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Childhood cancer patients at school

P.M. Lähteenmäki[a,*], J. Huostila[a], S. Hinkka[b], T.T. Salmi[a]

[a]*Department of Pediatrics, University of Turku, Kiinamyllynkatu 4-8, FIN-20520 Turku, Finland*
[b]*Department of Biostatistics, University of Turku, Kiinamyllynkatu 4-8, FIN-20520 Turku, Finland*

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Abstract

The aim of this study was to assess the school-related problems of childhood cancer patients. A cross-sectional questionnaire study for school-aged children with extracranial malignancies, in the area of Turku University Hospital serving around 1 000 000 people. Siblings, healthy pupils and teachers were studied as controls. 43 patients responded. None of the patients or controls was placed in special educational programmes. However, 30.8% of the patients, 15.7% of the controls and 3.7% of the siblings had required extra tutoring. The patients' results differed statistically from both the siblings' ($P=0.022$) and the controls' ($P=0.041$) results. The school marks in mathematics ($P=0.05$) and in foreign languages ($P=0.06$) tended to be worse for the patients than for the healthy controls. Bullying was reported by 31.7% of the patients, 10.9% of controls ($P=0.0012$) and 8.3% of the siblings ($P=0.056$). The biggest problem faced by the cancer patients was bullying—the patients reported approximately 3 times as much bullying as the healthy children did. It seems that there are still several aspects which need to be reconsidered when these children return to school or start their school-life as survivors of childhood cancer. Some proposals are presented.

Keywords: Adolescent; Bullying; Cancer; Child; Psychosocial; School

1. Introduction

During recent decades, cancer therapies have improved and the average life expectancy in children with cancer has greatly increased. Consequently, the physical and psychological problems following the disease and the therapies, and their effects on the child's adjustment, e.g. to school, have become a prominent issue.

The problems found in children with cancer include, e.g. emotional and adaptational problems such as fatigue, changing moods, depression, poor self-esteem, poor social abilities, somatic complaints, impairment in memory functions, learning disabilities and even mental deterioration [1–4]. Lower levels of athletic competence and physical education attendance have also been reported [5], as well as school phobia [6]. Furthermore, children, and especially adolescents, with cancer have been found to act in a more introverted way than their age-mates [1,7,8]. In addition, the sequelae of cancer treatment affecting their appearance or gait (loss of hair, weight gain, scars, amputations, and other disfigurements) may expose these children to bullying. However, individual tolerance of the adverse effects of cancer and its treatment is variable, and survivors may be like their age-mates, healthy and totally fit for all activities.

There have been only a few studies on bullying of cancer patients at school. In their retrospective study of 40 patients, Wasserman and colleagues [9] found that 40% of cancer survivors had bad memories about their classmates' attitude towards their illness. However, some cancer patients have been found to have an exceptionally good social reputation [5]. As Katz and Varni note in their article, despite the level of the child's academic achievement, going to school without looking forward to interacting with classmates might give him sufficient cause for avoiding school [10]. Supportive peer relations along with social support from the adults have, indeed, a crucial role in the child's readjustment to his original (premorbid) school environment [11].

Perceived social support by peers has also been found to be critical for long-term psychological adjustment among adolescent cancer patients [10]. Furthermore, findings in a recent study indicated that the most vulnerable areas of an adolescent patient's identity are connected with anxieties about being misunderstood and abandoned, and that the young patient needs to feel supported by peers and adults [12]. Psychic problems may emerge even years after the disease phase. Although actual psychopathology seems

* Corresponding author. Tel.: +358-2-313-0000; fax: +358-2-313-2416.
E-mail address: paivi.lahteenmaki@tyks.fi (P.M. Lähteenmäki).

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rare, there may be a danger that the basic trust in the support offered by significant others is shaken and that the shades of this disappointed attitude may persist in later interpersonal relationships. An interesting finding is that, whilst cancer survivors have a similar psychosocial profile to healthy peers, they are more likely to utilise avoidance strategies to manage problems.

