnoses were divided into four subgroups namely leukemia, lymphoma, CNS-tumors, and other. Of these, leukemia was the most common diagnosis (37.9 %) (Figure 2).

Four treatment modalities (Surgery, chemotherapy, SCT and radiation) had been used either alone or in different combinations, during the childhood cancer treatment in the study population. The most common treatment was a combination of surgery, chemotherapy, and radiation (25.5 %) followed by the monotherapy chemotherapy (22 %). (Figure 3).



6.2. General Distress and Moderate to severe distress

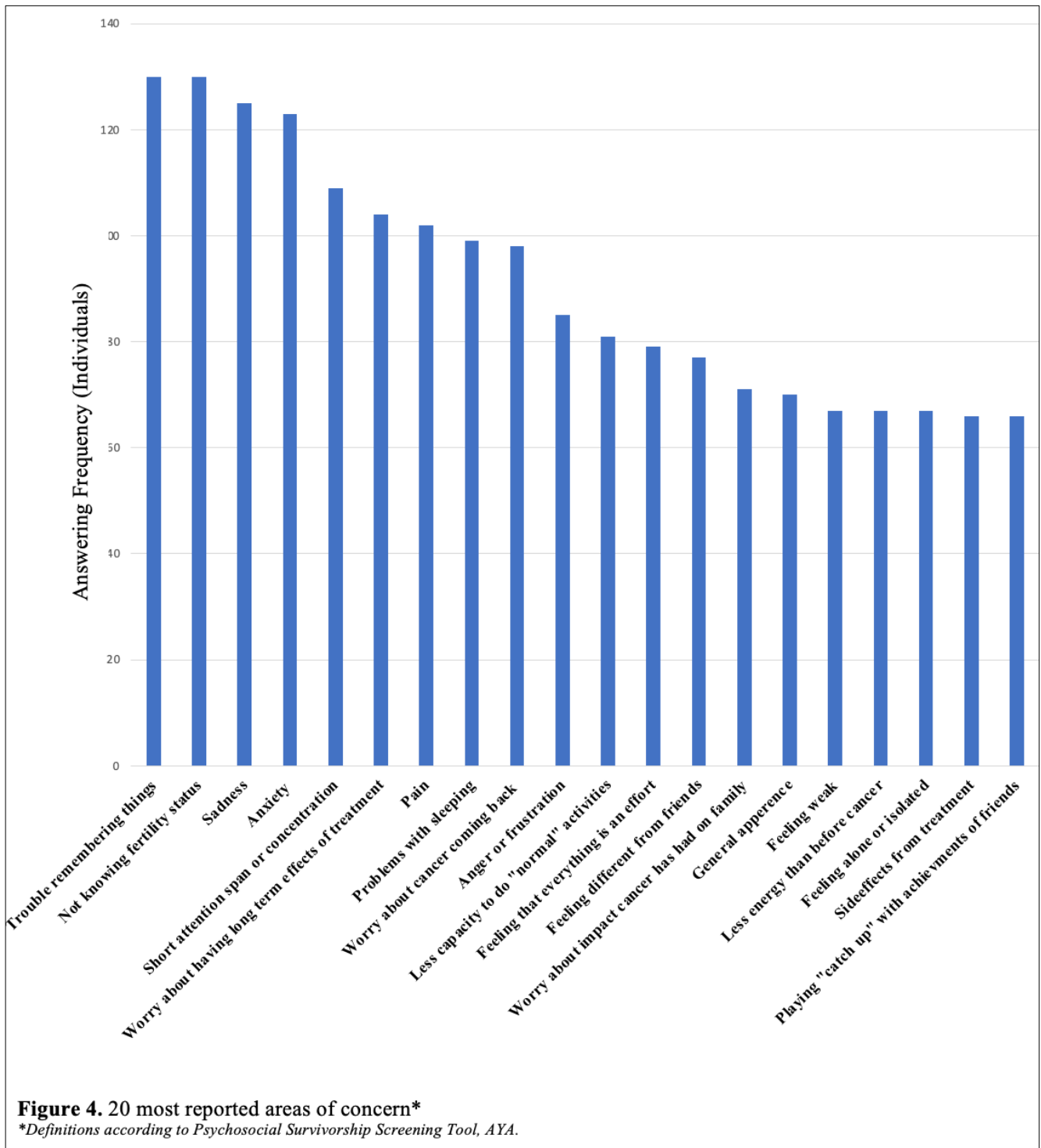
The mean general distress was 2.48 (SD 2.57). Forty-two patients did not complete the distress thermometer. The majority had low or no general distress. Moderate to severe general distress was experienced by 22 % of the participants. Of these, women consistently had the highest prevalence of moderate to severe distress (61 %) compared to men (38 %). ($\chi^2(1) = 4.82, p < 0.028$).

In a Kruskal-Wallis analysis of the prevalence of reported moderate to severe distress among the different age groups at follow-up including pairwise analysis, participants in the age group 18-24 y at follow-up reported moderate to severe distress more often than the age group 25-30 y (30.2 % vs 12.5 %) ($H(2) = 10.78, p = 0.018$). The prevalence was also significantly higher in the age group >30 y at follow-up compared to the age group 25-30 y (24.6 % vs 12.5 %) ($H(2) = 10.78, p = 0.011$).

The proportion of participants who had moderate to severe distress was higher in the unemployed/individuals on sick leave group than the group who worked or studied (33.3 % vs 19.8 %) ($\chi^2(2) = 7.51, p < 0.023$). There were no significant differences in prevalence of moderate to severe distress, between age groups at diagnose or the different diagnosis groups.

6.3. Main areas of Concern

The top ten main areas of concern, in falling order were, Trouble remembering things, Not knowing fertility status, Sadness, Anxiety, Short attention span or concentration, Worry about having long-term effects of treatment, Pain, Problems with sleeping, Worry about cancer coming back and Anger or frustration. The twenty most common areas of concern are presented below (Figure 4).



Results from analyzes of association between the top ten areas of concern and gender, occupation and the treatment modality CNS radiation presented. (Table 3).

