



## Research

# Longitudinal needs and cancer knowledge in Swiss childhood cancer survivors transitioning from pediatric to adult follow-up care: results from the ACCS project

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## Abstract

**Purpose** Childhood Cancer Survivors (CCSs) have an increased risk for treatment-related chronic health conditions, but the adherence to long-term follow-up (LTFU) care decreases over time. We therefore assessed the CCSs' development of cancer knowledge, cancer worries, self-management skills, and expectations for LTFU care in a structured, cancer center-based transition model—a crucial part for maintaining adherence.

**Methods** Using questionnaire-based surveys, we compared the CCSs' cancer knowledge with medical record data and assessed cancer worries (6 questions), self-management skills (15 questions), and expectations (12 questions) longitudinally by validated scales. We used descriptive statistics for presenting our results.

**Results** We analyzed 17 CCSs, 71% were female, had a median age of 8 years at diagnosis and 21 years at study enrollment. The knowledge about late effects increased during the transition process, except for the risk of secondary malignancies. Leukemia survivors had a decrease in cancer worries. At least 75% of the CCSs agreed to 11 of 15 self-management questions before and after transition, with the highest increase over time in less parental involvement. The CCSs expected the most, that physicians know the CCSs' cancer history, that the visit starts on time, and that physicians can always be called in case of questions.

**Conclusions** Our transition model improved cancer knowledge, especially the risk for late effects, decreased cancer worries, and identified expectations for LTFU care which should be considered in the future. A structured transition process with evidence-based tools further increases the knowledge of CCS for LTFU through empowerment.

**Keywords** Childhood cancer survivors · Adolescents · Transition · Needs · Knowledge · Worries

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Maria Otth and Katrin Scheinemann shared last authorship.

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## 1 Introduction

The number of childhood cancer survivors (CCSs) is growing since the 5-year survival rate of children diagnosed with cancer has increased to more than 80% in high-income countries over the last decades [1–3]. However, almost all CCSs will experience at least one chronic medical condition of various severity by the age of 45 or 50 [4, 5]. At least 80% of CCSs will experience a serious, disabling, or life-threatening chronic health condition by the age of 50 years, which is significantly higher compared to community controls [4, 5]. The risk to develop late effects increases as CCSs get older [6, 7]. Even though, a lifelong risk-based follow-up care is recommended in different guidelines [8–11], the adherence of CCSs to long-term follow-up (LTFU) care steadily decreases over time [12]. Especially the change from child-centered to adult-focused LTFU care—so called “transition”—is crucial for maintaining a high adherence to LTFU care [13, 14]. The transition mainly concerns adolescents and young adults as they often have to change their place of care due to restrictions in the healthcare system (e.g., young adults not everywhere allowed to be treated in the pediatric setting).

Since the CCS population is very heterogenous, not only in terms of cancer type, treatment, and risk for late effects, but also in terms of genetic factors and potential cancer predispositions, health behaviors, and socioeconomic factors, an individualized and risk-based approach for each CCS is crucial. Despite the different models for delivering LTFU care and transition, there is a consensus for the overall positive effect of survivorship care beyond childhood [15–19]. This includes for example the early detection of asymptomatic and treatable late effects through screening. The different models can roughly be divided into 3 groups: cancer center-based model, community-based model, and hybrid or shared model, each one with its advantages and disadvantages [20]. The International Guideline Harmonization Group recommends a risk-adapted LTFU care under the guidance of a cancer survivorship expert or cancer center throughout the CCSs’ lifespan, based on a joint decision between the CCS and physicians/health care providers [21]. A coordinated transition process, knowing the adult setting before actual transfer, CCSs’ self-management skills, knowledge, and a good communication between CCSs, parents, and health care providers are key facilitators for a successful transition [22]. On the other hand, CCSs’ lack of knowledge about cancer history, risk of late effects, and importance of LTFU care, but also health care providers’ lack about the importance and structure of LTFU care are key barriers for a successful transition [22]. Therefore, the transition process should be well planned and organized, individually adapted to the CCSs’ knowledge, and start at an early stage in the pediatric setting. Transition tools have been developed to detect worries, lack of self-management skills, or knowledge gaps concerning diagnosis, therapy, or late effects [23]. These tools have been used in few studies so far from Canada, Japan and Switzerland. However, they were used in a cross-sectional approach only, but not longitudinally [24–26].

In Switzerland, children and adolescents diagnosed with cancer are treated in nine dedicated pediatric oncology centers ([www.spog.ch](http://www.spog.ch)). Today, the CCSs’ age at transition and the model of transition differ between the centers. Some centers take care of the CCSs even in adulthood. Cancer center-based models are being built up in most centers, but community-based models and shared-care models are less often used.

In this study we aim to assess the longitudinal development of CCSs’ cancer knowledge, worries, self-management skills, and expectations regarding LTFU care during a structured transition process from pediatric- to adult-focused care. This information helps to identify potential gaps or themes relevant for CCSs during the transition process. By addressing such themes in the clinical context and care, the transition process will be optimized. This should finally result in better educated CCSs and a reduction in loss to long-term follow-up care following transition to adult care.