In the long run, the tendency of social isolation [8] of many childhood cancer patients may even lead to difficulties in sexual relationships. Ropponen and co-workers have shown that only 20% of male survivors of leukaemia reach the same level of psychosexual maturity as their age-mates [13]. Young men also tend to stay living with their parents for much longer than usually expected. Puukko and her co-workers have studied female survivors of childhood leukemia, and they found that girls do have a more infantile self-image than their age-mates but they do not differ from their age-mates in the timing of first contacts to the opposite sex [14].

The cognitive problems have been explained by many factors. The effects of emotional stress and long periods of absence from school have been studied, as well as the effects of cranial irradiation and chemotherapy [15–22]. It has been demonstrated that children who have received cranial irradiation and chemotherapy have poorer educational and intellectual skills than those receiving chemotherapy alone or than healthy controls [16,17,23–26]. The decline in the intelligence quotient (IQ) has been greatest in those children whose IQ before the treatment was the highest, and children under 5 years of age have been shown to be most sensitive to these changes. However, there is also a growing experience on long-term effects of prophylactic central nervous system chemotherapy, particularly in the area of academic achievement [21,27]. It has also been demonstrated that learning difficulties have a remarkable role in influencing social skills and adjustment for children and adolescents surviving cancer [28].

In Finland, approximately 140 children under 15 years of age are diagnosed with cancer each year. There are few studies available on school-related problems in children with cancer and due to some differences in the school systems, foreign studies cannot be directly applied. The Finnish comprehensive school consists of a 6-year primary school and a 3-year secondary school. School entry is normally at the age of 7 and finished at the age of 16 years. The educational system is run by the National Board of Education and private comprehensive schools do not exist. Thus, the contents of the education in different parts of the country vary only a little.

We describe here the results of a study performed during the school year 1997–1998 in the area of the Turku University Hospital, Finland. The aim of this descriptive study was to get a picture of childhood cancer patients' school problems in the area of one of the five University Hospitals treating childhood cancer patients in our country, so that recommendations concerning the need for supportive, both financial and educational, resources of this group of school children could be suggested to the authorities. Based on the few existing former studies in this field and our own findings during the clinical work, it was expected that poorer academic achievement, delays in school careers and a great amount of perceived problems with teaching logistics and in relationships to school-mates and teachers, as well as to other school authorities, would be found among the cancer patients. Because of the homogenity of the educational system in Finland, we believe that our country is a suitable surrounding for measuring the level of school-related problems of childhood cancer patients. Thus, our findings on the issues of academic functioning and psychological climate in schools may also be of international interest.

2. Patients and methods

During the school term of 1997–1998, questionnaires were mailed to all cancer patients (no central nervous system tumours) of comprehensive school age (born 1981–1990) in the area of Turku University Hospital. The number of patients fulfilling these inclusion criteria was 67 and 43 of them (64%, 18 females and 25 males) returned their questionnaire after one letter of reminder, either by mail or personally during their hospital appointment. In Table 1, there are presented the characteristics of the responders and non-responders. The sibling closest of age to the patient was asked to complete a similar questionnaire, and 28 siblings (16 females, 12 males) responded. Furthermore, the patients and their parents were asked for written permission to

Table 1
Characteristics of the responders and non-responders

	Responders	Non-responders	*P* value
n	43	24	
Gender			0.61[a]
Female	18 (42%)	12 (50%)	
Male	25	12	
Age at study (years)			0.42[b]
Median (range)	15 (8–18)	12.5 (7–17)	
Diagnosis			0.62[a]
Group 1	24 (56%)	15 (63%)	
Group 2	19	9	
Age at diagnosis			0.42[b]
Median (range)	6 (0–15)	3.5 (1–14)	
<7 years (*n*)	28 (65%)	17 (71%)	0.79[a]
Grade (level) at school			0.68a

