Adolescents’ and Young Adults’ Experiences of Childhood Cancer
Descriptions of Daily Life 5 Years After Diagnosis

KEY WORDS
Childhood cancer
Qualitative
Sense of coherence
Survivorship

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 been studied to a limited extent; an increased understanding of this young group is needed to improve follow-up care.

Objective: 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: Fifty-nine 11- to 22-year-olds were interviewed a median of 5 years after a cancer diagnosis (response rate, 66%). Data were collected through telephone interviews and were analyzed using qualitative content analysis techniques. Results: Three groups of informants were identified according to their descriptions of the influence of cancer treatment on their daily life: “feeling like anyone else” (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: Follow-up care is needed 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 pediatric 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 survive. In relation to chemotherapy treatment, children often experience early complications such as lack of energy/fatigue, drowsiness, nausea, pain, poor appetite, as well as physical discomfort and frailty. 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.

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, for example, identity, relationships, school, and future prospects in adulthood.

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 5 years since the cancer diagnosis. Long-term survivors are at an increased risk for long-term effects due to cancer and its treatment. Long-term adverse effects include chronic health problems such as growth and development, function of vital organs, fertility and reproduction, and secondary cancers. With this risk panorama, the young survivors may have to manage ongoing health problems that require long-term follow-up care by health professionals.

Studies examining the life situation among long-term survivors after childhood cancer report both positive and negative consequences. Negative impacts on social development and autonomy, sociodemographic issues such as employment and cohabitation/marriage, and the effects on psychological well-being related to the threat of recurrence and uncertainty about the future have been found. 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 toward life, and improved relationships.

There are only a few studies that have given voice to adolescents’ and young adults’ perceptions regarding the influence that cancer has on the rest of their lives. One previous publication included reports of adolescents attending a cancer adjustment camp regarding their life situation, the support they got, and the information they received about their illness. Another study involved interviews with young adult survivors to examine the long-term effects of childhood cancer on their self-image, relationships, and present lives. The findings revealed that all informants were contacted by telephone by 1 of 3 interviewers and consent to be filled in and sent back to the researchers. The letter containing the core category, “compensated life picture,” relating to how negative experiences of childhood cancer are compensated for by a positive view and expectation regarding life. In the present study, we followed a total national cohort of school-age children (7–16 years) in Sweden diagnosed with cancer for a 2-year period and then followed up 5 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 cancer. The present study involves data collected a median of 5 years after the cancer diagnosis.

Sample

The sample in the present study consists of children who were diagnosed with cancer between the ages of 7 and 16 years during 2004–2006. They were assessed on 3 occasions during initial treatment (n = 118). Children who were treated exclusively with surgery and/or stem cell transplantation and children from families not able to speak or read Swedish were not included in the sample. When the present study was conducted a median of 5 years (63 months) after diagnosis, 23 of the 118 children had died. In addition, 5 children were excluded because of the following reasons: cognitive impairment (n = 2), lack of address (n = 1), and 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 to 17 years, and young adults, as those aged 18 to 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 participants could withdraw from the study at any time. Written assent/consent was obtained from all informants, and for those younger than 18 years, parental permission was also obtained. Potential informants were contacted by telephone by 1 of 3 interviewers within 2 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 who 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

We interviewed participants 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 adult survivors of childhood cancer; based on the results, minor adjustments in the interview guide were made. The telephone interviews were conducted by the first author and 2 fellow researchers who had special training in telephone interview techniques. Interviews lasted a median of 19 minutes (range, 13–60 minutes), were tape-recorded, and then transcribed verbatim.

Data Analysis

The analysis of the transcribed data derived from the telephone interviews was guided by Graneheim and Lundman’s description of the qualitative content analysis process. 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 levels. This is a useful method for analyzing content from interview data with a focus on people’s experiences. The analysis was carried out by the first author, in continuous dialogue with 4 of the coauthors. 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 summarizing each description regarding impact on life. The interviews were then divided into 3 groups based on how its influence on daily life was described. Lastly, identified meaning units of the 3 groups were compared and 4 categories emerged revealing the differences between the groups (Table 2). The analysis was an ongoing process with repeated revisions and modifications until agreement was reached in the research group. Finally, 1 member of the research group not previously involved in the analysis process read half of the interviews and categorized them according to the identified descriptions of the 3 groups (Table 2). Agreement with the original categorization was 90%.