## 2 Methods

We report results from the Aftercare of Childhood Cancer Survivors (ACCS) in Switzerland study, a prospective, multicenter observational study divided into a cross-sectional and a longitudinal part [27]. The ACCS study aims to evaluate different transition models of Swiss CCSs, including the longitudinal assessment of cancer knowledge, worries, self-management skills, and expectations for LTFU care. In this study we analyzed the longitudinal data of CCSs transitioned in one hospital from the pediatric to the adult setting in a structured process [27]. The study is registered at ClinicalTrials.gov (NCT04284189), and ethics approval was issued by the cantonal ethics committee Ethikkommission Nordwest- und Zentralschweiz (EKNZ) in February 2019, in accordance with the declaration of Helsinki. Informed

consent was obtained from all individual participants included in the study. According to the Human Research Act, the consent of legal representatives is not required for a research project involving adolescents capable of judgement that involves only minimal risks, including questionnaire-based studies. As this is a questionnaire-based study and the participants were aged 16 years or older, no parental consent was required.

CCSs were eligible if at least 5 years have passed since treatment completion, if their diagnosis is covered by the International Childhood Cancer Classification, third edition (ICCC3), if they were aged < 18 years at cancer diagnosis, and if they were 16 years of age or older at time of enrollment. For the longitudinal part of the ACCS study, the CCSs had to be ready to transition from pediatric- to adult-focused LTFU care [27]. All CCSs eligible for the longitudinal part were recruited during a regular follow-up care visit. We excluded CCSs treated with surgery only, those still on treatment at recruitment or in a palliative situation, and those unable to complete the questionnaire due to cognitive disabilities or language barriers. CCSs treated with surgery only (e.g., mature teratoma, carcinoid of the appendix) were excluded, because they are often followed-up for a limited period only and are not at risk for late effects as per guidelines [27].

CCSs who participated in the longitudinal part received three questionnaires at three different time points. The baseline questionnaire was sent to the CCSs before their next visit at the pediatric LTFU clinic. Three months after the visit in the pediatric setting the CCSs received the first follow-up questionnaire. CCS who actually transitioned to adult LTFU care received a second follow-up questionnaire 15 months after the initial visit, corresponding to 3 months after the first visit in adult setting, since most CCSs have an interval of 1 year between follow-up visits.

The baseline questionnaire consists of five parts: general information; cancer knowledge, including risk for late effects; cancer worry scale (CWS); self-management skills scale (SMSS); and expectation scale. The baseline questionnaire further provides information on CCSs' current age, sex, highest completed or ongoing education, and the subjective evaluation of the current health status. We used validated scales to assess cancer worry, self-management skills, and expectations for ongoing care [23, 27, 28]. We officially translated the CWS and SMSS into German and the applicability was proved in a feasibility study [29]. The first follow-up questionnaire asks about cancer knowledge only. The second follow-up questionnaire is identical to the baseline questionnaire, with one additional question about the current follow-up situation. For electronic recording of the paper-based questionnaires, we used the software Remark Office OMR (Gravic, Inc). For data processing we used the statistical software Stata (StataCorp LLC). For medical data collection, the local investigator completes for each included CCS the questions regarding diagnosis, tumor location, patient's age at diagnosis, and relapse. Furthermore, the treating pediatric oncologist defines each individual CCSs' organs at risks for late effects based on the treatment received and according to the COG LTFU guidelines V5.0 [8, 11]. This information from the pediatric oncologists is needed to validate the CCSs knowledge about their cancer diagnosis/ treatment and the organ systems at risk for late effects.

The CWS consists of six questions, asking how much CCSs worry about their cancer history, relapse, late effects, fertility impairment, and secondary malignancy [23]. The SMSS covers topics about CCSs' independence and personal responsibility with 15 questions [23]. The 12 questions of the expectation scale covers different expectations CCSs could have regarding the medical team, organizational aspects of LTFU care, and structural processes in the clinics [23]. The answer options of all three scales included a Likert scale with the options "strongly disagree," "disagree," "agree," and "strongly agree". Only for the CWS, a scoring system and conversion table is provided by Klassen et al., ranging from 0 to 100, where high numbers indicate less cancer worries [23]. For the remaining scales, we combined the answer options "strongly disagree" and "disagree" as well as "agree" and "strongly agree". To assess the development of cancer knowledge, cancer worries, self-management skills, and expectations over time, we compare the answers from the baseline and second follow-up questionnaire. We use descriptive statistics to present the results. By comparing the physicians' answers for the topics on fertility and second malignancy with the respective answers from the CWS, we explore, if CCSs have inappropriate worries about these late effects. Four combinations are possible: at risk and worried, not at risk and worried, at risk and not worried, and not at risk and not worried. CCSs not at risk but worried are considered having inappropriate worries. There were no corresponding answers from the doctors for the remaining four topics of the CWS, so that inappropriate worries could not be analyzed for them.

### 3 Results

We contacted 79 CCSs, of whom 40 completed the baseline questionnaire. All non-responder belonged to the cross-sectional cohort. Twenty-one CCSs were eligible for the longitudinal part, and 17 were included in the final analysis. Three CCSs did not return the second follow-up questionnaire and one was excluded due to polytoxicomania with

many related medical conditions (Supplemental Figure S1). Most CCSs were female (71%), with a median age of 8 years (IQR 4–12) at diagnosis and 21 years (IQR 18–25) at baseline questionnaire. Leukemia or lymphoma were the most frequent diagnosed (41%). The median score of the subjective health status was 8.5 (IQR 7–9) at baseline and 9 (IQR 7–10) 15 months later (Table 1).