[a] Fisher's Exact test.
[b] Kruskal-Wallis test.
Group 1 = patients with leukaemia or non-Hodgkin's lymphoma, Group 2 = the other patients. *n*, number.

also send a questionnaire to the patient's teacher. Permission was obtained from 21 patients and all of the teachers requested (10 females and 11 males) also responded to the mailed questionnaires. The information from the healthy controls was collected in one primary school and one secondary school in the spring of 1998. A written informed consent was asked from the parents of students in one class of each grade ($n=220$) and 47% of them (49 females, 54 males) were allowed to participate. The questionnaires were given to the students at the beginning of a lesson by one of the researchers who also invigilated the session with the teacher of each class and collected the anonymous forms after they were filled in. The research plan was accepted by the Joint Commission on Ethics of Turku University and Turku University Central Hospital. A written informed consent was obtained from the parents of each study subject.

The patients had a median age of 15 years (range 8–18 years), the controls a median age of 11 years (range 7–17 years), the siblings a median age of 13.5 years (range 6–21 years), and the teachers a median age of 45.5 years (range 29–66 years). The patients were currently in the 8th (1–9) grade (median, range), the siblings on the 7th grade (1–finished) and the controls on the 5th grade (1–9). 21 of the patients were diagnosed with acute leukaemia; the other diagnoses included 3 Hodgkin's diseases, 3 non-Hodgkin's lymphomas, 6 Wilms' tumours, 4 neuroblastomas, 2 osteosarcomas, 3 soft-tissue sarcomas and 1 germ cell tumour.

The questionnaires (see Appendix) were developed from the clinicians' point of view. There were included questions dealing with themes which had been raised by the patients and their parents during the routine check-ups of the children with cancer, and also in connection with the research work of the authors dealing with the psychosocial well-being of childhood cancer patients and their families [29,30]. Some issues of these questionnaires were used already in our earlier study [30]. The questionnaires for each subject group and teachers were dealing with similar themes (see Appendix). They concentrated on the whole school career of the subject and contained questions about scholastic achievement (recent grades, perceived learning problems, need for remedial instruction or for special educational programmes), school community (friends, mobbing, problems with teachers) and problems or delays in school attendance due to the illness. Data on absenteeism during the nearest school term were also obtained. Most of the questions were forced-choices with the alternatives yes, no, or no need. In several items, extra space was left for voluntary comments of the subject.

2.1. Statistical methods

The analyses were carried out with the statistical software SAS for Windows (version 6.12; SAS Institute, Cary, NC, USA). For descriptive statistics, medians and ranges were calculated. Comparisons between patients and healthy controls were made for the whole study group ($n=43$). Comparisons between patients and siblings were only made in the group of patients ($n=28$) in which information from the siblings was available. Further, comparisons between the patient and the teacher were only made for those patients ($n=21$) whose teachers responded. Due to these different numbers of subjects in the data-sets, there was no need to adjust for multiple comparisons. The sibling group was used in comparisons in order to evaluate the possible effect of the home-environment or genetic factors on patients' results. Siblings were also compared with healthy controls to see whether the sibling group was more like them or like the patient group. The teachers were used as a comparison group to find out whether their opinions paralleled the patients' statements and as such confirmed or decreased the value of the findings.

The marks in the school reports of 21 patients, of 82 controls, and of 17 siblings only were available for statistical analyses. The children in the 1st and 2nd grades were given just a verbal evaluation that could not be used in the statistical analyses.

For further statistical analyses concerning patients' results, the patients were divided into two groups according to the comparability of their cancer treatments: group one included patients with leukaemia and non-Hodgkin's lymphoma ($n=24$) and group two included the rest ($n=19$). The explaining factor 'age at diagnosis' was divided in two categories (those who fell ill before school-age (<7 years, $n=28$), and those who fell ill at school-age ($\geqslant 7$ years, $n=15$)) for the statistical analyses. The third explaining factor was the gender of the patient.

