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Psychosocial health in children and adolescents surviving cancer

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Aim: To explore psychosocial health in children and adolescents surviving cancer three years after diagnosis compared with healthy controls, as assessed by adolescents themselves, their parents and teacher.

Material and methods: Case–control study included 50 children and adolescents diagnosed with cancer between 1 January 1993 and 1 January 2003 and treated at the Paediatric Department St. Olav's University Hospital, Trondheim, Norway. Data were collected using the Strengths and Difficulties Questionnaire (self-report, parent report and teacher report), as well as the Achenbach System of Empirically Based Assessment questionnaire (teacher report).

Results: Children surviving cancer had more emotional symptoms, higher total problem scores and poorer academic performance than their peers. Emotional problems were consistently reported by parents, teachers and adolescents themselves, in particular in children with brain tumours and among survivors with late effects.

Conclusion: Our study shows that children surviving cancer are at higher risk for emotional problems when compared with their friends, even after several years following diagnosis and treatment. We conclude that when planning long-term follow-up care, rehabilitation of children and adolescents with cancer, especially for survivors with brain tumours and late effects, should particularly take into account their psychological problems and psychosocial functioning.

Keywords: children, adolescents, cancer, survivors, mental health, psychosocial functioning, emotions, behaviour.

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Introduction

Cancer in children is no longer considered a fatal disease, but more as a chronic life-threatening illness that is potentially curable (1–4). Nonetheless, the diagnosis of cancer is a crisis for both the child and its family where they face many challenges to achieve normality after diagnosis (5). Intensive medical treatment together with its side effects and prolonged periods of uncertainty about the outcome can result in long-term physical and psychosocial problems for parents and child (6–10).

The increasing survival rates for childhood cancer have led to a concern in quality of life (11), psychological adjustment and late effects (9). However, research on psychosocial outcome for cancer survivors has shown varying and conflicting results (12–15). A number of studies and reviews have reported adverse outcomes including an increased prevalence of behavioural (16, 17), emotional (18–20) and learning problems (5) compared with healthy controls (21). Yet, other studies have found that depression in survivors of childhood cancer equal to that of healthy controls (13, 22, 23). Many studies have also demonstrated that cancer survivors, including children, fare the same or even better than those who have

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not had cancer (24, 25) in view of psychological well-being (8, 22, 26, 27), resilience and appreciation for life and relationships (9, 14, 15, 28, 29). However, children with cancer are a heterogenous group in respect to age, diagnosis and actual late effects. Thus, these varying results found in research on psychosocial outcome for survivors of childhood cancer may reflect the differences of the child's age, diagnosis or any late effects in the population studied.

Furthermore, many studies have included children and parent responses or parent and teacher responses in relation to psychosocial health (5, 26–30), whereas other studies (15, 21, 22, 24, 25, 31) have included a matched healthy control group. However, none of these studies particularly addressed the adolescents' psychological functioning as assessed by themselves, their parents and teachers.

The aim of this paper is to explore psychosocial health in children and adolescents surviving cancer at least 3 years after diagnosis compared with healthy controls as assessed by adolescents themselves, their parents and teacher.

Materials and methods

Study design

This population-based, case–control study was carried out between April 2007 and May 2008. It includes children and adolescents in Central Norway from the ages of six to 20 years who were diagnosed with cancer between 1 January 1993 and 1 January 2003. Eligible for participation were children that had completed their cancer treatment at the Paediatric Department, St. Olav's University Hospital, Trondheim, and survived at least three years after diagnosis. Data were collected using questionnaires mailed to the respective families and the invited child's teacher, and by reviewing the child's medical records. A control group was recruited by asking children and adolescents in the study group to invite one friend of the same gender and age (±1 year) to participate, as well as one of the friend's parents and teacher. Questionnaires were sent to these invited families and teachers.