Regarding cancer knowledge, most CCSs stated to recall their type of cancer (88%), the cancer location (94%), and their age at diagnosis (100%) at baseline. Fifteen months later, all CCSs stated to know these three aspects (Fig. 1A). The proportion of CCSs being sure about how often follow up visits take place decreased from baseline (88%) to 15 months (76%). Contrary, the proportion of CCSs who stated to know some or all potential late effects increased from 35 to 82% (Fig. 1A). Most CCSs recalled the treatments they received correctly when comparing it to the physicians' answers (Fig. 1A).

Regarding the potential risk for the nine late effects surveyed, 35–53% of CCSs reported being unsure at baseline. This proportion decreased for all organ systems except for secondary malignancies, where it remained at 53% (Fig. 1B, Supplemental Table S1). The largest decrease in CCSs being unsure was found for fertility. At baseline and after 15 months CCSs were least unsure about the risk of audiological late effects. The largest increase in knowledge could be shown for late effects of the heart, ear, eyes and bones with an approximation of the physicians' values. The physicians rated the risk for secondary malignancies (94%), fertility (88%), and bone health (71%) as endangered most frequently. At 15 months the CCSs rather underestimate their risk for late effects, especially for secondary malignancies, fertility, and memory deficits (Supplemental Table S1). Assigning the CCSs' answers "not sure" to "yes" results in an alignment with the physicians' assessment for heart, audiological and visual function, bone health, fertility, and memory function at baseline (Supplemental Figure S1A). Assigning the survivors' answers "not sure" to "no", resulted in an alignment with the physicians' assessments for pulmonary and endocrine function (Supplemental Figure S1B). After transition, the combination of "not sure" and "yes" resulted in an alignment for bone health, fertility, and memory function, and the combination of "not sure" and "no" for pulmonary, audiological, and endocrine function (Supplemental Figure S1C and D).

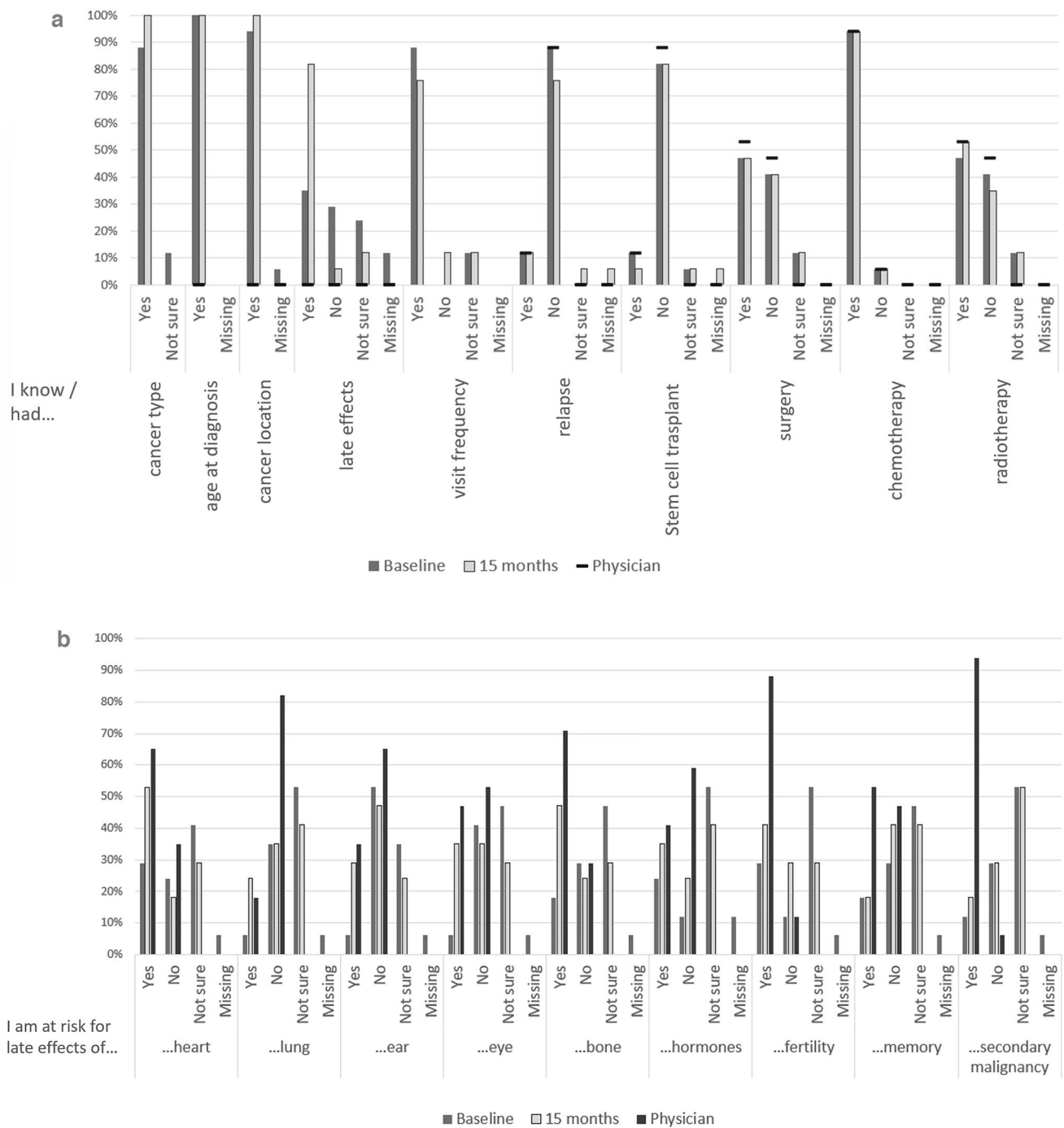
**Table 1** Characteristics of participants (n = 17)

