


ORIGINAL ARTICLE

The gap between expectations and reality: A qualitative study of psychosocial challenges of young childhood cancer survivors from the PACCS study

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Abstract

Objective: In this sub-study from the ‘PACCS’ study, we explored the psychosocial experiences of children and adolescents in everyday life post-cancer treatment and the possible factors that can moderate these experiences.

Methods: This is a qualitative explorative study using semi-structured interviews with 43 childhood cancer survivors between the ages of nine and 18 from Norway and Denmark. We conducted a secondary thematic analysis using Malterud’s systematic text condensation.

Results: Two main themes were identified: ‘The post-treatment gap between expectations and reality’ comprised two subthemes: (1) lack of mastery and feeling different and (2) lack of understanding and acceptance. The second main theme, ‘Managing the gap’, comprised three subthemes: (1) information and knowledge, (2) adjustments and adaptations and (3) social support and openness. The findings reveal that the psychosocial challenges resulted from the remaining ability gap(s). Measures such as tailored information, school adjustments and social support were potential dynamic factors affecting the gap(s) positively or negatively. Psychosocial challenges post-treatment are experiences of lack of acceptance and understanding from others.

Conclusion: To safeguard a positive transition back to everyday life, health care providers should support the survivors’ psychosocial care, including getting back to school and re-entering social interactions.

KEYWORDS

childhood cancer survivors, PACCS study, post-cancer, psychosocial, qualitative interviews

Marie Hamilton Larsen and Kjerstin Enger Hansson shared first authorship.

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1 | BACKGROUND

Survivors of childhood cancer may risk upsetting the psychosocial development secondary to their primary diagnosis, treatment and medical late effects (Brinkman et al., 2018). Hence, the cancer diagnosis and treatment may lead to acute distress, adjustment difficulties, maladaptive coping, missed educational prospects and reduced social engagement with peers (Desjardins et al., 2020; Sansom-Daly & Wakefield, 2013). Due to improvements in diagnostics and treatment options for childhood cancer, the current 5-year survival rate is around 85%, resulting in a rapidly growing population of survivors (Siegel et al., 2017). However, despite complete remission, survivors are at risk of adverse behavioural, emotional and social outcomes associated with treatment exposures and physical late effects (Brinkman et al., 2016).

In line with increasing survival rates, there has been a shift in attention towards the psychosocial aspects of survivorship (Darcy et al., 2016), aimed at providing more holistic cancer care. This effort is important, as children and adolescents who have survived cancer not only face the risk of adverse consequences of their disease and treatment but also face the normal developmental challenges associated with childhood and adolescence, such as rapid biological, emotional and social changes (Salchow et al., 2020). Survivors must therefore negotiate and master the cumulative psychosocial challenges from two different worlds—'the healthy' and 'the ill'—during this already vulnerable life phase.

Some research has been conducted into the subjective experiences of survivorship among adolescent childhood cancer survivors during adolescence (Belpame et al., 2019), but today's knowledge is mainly based on the retrospective perspectives of adult and young adult survivors of childhood cancer (Darcy et al., 2019). As a result, the voices of young survivors are currently poorly represented in the literature. Moreover, the existing studies often focus on specific aspects of how cancer affects life, such as studying the presence and significance of a few specific late effects or one specific cancer diagnosis (Baker et al., 2017). This approach may not capture the complexity of surviving cancer and how cancer can simultaneously affect many domains of everyday life. For example, physical late effects such as headache, fatigue or problems with coordination may affect the psychological, social and emotional areas of life (Kim et al., 2018).

School represents an important arena for children and adolescents. It is not only a place of academic development but also an arena for physical, psychological and social development, including socialisation, connecting with peers and receiving emotional and academic support from teachers, all of which are important factors for psychological well-being and adjustment (Jose et al., 2012; Plage et al., 2022). A recent systematic review found that re-entry to school was challenging for most childhood cancer survivors due to treatment side effects, prolonged absences, disrupted peer relationships, a lack of preparation and a lack of communication between schools, families and health care professionals (Martinez-Santos et al., 2021). Improved knowledge of the psychosocial challenges

faced by young survivors could therefore be useful to not only improve psychosocial care but also potentially better facilitate school re-entry and attendance.

Survivors report not only adverse outcomes after cancer but also positive post-cancer effects, such as increased empathy and post-traumatic growth (Steinberg et al., 2020). These aspects add to the complexity of attempting to understand how the cancer experience affects the lives of young survivors (Belpame et al., 2019). Exploring children and adolescents' psychosocial experiences in everyday post-cancer life will therefore provide important knowledge for more holistic follow-up care. Addressing the limitations of the current evidence base, this study aimed to explore the everyday psychosocial experiences of children and adolescents during the early years of post-cancer treatment and explore possible factors that can moderate these experiences.

2 | METHODS

This study is a sub-study of the larger international 'Physical Activity among Childhood Cancer Survivors (the PACCS study)' (Lie et al., 2022), with the primary aim of investigating physical activity and fitness among young childhood cancer survivors. It includes a qualitative study aimed at exploring the perspectives of young survivors and their parents on facilitators and barriers to physical activity after cancer through in-depth semi-structured interviews at the Norwegian and Danish sites. The interviews provided rich information not only on participation in physical activity but also many aspects of life after cancer, including psychosocial challenges. We therefore conducted an inductive secondary thematic analysis of their accounts of such challenges, which are presented in this sub-study.

2.1 | Sampling

A total of 43 Norwegian and Danish childhood cancer survivors (ages nine to 18) participated in semi-structured interviews. Inclusion criteria were having completed their cancer treatment at least 1 year before the interview. They received follow-up care at the Children and Adolescents' Clinic at Oslo University Hospital, Haukeland University Hospital or the Pediatric Oncology Outpatient Clinic at the University Hospital of Copenhagen (Rigshospitalet). Exclusion criteria were a lack of consent, language difficulties, cognitive dysfunction or mental retardation. A targeted selection strategy was carried out to maximise variation in ages, diagnoses, treatment protocols, time from the end of treatment and different places of residence (geographical and urban/rural).