The non-parametric Kruskal–Wallis test was used to analyse the numerical outcome variables, whereas the categorical ones were analysed with the Fisher's Exact test. Two-sided P values $\leqslant 0.05$ were interpreted as statistically significant.

3. Results

The results of the questions put forward to each study group are presented in Table 2. Seven per cent of both the patients and the siblings had started school later than normally, whereas none of the controls reported this (patients versus controls, $P=0.014$; siblings versus controls, $P=0.012$). A need to repeat a grade appeared in 9.3% of the patients, but the difference to the controls ($P=0.18$) or to the siblings ($P=0.32$) was not statistically significant. None of the patients or siblings was placed in special educational programmes.

However, 30.8% of the patients, 15.7% of the controls and 3.7% of the siblings had required extra tutoring.

Table 2
The results of the questions presented to each group of study subjects. (Values are percents unless otherwise indicated. Fisher's exact test was used in the statistical analyses.)

	Patients $n=43$	Controls $n=103$	Patients $n=28$	Siblings $n=28$	Patients $n=21$	Teachers $n=21$	Siblings $n=28$	Controls $n=103$
Have started school								
at normal age	90.7	91.3	89.3	92.9	85.7	85.7	92.9	91.3
later	7	0	7.1	7.1	14.3	14.3	7.1	0
cannot say	2.3	8.7	3.6	0	0	0	0	8.7
P value	0.014		0.7		1		0.012	
Have had to repeat a grade								
No	90.7	96.1	89.3	96.3	80.9	95	96.3	96.1
Yes	9.3	3.9	10.7	3.7	19.1	5	3.7	3.9
P value	0.18		0.32		0.19		0.69	
Have had extra tutoring at school								
No	69.2	84.3	73.1	96.3	84.2	85.7	96.3	84.3
Yes	30.8	15.7	26.9	3.7	15.8	14.3	3.7	15.7
P value	0.041		0.022		0.62		0.12	
Enough extra tutoring offered								
No	8.6	7.0	9.1	0	5.9	5	0	7
Yes	45.7	33.7	50	33.3	35.3	55	33.3	33.7
No need	45.7	59.3	40.9	66.7	58.8	40	66.7	59.3
P value	0.36		0.08		0.58		0.55	
Results at school worse during the latest term								
No	86.9	91.8	83.3	92	80	88.9	92	91.8
Yes	13.1	8.2	16.7	8	20	11.1	8	8.2
P value	0.35		0.34		0.45		1	
Results at school improved during the latest term								
No	81.8	73.5	76.5	79.2	80	75	79.2	73.5
Yes	18.2	26.5	23.5	20.8	20	25	20.8	26.5
P value	0.86		0.57		0.77		0.79	
Have had friends at school								
No	4.9	0	3.6	4.2	9.5	9.5	4.2	0
Yes	95.1	93.1	96.4	95.8	90.5	90.5	95.8	93.1
Cannot say	0	6.9	0	0	0	0	0	6.9
P value	0.025		0.72		1		0.09	
Have been bullied at school								
No	68.3	77.2	70.4	91.7	52.4	66.7	91.7	77.2
Yes	31.7	10.9	29.6	8.3	47.6	28.6	8.3	10.9
Cannot say	0	11.9	0	0	0	4.7	0	11.9
P value	0.0012		0.056		0.34		0.23	

n, number.

Patients' results differed statistically from both the siblings' ($P=0.022$) and the controls' ($P=0.041$) results; there was no significant difference between the siblings and the controls ($P=0.12$). According to the teachers, approximately 14% of the patients needed extra tutoring. There was no statistical difference between the subjects' opinions on the adequate amount of extra tutoring, but approximately 9% of the patients, 7% of the healthy students, and 5% of the teachers felt that the available amount was insufficient. The patient's diagnosis, age at diagnosis or gender had no statistically significant connection to any of the findings described above.