Table 3. 10 most reported areas of concern in association with gender, occupation, and CNS radiation

Areas of concern*	Gender		p-value	Occupation		p-value	CNS radiation***		p-value
	Men	Women		Student/employed	Unemployed/sick leave**		Yes	No	
Trouble remembering things	62 (39.5)	68 (41.2)	ns	92 (35.0)	37 (64.9)	0.000	50 (53.8)	80 (35.1)	0.006
Not knowing fertility status	58 (36.9)	72 (43.9)	ns	110 (41.8)	19 (33.3)	ns	40 (43)	89 (39)	ns
Sadness	50 (31.8)	75 (45.7)	0.011	96 (36.6)	28 (49.1)	ns	41 (44.6)	83 (36.4)	ns
Anxiety	43 (27.4)	80 (48.8)	0.000	89 (33.8)	33 (57.9)	0.001	32 (34.4)	90 (39.5)	ns
Short attention span or concentration	52 (31.1)	57 (34.8)	ns	72 (27.4)	36 (63.2)	0.000	44 (47.3)	65 (28.5)	0.004
Worry about having long term effects of treatment	42 (26.8)	62 (37.6)	0.038	82 (31.2)	21 (36.8)	ns	23 (24.7)	81 (35.5)	ns
Pain	40 (25.5)	62 (37.6)	0.020	72 (27.4)	29 (50.9)	0.001	37 (39.8)	65 (28.5)	ns
Problems with sleeping	42 (26.8)	57 (34.8)	ns	62 (23.6)	36 (63.2)	0.000	29 (31.2)	70 (30.7)	ns
Worry about cancer coming back	33 (21.0)	65 (39.4)	0.000	80 (30.4)	16 (28.1)	ns	20 (21.5)	78 (31.2)	ns
Anger or frustration	32 (20.5)	53 (32.3)	0.017	55 (20.9)	29 (50.9)	0.000	30 (32.3)	55 (24.1)	ns

*Psychosocial Survivorship Screening Tool, AYA. ** Sickleave is defined according to Swedish standards. All levels (25, 50, 75 % were included. Permanent sick leave defined as never returning to employment.
 *** CNS radiation including both cranial and full body radiation. Analyzed with Chi-square test.

6.3.1. Not knowing fertility status

Not knowing fertility status was reported by 40.4 %, and along with *Trouble remembering things*, the most prevalent patient reported areas of concern. When comparing not knowing fertility status with different age groups at follow-up, participants in the age groups at follow-up 25-30 y reported not knowing fertility status more frequently than the age group >30 y (42.9 %, vs 25.4 %) ($H(2) = 19.565$, $p = 0.023$). The prevalence was also significantly higher in the age groups at follow-up 18-24 y compared to the age group >30 y (55.2%, vs 25.4 %) ($H(2) = 19.565$, $p = 0.000$). No significant differences were found in not knowing fertility status between genders, treatment modality CNS radiation or not, occupation, age groups at diagnose, and diagnosis groups.

6.3.2. *Trouble remembering things & Short attention span or concentration*

Trouble remembering things was reported by 40.4 % of the participants. Individuals who received the treatment modality CNS radiation reported trouble remembering things more frequently than those who did not receive CNS radiation (53.8 % vs 35.1 %) ($\chi^2(2) = 10.25$, $p < 0.006$). Similarly unemployed/individuals on sick leave also reported trouble remembering things more frequently than employed/students (64.9 % vs 35 %) ($\chi^2(1) = 17.44$, $p < 0.000$). In a Kruskal-Wallis analysis of the prevalence of reported trouble remembering things among the different diagnosis groups including pairwise analysis, participants in the CNS group reported trouble remembering things significantly more frequently than participants from the lymphoma group (57.4 % vs 24.6 %) ($H(3) = 15.83$, $p = 0.003$). The prevalence was also significantly higher in the leukemia group compared to the lymphoma group (46.7 % vs 24.6 %) ($H(3) = 15.83$, $p = 0.020$) No significant differences were found among different age groups at diagnosis, different age groups at follow-up or genders.

Short attention span or concentration was reported by 33.9 % of the participants.

When comparing short attention span or concentration with diagnosis groups, participants in the CNS group reported short attention span or concentration more frequently than participants in the lymphoma group (53.2 % vs 23.1 %) ($H(4) = 12.018$, $p = 0.005$) and other (53.2 % vs 29.5 %) ($H(4) = 12.018$, $p = 0.035$).

Short attention span or concentration was more prevalent among those who received the treatment modality CNS radiation compared to those who had not (47.3 % vs 28.5 %) ($\chi^2(2) = 10.943$, $p < 0.004$). Unemployed/individuals on sick leave reported short attention span or concentration more frequently than employed/students (63.2 % vs 27.4 %) ($\chi^2(1) = 26.825$, p

< 0.000). No significant differences were found among different age groups at diagnosis, age groups at follow-up and genders.

6.3.3. *Sadness, Anxiety & Anger or frustration*

Sadness was reported by 38.8 % of the participants. Women experienced sadness more frequently (45.7 %) than men (31.8 %) ($\chi^2(1) = 6.504, p < 0.011$) When comparing sadness in different age groups at diagnose participants in the age group 6-12 y experienced sadness more prevalent than 13-18 y (48.6 % vs 33 %) ($H(2) = 6.366, p = 0.024$) and 0-5 y (48.6 % vs 35 %) ($H(2) = 6.366, p = 0.036$). When comparing sadness in different age groups at follow-up, participants in the age group 18-24 y experienced sadness more frequently than 25-30 y (49.5 % vs 33.9 %) ($H(2) = 6.308, p = 0.022$), and >30 y (49.5 % vs 35.1 %) ($H(2) = 6.308, p = 0.034$). There was a significant difference in the number of patients indicating sadness between age groups at follow-up, but this did not remain significant in a pairwise comparison. No significant differences were found among different diagnosis groups, occupation and the treatment modality CNS radiation or not.

Anxiety was reported by 38.2 % of the participants. Women experienced anxiety more frequently (48.8 %) than men (27.4 %) ($\chi^2(1) = 15.167, p < 0.000$). Unemployed/individuals on sick leave experienced anxiety more prevalent compared to employed/students (57.9 % vs 33.8 %) ($\chi^2(1) = 11.491, p < 0.001$). No significant differences were found among treatment modality CNS radiation or not, different age groups at diagnose, diagnosis groups and age groups at follow-up.

Anger or frustration was reported by 26.4 % of the participants. Women experienced anger or frustration more frequently (32.3 %) than men (20.5 %) ($\chi^2(1) = 5.706, p < 0.017$).

Unemployed/individuals on sick leave experienced anger or frustration more frequently than employed/students (50.9 % vs 20.9 %) ($\chi^2(1) = 21.727$, $p < 0.000$). When comparing anger or frustration in different diagnosis groups, participants in the CNS group reported anger or frustration significantly more frequent than participants in the lymphoma group (42.6 % vs 16.9 %) ($H(3) = 12.234$, $p = 0.015$) and leukemia (42.6 % vs 21.3 %) ($H(3) = 12.234$, $p = 0.030$). There were no significant differences between different diagnosis groups, age groups at diagnose, age groups at follow-up or CNS radiation vs no CNS radiation.