	Baseline	15 months	Difference
Sex, female	12 (71%)		
Age at diagnosis [years] (physician reported) Median (IQR), range	8 (4–12) range: 3–16		
Age at baseline questionnaire [years] Median (IQR), range	21 (18–25) range: 17–28		
Type of cancer (physician reported)			
- Leukemia and lymphoma	7 (41%)		
- CNS	3 (18%)		
- Other <sup>‡</sup>	7 (41%)		
Current health status* Median (IQR), range	8.5 (7–9) range: 6–10	9 (7–10) range: 6–10	5%
Cancer worry scale <sup>°</sup> Median (IQR), range	62 (51–66) range: 34–100	62 (47–82) range: 24–100	0%
Highest education completed			
- obligatory school	6 (35%)	2 (12%)	– 23%
- secondary school	9 (53%)	12 (70%)	17%
- tertiary school	1 (6%)	2 (12%)	6%
- missing	1 (6%)	1 (6%)	0%
Cancer Worry Scale (Strongly agree/agree)			
- I worry about fertility	53%	47%	– 6%
- I worry about late effects	41%	41%	0%
- Cancer is always in the back of my mind	47%	53%	6%
- I worry about new cancer	29%	24%	– 5%
- I worry about relapse	24%	24%	0%
- I worry about cancer every day	0%	6%	6%

\*Current health status: higher numbers indicate better perceived health

<sup>°</sup>Cancer worry scale: high numbers indicate less cancer worries

<sup>‡</sup> Other cancer types: Ewing Sarcoma (n = 3), Germ Cell Tumor (n = 3), thyroid carcinoma (n = 1), aggressive fibromatosis (n = 1), Osteosarcoma (n = 1), Nephroblastoma (n = 1)



**Fig. 1** Results on cancer knowledge. **A** Congruence on treatment exposure mentioned by childhood cancer survivors and physicians. **B** Congruence on organ systems considered at risk by childhood cancer survivors and physicians

Regarding cancer worries, CCSs showed moderate worries with a median CWS score of 62, which was identical at baseline and after transition, but the interquartile range (IQR) widened (Table 1). At both time points, the survivors worried the most about fertility, having cancer always in their mind, and late effects. The change in worries over time was different in leukemia survivors compared to survivors of other cancers. While leukemia survivors had an incline in the median CWS-Score of 17 (56.5 at baseline, 73.5 at 15 months), the survivors of other cancers had a decline of 4 (62 at baseline, 58 at 15 months) (Supplemental Table S2). Regarding fertility, one person showed inappropriate worries about the risk of late effects at baseline only. In contrast, many CCSs are at risk for fertility impairment and secondary malignancies but didn't report worries (Supplemental Table S3).

**Table 2** Results from the Self-Management Skills Scale (n=17)

		Baseline n (%)	15 months n (%)	Difference %	
Q1	I answer a doctor or nurse's questions	(Strongly) agree	15 (88)	16 (94)	6%
		(Strongly) disagree	0	1 (6)	6%
		Missing	2 (12)	0	- 12%
Q2	I participate in making decisions about my health	(Strongly) agree	16 (94)	17 (100)	6%
		(Strongly) disagree	0	0	0%
		Missing	1 (6)	0	- 6%
Q3	I make sure I go to all my doctor's appointments	(Strongly) agree	17 (100)	16 (94)	- 6%
		(Strongly) disagree	0	1 (6)	6%
		Missing	0	0	0%
Q4	I ask the doctor or nurse questions	(Strongly) agree	15 (88)	15 (88)	0%
		(Strongly) disagree	2 (12)	2 (12)	0%
		Missing	0	0	0%
Q5	I talk to a doctor or nurse when I have health concerns	(Strongly) agree	10 (59)	11 (65)	6%
		(Strongly) disagree	7 (41)	6 (35)	- 6%
		Missing	0	0	0%
Q6	I talk about my medical conditions to people when I need to	(Strongly) agree	13 (76)	12 (71)	- 5%
		(Strongly) disagree	4 (24)	5 (29)	5%
		Missing	0	0	0%
Q7	I am in charge of taking any medicine that I need	(Strongly) agree	14 (82)	14 (82)	0%
		(Strongly) disagree	1 (6)	1 (6)	0%
		Missing	2 (12)	2 (12)	0%
Q8	I know how to contact a doctor if I need to	(Strongly) agree	16 (94)	17 (100)	6%
		(Strongly) disagree	1 (6)	0	- 6%
		Missing	0	0	0%
Q9	I prefer it when a doctor speaks to me instead of my parent(s)	(Strongly) agree	9 (53)	12 (71)	18%
		(Strongly) disagree	8 (47)	5 (29)	- 18%
		Missing	0	0	0%
Q10	I can briefly describe my medical history when asked	(Strongly) agree	16 (94)	17 (100)	6%
		(Strongly) disagree	1 (6)	0	- 6%
		Missing	0	0	0%
Q11	I prefer to see a doctor or nurse without any parent(s) with me	(Strongly) agree	9 (53)	12 (71)	18%
		(Strongly) disagree	8 (47)	4 (24)	- 23%
		Missing	0	1 (6)	6%
Q12	I know how to access medical care when I travel	(Strongly) agree	14 (82)	14 (82)	0%
		(Strongly) disagree	1 (6)	2 (12)	6%
		Missing	2 (12)	1 (6)	- 6%
Q13	I book my own doctor's appointments	(Strongly) agree	12 (71)	14 (82)	11%
		(Strongly) disagree	5 (29)	3 (18)	- 11%
		Missing	0	0	0%
Q14	I know the type of medical insurance I have	(Strongly) agree	16 (94)	17 (100)	6%
		(Strongly) disagree	0	0	0%
		Missing	1 (6)	0	- 6%
Q15	I fill my own prescriptions when I need medicine	(Strongly) agree	13 (76)	15 (88)	12%
		(Strongly) disagree	3 (18)	2 (12)	- 6%
		Missing	1 (6)	0	- 6%

