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**ADOLESCENTS' AND YOUNG ADULTS' EXPERIENCES OF CHILDHOOD
CANCER – DESCRIPTIONS OF DAILY LIFE FIVE YEARS AFTER DIAGNOSIS**

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Abstract

Background: Survivors of childhood cancer are a growing population in society. These young people have a high risk of developing chronic health problems with a potential strong impact on their lives. How a childhood cancer experience affects survivors in adolescence has only been studied to a limited extent, and an increased understanding of this young group is needed to improve follow-up care.

Objective: The aim was to gain a deeper understanding of how childhood cancer affects the lives of survivors by exploring adolescents' and young adults' views of what it is like living with this experience.

Methods: Fifty-nine people 11-22 years old were interviewed a median of five years after diagnosis (response rate 66%). Data was collected through telephone interviews and analysed with qualitative content analysis.

Results: Three groups of informants were identified according to their descriptions of influence on daily life: 'Feeling like anyone else' (the informants who described that the cancer experience had almost no influence on current life) (49%), 'Feeling almost like others' (those who described some influence) (44%) and 'Feeling different' (those describing a great influence on current life) (7%).

Conclusions: Most of the adolescents and young adults appear to get along well, although many informants described that life was affected to some extent by having had cancer.

Implications for Practice: Necessary follow-up care that can identify those young survivors of childhood cancer having trouble with daily life and offer them support to strengthen their resources in managing difficulties in relation to having had cancer.

Background

In the last decades, the treatment regimen within paediatric oncology has improved dramatically, resulting in high survival rates. Almost 80% of the approximately 300 children (0-18 years) in Sweden who are diagnosed annually with cancer survive¹⁻³. In relation to chemotherapy treatment, children often experience early complications such as lack of energy/fatigue, drowsiness, nausea, pain⁴, poor appetite, as well as physical discomfort and frailty⁵. Changes related to appearance and hair loss, as well as psychological and emotional distress including fear of missing out on school and friends, have also been reported as distressing complications in relation to treatment^{6,7}.

The process of understanding and coping with a cancer diagnosis is closely linked to the individual's stage of life. Going through childhood cancer during adolescence has consequences that can affect various dimensions of the young person's life, e.g. identity, relationships, school and future prospects in adulthood^{8,9}.

An increasing number of adolescents and young adults are becoming long-term survivors of childhood cancer, defined as having been disease-free for at least five years since the cancer diagnosis¹⁰. Long-term survivors are at an increased risk for long-term effects due to cancer and its treatment¹¹. Long-term adverse effects include chronic health problems such as growth and development, function of vital organs, fertility and reproduction and secondary cancers¹². With this risk panorama, the young survivors may have to manage on-going health problems that require long-term follow-up care by health professionals¹³⁻¹⁵. Studies examining the life situation among long-term survivors following childhood cancer report both positive and negative consequences^{16,17}. Negative impacts on social development and autonomy, socio-demographic issues like employment and cohabitation/marriage, and the

effects on psychological well-being related to the threat of recurrence and uncertainty about the future have been found¹⁸. On the other hand, adolescent survivors of childhood cancer also report positive consequences from the cancer experience: personal growth, increased self-esteem, maturity, a positive attitude towards life and improved relationships^{17,19-21}.

There are only a few studies that have given voice to adolescents' and young adults' perceptions regarding the influence cancer has on the rest of their lives. One previous publication regarded adolescents attending a cancer adjustment camp, whose thoughts about their life situation, the support they got and the information they received about their illness were explored¹⁹. Another study interviewed young adult survivors to examine the long-term effects childhood cancer had on their self-images, relationships and present lives. The findings revealed that all interviews contained a core category 'Compensated life picture', relating to how negative experiences of childhood cancer are compensated for by a positive view on and positive expectation regarding life²². In the present study we followed a total national cohort of school-age children (7-16 years) in Sweden diagnosed with cancer for a two-year period and then participated in a follow-up five years later. The aim of this study was to gain a deeper understanding of how childhood cancer affects the lives of survivors by exploring adolescents' and young adults' views of what it is like living with this experience.

Methods

The present study is part of a national cohort study investigating the life situation of children and adolescents treated for childhood cancer²³⁻²⁵. The present study concerns a data collection occasion a median of five years after diagnosis.

Sample

The sample in the present study consists of children who were diagnosed with cancer between the ages of 7 and 16 during 2004-2006. They were assessed on three occasions during initial treatment (n=118). Children that were treated exclusively with surgery and/or stem cell transplantation and children from families that were not able to speak or read Swedish were not included in the sample. When the present study was conducted a median of five years (63 months) after diagnosis, 23 of the 118 children had died. Additionally, five people were excluded due to the following reasons: cognitive impairment (n=2), lack of address (n=1), undergoing treatment for current relapse or new cancer (n=2). The remaining 90 eligible informants were invited to participate in the study and 59 (66%) agreed to be interviewed. In this study, adolescents are defined as those aged 12-17 years, and young adults as those aged 18-22 years. The demographic and clinical characteristics of the informants are presented in Table 1.

Procedure

This study was approved by the Regional Ethical Review Board in Stockholm. All potential informants were sent a letter informing them about the study, including a form for informed consent to be filled in and sent back to the researchers. The letter highlighted that participation was voluntary and stressed the possibility to withdraw from the study at any time. Written consent was obtained from all informants, and for those below 18 years, parental consent was also obtained. Potential informants were contacted by telephone by one of three interviewers within two weeks after the informational letter was mailed. Provided that the person agreed to participate, a suitable time was scheduled for performing the telephone interview, or in some cases according to the informant's preference, the interview was conducted directly. For informants that were hard to reach, reminders were sent by mail. All

informants received a cinema ticket as a form of compensation for their participation in the study.

Data collection

Participating adolescents and young adults were interviewed by telephone using an interview guide covering the areas of current life situation, school situation/occupation, leisure and relation to friends. The interview guide was pilot tested among young adults with former childhood cancer experiences, and based on the results, minor adjustments were performed. The telephone interviews were conducted by the first author and two fellow researchers who had special training in telephone interview techniques. Interviews lasted a median of 19 minutes (range 13-60), were tape-recorded and then transcribed verbatim.

Data analysis

The analysis of the transcribed data derived from the telephone interviews was inspired by Graneheim's and Lundman's (2004) description of the qualitative content analysis process²⁶. Content analysis is a suitable approach for drawing conclusions by systematic and descriptive identification of the evident content that is communicated in text on various abstraction levels²⁷. This is a useful method for analysing content from interview data with a focus on people's experiences. The analysis was carried out by the first author, in continuous dialogue with four of the co-authors. First, all transcripts were read several times to get an overall sense of the interview. The interviews were then reread to identify meaning units that described how childhood cancer affects the lives of survivors. We continued by reading each informant's total interview transcript and summarising each description regarding impact on life. The interviews were then divided into three groups based on how its influence on daily life was described. Lastly, identified meaning units of the three groups were compared and four

categories emerged revealing the differences between the groups (these are presented in Table 2). The analysis was an on-going process with repeated revisions and modifications until agreement was reached in the research group. Finally, one member of the research group not previously involved in the analysis process read half of the interviews and categorised them according to the identified descriptions of the three groups (Table 2). Agreement with the original categorisation was 90%²⁸.

Results

The three groups based on the informants' views of what it is like living with the experience of childhood cancer were: 'Feeling like anyone else', 'Feeling almost like others' and 'Feeling different' (Table 2). In each group, the influence of having had cancer was described in terms of four categories: thoughts about having had cancer, presence of complications in daily life, ability to handle complications and view of life. The three groups in the aforementioned categories will be presented in the text below, illustrated with quotations.

Feeling like anyone else

49% of the informants were identified as belonging to the group 'Feeling like anyone else', since they reported that the cancer had almost no influence on their daily lives. A typical description of the situation from one informant in this group:

. . . It's not something you think about every day. You've got scars from surgeries and such things. // When one is supposed to do physically challenging activities like running around, one cannot put forth a maximum effort. // But I try to live a normal life as I did before and I'm not limited in any way. // I'm glad that I've been able to continue my life and my dreams as I originally

thought. The disease has not affected my dream job by any means. (Boy, 20 years).