6.3.4. Pain & Problems with sleeping

Pain was reported by 31.7 % of the participants. Women experienced pain more prevalent (37.6 %) compared to men (25.5 %) ($\chi^2(1) = 5.441$, $p < 0.020$). Unemployed/individuals on sick leave experienced pain more prevalent than employed/students (50.9 % vs 27.4 %) ($\chi^2(1) = 11.978$, $p < 0.001$).

When comparing pain between different age groups at follow-up, participants in the age group 18-24 y reported pain more prevalent than 25-30 y (37.5 % vs 19.6 %) ($H(2) = 11.485$, $p = 0.018$). The prevalence was also significantly higher in the age groups >30 y at follow-up compared to 25-30 y (38.6 % vs 19.6 %) ($H(2) = 11.485$, $p = 0.007$).

No statistical significances were found among different age groups at diagnose, diagnosis groups nor the treatment modality CNS radiation or not.

Problems with sleeping was reported by 30.7 % of the participants. Unemployed/individuals on sick leave reported problems with sleeping more prevalent than employed/students (63.2 % vs 23.6 %) ($\chi^2(1) = 34.549$, $p < 0.000$). When comparing problems with sleeping in different age groups at follow-up, participants in the age group 18-24 y reported problems

with sleeping more frequent than 25-30 y (42.7 % vs 24.1 %) ($H(2) = 9.417$, $p = 0.011$) and >30 y (42.7 % vs 27.2 %) ($H(2) = 9.417$, $p = 0.046$). No significant differences were found among genders, different age groups at diagnose, diagnosis groups and the treatment modality CNS radiation or not.

6.3.5. Worry about cancer coming back & Worry about having long-term effects of treatment

Worry about cancer coming back was reported by 30.4% of the participants. Women reported worry about cancer coming back more prevalent (39.4 %) than men (21 %) ($\chi^2(1) = 12.830$, $p < 0.000$). When comparing worry about cancer coming back in different age groups at diagnose, participants 13-18 y reported worry about cancer coming back more frequently than 0-5 y (43.6 % vs 23.1 %) ($H(2) = 11.282$, $p = 0.004$) and 6-12 y (43.6 % vs 27.1 %) ($H(2) = 11.282$, $p = 0.034$).

When comparing worry about cancer coming back in different diagnosis groups, participants in the lymphoma group reported worry about cancer coming back more frequently compared to the CNS group (44.6 % vs 17 %) ($H(3) = 11.415$, $p = 0.011$). No significant differences were found among different age groups at follow-up, the treatment modality CNS radiation or not and occupation.

Worry about having long-term effects of treatment was reported by 32.3 % of the participants. Women reported a worry about having long term effects of treatment more frequently (37.6 %) compared to men (26.8 %) ($\chi^2(1) = 4.311$, $p < 0.038$). Participants in the age group at diagnose 13-18 y reported worry about having long-term effects of treatment more prevalently than 0-5 y (41.5 % vs 23.1 %) ($H(2) = 8.500$, $p = 0.013$). No significances were

found among different age groups at follow-up, diagnosis groups, the treatment modality CNS radiation or not and occupation.

7. Results interview study

The results were summarized in four main categories, Security, Perceptiveness, Knowledge and Memory of plan and divided into subcategories as presented jointly, (Table 4). The study population consisted of 15 individuals, 73.3 % (n=11) males and 26.7 % (n=4) females. Seven received a care plan and eight did not. The median age at diagnose was 7, (Range 2-17) and the median age at interview was 34, (Range 20-52). The study population is presented as a group to prevent revealing identities of participants.

Table 4. *Categories and subcategories of interviews conducted at Long-term follow up clinic*

Categories	Subcategories
Security	Unguided care before visit Accessibility
Perceptiveness	Sense of acknowledgement
Knowledge	Increased knowledge Increased empowerment
Memory of plan	Received care plan No care plan

The overall theme of the interview study, health literacy, was chosen based on patients' described experiences of the visit at LTFU, that they expressed gaining increased knowledge about their medical history as well as risks of developing late complications stemming from childhood cancer treatment. With this knowledge patients expressed that the empowerment to advocate for their own health care also increased. The categories Security and Perceptiveness

are not included in the overall theme but were expressed as important by the participants and therefore added outside the theme.

7.1. Security

7.1.1. Unguided care before visit

Participants expressed feeling lonesome prior to their visit at LTFU. This feeling of lonesome was related to different aspects. When seeking health care for various needs throughout life, participants recalled feeling helpless, since the medical profession, apart from LTFU, did not possess the adequate knowledge related to their condition. They could not themselves advocate for relevant health care, as they felt uninformed both regarding what follow-up care was needed and their risks of developing late complications stemming from childhood cancer treatment. Citations include, *“I mean, I have lived alone for many years, more or less throughout my entire adult life, and felt very lonely. I always wanted to meet more survivors and doctors who understand. I have felt very lonely, in health centers and so on, no one has known that much about it.” (Female 52 years). “That there is someone who is following up on you basically. So that you are not just left on your own.” (Male 34 years).*

7.1.2. Accessibility

The sense of feeling secure was expressed among the participants, knowing that LTFU is easily accessible. They felt that they could make contact in any way, both in a short and long perspective, throughout life regarding any concern. Citations include, *“I thought it was good, you got like a document and it always feels safe to have a follow-up clinic supporting you, if you need something in the future, and so on.” (Male 20 years). “So, getting that response and knowing that I can always call them if anything comes up and that is enough for me.”*

(Female 52 years). "I mean, I think it's great. I think it's a luxury that it (the LTFU clinic) exists. You probably won't find so many other contexts where you get so much time with healthcare providers, or where it's even possible to get so much time. Or at least I haven't experienced that you have had the opportunity to sit down and talk to a doctor and a nurse and so on for about an hour or maybe more." (Female 36 years).