Study population

Children surviving cancer. Of the 109 eligible children, a total of 50 (46%) children and one of their parents participated. Of these 50 children were 29 (58%) boys and 21 (42%) girls, aged 6–20 years and born in the period of 1987–2001. The median age was 12.5 years (interquartile range: 10.0–16.0), with 29 (58%) being adolescents (12–20 years). The children took part in this study 4–16 years (median: 7.5; interquartile range: 6.0–10.2) after their cancer diagnosis and 1–13 years (median: 6.0; interquartile range: 4.0–7.2) after completion of treatment. The group included children with leukaemia (n = 20), malignant brain tumours (n = 13), lymphoma (n = 5) and solid or soft tissue tumours (n = 12) (Table 1). Of the 50 parents, 45 consented to further contact the child's teacher, whereof 36 teachers responded.

There were no differences between participants and nonparticipants regarding background data such as age, gender or diagnoses.

Control children. Of the 50 families in the study group, 40 gave written consent to contact one friend to participate as

Table 1 Background information of children included in the study

	Survivors		*Controls*		
	N	*%*	*N*	*%*	
Total	*50*	*100*	*29*	*100*	*p-value*
Gender					
Female	21	42	14	48	0.59
Male	29	58	15	52	
Age					
<12 years	21	42	8	27	0.20
≥12 years	29	58	21	73	
Family economical situation					
Poor economy	7	14	2	7	0.19
Average economy	21	42	5	17	
Good economy	18	36	11	38	
Children live with*					
Both parents or one parent with partner single parent	36	72	24	82	0.07
*Three participants (two young adults with cancer and one in the control group) lived on their own	12	24	2	7	

a control in the study, and 29 (73%) peers and one of their parents agreed to participate. Of these, 15 (52%) were men and 14 (48%) were women aged 6–20 years, born in the period of 1987–2001. The median age was 12.0 years (10–14.5), with 21 of the 29 (73%) being adolescents (Table 1). Of the 29 parents, 24 gave written consent to further contact the child's teacher and 19 teachers responded.

Study variables

Psychosocial health. The Strengths and Difficulties Questionnaire (SDQ) (32) is a brief behavioural screening questionnaire for children and adolescents aged 4–16 years. The SDQ was completed by the participants themselves, aged 12 years and older (self-report), while children and adolescents were also assessed by one of their parents (parent report) and teacher (teacher report). It includes 25 items (rated 0–1–2), constituting four problem scales (scored 0–10): emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, which are added to a total difficulties score (0–40), and a Prosocial behaviour scale (scored 0–10).

The *Emotional symptoms scale* includes questions about headaches, stomach-aches, worrying, as well as if the child is unhappy, nervous or clingy, or has many fears or easily becomes scared. *Conduct problems scale* covers behavioural problems, 'temper tantrums' or problems with lying or fighting. *Hyperactivity/Inattention scale* includes if the child is restless, overactive, fidgeting, being easily distracted or having a poor attention span. The *peer problems scale* includes if the child is rather solitary, has problems with friendship or bullied. The *pro-social scale* includes if the child is considerate of others, sharing with others and is helpful and kind.

Academic performance and adaptive functioning in school. The Achenbach System of Empirically Based Assessment (ASEBA) – Teacher Report Form (TRF) is a screening instrument on emotional and behavioural symptoms for ages 6–18 years (33). We used the Academic Performance and Adaptive functioning scales. These items were completed by teachers who were familiar with the child's functioning in school. The child's academic performance was evaluated on a scale from 1 to 5 (1: far below grade level, 5: far above grade level). The adaptive characteristic questions were evaluated on a scale from 1 to 7 (1: much less, 7: much more) compared to typical pupils of the same age, covering working habits, learning capacity, behaviour and mood.

Parents' socioeconomic status. Socioeconomic status (SES) was calculated according to Hollingshead's two-factor index of social position scaled one (low) to five (high), based on a combination of parents' education and occupation (34). Parents also evaluated their economical situation as 'poor', 'average' or 'good'; reports were completed by 46 (of 50) cancer survivors and 18 (of 29) controls.

Background data. Parents gave information about demographic data (where and who they lived with, number of children and marital status). Parents of a child with cancer were also asked about their child's diagnosis, as well as their child's health status at the time of this study. Based upon these questions, we defined a variable called late effects that included somatic health problems that could probably be related to the cancer diagnosis or its treatment. Somatic diagnoses and psychological symptoms were also collected from the child's medical records.