2.2 | Data collection

The participants received written information about the study from a study nurse, including an invitation to an interview when attending an

outpatient follow-up consultation. The study nurse also called the participants to confirm participation and schedule the interview. Recruitment and data collection were performed from January 2018 through May 2020.

The childhood cancer survivors were interviewed by experienced researchers, research assistants or nurses (EHL, HCL, SH, BG, NNP and MB) (five female and one male). The researchers were experienced within paediatric cancer survivorship research. The research assistants had received training prior to the interviews in communicating with children in a cancer setting. The nurses had extensive clinical experience from childhood oncology wards and all interviewers were used to communicating with children and adolescents. Only two of the interviewers (EHL and SH) knew some of the participants prior to the study, as they had been working as paediatric nurses at the hospital ward during the children's cancer treatment. These interviews were of the same quality as the others, indicating that the participants felt they could talk openly. None of the interviewers had been involved in the follow-up care provided to the participants. All interviews started by providing information about the study background and aim and a brief introduction of the interviewer. By using open-ended questions, we ensured that the participants could reflect on their own experiences and had the opportunity to introduce themes important to them. Psychological support was available at the hospital's child and adolescent mental health services if needed. The survivors and parent were interviewed separately in a suitable room at the hospital ($n = 33$) or in their homes ($n = 10$). All interviews, with the exception of four, were conducted without the presence of parents. The interviews were audio-recorded and transcribed verbatim. The mean duration of the interviews was 20 min [min-max 7–39].

The interview guide was based on the World Health Organization's International Classification of Functioning Disability and Health for Children and Youth (ICF-CY) (World Health Organization, 2007) in order to investigate barriers and facilitators to physical activity. The interview guide is available as Data S1. Although the focus of the interview guide was on physical activity, the explorative semi-structured method and open-ended questions elicited rich descriptions of psychosocial aspects of everyday life after cancer treatment.

2.3 | Ethical considerations

Ethical approval was granted through the Regional Committee for Medicine and Health Research Ethics 2016/953 in Norway and the Regional Ethics Committee for Denmark's Capital Region (file. H-19032270). The Data Protection Officer at the hospitals also approved the study. The consent text provided information about the study objective to explore barriers and facilitators to physical activity and potential psychosocial challenges in daily life after cancer treatment. All children received age-appropriate information that participation in the study was voluntary and that the data would be processed anonymously. Children under the age of 16 gave verbal consent and

their parents written, while older adolescents gave written consent before the interview started. The participants were assured that personal information would be treated confidentially and that they could withdraw from the study at any time without any consequences for their care.

2.4 | Data analysis

The secondary analysis of psychosocial issues was conducted separately from the analysis of barriers and facilitators to physical activity by KEH, HCL and EHL. We used an inductive approach based on Malterud's systematic text condensation (Malterud, 2012). NVivo 12 was also used as a qualitative data analysis tool (Jackson & Bazeley, 2019). The analysis included the four steps proposed by Malterud, while the fifth step consisted of a deductive approach to the Danish interviews performed by three authors (NNP, MKF and HBL). More details are provided in Table 1. Two main themes were identified, with subthemes including the analytical text with quotations.

The combined results after the deductive analysis were discussed in several digital meetings with the Norwegian and Danish teams to secure consistency and rigour in the results and to discuss cultural variances and illustrative quotes. The names of the themes and subthemes were revised and adjusted to their final form.

3 | FINDINGS

3.1 | Participants

Sixteen female and 27 male childhood cancer survivors participated in this study. Participant characteristics are provided in Table 2.

3.2 | Results from the systematic text condensation

Two main themes of everyday psychosocial experiences of children and adolescents were identified. The first main theme, *The post-treatment gap between expectations and reality*, deals with experienced psychosocial challenges in everyday life. The second main theme, *Managing the gap*, includes experiences identified as psychosocial factors that can alter these challenges. We chose to label these 'dynamic factors' as they affect 'the gap' by either widening or closing it.

3.2.1 | Theme 1 'The post-treatment gap between expectations and reality'

After completing cancer treatment, many of the psychosocial challenges reported by the young survivors could be perceived as ability gaps. These gaps appeared between their own and others'

TABLE 1 The four steps of systematic text condensation inspired by Malterud

Step	Description of tasks:
Step 1, From wilderness to themes.	<ul style="list-style-type: none"> To get an overview of the data, the first step involved repeated readings of the material. The impressions and thoughts were summarised in some themes that intuitively attracted our attention.
Step 2, Identifying and sorting meaning units	<ul style="list-style-type: none"> With the themes from Step 1 in mind, we systematically read through the interviews to capture and classify pieces of text into codes. The aim was to collect text that has something in common into codes. Four interviews were thoroughly read through and coded by the same two authors individually. These codes were then discussed and adjusted jointly. This safeguarded rigour in this part of the analysis. A codebook was created for further analysis, and all the other interviews were coded based on the codebook. A matrix was created for the organisation where the material under the various codes originated. This was a flexible process, the meaningful units were often double- and triple-coded, and the codes had to be re-evaluated and adjusted along the way. Any changes to the codebook were discussed and resulted in re-coding of interviews when necessary. This interaction gave breadth and depth to the analysis process.
Step 3, Condensation—from code to meaning	<ul style="list-style-type: none"> Here, we abstracted the knowledge that each code group represented into condensates. A matrix was used in this process to systematise the condensation. Illustrative quotes were identified.
Step 4, Summary—from condensation to descriptions and concepts	<ul style="list-style-type: none"> The condensates and illustrative quotations were used to create an analytical text, where the authors take on the role of a reteller and write in the third person. This step is called reconceptualising and led to adjustments of the main themes and sub-themes in step with our growing understanding of the research material.
Step 5, Deductive analysis of the Danish interviews	<ul style="list-style-type: none"> The Danish interviews were coded using the Norwegian codebook and the main themes and sub-themes from the inductive analysis. Three authors used a deductive approach to the Danish interviews. The Danish analysis consisted of the following steps: (1) thorough reading of the Norwegian findings to get an understanding of the main themes and sub-themes, (2) repeated readings of the Danish interviews to get an overview of the data and (3) systematically reading, coding and classify the main themes and the sub-themes.