7.2. Perceptiveness

7.2.1. Sense of acknowledgement

Participants expressed the feeling of being seen as individuals and listened to, by the medical team at LTFU, who were open to any questions. They also voiced that the team was flexible when it came to topics to discuss according to the needs of the participants as well as genuinely interested in getting a greater understanding of their situation. Thereby being able to give individualized recommendations regarding follow up care. Citations include, *"They felt perceptive to what I wanted to talk about. They really opened up many subjects for discussion. If I had worries that needed calming or if I had wanted to discuss the risk of recurrence or possible side effects, there were all possibilities to do so. But if they noticed that there was something else, I was more interested in or curious about, they switched over to it." (Male 26 years). "... it really did not feel stressful, they took their time, and if I forgot to ask about something, it was almost like they asked me about it. I truly felt that it was a two-way communication." (Female 52 years).*

7.3. Knowledge

7.3.1. Increased knowledge

Participants expressed that they gained increased knowledge regarding their childhood cancer, both medical history including treatment and late complications. An overall review of their previous disease, gave a greater insight about their present health situation. A frequently conveyed opinion amongst the interviewees was how coming in contact with LTFU and the medical team the visit at the clinic with the medical team, gave increased comprehension, of their medical status. That the symptoms that they experience in everyday life were in some cases linked with the childhood cancer treatment. Citations include, *“Growing up there have been many question marks surrounding my illness and everything. I really feel that I have gained more clarity in my life overall after this.” (Male 24 years)*. *“In this way, you get it in black and white, what really happened, since you were so young at the time. And then, even though you have talked about it all your life, not in this way and not with healthcare professionals.” (Male 48 years)*.

7.3.2. Increased empowerment

Participants expressed, that the visit at LTFU increased their knowledge both regarding medical history, received treatment, late complications, and necessary follow-up care. With the new knowledge, they also accepted and understood the need for continuous medical surveillance, throughout life. These insights gave some of the participants empowerment to take responsibility over their own health, and courage to take a more active approach in seeking individualized follow-up care when needed. Citations include, *“...they possess a knowledge that no one else has, which is very important. I received a lot of information. They*

also helped me to be able to make demands myself.” (Female 39 years). “It has meant a lot to me to meet them. It made me a little tougher also when I visit the primary care, as it has kind of made me stronger.” (Female 52 years).

7.4. Memory of plan

Whether participants received a STCP or not, the term care plan was unknown among all participants.

However, when asking about the visit and the short-term plan, the interviewees gave different descriptions regarding both how they perceived the visit at LTFU as well as the short-term plan.

7.4.1. Short term written care plan, STCP

Participants that had received a STCP from the visit, mentioned e.g. time for next follow-up appointment at LTFU, which blood tests LTFU prescribed and/or when necessary physical examinations were due. Citations include, *“...It was crystal clear that I was going to be referred to many medical providers.” (Male 40 years). “There would be a follow-up visit in three or four years.” (Male 41 years).*

7.4.2. No short term written care plan, STCP

Participants who did not receive a STCP relied on their parents’ knowledge about their medical history and expressed that they could not recall details from the visit or the short-term plan themselves. Citations include, *“I had a difficulty to remember what was said. I have a pretty bad memory. Mom knows quite a lot more than I do, so if there was something, I might ask her maybe, or I do not really know.” (Male 20 years). “... I think we will book a new*

appointment, in about two to three years. I don't remember. No, I don't remember anything. I actually don't remember." (Male 36 years)

8. Discussion cohort study

The majority in the study population experienced no or low general distress. However, moderate to severe distress, was found in approximately one fourth of the study population, which is in line with previous research that argue that childhood cancer survivors experience higher general distress compared to the general population (20). Consistently women reported a higher degree of general distress compared to men, which is a common finding in previous studies (17, 21, 22).

During late childhood and adolescence there are significant physical, cognitive, and emotional natural processes and dramatic changes taking place. Individuals seek their identity and try to find their way through life, which is customarily equally true for the general population.

Considering this, it is important to reflect if general distress would differ in the general population when measured during the same life period. However, since emotional concerns, worry about illness (18, 19, 22, 35), physical symptoms of pain (36, 37), sleep disturbances (38) and cognitive concerns (20, 39) are by research shown to be common late complications post childhood cancer; this affirms that the areas of concern qualifies as result of prior childhood cancer treatment (3).

Trouble remembering things and *Short attention span or concentration* was most frequent as expected, among individuals that had received CNS radiation and individuals diagnosed with CNS tumors. This was to be expected since brain surgery, high intracranial pressure before surgery and CNS radiation is known to be associated with cognitive impairment (13, 14). In this study trouble remembering things and short attention span or concentration were also

associated with leukemia treatment which could be an effect of that a comparably high part of this group had received prophylactic CNS radiation, as well as treatment with Methotrexate which in earlier studies also has been associated with cognitive impairment (13, 14).

Furthermore, unemployment or sick leave might influence this parameter. However, this group was limited in size suggesting difficulty of drawing clear conclusions about this group.

Among 6-12 years at diagnose and 18-24 years at follow-up *Sadness* was most frequently reported. Receiving a cancer diagnosis at the age of 6-12 years affects the whole family, which naturally will affect the child. In addition, the cancer diagnosis might limit participation in activities both in and outside school as well as interaction with children of their own age. This might manifest in sadness among other emotions. In the age group 18-24 years at follow up sadness could be a consequence of not being able to fulfill previous hopes and dreams about present or future. It could also be a mere consequence of being reminded of the risks of previous diagnosis and treatment when receiving the invitation to LTFU.

Participants in the CNS tumor group reported most prevalent *anger or frustration* among the diagnosis groups. This might be explained by being a natural reaction on the overall health issues both physical and cognitive impairment after childhood CNS tumor and treatment (13, 14, 40). However, CNS tumor patients did not report sadness or anxiety more often than other diagnosis groups. This is in line with the findings that patients with CNS tumor often suffer from more physical/cognitive late complications, rather than being affected emotionally (40).

Expressing emotions can manifest themselves in many ways. Maybe a feeling of anger or frustration, in reality is caused by sadness, anxiety or worry about illness. Among 13-18 years at diagnose with lymphoma *worry about cancer coming back and worry about late effects* was most prevalent. This could be attributed to receiving the diagnosis and treatment during

adolescence, when the childhood cancer survivor as well as the general population in the same age group naturally may experience many worries and concerns. The survivors have these worries in addition to the worry about the impact the cancer diagnose has on their life. The age group 18-24 years, at follow-up and > 30 years had the most frequently reported prevalence of *pain*.