Ethics

Ethical approval was obtained from the Regional Committee for Medical and Health Research Ethics in Central Norway (Ref.nr. 4.2006.2610), also ensuring that the project did not violate the UN Convention of the Rights of the Child (CRC) (1991). Approval was given for a single written reminder, whereas permission was not given to get in touch with the individual families by telephone. A letter with written information was sent to families of all eligible children inviting them to participate. Written consent to participate in this study, as well as access to the child's medical records, was given by the participant or by one of the child's parents, if the child was under 16 years of age. Families also gave written consent to contact the child's teacher and a friend of the same gender and age. Approval by the Norwegian Social Science Data Services (Ref.nr. 15372/JE) was obtained for a license to maintain a register containing personal data.

Statistical analysis

SPSS for Windows version 16.0 (SPSS Inc, Chicago, IL, USA) was used for data analysis. Group differences were analysed using Chi-square statistics and Mann–Whitney *U*-test for nonparametric data. Two-sided p-values ≤ 0.05 were considered statistically significant. We used a general linear model to control for sociodemographic covariates such as gender, age parental socioeconomic and marital status. Pearson correlation coefficient was used to study the association between the 'number of years after diagnosis' and the SDQ Symptom Score. We did not correct for multiple comparison because our results were coherent and such methods used for adjusting for multiple comparisons (i.e. Bonferroni correction) are conservative as well as likely to detract the results (35–38). Nonetheless, we have been careful in our interpretation of results with p-values between 0.01 and 0.05.

Results

Group characteristics

There were no group differences between children surviving cancer and the control group regarding the

children's age, gender or in the parents' educational and economical status (Table 1). Mean SES score was 3.8 (SD: 1.1) for parents of children with cancer, compared with 3.7 (SD: 1.2) in the control group (p = 0.8). Twelve (24%) children with cancer lived with single parents compared with two (7%) children in the control group (p = 0.07) (Table 1). There was no significant correlation found between 'number of years after diagnosis' and the SDQ Symptom Score for parents (r varying from −0.20; p = 0.17 to 0.172; p = 0.24).

Psychosocial health – SDQ results

Children surviving cancer had significantly higher mean scores on the *SDQ total difficulties score* when assessed by their parents compared with the control group (Table 2). This was particularly evident among children with brain tumours (p < 0.001). However, children with leukaemia also had higher mean total difficulty scores when assessed by their parents (p = 0.05). Teachers reported a higher total difficulties score for children with brain tumours than for control children (p = 0.003) (Table 2). There was no difference on the total difficulties score in the adolescent self-report, although the mean score for children with brain tumours was 14.1 (SD: 8.3) compared with 7.9 (SD: 3.8) in the control group (p = 0.09) (Table 2).

Table 2 Psychosocial health as assessed by the Strengths and Difficulties Questionnaire (SDQ), completed by parents, teachers and adolescents

	Survivors Mean (SD)	*Controls Mean (SD)*	
SDQ – parent report	*n = 50*	*n = 26*	*p-value*
Emotional symptom scale	2.28 (2, 4)	1.12 (2.2)	0.003
Conduct problem scale	1.28 (1.3)	0.88 (0.7)	0.36
Hyperactivity scale	3.37 (2.6)	1.85 (1.6)	0.01
Peer problem scale	2.31 (2.6)	1.04 (1.4)	0.04
Prosocial scale	8.21 (1.6)	8.65 (1.3)	0.27
Total difficulty scale	9.44 (6.8)	4.88 (4.2)	0.004
SDQ – teacher report	n = 36	n = 19	
Emotional symptom scale	1.67(2.2)	0.79 (2.3)	0.02
Conduct problem scale	0.58 (1.2)	0.95 (1.3)	0.20
Hyperactivity scale	2.83 (2.7)	2.58 (3.2)	0.47
Peer problem scale	2.00 (2.6)	1.05 (1.4)	0.33
Prosocial scale	6.74 (2.5)	8.58 (1.8)	0.003
Total difficulty scale	7.08 (7.0)	5,37 (6.8)	0.31
SDQ – adolescent self-report	n = 29	n = 21	
Emotional symptom scale	2.96 (2.6)	1.48 (1.9)	0.02
Conduct problem scale	1.93 (1.8)	1.30 (1.4)	0.31
Hyperactivity scale	3.78 (2.6)	4.00 (1.8)	0.72
Peer problem scale	1.93 (2.4)	1.05 (1.1)	0.35
Prosocial scale	8.38 (1.8)	8.52 (1.4)	0.95
Total difficulty scale	10.59 (6.7)	7.90 (3.8)	0.13