expectations versus their actual physical and cognitive abilities, which were often experienced to be limited compared to expectations. The psychosocial challenges that arose were the experience of (1) lacking mastery and feeling different and (2) absence of understanding and acceptance.

Lacking mastery and feeling different

The survivors talked about a functional gap resulting from cancer treatment, which affected their everyday lives. Fatigue was the late effect that most survivors experienced as hindering, and some felt that they could not master what they wanted to master, such as participating in certain recreational activities (Table 3a, illustrative quote Q1). The childhood cancer survivors also talked about additional cognitive late effects. Some experienced the academic level at school as problematic because they could not perform at the expected levels (Table 3a, Q2).

Closely linked to the experience of lack of mastery, the survivors experienced having thoughts about what could have been if it were not for the cancer, treatment and subsequent late effects. Several experienced the functional gap as giving them a different everyday life than they might have wanted or expected (Table 3a, Q3). Some talked about expecting to regain a functional level corresponding to their pre-cancer level and not being able to do activities as before or

because their peers made the functional gap and feeling of being different more evident. They expressed disappointment when they realised that their expectations did not always correspond to the perceived reality. For example, one girl described how her life had changed. Before the illness, she was an active athlete who competed on a national level, but post-cancer, she experienced failing the physical demands of her sport, which necessitated a change to her ambitions and redefining part of her identity (Table 3a, Q4). These experiences contrast with survivors who did not experience a difference in physical function after the cancer treatment compared to before (Table 3a, Q5).

For childhood cancer survivors who were very young at the time of diagnosis and did not remember their lives before they became ill, it was difficult to know what to compare themselves with and what was 'normal' and what was not (Table 3a, Q6). For them, feeling different resulted from comparing themselves to other friends and peers and voicing a desire to master what 'everyone else' achieved (Table 3a, Q7).

Absence of understanding and acceptance

Experiencing a perceived lack of understanding and acceptance from peers, family, teachers and coaches was mentioned by several as challenging. They voiced a need to be treated like everyone else, whether

TABLE 2 Participant characteristics

	n (%) Norway (n = 22)	n (%) Denmark (n = 21)	N (%) Total (N = 43)
Girls	8 (36)	8 (38)	16 (37.2)
Boys	14 (64)	13 (62)	27 (62.8)
Age and habitation	Mean (SD)		
Mean age at interview	14 (SD 2.7)	11.6 (2.6)	12.8 (2.7)
	n (%)		
10–14 years at interview	11 (50)	13 (62)	24 (56)
15–18 years at interview	11 (50)	8 (38)	19 (44)
Living in an urban setting	9 (40)	20 (95)	29 (67.4)
	Median (range)		
Median age at diagnosis	8 (0.5–15)	6 (1–17)	7(0.5–17)
Median years after treatment	4 (1–12)	6 (2.3–13.5)	5(1–13.5)
Diagnosis	n (%)		
Leukaemia	8 (36.4)	7(33.3)	15 (34.9)
Hodgkin lymphoma	3 (13.6)	1(4.8)	4 (9.3)
Non-Hodgkin lymphoma	5 (22.7)	1(4.8)	6 (14)
Extracranial solid tumours	3 (13.6)	1(4.8)	4 (9.3)
Central nervous system tumour	3 (13.6)	11 (52.4)	14 (32.6)
Treatment	n (%)		
Bone marrow–transplant	4 (18.2)	0	4 (9.3)
Radiation	7 (27.2)	6 (29)	12 (27.9)
Chemotherapy	22 (100)	17 (81)	39 (90.7)
Surgery	6 (27.2)	11 (52.4)	17 (39.5)

at school or hiking, for example. All the same, they needed recognition and understanding in situations in which they did not achieve the expected levels of performance. Especially fatigue reappeared as a late effect that could be difficult to understand, manage and accept, not only by the survivors but especially by those around them, such as friends, family and teachers at school (Table 3a, Q8). A lack of understanding and acceptance from friends could make the survivors feel different and in some cases, resulted in outright bullying (Table 3a, Q9 and Q10). There is also a gap between other people's and their own understanding and acceptance, between the childhood cancer survivors and their parents (Table 3a, Q11) and at school (Table 3a, Q12).

3.2.2 | Theme 2 'Managing the gap'

The second main theme identified psychosocial factors that could make the perceived ability gap less apparent or potentially non-existent, though at the same time could widen the perceived gap if lacking. This theme encompasses three subthemes: (1) information and knowledge, (2) adjustment and adaptation and (3) social support and openness.

Information and knowledge

Information about late effects was considered by many to be essential to increasing their own and others' understanding and

acceptance of the survivor's situation. In the Danish interviews, the young survivors rarely expressed a need for information about potential late effects, although some of the Danish participants were surprised by the late effects when they did arise, they did not let it interfere with their daily activities. In contrast, some Norwegian participants reflected on the need for more information about possible late effects, including fatigue, in order to increase their understanding and motivation to make the necessary adjustments in everyday life (Table 3b, Q13).