At baseline, CSSs (strongly) agreed to 5 of the 15 SMSS statements with at least 90%, and with 75% to 90% to 6 additional statements. The situation was very similar after transition (Table 2). CCSs seem very independent by being able to describe their medical history, participating in decision making, or knowing how to contact the physician if needed. The statements with the largest increase in agreement over time were when physicians talk and see CCSs alone and not



together with the parents. On the other hand, between 25 and 30% of CCSs rather disagree to talk to physicians or other people in case of health concerns, which did not change a lot over time (Table 2).

Regarding expectations, CCSs rate physicians' knowledge about the CCSs' history and timely start of the visit highest at both time points. That examinations take place the same day as the visit and that physicians take care of all medical problems were rated relevant at baseline only. The CCSs expect least, that the physician team spends a lot of time with them (Table 3).

**Table 3** Results from the expectation scale (n=17)

When leaving the children's hospital I expect that...		Baseline n (%)	15 months n (%)	Difference %	
S1	... My after care physician knows my cancer history	(Strongly) agree	17 (100)	17 (100)	0%
		(Strongly) disagree	0	0	0%
		Missing	0	0	0%
S2	... The visit starts on time	(Strongly) agree	16 (94)	17 (100)	6%
		(Strongly) disagree	1 (6)	0	- 6%
		Missing	0	0	0%
S3	... I get a call when I miss an appointment	(Strongly) agree	12 (71)	12 (71)	0%
		(Strongly) disagree	5 (29)	5 (29)	0%
		Missing	0	0	0%
S4	... I am always seen by the same physician	(Strongly) agree	11 (65)	12 (71)	6%
		(Strongly) disagree	6 (35)	5 (29)	- 6%
		Missing	0	0	0%
S5	... I get a reminder before each visit	(Strongly) agree	9 (53)	12 (71)	18%
		(Strongly) disagree	8 (47)	5 (29)	- 18%
		Missing	0	0	0%
S6	... I can always call my physician in case of questions	(Strongly) agree	12 (71)	16 (94)	23%
		(Strongly) disagree	5 (29)	1 (6)	- 23%
		Missing	0	0	0%
S7	... Other examinations for follow-up care take place on the same day	(Strongly) agree	14 (82)	12 (71)	- 11%
		(Strongly) disagree	3 (18)	5 (29)	11%
		Missing	0	0	0%
S8	... My parents can come to the visit	(Strongly) agree	9 (53)	8 (47)	- 6%
		(Strongly) disagree	8 (47)	8 (47)	0%
		Missing	0	1 (6)	6%
S9	... Thy physician takes care of all my medical problems	(Strongly) agree	13 (76)	10 (59)	- 17%
		(Strongly) disagree	4 (24)	6 (35)	11%
		Missing	0	1 (6)	6%
S10	... My follow-up care physician becomes like a friend	(Strongly) agree	4 (24)	5 (29)	6%
		(Strongly) disagree	12 (71)	12 (71)	0%
		Missing	1 (6)	0	- 6%
S11	... My follow-up care physician team spends a lot of time with me	(Strongly) agree	3 (18)	0	- 18%
		(Strongly) disagree	13 (76)	17 (100)	24%
		Missing	1 (6)	0	- 6%
S12	... I like going to my follow-up appointments	(Strongly) agree	9 (53)	8 (47)	- 6%
		(Strongly) disagree	6 (35)	9 (53)	18%
		Missing	2 (12)	0	- 12%

## 4 Discussion

The CCSs' knowledge about cancer type and treatment is on a high level at baseline and stays that high after transition. This high level of knowledge confirms our prepared and jointly implemented transition process. With all CCSs of our cohort indicating that they recall their type and location of cancer after transition, their knowledge is slightly higher compared to Canadian and American CCSs, and a previous Swiss cohort of the ACCS study [16, 26, 30]. One reason for the better knowledge compared to the previous ACCS study, could be the structured transition process. Our data show a considerable increase in knowledge for late effects of the heart, ear, eyes, and bones with an approximation of the physicians' values. These data highlight the importance of continuous education of CCSs, that can be achieved through regular LTFU visits. It is especially important to keep the awareness for late effects in adolescents and young adults high, since not all suffer from late effects so far, but are at a high risk for developing them in the future [6, 7]. As they become independent from their parents, adolescents and young adults need to have the knowledge themselves. However, we could show that some organ systems are still underestimated by CCS after 15 months, i.e. fertility, memory, and secondary malignancy, or that CCSs are not sure about their risk. Here CCSs they need to be more and better educated about in a targeted way. The decrease in the alignment between CCSs' combined answers "yes" and "not sure" with the physicians' answer "yes" indicates an increase in cancer knowledge over time.