Thoughts about having had cancer

Informants rarely thought about the cancer experience, and if they did so they did not perceive the thoughts as troublesome. Some informants described a relief that the cancer was over, indicating that the cancer experience is now a closed chapter in their life story and that life must go on:

I do not usually get any thoughts. I just think that it's done and yes . . . you should not think more about it. (Girl, 16 years).

Presence of complications in daily life

Informants reported that they experienced few or no complications that affected their daily lives. Complications could be limitations related to physical performance (e.g., not having the ability to fully exert themselves and getting tired more easily when performing sports), problems with fine motor skills, changes in their skin's appearance, scars or having to handle on-going medication.

Ability to handle complications

Informants that had complications stated that this was easily handled and did not take much attention in their lives:

. . . there might be some physical exercises that I'm not able to do the same as I've done before, since the treatment caused me to lose those muscles. Most of them I've gotten back since I play basketball five times a week. (Boy, 15 years).

View of life

Few of the informants said that the cancer experience affected their view of life. Those who described this said that even though the cancer experience was a negative and undesirable event in life, and a personal loss that impacted the informants' lives, the experience also had positive consequences. The cancer experience changed their priorities in life and made them more mature. The fact that things changed for the better was something that was encouraging and motivated them to do well in school and to carry on with their lives:

Well, I think about the time I lost in school when I had cancer, then think I am here today. I go to school, I get really good grades and just go on and everything is fine: it's still something that motivates me. (Girl, 14 years).

Feeling almost like others

44% of the informants were identified as belonging to the group 'Feeling almost like others', since they perceived that the cancer experience influenced daily life to a small extent. The informants stated that they sometimes thought about having had cancer: they had complications but did not perceive this as hindering daily life. They handled the complications and their view of life was often described as being influenced by the cancer experience. A typical description of the situation:

. . . Sometimes I think back, but it's not so often. There may be some thoughts from time to time, but not as often as before. // Yes, I have medications, growth hormones and such to help me grow and reach puberty. // I'm not the shortest in my school class and this pleases me, but I will probably not reach the height that was intended from the beginning, so to speak. // . . . I'm pretty mature for my age and definitely know a lot about health care and things like that. Much more

than what they (peers) know. They did not know what a CVK was, so I had to explain it to them. (Boy, 17 years).

Thoughts about having had cancer

Informants reported that at present, the cancer experience did not have a central role in their lives. They sometimes thought about their cancer experience, however these thoughts usually did not continue for long before they were taken over by thoughts of the present. Some mentioned that they had begun to reflect about the experience more and more:

Sometimes one thinks about it and, yes, then it feels like I haven't begun to reflect so much about it, but still it comes a little more and more. (Girl, 16 years).

Presence of complications in daily life

Informants described having complications from the disease and treatment that influenced daily life to a small extent and were not viewed as limiting; complications included both physical and mental problems. Physical complications included excess weight, visual scars, short stature, and having prostheses or using a wheelchair for transportation. Mental complications included worries about the recurrence of cancer and concerns about changes in body appearance. One girl said that the complications were diminishing:

. . . it disturbed the hunger centre a bit and my ability to feel full. It made me put on a lot of weight: I still weigh too much, but now I am taking part in a weight reduction program. (Girl, 19 years).

Ability to handle complications

Informants reported that they handled physical and mental complications and integrated them into normal life conditions, even though they had to do things differently compared to peers.

As this girl who had muscles removed in her left leg and worked in a restaurant explained:

Yes . . . e.g., when we go out and serve the food during the hectic hours, I tend to be the one who spills the food served in big dishes because I cannot walk as fast as the others. . . I choose not to serve the food because I often stumble and I do not want to mess around with the food. I also wear different shoes than the others, to make it easier to work. (Girl, 19 years).

View of life

Many of the informants reported a changed view of life. Informants expressed that they were fortunate to have survived cancer and were feeling proud of having managed to live through the cancer experience. There were informants who reported feeling more mature and/or having a changed view about what they regarded as important in life. This makes them have higher standards for relationships to close friends, and in everyday situations this could also make them feel different from their peers. Furthermore, their changed priorities in life influenced school attendance, and performance was valued more highly than before the cancer experience:

Yes, you have a different opinion of school once you have been away.

Previously, you thought that it was boring to go to school, but it's actually fun to live normally and make friends. It's not just school work: there are many other things in life too. You appreciate things that others might not. (Boy, 17 years).

Feeling different

7% of the informants were identified as belonging to the group 'Feeling different', since they perceived that the cancer experience affected and hindered daily life to a large extent. The informants stated that they thought about having had cancer frequently or all the time.

Further, they had complications that severely affected and hindered daily life: their view of life was often described as influenced by the cancer experience. A typical description of the situation of one of the informants in this group:

. . . because I was amputated, I am reminded every day of what I have been through and how hard it's been . . . I will be marked by this all my life. I still feel bad from it today. // I have to take a lot of high-dose tablets since I still have so much pain and that makes me pretty tired. // When I think about having had cancer and all I have gone through, it feels heavy. It's because I have lost . . . I've lost so much: friends, some of my adolescence and a bit of everything as well. But of course . . . with time, I have also begun to find things that are positive. I've grown a lot. (Boy, 20 years).

Thoughts about having had cancer

Informants reported that they frequently or constantly thought about having had cancer because there were things in their current lives that reminded them about the cancer and its on-going influence. Thoughts of relapse and possible future long-term complications also troubled them:

It is the . . . cancer that I think a lot about, all the time. What I think is that it might come back. If I get sick, I immediately think about if I have got the cancer back. So I think. (Girl 21 years).

Presence of complications in daily life

Informants reported how complications from the disease and treatment affected their daily lives to a large extent. Physical complications, e.g. having prostheses, decreased strength and chronic pain make it impossible for these informants to be as active as they want. They reported that they were not able to keep up the same pace as others and that from time to time they had to reconsider their activity level. Having to explain to others the reason for being physically weaker was also described as complicating daily life. Descriptions of mental complications included worries and concerns about how informants still had not dealt with having had cancer, as well as having a vulnerable health condition that threatened their future lives. There were also descriptions of feeling bad about not being able to handle their current life situation following the cancer and complications. Cognitive complications, e.g. memory problems, were also reported as affecting school performance and/or impacting ability to recall things in everyday life. Having to take responsibility for pharmacological treatment, e.g. hormone substitution and pain management, was described as complicating everyday life, and having to explain to others the reason for why they were taking medication was also described as a burden:

But I have my problems. My legs are swollen, I have to take medications (hormones that the body can no longer produce) and handle syringes daily. I cannot travel: I have to fight with the hospital to make them give me extra medication, and I have to plan things in detail. It's really complicated to live like this. (Girl, 22 years).

Ability to handle complications

The informants reported that they still felt bad about having had cancer and that they had not yet dealt with the experience. They expressed that it was hard to have complications and that

this still greatly affected their daily lives. They said that they consciously tried to find strategies to handle the complications, but found it hard to find strategies that were adequate and helpful. This informant was often absent from school five years after his initial diagnosis because of his mental complications:

Last time I was absent from school, it was because I felt mentally weak. That's usually the reason, since I feel psychologically fragile and do not have the mental strength to go there. (Boy, 20 years).

View of life

All informants in this group reported both negative and positive changes in their view on life. Negative consequences were described as: being marked for life and feelings of grief about having had cancer. The informants no longer took anything for granted and lived in fear of the cancer coming back, which constrained their outlook on life. Also, the cancer experience influenced who they are now, and this was difficult for others to understand. However, informants also reported that the cancer experience had a positive effect on their view of life, changing their values and priorities. The informants said that their self-knowledge had deepened, their relationships with others had become more positive and that they experienced increased maturity and self-esteem:

Well, I have matured so much. Thus, it might be in advance, but I feel I am a more confident person in myself and like I can stand up for myself and I know what I want and so on. (Girl, 22 years).

Discussion

The results from the present study show that five years after a cancer diagnosis, adolescents and young adults feel that having cancer resulted in them 'Feeling like anyone else', 'Feeling

almost like others' or 'Feeling different'. A clear majority of the young survivors seemed to get along well in spite of major or minor complications from their disease and treatment, which confirms findings from previous studies^{21,29}. However, a small group of the young survivors (7%) experienced influence from major complications that were difficult for them to handle.