Some childhood cancer survivors said they received information on the late effects too late because they had already 'pushed' themselves too hard and considered this a reason for why they developed more severe fatigue (Table 3b, Q14). Information emerged as something positive that could increase their own and others' understanding and acceptance, thereby increasing a sense of mastery and reducing a sense of being different. Consequently, information and knowledge helped to 'manage the gap'. Some survivors, however, also voiced a need to stop talking about cancer and get on with their lives, getting annoyed when health care professionals wanted them to reflect on the cancer experience (Table 3b, Q15).

Adjustments and adaptations

Several survivors stated a need for adjustments and adaptations in their own lives due to the ability gap (Table 3b, Q16). They needed to rest and adapt their activity level in everyday life depending on the

TABLE 3a Illustrative quotes from Theme 1

Quotations in text	Illustrative quotes
3.2.1 Theme 1 'The post-treatment gap between expectations and reality'	
Lacking mastery and feeling different	
Q1	<i>Female 16 years (p22):</i> 'It's kind of like ... I do not know if it is the right word, but you get a little inhibited in a way, not managing to exercise as much as you want. Because after cancer, I got fatigued, which means that you do not always manage to exercise as much as you would like'.
Q2	<i>Male 14 years (p1):</i> 'I have a lot of late effects, like concentration problems and I forget quickly, but I do remember something better if I've seen and heard it ... At school, it can be very challenging. I've only received extra assistance a few times and sometimes a bit more simplified tests. If there is a lot of new information, I can get very tired; it is worse than being physically tired. All my school subjects are difficult except the practical subjects, which I'm able to handle'.
Q3	<i>Female 13 years (p49):</i> 'I think I would be more physically active because I like to be physically active, but it [my foot] causes many restrictions. For example, I cannot run or buy any pair of running shoes. I have to get specially made shoes because my foot is different'.
Q4	<i>Female 17 years (p2):</i> 'I thought I would start training again (endurance sport), experience difficulties at first and then 'skyrocket' to where I was before [...]. When I started again, that was my mindset. It took six to 12 months before I realised that this would not happen. It was emotionally painful knowing that I was not going to reach the level where I wanted to be'.
Q5	<i>Male 15 years (p3):</i> 'I was a bit weak, I think, in the beginning. My body was broken down, but I built it up again and trained gradually and now I am back to normal. I exercise quite a lot and am in good condition'.
Q6	<i>Female 18 years (p14):</i> 'I'm aware that I've been sick, but I do not remember much of it (the treatment). So I do not know if these are side effects from the disease or if it's just that I'm tired in general or an average teen in that sense [...]. Because I have no idea [...]. It would have been different if I had gotten sick now because then I would've known how I was before'.
Q7	<i>Male 11 years (p15):</i> 'I could not keep up ... It was very difficult for me because before [cancer], no one could keep up with me'.
Absence of understanding and acceptance	
Q8	<i>Female 17 years (p12):</i> 'I feel that I cannot participate in gym class and that it affects my grade negatively ... And it's very difficult when I cannot do things. To be punished for that ... I do not have the necessary skills, I cannot manage things ... It's a bit like that, it's a bit tough'.
Q9	<i>Female 17 years (p2):</i> 'For me, the worst part was not the disease, but friends who just forgot me in a way. They thought I could not participate in things—so they just stopped inviting me [...] I was not bullied, I was banned [...] I sort of had friends "at school," but no "after-school" friends and that is actually quite different'.
Q10	<i>Female 17 years (p2):</i> 'I remember losing my friends. I had no one. None of my friends supported me and I never had any, I had none, everyone just disappeared. That's probably what I remember most [...]. I was bullied at school because I had short hair and stuff. Looking back, I think they were scared and did not dare to ask anything—it was easier not to relate to me than to ask me about things, but for me, it was like I thought they no longer liked me [...] I was very much alone then, I became very introverted by this, too, and ... it probably made me struggle. I am still struggling with anxiety and social anxiety. Because for me, the worst part in fact, what causes the most pain, were my friends and not the disease'.
Q11	<i>Male 14 years (p1):</i> 'He [his father] says I should be as active as he is, but I cannot do it all the time ... No ... but my dad does not understand that ... And then he gets irritable and then ...'
Q12	<i>Male 17 years (p31):</i> 'It was probably the fact that you have been through all this and the school cannot help you with the everyday learning you lost at school in basic subjects like math, Danish and English [...]. I have changed school three times because they could not help me'.

context, such as school, recreational activities/training and socialising with friends (Table 3b, Q17).

The importance of finding balance in everyday life was evident in the interviews. One girl elaborated on essential everyday goals, such as being at school alone, not needing a wheelchair and brushing her teeth without fainting. Her siblings and parents were essential facilitators in the transition back to 'normal' (Table 3b, Q18). Some survivors also talked about the perceived need for practical and educational facilitation at school, such as smaller groups, shorter days, limited classes or simplified assignments. The importance of support and

understanding from teachers was evident (Table 3b, Q19). One boy talked about the teacher who understood him and his lack of energy and explained it to the class, and who therefore was 'one of the best teachers in the world' (Table 3b, Q20). Some explicitly stated they had switched to smaller schools to manage their school attendance (Table 3b, Q21).