With a median CWS-Score of 62 at baseline and at 15 months, our cohort shows moderate cancer worries compared to two Canadian cohorts (mean CWS-Score 50.6 and 57.8) [24, 31]. Since two preceding Swiss studies showed similar scores (median 60 and 62), the lower worries in Swiss CCSs are reproducible [26, 29]. Our descriptive comparison shows, that leukemia survivors have lower cancer worries compared to other cancers. A potential explanation might be that survivors of solid tumors are more frequently reminded about their disease due to scars or musculoskeletal impairments [32].

Self-management skills improved over the study period. After transition, the self-management skills were equally high to the other Swiss cohorts [26, 29], but slightly lower than the skills of the Canadian cohort [24]. The lowest agreement at baseline (53%) is seen for the statement about seeing and talking to the physician alone, indicating the preference of parental involvement in Swiss CCSs in the pediatric setting. However, after 15 months the agreement increased in both statements with more CCSs who want to see the physicians alone, which is comparable to both other Swiss cohorts [26, 29]. These data highlight the need to not only educate but also empower CCSs to become independent. Most Swiss CCSs have very good knowledge about access to medical care when travelling, booking the doctor's appointment, knowing their type of medical insurance, and filling their own prescriptions. The strength of Swiss CCSs in skills required in the administrative field was already seen in the two other Swiss cohorts [26, 29].

The CCSs in our cohort show high expectations regarding the physicians' knowledge about the CCSs' history and that the appointment starts on time. The importance of physicians' knowledge about the CCSs' history is a key factor for establishing a reliable relationship between survivor and physician. This could be shown in previous publications [22, 33]. All expectations raised by the CCSs can be fulfilled in a cancer-center based or shared care LTFU care model, especially regarding the physicians' specific knowledge about late effects and survivorship. In addition, specific examinations (e.g., echocardiogram) and referrals to other specialists (e.g., cardio-oncology, endocrinology) familiar with the care of CCSs is easier when everything is at the same place.

Although CCSs going through our transition process show relatively low cancer worries, and high levels of cancer knowledge and self-management skills, further improvements to the process can be made. The proportion of CCSs who like to go to the follow-up visits decreased over time. Eventually, the structure and atmosphere in the adult setting does not completely fulfill the CCSs expectations. High satisfaction with LTFU visits is crucial to maintain adherence to LTFU care [22, 34]. It is therefore essential to implement a patient-centered service, where CCSs feel understood and comfortable. This might also motivate CCSs to talk about medical conditions or health concerns, what they don't often do according to our results (e.g., personal barriers like worries, community-made barriers like stigmata). For improvement in self-esteem and awareness for somatic and psychosocial late effects, and to give CCSs a feeling of belonging, group seminars could be an option beside the individual LTFU visit [35]. Besides somatic late effects and screening, mental health problems should be screened in regular intervals too [36]. Also socioeconomic development should be assessed, since the presence of late effects can have an impact on education, working situation, and respective satisfaction [37].

Limitations of this study include that only half of the respondents could be included in the longitudinal analysis, which might cause participation bias and result in findings not representative for all Swiss CCSs. We don't know whether CCSs with less late effects or better knowledge participated in this longitudinal part, or those with more late effects and less knowledge, or if these aspects are balanced. However, the CCSs' characteristics are comparable with other cohorts of



CCSs where transition and engagement in follow-up care are assessed. Due to the rather small sample size the weight of each individual answer is rather large, and statistical analysis stratified by cancer type or time since diagnosis were impossible and resulted in descriptive analysis only. The ACCS study was conducted during the Corona pandemic and not all CCSs wanted to attain LTFU care visits at the hospital because they were afraid to catch the virus in the hospital. This might also explain the low response rate. The long follow-up period of median 21 years (IQR 1–25) is a strength of this study. Under this aspect, the participation rate of 50% in the longitudinal part over 15 months and with repeated questionnaire is high.

## 5 Conclusion

The transition in our cancer center-based model resulted in improvement in cancer knowledge and especially the risk for late effects, a decrease in cancer worries in leukemia survivors, and in the identification of expectations for LTFU care. The impact of other transition models used in Switzerland on CCSs' cancer knowledge, worries, expectations, and self-management skills is currently unknown. Some of the tools used can be implemented in clinical practice to identify topics and knowledge gaps to be addressed during the LTFU care visit.

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**Code availability** Not applicable.