Going through childhood cancer is a stressful experience, and how an individual copes with this experience as well as the eventual effect of complications could, from a theoretical point of view, be explained by Antonovsky's salutogenic framework with the core concept Sense of coherence (SOC) and the components 'comprehensibility', 'manageability' and 'meaningfulness'³⁰. This theory explains the relationship between stressors, coping and health and can be measured by the SOC scale³⁰. In a study examining SOC among adolescents with congenital heart disease, results show a relation between low SOC and negatively perceived health³¹. Furthermore, young adults who had an occurrence of epileptic seizure scored lower on the SOC scale than those that were seizure free³². Furthermore, in another study of young adult survivors of childhood cancer, those in need for support rated their SOC statistic significantly lower, compared to those reporting no need of support³³. These prior studies indicate that SOC is an important factor in relation to well-being and perceived health³⁴. In the present study, the informants in the three identified groups described different views of how having childhood cancer affected their daily lives. Our results and the three categories that describe the differences between the groups will be discussed in relation to the three components of the SOC.

Thoughts of having had cancer

Most of the informants rarely or sometimes thought about having had cancer; however, for those in the group 'Feeling different', thoughts about the cancer experience, risk of relapse and how to handle on-going late complications dominated daily life. Seen from the perspective of SOC, informants in the 'Feeling different' group may require more care activities to understand their situation. The component 'comprehensibility' means the extent to which the individual has the ability to understand and make sense of things that happen in life so that future experiences will be perceived as ordered, predictable and explicable^{30,35}. Maybe the informants in the group 'Feeling different' could receive support to increase knowledge and understanding about their cancer experience, which may be a way to deal with the troubling thoughts about having had cancer.

Ability to handle complications

The informants in the groups 'Feeling almost like others' and 'Feeling different' had similar complications, but an interesting finding is that they handled them differently. Informants grouped as 'Feeling almost like others' reported that things like use of prostheses or wheelchair or life-long medication was today integrated into their daily lives. In contrast, informants grouped as 'Feeling different' expressed that their complications were hindering daily activities because they constantly had to reconsider and adjust their activity levels, and this made them feel limited and different from their peers. Seen from the perspective of the SOC, this difference can be understood by the component 'manageability', which refers to the individuals' own perception of being capable of dealing with demands and challenges in life^{30,35}. Informants in the group 'Feeling almost like others' appeared to have adequate resources to manage complications in daily life: they had self-confidence and felt confident that things would work out. The informants grouped as 'Feeling different' may not have had sufficient resources to manage their complications: they could not successfully integrate the

consequences of having had cancer into daily life, and therefore experienced their complications as burdensome.

View of life

A positive consequence on view of life was reported in all three groups, but the informants in the group 'Feeling different' also reported negative effects on their view of life. The reported positive changes including changed priorities, enhanced maturity, personal growth, increased self-esteem and changed relationships; aspects also described in other reports^{17,19-22} and may be an important way to handle the cancer experience. Experiencing positive changes after a cancer experience can be understood as a way to find meaning from the situation, which is consistent with the SOC component 'meaningfulness'^{30,35}. This can help informants adapt to their situation by taking control; however, this was not enough for informants in the group 'Feeling different', because the negative effect on their view of life was still too strong for them to handle and they were unable to adapt.

Being an adolescent is characterised by developing personal identity, gaining autonomy and adopting to new roles in life³⁶. This is probably also a period in life where an individual's SOC is most sensitive to change³. What impact a potential traumatic event such as cancer in childhood has on the formation of SOC has not yet been studied, but a study that compared SOC between young long-term survivors of childhood cancer and young adults in general showed no difference in mean SOC scores³³.

The present study can be seen as an illustration of the challenges faced by young childhood cancer survivors: they describe how their daily lives are affected about five years post diagnosis, depending on their ability to handle thoughts of the experience and long-term

complications. It is important to keep in mind that complications from the childhood cancer experience will continue to influence the individuals' lives³⁷. The three groups in the present study are on different points along the health/disease continuum³⁴; however, it is important to identify those individuals who are most vulnerable, i.e. those that have trouble understanding, handling and making sense of their cancer experience in daily life. With the salutogenic health model for orientation, focus should be on what constitutes health, i.e. how the individual can regain health, in spite of stressful life events³⁴.

Methodological considerations

The trustworthiness of a qualitative study can be considered from the concepts of credibility, dependability and transferability²⁶.

The credibility of the findings in the present study relies on the selection of the sample, the data collection and the analysis procedures. The sample selection is considered to be strong, since all informants belonged to a national cohort including variation in age, gender and residence in both urban and rural areas, and is representative of the most common childhood cancer diagnoses among school-aged children in Sweden. Another strength is that the results represents the view of the young survivors themselves, rather than reporting from parents or healthcare professionals. A response rate of 66% must be considered as acceptable, however the reasons for non-participation are unknown and it is therefore hard to determine whether non-participants experienced no, small or large effects from the childhood cancer experience. Telephone interviews were used for geographical reasons and because they were suitable for this age group of informants, who seemed to be at ease with sharing their experiences in the relative privacy of a telephone call. However, a limitation was that the younger informants more often gave short answers while the older informants gave more detailed descriptions.

Our judgment is that qualitative content analysis was a suitable method for gaining a deeper understanding of adolescents' and young adults' view of what it is like to live with this experience, and the inter-rater reliability of 90% ensures the credibility of the analysis.

The dependability of the findings in the present study is confirmed by the fact that data was collected in the same way from every informant. An interview guide with open-ended questions was used and the interviewers had special training for conducting telephone interviews. During the analysis process, the quality was ensured by continual discussions among the co-authors.

The transferability of the findings in the present study is dependent upon a good description of the study's context, selection and characteristics of the participants, data collection, the process of analysis and an in-depth presentation of the findings. We believe that the results of the present study could be transferred to other groups of young people who are living with long-term health conditions.

Conclusions and clinical implications

In line with previous reports, the findings in the present study show that most of the adolescents and young adults appeared to get along well in daily life, although many informants reported that life was to some extent affected by having had childhood cancer. However, a small group of survivors were troubled in daily life and would benefit from support: this would help them to mobilise the resources needed to manage their daily living situations. Follow-up care in which nurses and other health care professionals can identify those young survivors of childhood cancer that have trouble with daily life and offer them targeted support is needed. By using the salutogenic health model and structured dialogues in

health care it may be possible to identify difficulties in relation to having had cancer among young survivors. There are other studies³⁸ that have concluded that SOC theory can be used to understand how people reflect on how they cope with problems in their everyday lives. Sarenmalm et al. (2013) suggest that SOC could be useful as a tool for identifying individuals in need of support to cope with breast cancer³⁹. Strengthening existing resources and identification of new resources could help young survivors adapt to a changed life following childhood cancer. The chance to talk about the experience with health professionals and with peers who also have survived childhood cancer is a way to do this, since studies show that this increases the informants' knowledge about the disease and helps mobilise coping resources⁴⁰. Further, the survivors may also benefit from improved help from health professionals in terms of their medical complications (such as pain and handling long-term medication regimens).