Cancer treatment in general might lead to long term complications such as pain (37). Since the experience of pain is individual and can be based on prior experiences in life, affected by emotions such as worry, sadness, anger or frustration, psychosocial aspects as well as physical phenomena (41) it is hard to distinguish the actual feeling of pain from a mix of other areas of concern. This is also true for unemployed/individuals on sick leave who experienced more prevalent pain. Experience pain might make it impossible to uphold a work position. On the other hand, not being engaged in work gives opportunities to concentrate more on the feeling of pain than the tasks at hand. Thus, makes it difficult to know what the cause and effect is, and how they are interlinked. Nevertheless, it is crucial to confirm the childhood cancer survivors experience of pain, irrelevant of it is physical, psychosocial or emotional. The age group 18-24 years as well as unemployed/individuals on sick leave had the most prevalence of sleep disturbances which does not have to be an effect of previous diagnosis and treatment but may also be explained by psychosocial and economical concerns.

All participants in the study were diagnosed as children and long time has passed between the patients' diagnosis and follow-up depending on age, and ultimately some of them may not have their childhood cancer diagnose and risks for developing late complications top-of-mind. A reminder of their passed illness through an invitation to LTFU, may have increased their

perception of possible experienced symptoms, as well as a worry about their present and future health and life situation, and consequently influence the results in the cohort study.

How the participants interpret the questions in the psychosocial screening tool may differ and consequently also influence the results. The terminology used to describe i.e. emotional areas of concern may differ between studies depending on how the emotional domains are defined, thus hindering or influencing comparisons between already conducted or future studies.

The majority in our study population included employees and/or students with higher degrees of education, which is in contrast with earlier research (17, 23). Since both the educational and health care systems are free of charge in Sweden compared to other countries, this may have influenced the possibility to be able to attain higher standards of care and continued post graduate education from strictly an economic standpoint. Thus, this may be one explanation for contrasts found compared to the previous studies and should be investigated in further research (17, 23). If studies are performed in different countries and cultures, the results can be challenging to interpret and compare with Swedish studies (16, 20, 30).

This study implies a lack of knowledge regarding not knowing fertility status, with focus on primarily the two younger age groups, which may be explained by them being in a phase of life when considering children. Research consistently shows that there is a lack of knowledge regarding fertility and a mismatch between actual and perceived fertility status (8, 42, 43).

Growing older leads to acquired knowledge of fertility status by possibly bearing children and/or acceptance of inability to conceive, and therefore switching worry with long-term acceptance of fertility status.

One question that remains unanswered is how the areas of concern may be interlinked and affect each other individually or as a group. As stated in the research questions, the most

common patient reported psychosocial, and health related symptoms and concerns were studied. Exploring how they can affect each other should be addressed in further research, as this might increase understanding and the quality of care, for both caretaker and care giver. This study mainly reflects participants experienced general distress and areas of concern during the last month prior to visiting LTFU. In the care plan, individual medical and psychosocial interventions are prescribed that targets the patients' areas of concern. However, the interventions have not been evaluated in this study, or over time. This gives the opportunity for future researchers to evaluate which medical and psychosocial interventions may be appropriate for individuals or groups of patients. Either a qualitative or quantitative research method can be used pending on if statistical or psychosocial aspects are of greater interest for the researcher.

Since 2019 children treated for cancer, aged 13, 17 and 18 are offered a medical consultation, as part of the transition care (24), where the risk-profile of developing late complications as well as the fertility question among others are addressed, to gradually increase the patient's knowledge and thus, possibly prevent future distress. An interesting aspect would be to investigate whether future adult childhood cancer patients still see the fertility question as a main concern, as well as mismatch between actual and perceived fertility status, using a comparative survey-based study with this cohort as a foundation.

8.1. Strengths and weaknesses

The data used in this study was collected from already existing medical journals and the psychosocial screening tool, thus, did not demand any additional work for the patients at LTFU. Using a psychosocial screening tool is an easy and time efficient way to assure that the patients' concerns will be considered during the clinical visit. The distress thermometer is a

validated tool for screening general distress among young childhood cancer survivors (30, 32). However, the main part of the psychosocial screening tool is not yet validated, but with the participation rate of 71.7 % the result is likely to be valid and clinically relevant. Further studies will need to be performed to confirm this data.

The participants in this study were instructed to answer the questions in the psychosocial screening tool considering their experience of cancer. Naturally, other life stressors may have influenced their way of interpreting and answering the questions. It would have been interesting to compare the results in this study with a control group, but this was not possible due to time limit, thus an opportunity for future research. The internal loss of 42 participants, who did not mark anything on the distress thermometer adds some uncertainty regarding the results and might be explained by several factors. This could be attributed to patients lack of response upon the distress thermometer, a lack of understanding or misconception of the term general distress, insufficient information on how to mark the distress thermometer correctly or participants not experiencing any general distress and thus simply neglecting the question. Of the 42 missing datapoints there was an even distribution considering gender, which makes it possible to overlook the missing datapoints and still rely on the conclusion of distress being more prevalent among women.

9. Discussion interview study

Participants expressed a feeling of security in this interview study, learning that the medical team at LTFU were competent, easily accessible, good listeners and able to give medical advice in an individualized way, which made the patients feel less lonesome. In line with our findings, the importance of having an open communication between cancer survivors, and the

health care workers is stressed. However, little is known about how to implement this into clinical practice in this group (44). Participants expressed that the initial knowledge about their medical history in this interview study was insufficient prior to visiting LTFU since information was mainly conveyed to their parents during the period of childhood cancer treatment. The significance of gradually transferring knowledge and understanding from parent to patient regarding medical history stemming from childhood cancer has been acknowledged in research (45, 46). Proper transition of care between pediatric and adult health care seems to be important since this creates a foundation for self-management and taking responsibility for ones' future health (24). Participants in this interview study expressed gaining increased knowledge of diagnosis, treatment, and an overall enhanced understanding of late complications. These insights, giving some of the participants the empowerment and motivation to take a more active role, when advocating for their own health care, according to their capacity and needs in future contact with healthcare, supported in previous research (46, 47).

Though not comprehending the term care plan, the participants who received the STCP, described the visit at LTFU as well as the short-term plan in a clearer way. They could recall when the next appointment at LTFU was scheduled as well as other decided medical altercations. The group that did not receive the STCP relied on their parents or guardian's knowledge about their medical history. They could not recall anything from the visit or decided short term plans. The results in this interview study may have been influenced by many different factors. The age differences in both groups, 26-52 years (received STCP), 20-36 years (did not receive STCP) though not being vast, might have influenced the result, especially since the term care plan was unknown for both groups, implying that an older age

group has an advantage in acquiring knowledge, previously addressed in research (46). The participants initial knowledge about their medical history and risks for developing late complications stemming from childhood cancer treatment, before the visit at LTFU is unknown and may vary vastly between the individuals. Since the initial knowledge is an unknown factor, it is uncertain if or how it affects the outcome. With initial knowledge, even if it is low, it is easier to acquire additional knowledge within the same field, compared to being unformed. This could suggest that the STCP, can act as an aid in recalling information even if not understanding the actual concept care plan. However, age, initial knowledge and current health status are among many factors that can affect the outcome. Thus, might be the actual reason for variations in the descriptions.