On the *emotional symptom scale*, children surviving cancer had higher mean scores than children in the control group, on the parent, teacher and self-report (Table 2). Mean scores on the parent report were considerably higher on the emotional symptom scale both in children with brain tumours (p = 0.005 vs. control) as well as in children with leukaemia (p = 0.01 vs. control), whereas teachers reported higher mean scores in children with brain tumours (p < 0.001). Although mean scores for adolescents with brain tumours were 4.0 (SD: 3.6) and leukaemia 2.3 (SD: 1.8), they did not differ statistically significant from controls (p = 0.08 and p = 0.09, respectively). The first item on the emotional subscale concerns head/abdominal pain, and to explore if this item was the dominating factor explaining the higher emotional scores in the case group, we re-analysed our data excluding this item. In this case, the differences on the emotional subscale between cases and controls persisted on the parent and on the adolescent self-report; however, it disappeared when rated by teachers.

On the *conduct problem scale*, children surviving cancer did not differ from control children on any reports. Parents, however, reported higher mean *hyperactivity/inattention scale* score for the cancer group as a whole as well as for children with brain tumours (p = 0.005) and leukaemia (p = 0.01), when compared with the control group.

On the *peer problem scale*, children surviving cancer had higher mean scores than control children when assessed by their parents. However, no difference was reported specifically in children with brain tumours or leukaemia (parent report). Teachers reported only higher mean scores in children with brain tumours (p = 0.003) compared with the control group.

On the *pro-social behaviour scale*, only teachers reported lower mean scores for children surviving cancer compared with control children, which applied also in the subgroups with brain tumours (p = 0.001) and leukaemia (p = 0.01).

In multivariable analysis age, gender and parental marital status did not change the main results obtained on the parent report (for emotional and total difficulty scores) for children surviving cancer as a whole, nor for children surviving a brain tumour and late effects. Adjusting for sex and parental marital status did not change the results on the adolescent self-report, while the difference on the emotional symptom scale between adolescents surviving cancer and controls became statistically borderline significant (p = 0.06) when adjusted for age and nonsignificant when adjusted for socioeconomic status. On the teacher report, the difference on the emotional symptom score between the case and control disappeared while differences on the pro-social score persisted when adjusted for sex, age, socioeconomic and parental marital status (data not shown).

Table 3 Academic performance and adaptive functioning assessed by the Achenbach System of Empirically Based Assessment (ASEBA) questionnaire, completed by teachers

	Survivors n = 36	*Controls n = 18*	
Aseba – teacher	*Mean (SD)*	*Mean (SD)*	*p-value*
Academic performance	2.65 (1.1)	3.44 (0.63)	0.01
How hard is he/she working?	3.77 (1.7)	4.56 (1.7)	0.13
How appropiately is he/she behaving?	4.86 (1.4)	4.83 (1.5)	0.89
How much is he/she learning?	3.78 (1.7)	4.65 (1.2)	0.07
How happy is he/she?	4.28 (1.2)	5.06 (1.1)	0.02
Total adaptive functioning sum – (excluding academic performance)	16.70 (4.8)	19.1 (4.9)	0.12

Academic performance and total adaptive functioning – ASEBA teacher report (TRF)

Children with cancer had lower mean scores on their academic performance, as well as on some adaptive characteristic questions, compared with control children (Table 3). This was especially evident in the group of children with brain tumours for academic performance ($p = 0.001$) and total adaptive score ($p = 0.005$; data not shown). There was a trend in the same direction also for children with leukaemia academic performance ($p = 0.07$) and how happy he/she is ($p = 0.06$; data not shown).