The amount of patients' absence from school during the term prior to the study did not differ significantly from that of the healthy controls ($P=0.08$) or siblings ($P=0.73$). The median of hours of absence in each group was 0 h, the ranges were 0–270 h in patients, 0–200 h in controls and 0–50 h in siblings. The age at diagnosis ($P=0.0001$) naturally had an effect on the amount of absence; the patients who had fallen ill at school age had been absent from school approximately (median, range) 23.5 (0–270) h during the past term. The hours of absenteeism immediately after having cancer diagnosis was reported to be 68 hours (median). Only 1 patient had had problems arranging transportation to school.

39% of the patients in group 1 and 50% in group 2 felt that they had needed private tutoring at home. This was arranged for 30% in group 1, but only for 11% in

group 2. 27% of the patients in group 1 and 22% in group 2 had had tutoring in the hospital, whereas the perceived need would have been 73 and 68%, respectively.

Statistically significant differences in school marks between the study groups did not appear, although the grades in mathematics ($P=0.05$) and in foreign languages ($P=0.06$) tended to be worse in the patients than in the healthy controls. When we compared the patients with the siblings, there was no such tendency. The patient's gender, diagnosis or age at diagnosis had no clear connection to the grades, except that the grades in physical education were lower in group 1 ($P=0.03$).

Only 53% of the patients reported to know for sure that their classmates had been told about their illness. This had usually been done by the teacher. Over half of the patients thought that information to the class should be given either by the teacher or by a representative of the hospital. Only 15% of patients thought that it should be given by the parents or the patient himself.

Bullying was reported by 31.7% of the patients, 10.9% of controls and 8.3% of the siblings. There was a difference between the answers of the patients and the siblings ($P=0.056$) and of the patients and the controls ($P=0.0012$). According to the teachers, 28.6% of the patients were victims of bullying, whereas the number given by their pupils was 47.6% ($P=0.34$), in this group of 21 patients. The reasons for mobbing, as reported by the patients, were almost without exception (77%) connected to the illness or to the patient's appearance. Patient's diagnosis, age at diagnosis or gender did not have a significant effect on the occurrence of mobbing. Of those patients who fell ill before school age, 34.6% had been bullied, whereas the number for those who fell ill at school age was 26.7% ($P=0.73$). Although almost everyone of the subjects had good friends at school, 4.9% of the patients suffered from a lack of friends and the difference to the healthy controls was significant ($P=0.025$).

4. Discussion

In this descriptive, cross-sectional questionnaire study, the information was primarily collected from the patients themselves, not from proxy respondents, and the response rate was 64%, which was regarded as acceptable. No statistical difference was found between the characteristics of respondents and non-respondents, and thus we consider that there is no remarkable no-response bias. As a single centre study, the numbers of the participants are rather small, a fact which may have an influence on the validity of the results. However, by using the sibling group and unrelated healthy controls, as well as the opinions of the teachers in the comparisons, we should have increased the reliability of our findings. The students' academic functioning was assessed by using the school report marks. As the grounds for the marks are quite convergent in the Finnish school system, this means of assessment can be considered reliable.

As a whole, the identification of possible cognitive decline and learning difficulties of childhood cancer patients is problematic [33]. Children who are severely disabled are easily identified by all involved. A problematic group is those children who have what appear to be minimal cognitive problems. More survivors than expected may have experienced a kind of drop in their cognitive level, although they still function within the normal range. However, the teacher is faced with a child who may be of average or above average intelligence, but who cannot make that native intelligence work for him or her. Although the student may appear to be functioning well within the average range, the student is aware that he/she is no longer able to function as he/she once did. These students are not as quick as before, they forget too many things, new information is not retained or recalled as easily, and organisational skills that were once superior are no longer so.