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References

1. Gatta G, Capocaccia R, De Angelis R, Stiller C, Coebergh JW, Group EW. Cancer survival in European adolescents and young adults. *Eur J Cancer*. 2003;39(18):2600-2610.
2. Gustafsson G, Heyman M, Vernby Å, eds. *The development of pediatric oncology in sweden. Childhood cancer Incidence and Survival in Sweden 1984-2005*. Stockholm: R. f. t. S. C. C. Registry; 2007.
3. Honkinen PL, Suominen S, Helenius H, et al. Stability of the sense of coherence in adolescence. *Int J Adolesc Med Health*. 2008;20(1):85-91.
4. Baggott C, Dodd M, Kennedy C, et al. Changes in children's reports of symptom occurrence and severity during a course of myelosuppressive chemotherapy. *J Pediatr Oncol Nurs*. 2010;27(6):307-315.
5. Moody K, Meyer M, Mancuso CA, Charlson M, Robbins L. Exploring concerns of children with cancer. *Support Care Cancer*. 2006;14(9):960-966.
6. Hedström M, Ljungman G, von Essen L. Perceptions of distress among adolescents recently diagnosed with cancer. *J Pediatr Hematol Oncol*. 2005;27(1):15-22.
7. Jörngården A, Mattsson E, von Essen L. Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: a prospective longitudinal study. *Eur J Cancer*. 2007;43(13):1952-1958.
8. Larouche SS, Chin-Peuckert L. Changes in body image experienced by adolescents with cancer. *J Pediatr Oncol Nurs*. 2006;23(4):200-209.
9. Thompson K, Palmer S, Dyson G. Adolescents & young adults: Issues in transition from active therapy into follow-up care. *European Journal of Oncology Nursing*. 2009;13:207-212.
10. Cantrell MA, Conte TM. Between being cured and being healed: the paradox of childhood cancer survivorship. *Qual Health Res*. 2009;19(3):312-322.
11. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol*. 2003;13(3):248-266.
12. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355(15):1572-1582.
13. Shad A, Myers SN, Hennessy K. Late effects in cancer survivors: "the shared care model". *Curr Oncol Rep*. 2012;14(2):182-190.
14. Kopp LM, Gupta P, Pelayo-Katsanis L, Wittman B, Katsanis E. Late effects in adult survivors of pediatric cancer: a guide for the primary care physician. *Am J Med*. 2012;125(7):636-641.
15. Prasad PK, Bowles T, Friedman DL. Is there a role for a specialized follow-up clinic for survivors of pediatric cancer? *Cancer Treat Rev*. 2010;36(4):372-376.
16. McDougall J, Tsonis M. Quality of life in survivors of childhood cancer: a systematic review of the literature (2001-2008). *Support Care Cancer*. 2009;17(10):1231-1246.
17. Sundberg KK, Lampic C, Björk O, Arvidson J, Wettergren L. Positive and negative consequences of childhood cancer influencing the lives of young adults. *Eur J Oncol Nurs*. 2009;13(3):164-170.
18. Stam H, Grootenhuis MA, Last BF. The course of life of survivors of childhood cancer. *Psychooncology*. 2005;14(3):227-238.
19. Hokkanen H, Eriksson E, Ahonen O, Salanterä S. Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nurs*. 2004;27(4):325-335.
20. Woodgate R, McClement S. Symptom distress in children with cancer: the need to adopt a meaning-centered approach. *J Pediatr Oncol Nurs*. 1998;15(1):3-12.

21. Mattsson E, Ringnér A, Ljungman G, von Essen L. Positive and negative consequences with regard to cancer during adolescence. Experiences two years after diagnosis. *Psychooncology*. 2007;16(11):1003-1009.
22. Enskär K, Berterö C. Young adult survivors of childhood cancer; experiences affecting self-image, relationships, and present life. *Cancer Nurs*. 2010;33(1):E18-24.
23. af Sandeberg M, Johansson E, Björk O, Wettergren L. Health-related quality of life relates to school attendance in children on treatment for cancer. *J Pediatr Oncol Nurs*. 2008;25(5):265-274.
24. Jervaeus A, Kottorp A, Wettergren L. Psychometric properties of KIDSCREEN-27 among childhood cancer survivors and age matched peers - a Rasch analysis. *Quality of Life Research*. 2012;21(Supplement 1).
25. Berg Doukkali E, Winterling J, Eriksson LE, Lampic C, af Sandeberg M, Wettergren L. Adolescent and Young Adult Views of Daily Life Five Years After a Childhood Cancer Diagnosis. *Pediatric, Blood & Cancer*. 2012;59(6):1131.
26. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. Feb 2004;24(2):105-112.
27. Patton M. *Qualitative research & Evaluation Methods*. Thousand Oaks, California: Sage Publications Inc.; 2002.
28. Kazdin AE. *Research Design in Clinical Psychology*. Vol Fourth Edition. Boston: Pearson Education Company; 2010.
29. Wicks L, Mitchell A. The adolescent cancer experience: loss of control and benefit finding. *Eur J Cancer Care (Engl)*. 2010;19(6):778-785.
30. Antonovsky A. *Unraveling the mystery of health; How people manage stress and stay well*. San Francisco, CA: Jossey-Bass Publishers; 1987.
31. Apers S, Luyckx K, Rassart J, Goosens E, Budts W, Moons P. Sense of coherence is a predictor of perceived health in adolescents with congenital heart disease: A cross-lagged prospective study. *International Journal of Nursing Studies*. 2012;07.
32. Gauffin H, Landtblom AM, Råty L. Self-esteem and sense of coherence in young people with uncomplicated epilepsy: a 5-year follow-up. *Epilepsy Behav*. 2010;17(4):520-524.
33. Sundberg KK, Lampic C, Arvidson J, Wettergren L. Sense of coherence and need for support among long-term survivors of childhood cancer. *Cancer Nurs*. 2012;35(4):E43-49.
34. Antonovsky A. The salutogenic model as a theory to guide health promotion¹. *Health Promotion International*. 1996;11. 1:11-18.
35. Flensburg-Madsen T, Ventegodt S, Merrick J. Why is Antonovsky's sense of coherence not correlated to physical health? Analysing Antonovsky's 29-item Sense of Coherence Scale (SOC-29). *ScientificWorldJournal*. 2005;5:767-776.
36. Homburger Eriksson E. *The life cycle completed*. In: Ed., ed. Stockholm: Natur och Kultur; 2004.
37. Shepherd EJ, Woodgate RL. Cancer survivorship in children and young adults: a concept analysis. *J Pediatr Oncol Nurs*. 2010;27(2):109-118.
38. Griffiths CA, Ryan P, Foster JH. Thematic analysis of Antonovsky's sense of coherence theory. *Scand J Psychol*. 2011;52(2):168-173.
39. Sarenmalm EK, Browall M, Persson LO, Fall-Dickson J, Gaston-Johansson F. Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. *Psychooncology*. 2013;22(1):20-27.
40. Patterson P, Millar P, Desille N, Mc Donald F. The Unmet Needs of Emergin Adults With a Cancer Diagnosis. *Cancer Nursing*. 2012;35. 3:32-40.

Table 1. Demographic and Clinical Characteristics of Participating Childhood Cancer Survivors Presented by the Three Identified Groups

	Total Sample	'Feeling Like Anyone Else'	'Feeling Almost Like Others'	'Feeling Different'
Total number, n (%)	59 (100)	29 (49)	26 (44)	4 (7)
Gender, n (%)				
Female	24 (41)	13 (45)	9 (35)	2 (50)
Male	35 (59)	16 (55)	17 (65)	2 (50)
Age at diagnosis, median (min-max)	12 (7-16)	10 (7-15)	13 (8-15)	15 (14-16)
Age at interview, median (min-max)	17 (12-22)	14 (12-21)	18 (12-21)	21 (19-22)
Living situation, n (%)				
With parent/s	52 (88)			
Alone	4 (7)			
Other constellation	3 (5)			
Occupation, n (%)				
School	48 (81)			
Work	6 (10)			
Sick leave	2 (3)			
Diagnosis, n (%)				
Acute lymphoblastic leukaemia	20 (34)			
Skeletal and soft tissue sarcoma	13 (22)			
Tumours of the central nervous system	8 (14)			
Hodgkin's lymphoma	6 (10)			
Non-Hodgkin's lymphoma	5 (8)			
Acute myeloid leukaemia	3 (5)			
Other ^a	4 (7)			

^aSertoli leydig cell tumour and germ cells tumour

Table 2. Description of the Characteristics of the Four Categories by the Three Identified Groups

Identified Groups	Thoughts of Having Had Cancer	Presence of Complications in Daily Life	Ability to Handle Complications	View of Life
Feeling like anyone else	Only rarely think about having had cancer	Have minor or no complications from disease or treatment that influence daily life	If any complications, these are easily handled and not perceived as hindering daily life	View of life is rarely influenced
Feeling almost like others	Sometimes think about having had cancer	Have complications from disease and treatment that to a small extent influence daily life	Complications are not perceived as hindering daily life	View of life is often influenced
Feeling different	Often think about having had cancer	Have complications from disease and treatment that to a large extent influence daily life	Complications are perceived as hindering daily life	View of life is often influenced

**ADOLESCENTS' AND YOUNG ADULTS' EXPERIENCES OF CHILDHOOD
CANCER – DESCRIPTIONS OF DAILY LIFE FIVE YEARS AFTER DIAGNOSIS**

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Abstract

Background: Survivors of childhood cancer are a growing population in society. These young people have a high risk of developing chronic health problems with a potential strong impact on their lives. How a childhood cancer experience affects survivors in adolescence has only been studied to a limited extent, and an increased understanding of this young group is needed to improve follow-up care.