Somatic late effects in children surviving cancer

Twenty (40%) parents indicated that their child had late effects, something which was also confirmed through the children's medical records. All 20 children had physical problems, including pituitary (n = 6) and gonad (n = 3) deficiency, growth problems (n = 1), diffuse muscle pain (n = 5), lung problems (n = 2), dry eyes (n = 1), blindness (n = 2), impaired eyesight (n = 1), trembling/shaky hands (n = 1), as well as weight problems (n = 2) and problems with teeth enamel (n = 2).

Of these 20 (40%) children registered with one or more late effects, eight (40%) were diagnosed with leukaemia, nine (45%) with brain tumours, three (15%) with solid or soft tissue tumours. There were no late effects registered for children diagnosed with lymphoma.

Psychological problems in children surviving cancer

Sixteen of the 20 children registered with late effects also had psychological symptoms, eight (50%) children with brain tumours and six (38%) with leukaemia. According to medical records, 12 of these 16 children (75%) had been referred to Child and Adolescent Psychiatric Services because of symptoms of anxiety (n = 4), depression (n = 4), behavioural problems (n = 4), eating problems (n = 1) or suspected attention deficit-hyperactivity disorder (n = 2). The remaining four (25%) children had concentration problems, fatigue, cognitive and learning disabilities, or were socially isolated. Through the children's medical records, there were no other children registered in this study with psychological problems.

The association between somatic late effects and psychosocial health

Children with late effects had higher SDQ mean scores than control children on the total difficulties, emotional symptoms and peer problems scales, as reported by parents ($p \leq 0.001$), teachers ($p < 0.01$) and the adolescents themselves ($p < 0.05$) (Table 4). In addition, children with cancer who had late effects had higher SDQ mean scores than children *without* late effects on total difficulties, emotional symptoms and peer problems scales, as reported by parents ($p \leq 0.001$) and teachers ($p < 0.01$), but only on peer problems scales on self-reports ($p = 0.02$). Parents also reported higher mean scores for children with late effects on the conduct problems and hyperactivity/inattention scales. Teachers reported lower mean scores on the pro-social behaviour scale for both children with and without late effects compared with the control group ($p = 0.001$ and $p = 0.05$ respectively). Teachers also scored lower on the pro-social behaviour scale for children with late effects when compared with children without late effects ($p = 0.03$). Teachers also reported higher mean scores on the conduct problems scale for children without late effects compared with the control group ($p = 0.04$). Adolescents showed a trend to higher mean scores on the emotional symptoms scale also for children without late effects ($p = 0.07$).

Academic performance, as well as several adaptive characteristics, was scored lower (by teacher) for children with cancer who had late effects than for children with no late effects ($p = 0.005$) as well as healthy control children ($p < 0.001$) (Table 5). Furthermore, there was a tendency of lower mean scores reported by teachers on one of the adaptive questions of 'how happy he or she is' for children with *no* late effects compared with the control group ($p = 0.07$).

Table 4 Psychosocial health as assessed by Strengths and Difficulties Questionnaire (SDQ) in children with and without somatic late effects

	No late effects Survivors Mean (SD)	*Late effects Survivors Mean (SD)*	*Controls Mean (SD)*
SDQ – parent report	n = 30	n = 20	n = 26
Emotional symptoms scale	1.30 (1.7)	3.75 (2.5)***	1.12 (2.2)
Conduct problems scale	1.10 (1.3)	1.55 (1.2)*	0.88 (0.7)
Hyperactivity scale	2.52 (2.3)	4.60 (2.6)***	1.85 (1.6)
Peer problems scale	1.17 (1.6)	3.95 (2.8)***	1.04 (1.4)
Prosocial behaviour scale	8.39 (1.4)	7.95 (2.0)	8.65 (1.3)
Total difficulties score	6.29 (5.3)	13.85 (6.2)***	4.88 (4.2)
SDQ – teacher report	n = 24	n = 12	n = 19
Emotional symptoms scale	1.00 (1.7)	3.00 (2.5)***	0.79 (2.3)
Conduct problems scale	0.38 (1.1)*	1.00 (1.2)	0.95 (1.3)
Hyperactivity scale	2.08 (2.2)	4.33 (2.9)	2.58 (3.2)
Peer problems scale	1.12 (2.1)	3.75 (2.7)**	1.05 (1.4)
Prosocial behaviour scale	7.41 (2.2)*	5.50 (2.5)***	8.58 (1.8)
Total difficulties score	4.58 (5.8)	12.08 (6.8)**	5.37 (6.8)
SDQ – adolescent self-report	n = 19	n = 9	n = 21
Emotional symptoms scale	2.42 (2.2)	4.11 (3.1)*	1.48 (2.3)
Conduct problems scale	1.89 (1.6)	2.00 (2.3)	1.30 (1.1)
Hyperactivity scale	3.89 (2.9)	3.56 (2.2)*	4.00 (2.0)
Peer problems scale	1.16 (1.5)	3.56 (3.2)	1.05 (1.1)
Prosocial behaviour scale	8.45 (1.6)	8.22 (2.3)	8.52 (1.4)
Total difficulties score	9.28 (6.4)	13.22 (6.8)*	7.90 (4.8)