Social support and openness

Several children and adolescents described the importance of social support from friends, family, teachers and health professionals, both

TABLE 3b Illustrative codes from Theme 2**3.2.2 Theme 2: Managing the gap**

Information and knowledge

- Q13 *Female 16 years (p22)*: ‘Umm ... [long pause] That's probably the thing. I had no idea what things would be like after cancer. It actually took a year before I could do physical exercise again. And I did not know that exercise affected me—that it could help me stay stronger. So if someone had informed me about that earlier, I think it might have helped me’.
- Q14 *Female 18 years (p12)*: ‘I do not remember hearing anything about it (fatigue) before I got it. I did not think about it, so I went back to everyday life in a way [...] I pushed myself too hard for a long time—and then my body reacted because I become so exhausted. I think it is important that they [future CCS] explain this clearly, so they do not make the same mistake I did’.
- Q15 *Female 18 years (p12)*: ‘So when I was talking to the psychologist, what he wanted was to talk about the past and stuff, to accept what has happened, but I was not interested in that because I have accepted what has happened and that's the way it is. So, we ended it (psychologist appointments) [smiles]. I was not interested, I just wanted to move on, look forward and not back’.

Adjustments and adaptations

- Q16 *Male 17 years (p31)*: ‘About an hour before [physical activity], I take some acetaminophen and it reduces the pain. I can then endure a bit longer and then take more acetaminophen when I'm done [with physical activity]’.
- Q17 *Female 16 years (p22)*: ‘After the cancer treatment, I learned that I needed to be better at scheduling activities and things I do with friends. The things that require that I focus more. For example, if we are having a sleepover, I kind of have to make sure I can go to sleep a bit early. I can then handle being with my friends all day instead of having to lie down all the next day, doing nothing’.
- Q18 *Female 17 years (p12)*: ‘I remember I went to school, was there for half an hour sitting in a wheelchair, and then my mom had to come and pick me up again. So, my mother simply sat in the car in the parking lot, waiting for me’.
- Q19 *Male, 17 years (p39)*: ‘No, I think they [the physical education teachers] kept an extra eye on me. When I said that something hurt, they understood why. Otherwise, I would participate in all activities in physical education class’.
- Q20 *Male 11 years (p15)*: ‘He is one of the world's best teachers if you ask me. As [name] our teacher explained, usually, when people sleep, their battery recharges fully. But mine was only half full and was used up again much faster’.
- Q21 *Female, 15 years (p57)*: ‘I had to switch schools because there were stairs and that's not the best conditions for a wheelchair. So I was behind in class, so it was easier to start a new school and repeat a year’.

Social support and openness

- Q22 *Female 17 years (p2)*: ‘When I mention something I'm struggling with, they [the friends] help a lot. I have this scar from the Venous Access Port ... And especially when I found out one day that you can actually feel where the pipe was by the neck [points], they helped me a lot by saying ‘It's okay, [her name]’ and things like that, and that “you should almost show it more”—because it shows that you have gone through something hard’.
- Q23 *Male, 13 years (p16)*: ‘If they ask, I talk about it, but it's usually not a topic I bring up ... I talk about it, but not much. I'm done talking’.
- Q24 *Female 17 years (p2)*: ‘It's like, I often say, “I've had cancer and I could have died,” [...] and I use it a little too much [...] We have a lot of fun with it really. Because, it sounds a bit wrong, but I'm a bit dependent on being able to talk about it because it was really traumatic [...] I also think it's so much fun to see how shocked people are when I tell them that I've had cancer’.
- Q25 *Female, 15 years (p57)*: ‘It's a long time ago now, but I do remember some things. I remember the operations before and after, like the [treatment-related] side effects like fatigue. I remember the doctors and nurses at the hospital. And the other kids. The overall positive atmosphere in the hospital, even though it was a very serious situation. It was homey and there were always activities to do’.
- Q26 *Female, 17 years (p19)*: ‘In a way, I've determined the path I want to take [as a nurse]. It's in the department here [the paediatric ward at the hospital]’.

during their illness and on returning to everyday life. One girl talked about how her friends helped her accept a treatment-related scar, thereby changing her view of its significance (Table 3b, Q22).

Openness emerged as essential for receiving social support, increasing understanding, acceptance, facilitation and mastery, and consequently, support in reducing and ‘managing the gap’. The survivors believed it was essential to be open about their cancer in their relationships with friends and peers. The vast majority of the childhood cancer survivors said that their friends knew that they had had cancer and thought it was important to answer questions that others may have. Some said they no longer needed to talk about cancer, as they no longer thought about the disease (Table 3b, Q23). This is in contrast to one adolescent girl, who actively used her cancer

experience in social contexts with friends. Through humour, she garnished attention, which also stimulated her need to process the experience (Table 3b, Q24).

Positive experiences related to cancer treatment and how it affected them in their everyday lives were highlighted. The survivors described positive memories from hospital stays, such as meeting new people and the friendly hospital staff (Table 3b, Q25). One adolescent talked about having changed her career path to paediatric nursing, giving her a sense of ‘deeper meaning’ in life, stating a desire to contribute with her own experiences (Table 3b, Q26). It emerged that thinking positive thinking or focusing on opportunities rather than restrictions can be essential to moderating the gap or making it less prominent.

4 | DISCUSSION

This study aimed to explore how childhood cancer survivors experience the post-treatment psychosocial consequences of cancer. A secondary aim was to investigate possible factors that might moderate these experiences. An important finding was that the psychosocial challenges discussed were often a consequence of a 'gap' between the survivors' or others' expectations of how things should be after treatment completion compared to how they were experienced. This 'gap' can be seen as a result of the survivors' altered physical capacities or capabilities before and after cancer. For children diagnosed at a young age, the 'gap' mirrors a difference with their peers. The perceived size of the 'gap' varied across the sample. It can be argued that our study, with its focus on activity, is biased in these findings. However, our results are similar to a German study focusing on parental perspectives during their child's cancer trajectory and reintegration process. That study found that parents of survivors of leukaemia or brain tumours experienced that their children slowly regained physical strength after the end of treatment. Due to exhaustion from obligatory activities, reintegration into recreational activities was experienced as demanding and it was physically and emotionally challenging for some children to continue their daily activities. Twenty of the 49 parents interviewed reported that their children suffered long-term physical consequences or cognitive consequences of their cancer and its treatment (Inhestern et al., 2020). Another study found similar results in long-term childhood cancer survivors (age 19 to 39). Additionally, these survivors showed considerable understanding of their physical strength levels and found an appropriate balance between activities and rest and replenished their energy when they felt tired, which is in line with our results (Hong et al., 2021).