## Declarations

**Competing interests** The authors declare no competing interests.

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## References

1. Schindler M, Belle FN, Grotzer MA, von der Weid NX, Kuehni CE. Swiss paediatric oncology G. Childhood cancer survival in Switzerland (1976–2013): time-trends and predictors. *Int J Cancer*. 2017;140(1):62–74. <https://doi.org/10.1002/ijc.30434>.
2. Gatta G, Botta L, Rossi S, Aareleid T, Bielska-Lasota M, Clavel J, et al. Childhood cancer survival in Europe 1999–2007: results of EURO CARE-5—a population-based study. *Lancet Oncol*. 2014;15(1):35–47. [https://doi.org/10.1016/S1470-2045\(13\)70548-5](https://doi.org/10.1016/S1470-2045(13)70548-5).
3. Cancer Research UK. Children's cancer statistics. 2024. <https://www.cancerresearchuk.org/health-professional/cancer-statistics/childrens-cancers#heading=Two>. Accessed 15 Feb 2024.
4. Bhakta N, Liu Q, Ness KK, Baassiri M, Eissa H, Yeo F, et al. The cumulative burden of surviving childhood cancer: an initial report from the St Jude Lifetime Cohort Study (SJLIFE). *Lancet*. 2017. [https://doi.org/10.1016/S0140-6736\(17\)31610-0](https://doi.org/10.1016/S0140-6736(17)31610-0).
5. Hudson MM, Ness KK, Gurney JG, Mulrooney DA, Chemaitilly W, Krull KR, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA*. 2013;309(22):2371–81. <https://doi.org/10.1001/jama.2013.6296>.
6. Armstrong GT, Kawashima T, Leisenring W, Stratton K, Stovall M, Hudson MM, et al. Aging and risk of severe, disabling, life-threatening, and fatal events in the childhood cancer survivor study. *J Clin Oncol*. 2014;32(12):1218–27. <https://doi.org/10.1200/jco.2013.51.1055>.
7. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355(15):1572–82. <https://doi.org/10.1056/NEJMsa060185>.
8. Children's Oncology Group [COG]. Long Term Follow-Up guidelines. 2013. <http://www.survivorshipguidelines.org>.