A visit at a medical clinic can be a stressful situation for anyone and make it difficult to understand and comprehend information. This is also true for childhood cancer survivors that may suffer from multiple issues such as emotional concerns (18, 19, 22, 35), physical symptoms in form of pain (36, 37), sleep disturbances (38) and cognitive concerns (20, 39) and thereby may affect how they comprehend previous medical history, and the importance of future medical surveillance. A vague knowledge is linked to not engaging in follow-up care (48). In addition, if suffering from many health issues, it may be a challenge to acquire new knowledge regarding risks of developing late complications, even though being properly conveyed by LTFU (45, 46).

Considering the overall theme health literacy, defined as: *"The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions"*(28), and the results from the interview study, this indicates that patients from the interview study, gained improved health literacy (49, 50).

Referring to the citations from the interviews, participants expressed that the visit at LTFU increased their knowledge, and thus empowered them to manage their own health and follow-up care. However, it is important to mention that even if the degree of health literacy increases for every patient, it varies individually. The more aggressive treatment received as a child, the more likely it is to develop severe late complications (51) and consequently need more guidance from LTFU.

All interviewees expressed a feeling of security both knowing that the LTFU clinic was easily accessible and that the medical team at LTFU possessed adequate knowledge regarding their medical condition as well as needed medical surveillance. In addition, they expressed being acknowledged by the medical team. Though not being included in the theme health literacy, one could argue that these factors might act as a foundation for the possibility of acquiring patients' increased health literacy. When feeling secure as well as acknowledged it is easier to take in and understand new information.

Furthermore, the results obtained may benefit the understanding of possibilities when interlinking increased health literacy and use of narrative medicine and person-centered care. Narrative medicine and person-centered care are closely correlated with the patient's narrative in focus. This makes it easier to interpret and understand information and read between the lines, as well as building trust between the medical professionals and the patient, leading to a mutual-beneficial meeting (52, 53).

To evaluate STCP, it may be of value to convert the interview study into a quantitative study, to see if there is a significant difference in remembrance between the group that received the STCP and the group that did not. Furthermore, since adult childhood cancer survivors with

cognitive deficits often suffer from memory issues (20, 39), studies that focus on a tool that may help to recall information more easily would be of great clinical value.

9.1. Strengths and weaknesses

The one-to-one interviews were conducted through ZOOM. The fact that the interviews took place online may have influenced the outcome, since it is more difficult to interact and create a platform based on trust, compared to an interview face to face. At the same time this can be an advantage, because the participants are not influenced by the interviewer in the same way as when meeting in person. They may be able to express themselves more freely as well as, perhaps feeling more at ease when sitting in a perceived safe environment of choice such as the patients home.

Having an interview-based study and performing a content analysis, provides a platform for understanding on a deeper level and make clarifications when needed. Creating categories and subcategories, using content analysis made it easier to understand which areas patients addressed most important and thus understand how they perceived their situation before and after the visit at LTFU. The study population was limited in size and dominated by the male gender. As a result, the study may predominately reflect what degree men recall information at LTFU and not represent both genders. In total, the study population of 15 individuals gives an indication of transferability within the group studied.

9.1.1. Delimitations

Though it would have been interesting to study similar long term follow up clinics in different countries and cultures with other sociodemographic and economical settings, it was perceived more beneficial to get at deeper understanding of the care given at LTFU in Gothenburg. This delimitation was chosen considering both time-based and economic factors. In addition, it may be fruitful to study if and in what way an improved transition care may affect cancer survivors' knowledge of current and future health related concerns. The term is included and presented in the background of this thesis as transition care may be of close proximity depending on patients age when enrolled at LTFU. Improving transition care can be an important foundation for increasing patients' knowledge prior to the first visit at LTFU.

10. Conclusions cohort and interview study

The top two concerns among the ten most reported in this study were trouble remembering things and not knowing fertility status. Other noticeable mental issues concerns were sadness, anxiety and anger or frustration. Therefore, information about medical issues together with handling of psychosocial concerns are of essential importance for Long-term follow up clinics. Since trouble remembering things and short attention span or concentration were shown to be frequent concerns in this patient cohort, tools to improve the communication of important information are valuable and should be further researched. The short term written care plan may aid in remembrance and could be an important tool that needs to be further investigated. The participants in the interview study expressed gaining more knowledge about their medical history and risks of developing late complications stemming from childhood cancer treatment. The Long- term follow up clinics' patient-centered care approach by

focusing on the individuals' medical history, psychosocial and/or medical concerns as well as necessary medical surveillance gives key advantage. They can give individualized follow-up recommendations, and simultaneously increase patient's knowledge of medical history and risks of developing late complications. Consequently, the patients gained increased health literacy and empowerment to advocate for their own health care according to their capacity and needs.

Considering the consistently increasing number of childhood cancer survivors, one cannot stress enough the importance of evolving the area of this field of research and thus aid in improving the care of current and future childhood cancer survivors.

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Populärvetenskaplig sammanfattning

Psykosociala, sociala och hälsorelaterade komplikationer och bekymmer efter sjukdom och behandling hos vuxna barncanceröverlevare

En långtidsstudie på Sahlgrenska Universitetssjukhuset, Göteborg

Tack vare medicinska framsteg är överlevnaden efter barncancer cirka 85 %, varav 70–80 % drabbas av sena komplikationer till följd av den tidigare sjukdomen och behandlingen.

Kunskap om både sin tidigare medicinska historia och risk för sena komplikationer och bekymmer hos vuxna barncanceröverlevare varierar stort inom gruppen.

Studien är uppdelad i två delar, en kvantitativ och en kvalitativ. I den kvantitativa delen sammanställdes uppgifter från medicinska journaler samt ett frågeformulär där 322 individer deltog. Den påvisar vanligaste förekommande behov och bekymmer hos vuxna barncanceröverlevare på Uppföljningsmottagningen för vuxna efter barncancer i Göteborg och undersöker om dessa har samband med genomgången cancer inklusive behandling som barn. I en kvalitativ intervjustudie med 15 deltagare får patienterna berätta om sina upplevelser av besöket på mottagningen. Av dessa 15 fick hälften en skriftlig kortsiktig vårdplan. Intervjuernas innehåll analyserades samtidigt som ett övergripande tema med huvud- respektive undergrupper skapades.