*p < 0.05; **p < 0.01; ***p < 0.001 vs. controls.

Table 5 Academic performance and adaptive functioning as assessed by Achenbach System of Empirically Based Assessment (ASEBA) questionnaire in children with and without somatic late effects

Aseba teacher report	*No late effects Survivors Mean (SD)* *n = 18*	*Late effects Survivors Mean (SD)* *n = 13*	*Controls Mean (SD)* *n = 18*
Academic performance	3.02 (0.9)	2.00 (1.0)[c],**	3.44 (0.6)
How hard is he/she working?	4.17 (1.5)	3.07 (1.9)[a]	4.55 (1.6)
How appropiately is he/she behaving?	5.26 (1.2)	4.15 (1.5)*	4.83 (1.5)
How much is he/she learning?	4.30 (1.6)	2.84 (1.4)[c],**	4.06 (1.6)
How happy is he/she?	4.39 (1.2)	4.07 (1.1)[a]	4.52 (1.2)
Total adaptive functioning sum – (excluding academic performance)	18.13 (4.3)	14.15 (4.7)[b],*	17.45 (4.9)

[a]p < 0.05; [b]p < 0.01; [c]p < 0.001; late effects vs. controls.
*p < 0.05; **p < 0.05; late effects vs. no late effects.

Discussion

We found that children surviving cancer had more emotional symptoms, higher total problem scores and poorer academic performance than their peers. Emotional problems were consistently reported by parents, teachers and adolescents themselves, in particular for childhood survivors with brain tumours and late effects. Parents, teachers and adolescents, in addition, assessed different problems as being of significance.

Strengths of the study are the comprehensive assessment of psychosocial health by the adolescents themselves, their parents and school teachers, as well as the inclusion of children with different cancer diagnoses and a control group. Moreover, both SDQ and ASEBA are well-established questionnaires that have been tested for their reliability and validity in the Norwegian population (32, 33, 36, 37).

The relatively low number of participants, resulting in low power to demonstrate small differences, may be a limitation. Lack of statistically significant findings should therefore be interpreted with caution. However, the observed differences found between children surviving cancer and controls were statistically highly significant,

making chance an unlikely cause of the main findings. We did not correct for multiple comparisons, because the results were coherent. Moreover, methods correcting for multiple testing are highly conservative and may thus detract the results (35, 37). The low response rate (48%), although not uncommon in long-term follow-up studies (39) and particularly in mailed surveys (25), is another limitation. In the control group, the response rate regarding SES and 'economical situation' was even lower than the group of childhood cancer survivors. However, there were no obvious differences between participants and nonparticipants regarding background data such as age, gender or diagnoses.

Confounding by sociodemographic key variables such as age, gender, parental marital and socioeconomic status is unlikely because there were no differences between the case and control groups. Moreover, multivariable analyses did not essentially change the results, the main results on the parent report of the SDQ emotional and total score persisted for survivors of a brain tumour and late effects. Furthermore, even though there was a great variation between the years elapsed after the child's diagnosis (4–16 years), there was no significant correlation found between the 'number of years after diagnosis' and the SDQ Symptom Score for parents.