9. Skion Later Studie—SKION LATER Study. <https://www.skionlaterstudie.nl/english/43:skion-later-study/>. Accessed 26.12.2021.
10. International Guideline Harmonization Group for Late Effects of Childhood Cancer. <http://www.ighg.org/>. Accessed 04 Jan 2019.
11. [COG] CsOG. Long Term Follow-Up guidelines Version 5.0. 2018. [http://www.survivorshipguidelines.org/pdf/2018/COG\\_LTFU\\_Guidelines\\_v5.pdf](http://www.survivorshipguidelines.org/pdf/2018/COG_LTFU_Guidelines_v5.pdf). Accessed 14 Jul 2021.
12. Rokitka DA, Curtin C, Heffler JE, Zevon MA, Attwood K, Mahoney MC. Patterns of loss to follow-up care among childhood cancer survivors. *J Adolesc Young Adult Oncol*. 2017;6(1):67–73. <https://doi.org/10.1089/jayao.2016.0023>.
13. Reppucci ML, Schleien CL, Fish JD. Looking for trouble: adherence to late-effects surveillance among childhood cancer survivors. *Pediatr Blood Cancer*. 2017;64(2):353–7. <https://doi.org/10.1002/psc.26205>.
14. Daly A, Lewis RW, Vangile K, Masker KW, Effinger KE, Meacham LR, et al. Survivor clinic attendance among pediatric- and adolescent-aged survivors of childhood cancer. *J Cancer Surviv Res Pract*. 2019;13(1):56–65. <https://doi.org/10.1007/s11764-018-0727-3>.
15. Dixon SB, Bjornard KL, Alberts NM, Armstrong GT, Brinkman TM, Chemaitilly W, et al. Factors influencing risk-based care of the childhood cancer survivor in the 21st century. *CA Cancer J Clin*. 2018. <https://doi.org/10.3322/caac.21445>.
16. Lindell RB, Koh SJ, Alvarez JM, Koyama T, Esbenschade AJ, Simmons JH, et al. Knowledge of diagnosis, treatment history, and risk of late effects among childhood cancer survivors and parents: the impact of a survivorship clinic. *Pediatr Blood Cancer*. 2015;62(8):1444–51. <https://doi.org/10.1002/psc.25509>.
17. Oeffinger KC, McCabe MS. Models for delivering survivorship care. *J Clin Oncol*. 2006;24(32):5117–24. <https://doi.org/10.1200/jco.2006.07.0474>.
18. Eshelman-Kent D, Kinahan KE, Hobbie W, Landier W, Teal S, Friedman D, et al. Cancer survivorship practices, services, and delivery: a report from the children's oncology group (COG) nursing discipline, adolescent/young adult, and late effects committees. *J Cancer Surviv Res Pract*. 2011;5(4):345–57. <https://doi.org/10.1007/s11764-011-0192-8>.
19. Friedman DL, Freyer DR, Levitt GA. Models of care for survivors of childhood cancer. *Pediatr Blood Cancer*. 2006;46(2):159–68. <https://doi.org/10.1002/psc.20611>.
20. Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *J Clin Oncol*. 2010;28(32):4810–8. <https://doi.org/10.1200/jco.2009.23.4278>.
21. Michel G, Mulder RL, van der Pal HJH, Skinner R, Bárdi E, Brown MC, et al. Evidence-based recommendations for the organization of long-term follow-up care for childhood and adolescent cancer survivors: a report from the PanCareSurFup guidelines working group. *J Cancer Surviv Res Pract*. 2019;13(5):759–72. <https://doi.org/10.1007/s11764-019-00795-5>.
22. Otth M, Denzler S, Koenig C, Koehler H, Scheinemann K. Transition from pediatric to adult follow-up care in childhood cancer survivors—a systematic review. *J Cancer Surviv Res Pract*. 2020. <https://doi.org/10.1007/s11764-020-00920-9>.
23. Klassen AF, Rosenberg-Yunger ZR, D'Agostino NM, Cano SJ, Barr R, Syed I, et al. The development of scales to measure childhood cancer survivors' readiness for transition to long-term follow-up care as adults. *Health Expect*. 2015;18(6):1941–55. <https://doi.org/10.1111/hex.12241>.
24. Kam V, Hendershot E, Anderson L, Marjerrison S. Evaluation of a joint adult and pediatric clinic for cancer survivorship care. *Pediatr Blood Cancer*. 2017. <https://doi.org/10.1002/psc.26476>.
25. Ishida Y, Tezuka M, Hayashi M, Inoue F. Japanese childhood cancer survivors' readiness for care as adults: a cross-sectional survey using the transition scales. *Psychooncology*. 2017;26(7):1019–26. <https://doi.org/10.1002/pon.4276>.
26. Otth M, Denzler S, Diesch-Furlanetto T, Scheinemann K. Cancer knowledge and health-consciousness in childhood cancer survivors following transition into adult care—results from the ACCS project. *Front Oncol*. 2022;12:946281. <https://doi.org/10.3389/fonc.2022.946281>.
27. Denzler S, Otth M, Scheinemann K. Aftercare of childhood cancer survivors in switzerland: protocol for a prospective multicenter observational study. *JMIR Res Protoc*. 2020;9(8): e18898. <https://doi.org/10.2196/18898>.
28. Klassen AF, Grant C, Barr R, Brill H, Kraus de Camargo O, Ronen GM, et al. Development and validation of a generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions: the TRANSITION-Q. *Child Care, Health Dev*. 2015;41(4):547–58. <https://doi.org/10.1111/cch.12207>.
29. Otth M, Wechsler P, Denzler S, Koehler H, Scheinemann K. Determining transition readiness in Swiss childhood cancer survivors—a feasibility study. *BMC Cancer*. 2020. <https://doi.org/10.1186/s12885-021-07787-8>.
30. Syed IA, Klassen AF, Barr R, Wang R, Dix D, Nelson M, et al. Factors associated with childhood cancer survivors' knowledge about their diagnosis, treatment, and risk for late effects. *J Cancer Surviv Res Pract*. 2016;10(2):363–74. <https://doi.org/10.1007/s11764-015-0482-7>.
31. Wang R, Syed IA, Nathan PC, Barr RD, Rosenberg-Yunger ZR, Klassen AF. Exploring cancer worry in adolescent and young adult survivors of childhood cancers. *J Adolesc Young Adult Oncol*. 2015;4(4):192–9. <https://doi.org/10.1089/jayao.2015.0029>.
32. Christen S, Roser K, Mader L, Otth M, Scheinemann K, Sommer G, et al. Incidence and prevalence of musculoskeletal health conditions in survivors of childhood and adolescent cancers: a report from the Swiss childhood cancer survivor study. *Cancer Med*. 2024;13(8): e7204. <https://doi.org/10.1002/cam4.7204>.
33. Rosenberg-Yunger ZR, Klassen AF, Amin L, Granek L, D'Agostino NM, Boydell KM, et al. Barriers and facilitators of transition from pediatric to adult long-term follow-up care in childhood cancer survivors. *J Adolesc Young Adult Oncol*. 2013;2(3):104–11. <https://doi.org/10.1089/jayao.2013.0003>.
34. Nandakumar BS, Fardell JE, Wakefield CE, Signorelli C, McLoone JK, Skeen J, et al. Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care. *Support Care Cancer*. 2018;26(8):2743–50. <https://doi.org/10.1007/s00520-018-4077-5>.
35. Pletschko T, Krottendorfer K, Schlifflner J, Schwarzinger A, Fohn-Erhold V, Weiler-Wichtl L, et al. A Psychosocial support program for young adult childhood cancer survivors in austria: a qualitative evaluation study. *J Cancer Educ*. 2023;38(1):96–105. <https://doi.org/10.1007/s13187-021-02083-2>.
36. Marchak JG, Christen S, Mulder RL, Baust K, Blom JMC, Brinkman TM, et al. Recommendations for the surveillance of mental health problems in childhood, adolescent, and young adult cancer survivors: a report from the international late effects of childhood cancer guideline harmonization group. *Lancet Oncol*. 2022;23(4):e184–96. [https://doi.org/10.1016/s1470-2045\(21\)00750-6](https://doi.org/10.1016/s1470-2045(21)00750-6).

37. Dionisi-Vici M, Godono A, Castiglione A, Gatti F, Fortunati N, Clari M, et al. Work placement and job satisfaction in long-term childhood cancer survivors: the impact of late effects. *Cancers*. 2022. <https://doi.org/10.3390/cancers14163984>.

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