De vanligaste behoven och bekymren som framkom var minnesproblematik. En skriftlig vårdplan kan eventuellt underlätta för patienter att komma ihåg besöket på mottagningen samt vårdplanen kortsiktigt. Uppföljningsmottagningen för vuxna efter barncancer i Göteborg bidrar till att öka patienters medvetenhet om hälsa och sjukdom samt uppmuntrar och stärker

patienten att ta ansvar för sin hälsa efter individuell förmåga. Studien understryker vikten av en strukturerad uppföljning efter barncancer.

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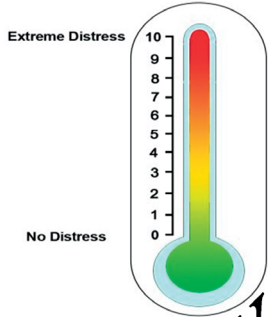
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Appendix 1

Psykosocial screening för vuxna som haft cancer före 18 års ålder

Uppföljningsmott. efter barncancer/Väst
 Namn: _____
 Datum för ifyllande: _____

190702



1. Distress allmänt

Ringa in den siffran (0-10) som bäst beskriver hur mycket distress (bekymmer) du upplevt den senaste veckan.

Här ska upplevelsen vara kopplad till din cancerdiagnos och/eller den cancerbehandling du fått.

! Specifika områden för bekymmer, svår eller anpassningsförmåga?

/är snäll och kryssa för de områden som har varit ett problem för dig under den senaste månaden (behöver inte vara direkt relaterat till din diagnos/cancerbehandling):

Fysiskt	Känslomässigt
<input type="checkbox"/> Allmänt västånd	<input type="checkbox"/> Nedstämd/ledsen
<input type="checkbox"/> Åtande eller aptit	<input type="checkbox"/> Känner mig ensam eller isolerad
<input type="checkbox"/> Förstoppning eller diarré	<input type="checkbox"/> Oro/ängest eller rädsla
<input type="checkbox"/> Sexuella bekymmer	<input type="checkbox"/> Uttråkad
<input type="checkbox"/> Smärta/värk	<input type="checkbox"/> Ilkska eller frustration
<input type="checkbox"/> Anpassning till ny funktionsnivå	<input type="checkbox"/> Extremt negativa känslor
<input type="checkbox"/> Mindre ork än före cancer	<input type="checkbox"/> Känns som allting kräver en ansträngning
<input type="checkbox"/> Lägre kapacitet för "normala" aktiviteter	<input type="checkbox"/> Känsla av hopplöshet eller hjälplöshet
<input type="checkbox"/> Oförmögen att träna som jag brukade	<input type="checkbox"/> Känsla av förvirring
<input type="checkbox"/> Känner mig svag	<input type="checkbox"/> Livet känns meningslöst
<input type="checkbox"/> Somnproblem	<input type="checkbox"/> Självmordstankar
<input type="checkbox"/> Biverkningar av behandlingen	

Page 1

Vad är dina mål för framtiden?

1. _____
 2. _____
 3. _____
 4. _____

Andra saker jag vill ta upp...

3. Var snäll och markera om du vill ha ytterligare information om något av följande:

<input type="checkbox"/> Din cancerdiagnos	<input type="checkbox"/> Långtidsuppföljning	<input type="checkbox"/> Tidig åtgärdsplanering
<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"/> Sagar till förbättra hälsa
<input type="checkbox"/> Stödgrupper	<input type="checkbox"/> Arftlig cancer	<input type="checkbox"/> Fritidssysselsättningar

4. Här nedan följer ett antal frågor som är mycket värdefulla för vårt fortsatta omhändertagande av dig och vår fortsatta verksamhet (skriv det du själv vet)

Vilken sjukdom har du fått cancerbehandling för före 18 års ålder:

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/SCT

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

Ja Nej

Om ja, vilket/vilka? _____

Page 3

Socialt	Livsstil
<input type="checkbox"/> Känner mig isolerad från vänner	<input type="checkbox"/> Röker cigaretter
<input type="checkbox"/> Vill/kan inte göra "normala saker" med mina vänner	<input type="checkbox"/> Dricker alkohol
<input type="checkbox"/> Mina vänner förstår mig inte	<input type="checkbox"/> Använder droger
<input type="checkbox"/> Känner mig annorlunda jämfört med mina vänner	<input type="checkbox"/> Har oskyddad sex
<input type="checkbox"/> Vill/kan inte träffa nya människor	<input type="checkbox"/> Har en ohälsosam livsstil
<input type="checkbox"/> Oro för flick-/pojkvän/partner	<input type="checkbox"/> Sköter inte bokade möten (bla vårdbesök)
<input type="checkbox"/> Kris i relationen med partner	<input type="checkbox"/> Gör andra saker som riskerar livet
	Survivorship/överlevnad
Koncentration	<input type="checkbox"/> Vill inte berätta för andra att jag haft cancer
<input type="checkbox"/> Kort uppmärksamhetsfokus eller koncentrationsförmåga	<input type="checkbox"/> Döljer "äkta" känslor
<input type="checkbox"/> Känsla av att leva i en bubbla	<input type="checkbox"/> Håller "skenet tätt" inför kompisar
<input type="checkbox"/> Problem att komma ihåg saker	<input type="checkbox"/> Upplever att jag gått miste om livet pga. cancer
<input type="checkbox"/> Tar längre tid att slutföra saker än tidigare	<input type="checkbox"/> Svårt att acceptera ändrade omständigheter pga. cancer
	Fertilitet/fortplantning
<input type="checkbox"/> Vet inte om jag kan få barn	<input type="checkbox"/> Oro för att vänner ska få cancer
<input type="checkbox"/> Känner inte till vilken hjälp som finns att få för att få barn	<input type="checkbox"/> Oro för att familjen har "cancer-gen"
<input type="checkbox"/> Oro för kostnader för fertilitetsbehandling	<input type="checkbox"/> Oro för sen-effekter pga. cancerbehandling
<input type="checkbox"/> Oro över att diskutera fertilitet med partner/framtida partner	<input type="checkbox"/> Oro för att cancer ska komma tillbaka
<input type="checkbox"/> Sorg över barnlöshet	<input type="checkbox"/> Orostankar om död och döende
	Arbetsmarknad
Konsekvenser av min cancer-behandling	<input type="checkbox"/> Att få ett jobb
<input type="checkbox"/> Avsaknad av tryck framåt	<input type="checkbox"/> Återgång i arbetet
<input type="checkbox"/> Identitets förändring	<input type="checkbox"/> Stöd från arbetsgivare
<input type="checkbox"/> Förlust av livsmotiv för livet	<input type="checkbox"/> Diskriminering på arbetet
<input type="checkbox"/> Förlust av ekonomisk självständighet	
<input type="checkbox"/> Sorg över andra patienters död	Utbildning
<input type="checkbox"/> Skuld över andra patienters död ("överlevnads-skuld")	<input type="checkbox"/> Återgång till utbildning
<input type="checkbox"/> Känner ansvar för att leva meningsfullt liv	<input type="checkbox"/> Komma ikapp med studier
	<input type="checkbox"/> Funderingar kring vilka rättigheter/skyldigheter som finns
Familjen	
<input type="checkbox"/> Upplever att familjen inte förstår	
<input type="checkbox"/> Brist på stöd från familjen	
<input type="checkbox"/> Känner ansvar för att "skydda" familjen från sanningen	
<input type="checkbox"/> Behov av mer hjälp/stöd än familjen kan ge	
<input type="checkbox"/> Oro för vilken påverkan canceren haft på familjen	
<input type="checkbox"/> Oro för familjemedlemmar	