Objective: The aim was to gain a deeper understanding of how childhood cancer affects the lives of survivors by exploring adolescents' and young adults' views of what it is like living with this experience.

Methods: Fifty-nine people 11-22 years old were interviewed a median of five years after diagnosis (response rate 66%). Data was collected through telephone interviews and analysed with qualitative content analysis.

Results: Three groups of informants were identified according to their descriptions of influence on daily life: 'Feeling like anyone else' (the informants who described that the cancer experience had almost no influence on current life) (49%), 'Feeling almost like others' (those who described some influence) (44%) and 'Feeling different' (those describing a great influence on current life) (7%).

Conclusions: Most of the adolescents and young adults appear to get along well, although many informants described that life was affected to some extent by having had cancer.

Implications for Practice: Necessary follow-up care that can identify those young survivors of childhood cancer having trouble with daily life and offer them support to strengthen their resources in managing difficulties in relation to having had cancer.

Background

In the last decades, the treatment regimen within paediatric oncology has improved dramatically, resulting in high survival rates. Almost 80% of the approximately 300 children (0-18 years) in Sweden who are diagnosed annually with cancer survive¹⁻³. In relation to chemotherapy treatment, children often experience early complications such as lack of energy/fatigue, drowsiness, nausea, pain⁴, poor appetite, as well as physical discomfort and frailty⁵. Changes related to appearance and hair loss, as well as psychological and emotional distress including fear of missing out on school and friends, have also been reported as distressing complications in relation to treatment^{6,7}.

The process of understanding and coping with a cancer diagnosis is closely linked to the individual's stage of life. Going through childhood cancer during adolescence has consequences that can affect various dimensions of the young person's life, e.g. identity, relationships, school and future prospects in adulthood^{8,9}.

An increasing number of adolescents and young adults are becoming long-term survivors of childhood cancer, defined as having been disease-free for at least five years since the cancer diagnosis¹⁰. Long-term survivors are at an increased risk for long-term effects due to cancer and its treatment¹¹. Long-term adverse effects include chronic health problems such as growth and development, function of vital organs, fertility and reproduction and secondary cancers¹². With this risk panorama, the young survivors may have to manage on-going health problems that require long-term follow-up care by health professionals¹³⁻¹⁵. Studies examining the life situation among long-term survivors following childhood cancer report both positive and negative consequences^{16,17}. Negative impacts on social development and autonomy, socio-demographic issues like employment and cohabitation/marriage, and the

effects on psychological well-being related to the threat of recurrence and uncertainty about the future have been found¹⁸. On the other hand, adolescent survivors of childhood cancer also report positive consequences from the cancer experience: personal growth, increased self-esteem, maturity, a positive attitude towards life and improved relationships^{17,19-21}.

There are only a few studies that have given voice to adolescents' and young adults' perceptions regarding the influence cancer has on the rest of their lives. One previous publication regarded adolescents attending a cancer adjustment camp, whose thoughts about their life situation, the support they got and the information they received about their illness were explored¹⁹. Another study interviewed young adult survivors to examine the long-term effects childhood cancer had on their self-images, relationships and present lives. The findings revealed that all interviews contained a core category 'Compensated life picture', relating to how negative experiences of childhood cancer are compensated for by a positive view on and positive expectation regarding life²². In the present study we followed a total national cohort of school-age children (7-16 years) in Sweden diagnosed with cancer for a two-year period and then participated in a follow-up five years later. The aim of this study was to gain a deeper understanding of how childhood cancer affects the lives of survivors by exploring adolescents' and young adults' views of what it is like living with this experience.

Methods

The present study is part of a national cohort study investigating the life situation of children and adolescents treated for childhood cancer²³⁻²⁵. The present study concerns a data collection occasion a median of five years after diagnosis.

Sample

The sample in the present study consists of children who were diagnosed with cancer between the ages of 7 and 16 during 2004-2006. They were assessed on three occasions during initial treatment (n=118). Children that were treated exclusively with surgery and/or stem cell transplantation and children from families that were not able to speak or read Swedish were not included in the sample. When the present study was conducted a median of five years (63 months) after diagnosis, 23 of the 118 children had died. Additionally, five people were excluded due to the following reasons: cognitive impairment (n=2), lack of address (n=1), undergoing treatment for current relapse or new cancer (n=2). The remaining 90 eligible informants were invited to participate in the study and 59 (66%) agreed to be interviewed. In this study, adolescents are defined as those aged 12-17 years, and young adults as those aged 18-22 years. The demographic and clinical characteristics of the informants are presented in Table 1.

Procedure

This study was approved by the Regional Ethical Review Board in Stockholm. All potential informants were sent a letter informing them about the study, including a form for informed consent to be filled in and sent back to the researchers. The letter highlighted that participation was voluntary and stressed the possibility to withdraw from the study at any time. Written consent was obtained from all informants, and for those below 18 years, parental consent was also obtained. Potential informants were contacted by telephone by one of three interviewers within two weeks after the informational letter was mailed. Provided that the person agreed to participate, a suitable time was scheduled for performing the telephone interview, or in some cases according to the informant's preference, the interview was conducted directly. For informants that were hard to reach, reminders were sent by mail. All

informants received a cinema ticket as a form of compensation for their participation in the study.

Data collection

Participating adolescents and young adults were interviewed by telephone using an interview guide covering the areas of current life situation, school situation/occupation, leisure and relation to friends. The interview guide was pilot tested among young adults with former childhood cancer experiences, and based on the results, minor adjustments were performed. The telephone interviews were conducted by the first author and two fellow researchers who had special training in telephone interview techniques. Interviews lasted a median of 19 minutes (range 13-60), were tape-recorded and then transcribed verbatim.

Data analysis

The analysis of the transcribed data derived from the telephone interviews was inspired by Graneheim's and Lundman's (2004) description of the qualitative content analysis process²⁶. Content analysis is a suitable approach for drawing conclusions by systematic and descriptive identification of the evident content that is communicated in text on various abstraction levels²⁷. This is a useful method for analysing content from interview data with a focus on people's experiences. The analysis was carried out by the first author, in continuous dialogue with four of the co-authors. First, all transcripts were read several times to get an overall sense of the interview. The interviews were then reread to identify meaning units that described how childhood cancer affects the lives of survivors. We continued by reading each informant's total interview transcript and summarising each description regarding impact on life. The interviews were then divided into three groups based on how its influence on daily life was described. Lastly, identified meaning units of the three groups were compared and four

categories emerged revealing the differences between the groups (these are presented in Table 2). The analysis was an on-going process with repeated revisions and modifications until agreement was reached in the research group. Finally, one member of the research group not previously involved in the analysis process read half of the interviews and categorised them according to the identified descriptions of the three groups (Table 2). Agreement with the original categorisation was 90% ²⁸.

Results

The three groups based on the informants' views of what it is like living with the experience of childhood cancer were: 'Feeling like anyone else', 'Feeling almost like others' and 'Feeling different' (Table 2). In each group, the influence of having had cancer was described in terms of four categories: thoughts about having had cancer, presence of complications in daily life, ability to handle complications and view of life. The three groups in the aforementioned categories will be presented in the text below, illustrated with quotations.

Feeling like anyone else

49% of the informants were identified as belonging to the group 'Feeling like anyone else', since they reported that the cancer had almost no influence on their daily lives. A typical description of the situation from one informant in this group:

. . . It's not something you think about every day. You've got scars from surgeries and such things. // When one is supposed to do physically challenging activities like running around, one cannot put forth a maximum effort. // But I try to live a normal life as I did before and I'm not limited in any way. // I'm glad that I've been able to continue my life and my dreams as I originally

thought. The disease has not affected my dream job by any means. (Boy, 20 years).