Although the main results were mainly consistent for emotional problems on all reports, some information bias cannot be ruled out because parents and teachers were aware of the cancer diagnosis and may, hence, have overemphasized any problems in the case group. However, studies including diagnostic assessment of mental health in children with other chronic diseases such as cerebral palsy (41) and children of very low birth weight (42) have found SDQ completed by parents to give reliable information about the children's mental health status, thus making information bias less likely. In addition, peers as controls can be another potential bias, because they may not be representative of the background population (40). One possible bias could be that the control group is 'supernormal'. However, the SDQ scores in the control group of the present study are very similar to the scores in a randomly selected control group of adolescents from the same region (42). Finally, an epidemiological study did not find significant differences between friends as controls or an 'ideal' control group with respect to paternal age as well as maternal and paternal education, even if it was not considered an optimal control group in that study (40). On the other hand, peers selected as a control group (24, 43) may be more likely to share common interests (8) and attitudes with the case group and may therefore be more similar in terms of psychosocial health. This would be expected to decrease differences between groups.

The large differences in mean scores between the case and the control group may support a causal relation. Moreover, our finding of higher emotional problem scores, especially in brain tumour survivors and survivors with late effects, is consistent with a number of previous studies and reviews of mental health and psychosocial functioning in childhood cancer survivors (5, 18, 20, 21). However, other studies found that most survivors of childhood cancer function well psychologically (8, 13–15, 23–26) and did not have more emotional problems than controls (24). Yet, few studies have reported results from adolescent themselves, compared with controls. This inconsistency in outcomes between studies may be because of differences in sample size and outcome measures, as well as to the selection of the case population and comparison group (15). In this study, our findings of more emotional symptoms, higher total problem scores and poorer academic performance, especially in children surviving brain tumours and late effects, may support these varying results. Most importantly in this respect is that our results are in keeping with two comparable studies of childhood cancer survivors using the SDQ as an outcome measure (5, 21). In one of these studies, Upton and Eiser (2006) found higher mean scores for brain tumour survivors reported by parents and teachers, while in another study, Reinfjell et al. (2009) found higher mean scores for ALL (acute lymphoblastic leukaemia) on the parent report. Reinfjell et al. (2009) found no differences for ALL compared to controls on the adolescent self-report, which may be consistent with our results, although the difference on the emotional symptom scale between adolescents surviving cancer and controls became statistically borderline significant ($p = 0.06$) when adjusted for age and nonsignificant when adjusted for socioeconomic status. Moreover, the difference on the emotional symptom score between the case and control disappeared when adjusted for sex, age, socioeconomic and parental marital status on the teacher report.

The differences in emotional scores between cases and controls were not explained by a higher score on the 1st item ('headache or abdominal pain') of the emotional subscale.

Moreover, our results are also consistent with three other studies in older age groups, using other outcome measures as well as other control groups (i.e. siblings) (15, 18, 29). Although in two of the studies (15, 29), this applied only for a subset of adult survivors of childhood cancer. In addition, our results were also consistent with a study in adult cancer survivors (49).

However, even though our results are unlikely to be due to chance, bias or confounding, they are consistent with a number of other studies and many of the differences between cases and controls were significant, we can in this study only speculate on causality. Emotional problems in children surviving cancer may be caused by biological side effects of the child's cancer diagnosis (i.e. brain tumours; CNS-leukaemia), type and length of the cancer treatment (i.e. radiation, surgery, neurotoxin side effects of drugs)

and its complications (i.e. severe, systematic infections, bleedings, scars), as well as the psychological strain of suffering from a potentially fatal disease or its severe treatment. Long-term and intense cancer treatment and thus long absences from normal social activities may as well lead to emotional problems.

The poorer academic performance in children with brain tumours and leukaemia observed in this study may have the same causes as emotional problems (44–47). Although emotional distress may contribute to poorer academic performance at school (17), many poor academic performance at school in itself contributes to emotional distress. In brain tumour survivors, poor social skills, peer relationship problems and academic difficulties are most likely to be explained by a global brain damage resulting in a general cognitive impairment (51).

More emotional problems and poorer academic performance were mainly found among survivors *with* physical late effects. Twenty (40%) children in our study had such late effects reported by parents as well as recorded in the medical records, and sixteen of these 20 children also had psychological symptoms recorded in their medical records. Twelve of these children had been referred to the Department of Child and Adolescent Psychiatry. In contrast, no psychological symptoms were recorded among children without physical late effects. Taken together, these findings may be in favour of a biological cause for emotional problems and poorer academic performance among children who have survived cancer observed in this study. We are, however, unable to state whether the cause is the ongoing physical problems, the cancer diagnosis and its treatment or a combination of the two.