In our study, some survivors identified that a lack of mastery of activities and tasks led to feeling lonely or different from how they were before cancer or from their peers. This became especially evident in social settings at school, where classmates showed a different level of maturity. Another aspect is that late effects, both physical and psychosocial, can affect a survivor's everyday life (van Deuren et al., 2020). Previous research shows that returning to school and re-entering other social interactions after cancer is essential for normal psychosocial maturation (Helms et al., 2016). This corresponds with the conclusion that most survivors do well without major psychosocial problems after being treated for cancer (Bitsko et al., 2016). However, an important insight offered by the current study is that many survivors struggled to manage the 'gap' after treatment completion, but found ways to manage it, thereby eliminating or reducing their experience of psychosocial challenges.

An important psychosocial challenge was the experience of a lack of acceptance and understanding from others and several talked about losing friends or having to make new ones. Physical changes, such as hair loss or weight change, can make children and young people vulnerable to social exclusion and rejection from friends (Helms et al., 2016). Moreover, physical changes can develop into emotional ailments in feeling different, experiencing social isolation and influencing psychological maturation processes such as identity development

and self-esteem (Kim et al., 2018). This is consistent with our findings and aligns with research showing that the risk of being bullied is higher in cancer survivors than in the general population (Collins et al., 2019).

A Swedish study (Darcy et al., 2019) explored how small children experienced everyday life during 3 years of cancer. This study found experiences similar to those in our study: the desire to be like other children, the need for security and control and a sense of loneliness and not fitting in. The importance of feeling 'normal' and that childhood cancer gives them a sense of being different from healthy peers is also obvious in our findings. Hence, maintaining normality is described as a struggle in several studies (Belpame et al., 2019). At the same time, these findings address an essential balance in the survivor experience that our participants voiced, namely, being considered 'normal' alongside the acknowledgement of the significance of the cancer ordeal they had been through.

In the second main theme, 'Managing the gap', several factors were identified that could positively affect everyday life and the perceived functional gap, referred to as dynamic moderators. There seems to be a connection between their presence and the experience of the post-treatment gap. It has previously been shown that adults who have been treated for childhood cancer were not aware of the increased risk of late effects (Ruud et al., 2012). In this study, some participants voiced a need for more information about late effects from health care professionals, especially regarding fatigue. Their experience seemed to be that too much activity too soon post-treatment made them more fatigued in the longer term. However, studies show that increased physical activity is associated with less cancer-related fatigue, both during treatment and in the first years post-treatment (Spreafico et al., 2021; Van Dijk-Lokkart et al., 2019).

Two critical points emerge here that are consistent with previous research. On the one hand, late effect information should be provided to all children and adolescent patients and their families in order to enhance their health autonomy (Gianinazzi et al., 2022). A previous study found that adult lymphoma survivors wanted information about late effects, preferably in young adulthood (Lie et al., 2015). On the other hand, information, especially aimed at children and adolescents, is challenging in terms of how much and which type of information they want or can deal with emotionally (Zebrack & Isaacson, 2012). This underscores the importance of also directing such information to parents and the social support system (Darcy et al., 2019).

The importance of social support and facilitation of activities is clear through all subthemes, from family, friends, teachers and health care professionals alike. Social support is vital for everyday life function (Darcy et al., 2016). The vast majority of participants are open about the disease with their friends. For some survivors, this openness was a way to elicit increased acceptance and understanding. Another possible reason for openness is a desire for more support and to increase the possibility of facilitation. A meta-analysis (Helms et al., 2016) highlights the importance of interventions in strengthening social support. They found a significant effect of support

programmes for returning to school, so-called 're-entry programmes', to increase academic achievement and lower the risk of depression. By increasing the classmates' level of knowledge, their fears were reduced, resulting in increased positive attitudes towards the child with cancer.

Several survivors wanted to focus on the future and were 'done talking' about cancer, potentially testifying a sense of normality. This correlates with research that shows that childhood cancer survivors do quite well in everyday life, even if the cancer experience has a significant impact on their functioning (Belpame et al., 2019). Studies have explored post-traumatic growth in childhood cancer survivors in recent years, that is, experiencing positive psychological changes after a trauma, such as concerning one's life perspective, priorities and relationships (Turner et al., 2018).

4.1 | Strengths and limitations

One strength of this study is that the psychosocial themes emerged spontaneously and were not prompted by questions in the interview guide, as the questions were primarily about physical activity. We therefore assume that these themes are important to the childhood cancer survivors interviewed. The large sample size and three study sites provide variation in terms of participant diagnosis, type of treatment, age, country of origin and time span after finished treatment, which is also a strength, reflecting a broad range of experiences. The fact that the Danish deductive approach verified the Norwegian findings in all subthemes strengthens our findings.

There are also weaknesses worth noting. This is a secondary analysis of spontaneously occurring themes, so essential follow-up questions may not have been asked. Our findings describing the 'gap' that develops as a result of the changed physical capabilities might also reflect the physical activity focus of the study and could have resulted in a bias towards the physical impact of cancer, including the effects of fatigue and their psychosocial consequences. However, for young survivors, physical activities represent important arenas for being social with friends. Therefore, it appeared that the survivors naturally discussed both topics as an integrated whole. Importantly, there were no questions directed at late effects or fatigue specifically. Therefore, information on fatigue and other psychosocial aspects of their everyday life arose spontaneously during the interviews, not elicited by the interviewers. The secondary analysis was also initiated based on the notion that information about psychosocial challenges and experiences characterise childhood cancer survivors' everyday lives. This can be seen both as a strength and a weakness.