Thoughts about having had cancer

Informants rarely thought about the cancer experience, and if they did so they did not perceive the thoughts as troublesome. Some informants described a relief that the cancer was over, indicating that the cancer experience is now a closed chapter in their life story and that life must go on:

I do not usually get any thoughts. I just think that it's done and yes . . . you should not think more about it. (Girl, 16 years).

Presence of complications in daily life

Informants reported that they experienced few or no complications that affected their daily lives. Complications could be limitations related to physical performance (e.g., not having the ability to fully exert themselves and getting tired more easily when performing sports), problems with fine motor skills, changes in their skin's appearance, scars or having to handle on-going medication.

Ability to handle complications

Informants that had complications stated that this was easily handled and did not take much attention in their lives:

. . . there might be some physical exercises that I'm not able to do the same as I've done before, since the treatment caused me to lose those muscles. Most of them I've gotten back since I play basketball five times a week. (Boy, 15 years).

View of life

Few of the informants said that the cancer experience affected their view of life. Those who described this said that even though the cancer experience was a negative and undesirable event in life, and a personal loss that impacted the informants' lives, the experience also had positive consequences. The cancer experience changed their priorities in life and made them more mature. The fact that things changed for the better was something that was encouraging and motivated them to do well in school and to carry on with their lives:

Well, I think about the time I lost in school when I had cancer, then think I am here today. I go to school, I get really good grades and just go on and everything is fine: it's still something that motivates me. (Girl, 14 years).

Feeling almost like others

44% of the informants were identified as belonging to the group 'Feeling almost like others', since they perceived that the cancer experience influenced daily life to a small extent. The informants stated that they sometimes thought about having had cancer: they had complications but did not perceive this as hindering daily life. They handled the complications and their view of life was often described as being influenced by the cancer experience. A typical description of the situation:

. . . Sometimes I think back, but it's not so often. There may be some thoughts from time to time, but not as often as before. // Yes, I have medications, growth hormones and such to help me grow and reach puberty. // I'm not the shortest in my school class and this pleases me, but I will probably not reach the height that was intended from the beginning, so to speak. // . . . I'm pretty mature for my age and definitely know a lot about health care and things like that. Much more

than what they (peers) know. They did not know what a CVK was, so I had to explain it to them. (Boy, 17 years).

Thoughts about having had cancer

Informants reported that at present, the cancer experience did not have a central role in their lives. They sometimes thought about their cancer experience, however these thoughts usually did not continue for long before they were taken over by thoughts of the present. Some mentioned that they had begun to reflect about the experience more and more:

Sometimes one thinks about it and, yes, then it feels like I haven't begun to reflect so much about it, but still it comes a little more and more. (Girl, 16 years).

Presence of complications in daily life

Informants described having complications from the disease and treatment that influenced daily life to a small extent and were not viewed as limiting; complications included both physical and mental problems. Physical complications included excess weight, visual scars, short stature, and having prostheses or using a wheelchair for transportation. Mental complications included worries about the recurrence of cancer and concerns about changes in body appearance. One girl said that the complications were diminishing:

. . . it disturbed the hunger centre a bit and my ability to feel full. It made me put on a lot of weight: I still weigh too much, but now I am taking part in a weight reduction program. (Girl, 19 years).

Ability to handle complications

Informants reported that they handled physical and mental complications and integrated them into normal life conditions, even though they had to do things differently compared to peers.

As this girl who had muscles removed in her left leg and worked in a restaurant explained:

Yes . . . e.g., when we go out and serve the food during the hectic hours, I tend to be the one who spills the food served in big dishes because I cannot walk as fast as the others. . . I choose not to serve the food because I often stumble and I do not want to mess around with the food. I also wear different shoes than the others, to make it easier to work. (Girl, 19 years).

View of life

Many of the informants reported a changed view of life. Informants expressed that they were fortunate to have survived cancer and were feeling proud of having managed to live through the cancer experience. There were informants who reported feeling more mature and/or having a changed view about what they regarded as important in life. This makes them have higher standards for relationships to close friends, and in everyday situations this could also make them feel different from their peers. Furthermore, their changed priorities in life influenced school attendance, and performance was valued more highly than before the cancer experience:

Yes, you have a different opinion of school once you have been away.

Previously, you thought that it was boring to go to school, but it's actually fun to live normally and make friends. It's not just school work: there are many other things in life too. You appreciate things that others might not. (Boy, 17 years).

Feeling different

7% of the informants were identified as belonging to the group 'Feeling different', since they perceived that the cancer experience affected and hindered daily life to a large extent. The informants stated that they thought about having had cancer frequently or all the time.

Further, they had complications that severely affected and hindered daily life: their view of life was often described as influenced by the cancer experience. A typical description of the situation of one of the informants in this group:

. . . because I was amputated, I am reminded every day of what I have been through and how hard it's been . . . I will be marked by this all my life. I still feel bad from it today. // I have to take a lot of high-dose tablets since I still have so much pain and that makes me pretty tired. // When I think about having had cancer and all I have gone through, it feels heavy. It's because I have lost . . . I've lost so much: friends, some of my adolescence and a bit of everything as well. But of course . . . with time, I have also begun to find things that are positive. I've grown a lot. (Boy, 20 years).

Thoughts about having had cancer

Informants reported that they frequently or constantly thought about having had cancer because there were things in their current lives that reminded them about the cancer and its on-going influence. Thoughts of relapse and possible future long-term complications also troubled them:

It is the . . . cancer that I think a lot about, all the time. What I think is that it might come back. If I get sick, I immediately think about if I have got the cancer back. So I think. (Girl 21 years).

Presence of complications in daily life

Informants reported how complications from the disease and treatment affected their daily lives to a large extent. Physical complications, e.g. having prostheses, decreased strength and chronic pain make it impossible for these informants to be as active as they want. They reported that they were not able to keep up the same pace as others and that from time to time they had to reconsider their activity level. Having to explain to others the reason for being physically weaker was also described as complicating daily life. Descriptions of mental complications included worries and concerns about how informants still had not dealt with having had cancer, as well as having a vulnerable health condition that threatened their future lives. There were also descriptions of feeling bad about not being able to handle their current life situation following the cancer and complications. Cognitive complications, e.g. memory problems, were also reported as affecting school performance and/or impacting ability to recall things in everyday life. Having to take responsibility for pharmacological treatment, e.g. hormone substitution and pain management, was described as complicating everyday life, and having to explain to others the reason for why they were taking medication was also described as a burden:

But I have my problems. My legs are swollen, I have to take medications (hormones that the body can no longer produce) and handle syringes daily. I cannot travel: I have to fight with the hospital to make them give me extra medication, and I have to plan things in detail. It's really complicated to live like this. (Girl, 22 years).

Ability to handle complications

The informants reported that they still felt bad about having had cancer and that they had not yet dealt with the experience. They expressed that it was hard to have complications and that

this still greatly affected their daily lives. They said that they consciously tried to find strategies to handle the complications, but found it hard to find strategies that were adequate and helpful. This informant was often absent from school five years after his initial diagnosis because of his mental complications:

Last time I was absent from school, it was because I felt mentally weak. That's usually the reason, since I feel psychologically fragile and do not have the mental strength to go there. (Boy, 20 years).

View of life

All informants in this group reported both negative and positive changes in their view on life. Negative consequences were described as: being marked for life and feelings of grief about having had cancer. The informants no longer took anything for granted and lived in fear of the cancer coming back, which constrained their outlook on life. Also, the cancer experience influenced who they are now, and this was difficult for others to understand. However, informants also reported that the cancer experience had a positive effect on their view of life, changing their values and priorities. The informants said that their self-knowledge had deepened, their relationships with others had become more positive and that they experienced increased maturity and self-esteem:

Well, I have matured so much. Thus, it might be in advance, but I feel I am a more confident person in myself and like I can stand up for myself and I know what I want and so on. (Girl, 22 years).

Discussion

The results from the present study show that five years after a cancer diagnosis, adolescents and young adults feel that having cancer resulted in them 'Feeling like anyone else', 'Feeling

almost like others' or 'Feeling different'. A clear majority of the young survivors seemed to get along well in spite of major or minor complications from their disease and treatment, which confirms findings from previous studies^{21,29}. However, a small group of the young survivors (7%) experienced influence from major complications that were difficult for them to handle.