Page 2

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 intresse: _____

Jag godkänner att ovanstående information får användas av mitt team på Uppföljningsmottagningen för mitt fortsatta omhändertagande samt även med avidentifierade uppgifter för forskning

Underskrift/patient: _____ Datum: _____

Page 4

Appendix 2

Psykosocial vårdplan för vuxna som haft cancer före 18 års ålder

Uppföljningsmott. för vuxna efter barncancer
Namn:
Personnummer:
Datum för ifyllande:

Din e-post:
Telefon:

Bekymmer/besvär (hoppa över de områden som inte är aktuella)	Planering (Vad ska göras, vem gör vad, uppföljning)	Referens (Namn, adress, uppgifter, datum)
Fysiskt		
Känslomässigt		
Koncentration		
Fertilitet/fortplantning		

Page 1

Familjen		
Socialt		
Livsstil		
Arbetsmarknad/utbildning		
Återbesök/Återkoppling		

Sammanfattning av behandling skickas till:
--

Psykosocial vårdplan har tagits fram gemensamt av följande personer:	
Underskrift/patient:	Datum:
Underskrift/mottagningen:	Datum:

Page 2

Personnr: 2000-01-01-0000
Namn: nn nn

Personnr: 2000-01-01-0000
Namn: nn nn

Sammanställning av din cancerbehandling med uppföljningsrekommendationer

Denna sammanställning av din tidigare cancerbehandling är baserad på uppgifter i Svenska Barncancerregistret och är utarbetad av Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB).

Sammanställningen fungerar som ett så kallat "Survivorship Passport". Meningen med ett sådant är att din behandling sammanfattas på ett överskådligt sätt. I dokumentet finns också uppgifter om ditt hälsotillstånd vid den tidpunkt du fick sammanställningen samt vilka uppföljande kontroller som rekommenderas. Dessa rekommendationer kan komma att ändras i framtiden när vi fått ytterligare kunskap om eventuella bieffekter av just din behandling som du fått.

Sammanställningen syftar förstås till att ge dig utförlig och skriftlig information om hur din behandling sett ut och kan vara bra att ha med om du söker sjukvård i framtiden. Om du tappar bort dokumentet, kan du kontakta Svenska Barncancerregistret (se www.ceg.ki.se för aktuella kontaktuppgifter) för att få ett nytt.

Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

Sida 1 av 8

Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

Sida 2 av 8

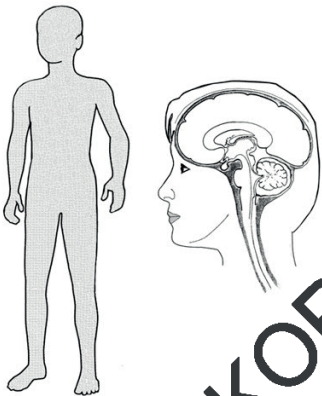
Page 1

Page 2

Personnr: 2000-01-01-0000
Namn: nn nn

Personnr: 2000-01-01-0000
Namn: nn nn

Lokal(er) se fig.



Behandling 1

Protokoll	
Start:	Slut:
Cytostatikabehandling Ja <input type="checkbox"/> Nej <input checked="" type="checkbox"/>	
Annan läkemedelsbehandling Ja <input type="checkbox"/> Nej <input checked="" type="checkbox"/>	
Kirurgi Ja <input type="checkbox"/> Nej <input checked="" type="checkbox"/>	
Strålbehandling Ja <input type="checkbox"/> Nej <input checked="" type="checkbox"/>	
Stamcellsbehandling Ja <input type="checkbox"/> Nej <input checked="" type="checkbox"/>	

Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

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Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

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Page 3

Page 4

Personnr: 2000-01-01-0000
 Namn: rin rin

Kumulativa doser

Cytostatika	Totaldos	Enhet
-------------	----------	-------

Personnr: 2000-01-01-0000
 Namn: rin rin

Komplikationer/Uppföljning

Aktuella uppgifter

Rekommenderad uppföljning

1. Psykosocialt
2. Tillväxt
3. Metabol funktion
4. Pubertet/könshormon
5. Sköldkörtel
6. Fertilitet

Fertilitetsbevarande åtgärd:
 Ingen uppgift

7. Hjärta
8. Blodtryck
9. Lungor
10. Fysisk prestationsförmåga
11. Njurar
12. Urinblåsa
13. Mag/tarm
14. Lever
15. Nervsystem
16. Hörsel
17. Syn
18. Neuropsykologisk funktion

Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

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Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

Page 6

Sida 6 av 8

Personnr: 2000-01-01-0000
 Namn: rin rin

19. Skelett/mjukdelar

20. Mun/svalg/tänder

21. Bröst

22. Hud

23. Blodbild

24. Immunitet

25. Sekundär malignitet

26. Övrigt

Personnr: 2000-01-01-0000
 Namn: rin rin

Remitterad till:

Datum: Ort:

Läkare: Telefon:

Att tänka på:

Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

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Svenska Arbetsgruppen för Långtidsuppföljning efter Barncancer (SALUB)

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