5 | CONCLUSION

In this study, emerging ability 'gaps' between expectations and the reality of everyday life after cancer treatment were identified. These

gaps were associated with psychosocial challenges that affected the participants' daily lives in various ways and to varying degrees. Our study identified several factors that positively reduced these gaps, such as tailored information, adjustments in school and social support, which endorse the call for individualised, psychosocial follow-up after cancer treatment. As such, our results add to the scarce literature on psychosocial challenges of young childhood cancer survivors, including information about helpful ways to deal with these challenges. This knowledge might be helpful in informing about more holistic follow-up care and future interventions focusing on psychosocial issues in early survivorship after childhood cancer.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request and subject to approval by the local data protection officer and the regional committees for medical and health research ethics.

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REFERENCES

- Baker, K. S., Toogood, A. A., Hawkins, M., & Nathan, P. C. (2017). Adolescent and young adult cancer survivors: Late effects of treatment. In A. Bleyer, R. Barr, L. Ries, J. Whelan, & A. Ferrari (Eds.), *Cancer in adolescents and young adults* (pp. 687–710). Springer International Publishing. https://doi.org/10.1007/978-3-319-33679-4_28
- Belpame, N., Kars, M. C., Deslypere, E., Rober, P., Van Hecke, A., & Verhaeghe, S. (2019). Living as a cancer survivor: A qualitative study on the experiences of Belgian adolescents and young adults (AYAs) after childhood cancer. *Journal of Pediatric Nursing*, 49, e29–e35. <https://doi.org/10.1016/j.pedn.2019.07.015>
- Bitsko, M. J., Cohen, D., Dillon, R., Harvey, J., Krull, K., & Klosky, J. L. (2016). Psychosocial late effects in pediatric Cancer survivors: A report from the children's oncology group. *Pediatric Blood & Cancer*, 63, 337–343. <https://doi.org/10.1002/pbc.25773>
- Brinkman, T. M., Li, C., Vannatta, K., Marchak, J. G., Lai, J. S., Prasad, P. K., Kimberg, C., Vuotto, S., di, C., Srivastava, D., Robison, L. L., Armstrong, G. T., & Krull, K. R. (2016). Behavioral, social, and emotional symptom comorbidities and profiles in adolescent survivors of childhood cancer: A report from the childhood cancer survivor study.

- Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 34, 3417–3425. <https://doi.org/10.1200/jco.2016.66.4789>
- Brinkman, T. M., Recklitis, C. J., Michel, G., Grootenhuys, M. A., & Klosky, J. L. (2018). Psychological symptoms, social outcomes, socioeconomic attainment, and health behaviors among survivors of childhood Cancer: Current state of the literature. *Journal of Clinical Oncology*, 36, 2190–2197. <https://doi.org/10.1200/jco.2017.76.5552>
- Collins, D. E., Ellis, S. J., Janin, M. M., Wakefield, C. E., Bussey, K., Cohn, R. J., Lah, S., & Fardell, J. E. (2019). A systematic review summarizing the state of evidence on bullying in childhood cancer patients/survivors. *Journal of Pediatric Oncology Nursing*, 36, 55–68. <https://doi.org/10.1177/1043454218810136>
- Darcy, L., Björk, M., Knutsson, S., Granlund, M., & Enskär, K. (2016). Following young children's health and functioning in everyday life through their cancer trajectory. *Journal of Pediatric Oncology Nursing*, 33, 173–189. <https://doi.org/10.1177/1043454215610489>
- Darcy, L., Enskär, K., & Björk, M. (2019). Young children's experiences of living an everyday life with cancer—a three year interview study. *European Journal of Oncology Nursing*, 39, 1–9. <https://doi.org/10.1016/j.ejon.2018.12.007>
- Desjardins, L., Rodríguez, E., Dunn, M., Bemis, H., Murphy, L., Manring, S., Winning, A., Vannatta, K., Gerhardt, C. A., & Compas, B. E. (2020). Coping and social adjustment in pediatric oncology: From diagnosis to 12 months. *Journal of Pediatric Psychology*, 45(10), 1199–1207. <https://doi.org/10.1093/jpepsy/jsaa077>
- Gianinazzi, M. E., Kiserud, C. E., Ruud, E., & Lie, H. C. (2022). Who knows? Information received, and knowledge about, cancer, treatment and late effects in a national cohort of long-term childhood, adolescent and young adult cancer survivors. *Cancers*, 14, 1534. <https://doi.org/10.3390/cancers14061534>
- Helms, A. S., Schmiegelow, K., Brok, J., Johansen, C., Thorsteinsson, T., Simovska, V., & Larsen, H. B. (2016). Facilitation of school re-entry and peer acceptance of children with cancer: A review and meta-analysis of intervention studies. *European Journal of Cancer Care*, 25, 170–179. <https://doi.org/10.1111/ecc.12230>
- Hong, H. C., Min, A., & Choi, S. (2021). Living with the late effects of childhood cancer treatment: A descriptive qualitative study. *International Journal of Environmental Research and Public Health*, 18(16), 8392. <https://doi.org/10.3390/ijerph18168392>
- Inhestern, L., Peikert, M. L., Krauth, K. A., Escherich, G., Rutkowski, S., Kandels, D., & Bergelt, C. (2020). Parents' perception of their children's process of reintegration after childhood cancer treatment. *PLoS ONE*, 15(10), e0239967. <https://doi.org/10.3390/ijerph18168392>
- Jackson, K., & Bazeley, P. (2019). *Qualitative data analysis with NVivo*. Sage.
- Jose, P. E., Ryan, N., & Pryor, J. (2012). Does social connectedness promote a greater sense of well-being in adolescence over time? *Journal of Research on Adolescence*, 22(2), 235–251. <https://doi.org/10.1111/j.1532-7795.2012.00783.x>
- Kim, Y., Lee, K. S., & Koh, K. N. (2018). Difficulties faced by long-term childhood cancer survivors: A qualitative study. *European Journal of Oncology Nursing*, 36, 129–134. <https://doi.org/10.1016/j.ejon.2018.08.003>
- Lie, H. C., Anderssen, S., Rueegg, C. S., Raastad, T., Grydeland, M., Thorsen, L., Stensrud, T., Edvardsen, E., Larsen, M. H., Torsvik, I. K., Bovim, L. P., Götte, M., Lähteenmäki, P. M., Kriemler, S., Larsen, H. B., Fridh, M. K., Ørstavik, K., Brun, H., Matthews, I., ... Ruud, E. (2022). The Physical Activity and Fitness in Childhood Cancer Survivors (PACCS) study: Protocol for an international mixed methods study. *JMIR Research Protocols*, 11(3), e35838. <https://doi.org/10.2196/35838>
- Lie, H. C., Loge, J. H., Fosså, S. D., Hamre, H. M., Hess, S. L., Mellblom, A. V., Ruud, E., & Finset, A. (2015). Providing information about late effects after childhood cancer: Lymphoma survivors' preferences for what, how and when. *Patient Education and Counseling*, 98, 604–611. <https://doi.org/10.1016/j.pec.2015.01.016>
- Malterud, K. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, 40, 795–805. <https://doi.org/10.1177/1403494812465030>
- Martinez-Santos, A. E., Fernandez-De-La-Iglesia, J. D. C., Sheaf, G., & Coyne, I. (2021). A systematic review of the educational experiences and needs of children with cancer returning to school. *Journal of Advanced Nursing*, 77, 2971–2994. <https://doi.org/10.1111/jan.14784>
- Plage, S., Kuskoff, E., Hoang, N.-P., & Povey, J. (2022). Educational participation of primary school children with cancer from a life course perspective: A critical review of the literature. *International Journal of Educational Research*, 114, 101990. <https://doi.org/10.1016/j.ijer.2022.101990>
- Ruud, E., Kanellopoulos, A., Zeller, B., Widing, E., Tjønnfjord, G. E., & Fosså, S. D. (2012). Patient knowledge of late effects of acute lymphoblastic leukaemia. *Tidsskrift for den Norske Lægeforening*, 132, 2052–2055. <https://doi.org/10.4045/tidsskr.12.0153>
- Salchow, J., Mann, J., Koch, B., von Grundherr, J., Jensen, W., Elmers, S., Straub, L. A., Vettorazzi, E., Escherich, G., Rutkowski, S., Dwinger, S., Bergelt, C., Sokalska-Duhme, M., Bielack, S., Calaminus, G., Baust, K., Classen, C. F., Rössig, C., Faber, J., ... Stein, A. (2020). Comprehensive assessments and related interventions to enhance the long-term outcomes of child, adolescent and young adult cancer survivors—presentation of the CARE for CAYA-Program study protocol and associated literature review. *BMC Cancer*, 20, 16. <https://doi.org/10.1186/s12885-019-6492-5>
- Sansom-Daly, U. M., & Wakefield, C. E. (2013). Distress and adjustment among adolescents and young adults with cancer: An empirical and conceptual review. *Translational Pediatrics*, 2(4), 167–197. <https://doi.org/10.3978/j.issn.2224-4336.2013.10.06>
- Siegel, R. L., Miller, K. D., & Jemal, A. (2017). *Cancer Statistics, 2017*. CA: A Cancer Journal for Clinicians, 67, 7–30. <https://doi.org/10.3322/caac.21387>
- Spreafico, F., Barretta, F., Murelli, M., Chisari, M., Gattuso, G., Terenziani, M., Ferrari, A., Veneroni, L., Meazza, C., & Massimino, M. (2021). Positive impact of organized physical exercise on quality of life and fatigue in children and adolescents with cancer. *Frontiers in Pediatrics*, 9(523), 627876. <https://doi.org/10.3389/fped.2021.627876>
- Steinberg, D. M., Santiago, R. A., Tanenbaum, M. L., Cline, G. D., & Schneider, N. M. (2020). “It made me the person I am today ...”: Survivors of childhood, adolescent, and young adult cancer reflect on their experiences. *Journal of Adolescent and Young Adult Oncology*, 9, 239–246. <https://doi.org/10.1089/jayao.2019.0122>
- Turner, J. K., Hutchinson, A., & Wilson, C. (2018). Correlates of post-traumatic growth following childhood and adolescent cancer: A systematic review and meta-analysis. *Psycho-Oncology*, 27, 1100–1109. <https://doi.org/10.1002/pon.4577>
- van Deuren, S., Boonstra, A., van Dulmen-den Broeder, E., Blijlevens, N., Knoop, H., & Loonen, J. (2020). Severe fatigue after treatment for childhood cancer. *Cochrane Database of Systematic Reviews*, 3, CD012681. <https://doi.org/10.1002/14651858.CD012681.pub2>
- van Dijk-Lokkart, E., Steur, L. M. H., Braam, K. I., Veening, M. A., Huisman, J., Takken, T., Bierings, M., Merks, J. H., van den Heuvel-Eibrink, M., Kaspers, G. J. L., van Dulmen-den Broeder, E., & van Litsenburg, R. (2019). Longitudinal development of cancer-related fatigue and physical activity in childhood cancer patients. *Pediatric Blood & Cancer*, 66(12), e27949. <https://doi.org/10.1002/pbc.27949>

World Health Organization. (2007). *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY*. World Health Organization.

Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 30, 1221–1226. <https://doi.org/10.1200/jco.2011.39.5467>

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