Going through childhood cancer is a stressful experience, and how an individual copes with this experience as well as the eventual effect of complications could, from a theoretical point of view, be explained by Antonovsky's salutogenic framework with the core concept Sense of coherence (SOC) and the components 'comprehensibility', 'manageability' and 'meaningfulness'³⁰. This theory explains the relationship between stressors, coping and health and can be measured by the SOC scale³⁰. In a study examining SOC among adolescents with congenital heart disease, results show a relation between low SOC and negatively perceived health³¹. Furthermore, young adults who had an occurrence of epileptic seizure scored lower on the SOC scale than those that were seizure free³². Furthermore, in another study of young adult survivors of childhood cancer, those in need for support rated their SOC statistic significantly lower, compared to those reporting no need of support³³. These prior studies indicate that SOC is an important factor in relation to well-being and perceived health³⁴. In the present study, the informants in the three identified groups described different views of how having childhood cancer affected their daily lives. Our results and the three categories that describe the differences between the groups will be discussed in relation to the three components of the SOC.

Thoughts of having had cancer

Most of the informants rarely or sometimes thought about having had cancer; however, for those in the group 'Feeling different', thoughts about the cancer experience, risk of relapse and how to handle on-going late complications dominated daily life. Seen from the perspective of SOC, informants in the 'Feeling different' group may require more care activities to understand their situation. The component 'comprehensibility' means the extent to which the individual has the ability to understand and make sense of things that happen in life so that future experiences will be perceived as ordered, predictable and explicable^{30,35}. Maybe the informants in the group 'Feeling different' could receive support to increase knowledge and understanding about their cancer experience, which may be a way to deal with the troubling thoughts about having had cancer.

Ability to handle complications

The informants in the groups 'Feeling almost like others' and 'Feeling different' had similar complications, but an interesting finding is that they handled them differently. Informants grouped as 'Feeling almost like others' reported that things like use of prostheses or wheelchair or life-long medication was today integrated into their daily lives. In contrast, informants grouped as 'Feeling different' expressed that their complications were hindering daily activities because they constantly had to reconsider and adjust their activity levels, and this made them feel limited and different from their peers. Seen from the perspective of the SOC, this difference can be understood by the component 'manageability', which refers to the individuals' own perception of being capable of dealing with demands and challenges in life^{30,35}. Informants in the group 'Feeling almost like others' appeared to have adequate resources to manage complications in daily life: they had self-confidence and felt confident that things would work out. The informants grouped as 'Feeling different' may not have had sufficient resources to manage their complications: they could not successfully integrate the

consequences of having had cancer into daily life, and therefore experienced their complications as burdensome.

View of life

A positive consequence on view of life was reported in all three groups, but the informants in the group 'Feeling different' also reported negative effects on their view of life. The reported positive changes including changed priorities, enhanced maturity, personal growth, increased self-esteem and changed relationships; aspects also described in other reports^{17,19-22} and may be an important way to handle the cancer experience. Experiencing positive changes after a cancer experience can be understood as a way to find meaning from the situation, which is consistent with the SOC component 'meaningfulness'^{30,35}. This can help informants adapt to their situation by taking control; however, this was not enough for informants in the group 'Feeling different', because the negative effect on their view of life was still too strong for them to handle and they were unable to adapt.

Being an adolescent is characterised by developing personal identity, gaining autonomy and adopting to new roles in life³⁶. This is probably also a period in life where an individual's SOC is most sensitive to change³. What impact a potential traumatic event such as cancer in childhood has on the formation of SOC has not yet been studied, but a study that compared SOC between young long-term survivors of childhood cancer and young adults in general showed no difference in mean SOC scores³³.

The present study can be seen as an illustration of the challenges faced by young childhood cancer survivors: they describe how their daily lives are affected about five years post diagnosis, depending on their ability to handle thoughts of the experience and long-term

complications. It is important to keep in mind that complications from the childhood cancer experience will continue to influence the individuals' lives³⁷. The three groups in the present study are on different points along the health/disease continuum³⁴; however, it is important to identify those individuals who are most vulnerable, i.e. those that have trouble understanding, handling and making sense of their cancer experience in daily life. With the salutogenic health model for orientation, focus should be on what constitutes health, i.e. how the individual can regain health, in spite of stressful life events³⁴.

Methodological considerations

The trustworthiness of a qualitative study can be considered from the concepts of credibility, dependability and transferability²⁶.

The credibility of the findings in the present study relies on the selection of the sample, the data collection and the analysis procedures. The sample selection is considered to be strong, since all informants belonged to a national cohort including variation in age, gender and residence in both urban and rural areas, and is representative of the most common childhood cancer diagnoses among school-aged children in Sweden. Another strength is that the results represents the view of the young survivors themselves, rather than reporting from parents or healthcare professionals. A response rate of 66% must be considered as acceptable, however the reasons for non-participation are unknown and it is therefore hard to determine whether non-participants experienced no, small or large effects from the childhood cancer experience. Telephone interviews were used for geographical reasons and because they were suitable for this age group of informants, who seemed to be at ease with sharing their experiences in the relative privacy of a telephone call. However, a limitation was that the younger informants more often gave short answers while the older informants gave more detailed descriptions.

Our judgment is that qualitative content analysis was a suitable method for gaining a deeper understanding of adolescents' and young adults' view of what it is like to live with this experience, and the inter-rater reliability of 90% ensures the credibility of the analysis.

The dependability of the findings in the present study is confirmed by the fact that data was collected in the same way from every informant. An interview guide with open-ended questions was used and the interviewers had special training for conducting telephone interviews. During the analysis process, the quality was ensured by continual discussions among the co-authors.

The transferability of the findings in the present study is dependent upon a good description of the study's context, selection and characteristics of the participants, data collection, the process of analysis and an in-depth presentation of the findings. We believe that the results of the present study could be transferred to other groups of young people who are living with long-term health conditions.

Conclusions and clinical implications

In line with previous reports, the findings in the present study show that most of the adolescents and young adults appeared to get along well in daily life, although many informants reported that life was to some extent affected by having had childhood cancer. However, a small group of survivors were troubled in daily life and would benefit from support: this would help them to mobilise the resources needed to manage their daily living situations. Follow-up care in which nurses and other health care professionals can identify those young survivors of childhood cancer that have trouble with daily life and offer them targeted support is needed. By using the salutogenic health model and structured dialogues in

health care it may be possible to identify difficulties in relation to having had cancer among young survivors. There are other studies³⁸ that have concluded that SOC theory can be used to understand how people reflect on how they cope with problems in their everyday lives. Sarenmalm et al. (2013) suggest that SOC could be useful as a tool for identifying individuals in need of support to cope with breast cancer³⁹. Strengthening existing resources and identification of new resources could help young survivors adapt to a changed life following childhood cancer. The chance to talk about the experience with health professionals and with peers who also have survived childhood cancer is a way to do this, since studies show that this increases the informants' knowledge about the disease and helps mobilise coping resources⁴⁰. Further, the survivors may also benefit from improved help from health professionals in terms of their medical complications (such as pain and handling long-term medication regimens).