Results

Overall themes indicated that participants were primarily in 1 of 3 groups: “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 4 categories: thoughts about having had cancer, presence of complications in daily life, ability to handle complications, and view of life.
The 3 groups in the aforementioned categories will be presented in the text below, illustrated with quotations.

### Feeling Like Anyone Else

Forty-nine percent of the informants were identified as belonging to the group “feeling like anyone else” because they reported that the cancer had almost no influence on their daily lives. A typical description of the situation from 1 informant in this group is as follows:

...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 COMPICATIONS 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 (eg, 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 ongoing medication.

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

### Ability to Handle Complications

Informants who 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 5 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 affected their 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

Forty-four percent of the informants were identified as belonging to the group “feeling almost like others” because 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 is as follows:

...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 but 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 center 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 changes and integrated them into normal life conditions, even though they had to do things differently compared with their peers. As this girl who had muscles removed in her left leg and worked in a restaurant explained:

Yes...eg, 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 that they were fortunate to have survived cancer and were 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. Both feelings were perceived as contributing to having 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:

...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 sad 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 ongoing 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, for example, 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 after the cancer and complications. Cognitive complications, for example, memory problems, were also reported as affecting school performance and/or impacting the ability to recall things in everyday life. Having to take responsibility for pharmacological treatment, for example, 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 5 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. In addition, 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 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 5 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 despite major or minor complications from their disease and treatment, which confirms findings from previous studies. 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.” This theory explains the relationship between stressors, coping, and health and can be measured by the SOC scale. In a study examining SOC among adolescents with congenital heart disease, results show a relation between low SOC and negatively perceived health. Furthermore, young adults who had an occurrence of epileptic seizure scored lower on the SOC scale than did those who were seizure free. Furthermore, in another study of young adult survivors of childhood cancer, those in need of support rated their SOC statistic significantly lower, compared with those reporting no need of support. These previous studies indicate that SOC is an important factor in relation to wellbeing and perceived health. In the present study, the informants in the 3 identified groups described different views of how having childhood cancer affected their daily lives. Our results and the 3 categories that describe the differences between the groups will be discussed in relation to the 3 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 ongoing 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. Perhaps, 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 such as use of prostheses or wheelchair or life-long medication were 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. 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 3 groups, but the informants in the group “feeling different” also reported negative effects on their view of life. The reported positive changes included changed priorities, enhanced maturity, personal growth, increased self-esteem, and changed relationships, aspects also described in other reports. 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 characterized by developing personal identity, gaining autonomy, and adapting to new roles in life. This is probably also a period in life where an individual’s SOC is most sensitive to change. 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 scores.

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 5 years after 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’ lives. The 3 groups in the present study are on different points along the health/disease continuum; however, it is important to identify those individuals who are most vulnerable, that is, those who 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, that is, how the individual can regain health, despite stressful life events.

Methodological Considerations

The trustworthiness of a qualitative study can be considered from the concepts of credibility, dependability, and transferability. 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 because 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 represent the view of the young survivors themselves, rather than reporting from parents or health care professionals. A response rate of 66% is considered acceptable; however, the reasons for nonparticipation are unknown, and it is therefore hard to determine whether nonparticipants 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, whereas 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 interrater 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 were 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.

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 mobilize 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 who 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 studies 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 suggest that SOC could be useful as a tool for identifying
individuals in need of support to cope with breast cancer. Strengthening existing resources and identification of new resources could help young survivors adapt to a changed life after 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 mobilize coping resources. Furthermore, the survivors may also benefit from improved help from health professionals in terms of their medical complications (e.g., pain and handling long-term medication regimens).

ACKNOWLEDGMENTS

The authors thank the adolescents who agreed to participate in the study and so generously shared their experiences. They also thank the consultant nurses at the 6 national childhood cancer centers in Sweden for their help in recruiting the informants.

References