On the other hand, the adolescent self-report also showed a trend towards higher scores on the emotional symptom scale for survivors *without* late effects ($p = 0.07$) compared to controls. Thus, we speculate that psychological strain of the disease and treatment may also be a factor and play a role in the cause of emotional problems and poorer performance among children who have survived cancer in our study. In various other studies (15, 22, 24) suggesting that childhood cancer survivors function well psychologically despite a seemingly traumatic childhood experience, it was unclear whether survivors were suffering from late effects or not, independent of their cancer diagnosis.

There were also some notable differences in our findings between the parent and teacher report. While parents report no difference of pro-social behaviour for survivors compared with controls, teachers suggested an abnormal pro-social behaviour for all survivors as well as brain tumour survivors and leukaemia. This is somewhat in contrast to the study by Upton and Eiser (2006) where parent ratings showed a significant difference in pro-social behaviour, while teacher ratings showed no significant difference. Upton and Eiser (2006) studied children with brain tumours exclusively and used British norms for comparison. Nevertheless, the lower mean score on the Pro-social scale may reflect being less helpful and more unwilling to share with others, something which may be an understandable consequence following the intense and long-term cancer treatment per se, something teachers might emphasize more than parents. In addition, the long-term cancer treatment can contribute to long absences from normal social and school activities and consequently impaired interaction with others. This adverse development could have more impact and thus be more evident in a school setting than at home. Psychosocial support is essential to promote optimal adjustment for the child and their family both at home and at school (50).

Another interesting finding is also the differences and similarities of how the children assessed themselves and how they were assessed by their parents and teachers. In general, adolescents reported fewer problems than their parents did on the SDQ. This is consistent with other studies of childhood cancer comparing parent and child ratings on the same measures (8, 21, 48).

Implications

Our results indicate the need to develop adequate supportive interventions and programs for long-term follow-up care of children with cancer, including assessments of mental health, especially for survivors with brain tumours and with late effects but also for children surviving leukaemia. Most importantly, child and adolescent psychiatric professionals should be part of the professional collaborative team planning and performing follow-up care. It is essential for the child that collaboration with parents, primary health care professionals and teachers should be established already at diagnosis to prevent maladjustments and promote optimal psychosocial health. This is also essential to help teachers, peers, siblings and parents to cope with these issues. This interdisciplinary collaboration should continue regularly during treatment and follow-up. We have previously found that both health and nonhealth professionals find such collaboration to be a positive intervention in supporting children and their families (50).

Further research is needed to explore what contributes to long-term survivors' positive adaptation, to obtain an even more comprehensive understanding. Moreover, further study of childhood cancer survivors by using mixed methodologies to provide a more in-depth understanding of their experiences is essential, especially in view of the varying and conflicting results of psychosocial outcomes for cancer survivors.

Conclusion

Our study shows that children surviving cancer are at higher risk for emotional problems when compared with

their friends, even after several years following diagnosis and treatment. We conclude that when planning long-term follow-up care, rehabilitation of children and adolescents with cancer, especially for survivors with brain tumours and late effects, should particularly take into account their psychological problems and psychosocial functioning.

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Author contribution

All authors contributed actively to the design of the study and to the selection of the methods, as well as having read and approved the final version of the manuscript. In addition, the contribution by each author was: Mary-Elizabeth B. Eilertsen collected the data, performed the statistical analyses and wrote the first draft and final version of the manuscript. Toril Rannestad critically revised the manuscript, in general and specifically from a nurses' perspective. Marit S. Indredavik critically revised the manuscript, in general and specifically from a child psychiatrist perspective. Torstein Vik supervised the data analyses and critically revised the manuscript, in general but also specifically the pediatric oncology issues (main supervisor).

Ethical approval

Ethical approval was obtained from the Regional Committee for Medical and Health Research Ethics in Central Norway (Ref.nr. 4.2006.2610).

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