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References

1. Gatta G, Capocaccia R, De Angelis R, Stiller C, Coebergh JW, Group EW. Cancer survival in European adolescents and young adults. *Eur J Cancer*. 2003;39(18):2600-2610.
2. Gustafsson G, Heyman M, Vernby Å, eds. *The development of pediatric oncology in sweden. Childhood cancer Incidence and Survival in Sweden 1984-2005*. Stockholm: R. f. t. S. C. C. Registry; 2007.
3. Honkinen PL, Suominen S, Helenius H, et al. Stability of the sense of coherence in adolescence. *Int J Adolesc Med Health*. 2008;20(1):85-91.
4. Baggott C, Dodd M, Kennedy C, et al. Changes in children's reports of symptom occurrence and severity during a course of myelosuppressive chemotherapy. *J Pediatr Oncol Nurs*. 2010;27(6):307-315.
5. Moody K, Meyer M, Mancuso CA, Charlson M, Robbins L. Exploring concerns of children with cancer. *Support Care Cancer*. 2006;14(9):960-966.
6. Hedström M, Ljungman G, von Essen L. Perceptions of distress among adolescents recently diagnosed with cancer. *J Pediatr Hematol Oncol*. 2005;27(1):15-22.
7. Jörngården A, Mattsson E, von Essen L. Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: a prospective longitudinal study. *Eur J Cancer*. 2007;43(13):1952-1958.
8. Larouche SS, Chin-Peuckert L. Changes in body image experienced by adolescents with cancer. *J Pediatr Oncol Nurs*. 2006;23(4):200-209.
9. Thompson K, Palmer S, Dyson G. Adolescents & young adults: Issues in transition from active therapy into follow-up care. *European Journal of Oncology Nursing*. 2009;13:207-212.
10. Cantrell MA, Conte TM. Between being cured and being healed: the paradox of childhood cancer survivorship. *Qual Health Res*. 2009;19(3):312-322.
11. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. *Semin Radiat Oncol*. 2003;13(3):248-266.
12. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. *N Engl J Med*. 2006;355(15):1572-1582.
13. Shad A, Myers SN, Hennessy K. Late effects in cancer survivors: "the shared care model". *Curr Oncol Rep*. 2012;14(2):182-190.
14. Kopp LM, Gupta P, Pelayo-Katsanis L, Wittman B, Katsanis E. Late effects in adult survivors of pediatric cancer: a guide for the primary care physician. *Am J Med*. 2012;125(7):636-641.
15. Prasad PK, Bowles T, Friedman DL. Is there a role for a specialized follow-up clinic for survivors of pediatric cancer? *Cancer Treat Rev*. 2010;36(4):372-376.
16. McDougall J, Tsonis M. Quality of life in survivors of childhood cancer: a systematic review of the literature (2001-2008). *Support Care Cancer*. 2009;17(10):1231-1246.
17. Sundberg KK, Lampic C, Björk O, Arvidson J, Wettergren L. Positive and negative consequences of childhood cancer influencing the lives of young adults. *Eur J Oncol Nurs*. 2009;13(3):164-170.
18. Stam H, Grootenhuis MA, Last BF. The course of life of survivors of childhood cancer. *Psychooncology*. 2005;14(3):227-238.
19. Hokkanen H, Eriksson E, Ahonen O, Salanterä S. Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nurs*. 2004;27(4):325-335.
20. Woodgate R, McClement S. Symptom distress in children with cancer: the need to adopt a meaning-centered approach. *J Pediatr Oncol Nurs*. 1998;15(1):3-12.

21. Mattsson E, Ringnér A, Ljungman G, von Essen L. Positive and negative consequences with regard to cancer during adolescence. Experiences two years after diagnosis. *Psychooncology*. 2007;16(11):1003-1009.
22. Enskär K, Berterö C. Young adult survivors of childhood cancer; experiences affecting self-image, relationships, and present life. *Cancer Nurs*. 2010;33(1):E18-24.
23. af Sandeberg M, Johansson E, Björk O, Wettergren L. Health-related quality of life relates to school attendance in children on treatment for cancer. *J Pediatr Oncol Nurs*. 2008;25(5):265-274.
24. Jervaeus A, Kottorp A, Wettergren L. Psychometric properties of KIDSCREEN-27 among childhood cancer survivors and age matched peers - a Rasch analysis. *Quality of Life Research*. 2012;21(Supplement 1).
25. Berg Doukkali E, Winterling J, Eriksson LE, Lampic C, af Sandeberg M, Wettergren L. Adolescent and Young Adult Views of Daily Life Five Years After a Childhood Cancer Diagnosis. *Pediatric, Blood & Cancer*. 2012;59(6):1131.
26. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. Feb 2004;24(2):105-112.
27. Patton M. *Qualitative research & Evaluation Methods*. Thousand Oaks, California: Sage Publications Inc.; 2002.
28. Kazdin AE. *Research Design in Clinical Psychology*. Vol Fourth Edition. Boston: Pearson Education Company; 2010.
29. Wicks L, Mitchell A. The adolescent cancer experience: loss of control and benefit finding. *Eur J Cancer Care (Engl)*. 2010;19(6):778-785.
30. Antonovsky A. *Unraveling the mystery of health; How people manage stress and stay well*. San Francisco, CA: Jossey-Bass Publishers; 1987.
31. Apers S, Luyckx K, Rassart J, Goosens E, Budts W, Moons P. Sense of coherence is a predictor of perceived health in adolescents with congenital heart disease: A cross-lagged prospective study. *International Journal of Nursing Studies*. 2012;07.
32. Gauffin H, Landtblom AM, Råty L. Self-esteem and sense of coherence in young people with uncomplicated epilepsy: a 5-year follow-up. *Epilepsy Behav*. 2010;17(4):520-524.
33. Sundberg KK, Lampic C, Arvidson J, Wettergren L. Sense of coherence and need for support among long-term survivors of childhood cancer. *Cancer Nurs*. 2012;35(4):E43-49.
34. Antonovsky A. The salutogenic model as a theory to guide health promotion¹. *Health Promotion International*. 1996;11. 1:11-18.
35. Flensburg-Madsen T, Ventegodt S, Merrick J. Why is Antonovsky's sense of coherence not correlated to physical health? Analysing Antonovsky's 29-item Sense of Coherence Scale (SOC-29). *ScientificWorldJournal*. 2005;5:767-776.
36. Homburger Eriksson E. *The life cycle completed*. In: Ed., ed. Stockholm: Natur och Kultur; 2004.
37. Shepherd EJ, Woodgate RL. Cancer survivorship in children and young adults: a concept analysis. *J Pediatr Oncol Nurs*. 2010;27(2):109-118.
38. Griffiths CA, Ryan P, Foster JH. Thematic analysis of Antonovsky's sense of coherence theory. *Scand J Psychol*. 2011;52(2):168-173.
39. Sarenmalm EK, Browall M, Persson LO, Fall-Dickson J, Gaston-Johansson F. Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. *Psychooncology*. 2013;22(1):20-27.
40. Patterson P, Millar P, Desille N, Mc Donald F. The Unmet Needs of Emergin Adults With a Cancer Diagnosis. *Cancer Nursing*. 2012;35. 3:32-40.

Table 1. Demographic and Clinical Characteristics of Participating Childhood Cancer Survivors Presented by the Three Identified Groups

	Total Sample	'Feeling Like Anyone Else'	'Feeling Almost Like Others'	'Feeling Different'
Total number, n (%)	59 (100)	29 (49)	26 (44)	4 (7)
Gender, n (%)				
Female	24 (41)	13 (45)	9 (35)	2 (50)
Male	35 (59)	16 (55)	17 (65)	2 (50)
Age at diagnosis, median (min-max)	12 (7-16)	10 (7-15)	13 (8-15)	15 (14-16)
Age at interview, median (min-max)	17 (12-22)	14 (12-21)	18 (12-21)	21 (19-22)
Living situation, n (%)				
With parent/s	52 (88)			
Alone	4 (7)			
Other constellation	3 (5)			
Occupation, n (%)				
School	48 (81)			
Work	6 (10)			
Sick leave	2 (3)			
Diagnosis, n (%)				
Acute lymphoblastic leukaemia	20 (34)			
Skeletal and soft tissue sarcoma	13 (22)			
Tumours of the central nervous system	8 (14)			
Hodgkin's lymphoma	6 (10)			
Non-Hodgkin's lymphoma	5 (8)			
Acute myeloid leukaemia	3 (5)			
Other ^a	4 (7)			

^aSertoli leydig cell tumour and germ cells tumour

Table 2. Description of the Characteristics of the Four Categories by the Three Identified Groups

Identified Groups	Thoughts of Having Had Cancer	Presence of Complications in Daily Life	Ability to Handle Complications	View of Life
Feeling like anyone else	Only rarely think about having had cancer	Have minor or no complications from disease or treatment that influence daily life	If any complications, these are easily handled and not perceived as hindering daily life	View of life is rarely influenced
Feeling almost like others	Sometimes think about having had cancer	Have complications from disease and treatment that to a small extent influence daily life	Complications are not perceived as hindering daily life	View of life is often influenced
Feeling different	Often think about having had cancer	Have complications from disease and treatment that to a large extent influence daily life	Complications are perceived as hindering daily life	View of life is often influenced