In keeping with the above mentioned issues, a great number of the patients reported that they had needed extra tutoring at school. In this variable, the patients differed significantly from both the healthy controls and the siblings. This suggests that the need for extra tutoring is associated more with the illness itself instead of being due to social factors, such as the home environment. However, in disagreement with the reports of Mulhern [3], Kingma and co-workers [31], we did not find our patients been placed in any special educational programmes. Mulhern and co-workers [3] reported a study on 183 survivors 5 or more years after the diagnosis of childhood cancer; the survivors had 4 times more school problems and somatic complaints than healthy controls, 26% of survivors had repeated one or more grades at school and 11% of all survivors had been moved to special classes. In Kingma's [31] report concerning 49 survivors of acute leukaemia, significantly more patients than siblings were placed in special educational programmes and also a significant difference was found for the level of secondary education.

The possible delay in getting education has also been proposed as an explanation for the poorer academic achievement of childhood cancer patients [4] but, in our study, the patients did not differ from their siblings in terms of the age at starting school or the need to repeat a grade. The hours of absenteeism immediately after having a cancer diagnosis (those who fell ill at school-age) was reported to be 68 h (median), which is not very many, and the hours of absenteeism during the term prior to this study were not significantly more numerous among the patients than those among the two control groups.

The need for extra tutoring of the cancer patients was estimated also by their teachers. The teachers' estimates on the need for remedial instruction paralleled the patients' opinions, although teachers estimated the offered amount of tutoring to be more sufficient than the students did. Unfortunately, a lack of an adequate amount of extra tutoring seems to be a common problem in schools today. As a consequence of budget cuts, the funds are often insufficient to meet the special educational needs of not only children with a chronic illness, but also of many otherwise healthy students. It is thus obvious that in order to optimise the education for chronically-ill children, more funds should be directed to their tutoring in the future.

None of the teachers in this study had been in contact with a childhood cancer patient before this one in question—the study patient—appeared in their class. Teachers are often unsure about the demands they should put on a cancer patient as a student. Thus, the teachers have to be adequately informed, preferably by the physicians or psychologists involved in the student's treatment [38]. In our hospital, the social worker is the team member who primarily organises the contacts with the school of the patient. A previous study stresses the role of the teacher also in the ongoing care of the student with cancer, as the teacher usually knows the patient's premorbid level of academic functioning and is familiar with the school's climate and resources regarding children with special needs [33].

A great number of the patients also reported that they would have needed more tutoring at the hospital. This was surprising, as there is a well-organised hospital school in our hospital and teaching is arranged for all patients if requested. Perhaps the tutoring should be more actively suggested to the patients and the possibility should be discussed more with the family as well. However, the treatments can often make the patients too tired to study, even if they wanted to. There is also a tendency to send the patients home as soon as possible and thus the in-patient periods are nowadays quite short.

Parallel to previous reports [4,18,27,32–36], the patients' grades in mathematics and in foreign languages tended to be worse than those of the healthy students. It seems, however, that among the healthy controls there were less secondary school pupils than in the groups of patients or siblings. The age difference might have had an influence on the results: school marks tend to get worse when the demands grow; i.e. at secondary school the healthy controls also might have had poorer school-marks. In this study, no significant difference was observed in scholastic achievement between the genders.

The low grades in physical education in patients with leukaemia and non-Hodgkin's lymphoma can be, at least partially, explained by the cancer treatment containing vinca-alkaloids which are known to cause clumsiness. The impairment in the physical capacity of the children with cancer is a notable fact when considering the need for transportation to school.

School-aged children and adolescents may also be particularly sensitive to interruptions in their developing peer and intimate relationships, school and extracurricular activities, and plans for future lifestyle and occupation [2,3,23]. Friends may disappear during cancer treatment and patients themselves, mainly due to poor self-esteem, withdraw from social relationships [5]. In our study, over half of the patients thought that their classmates should be informed about their illness by someone outside their family. Even though the patients have been encouraged to openly talk about their illness, it might be best if the teacher or someone from the medical team told the classmates what they should know about the patient's condition. It has been demonstrated that if it is explained to the class what it means to have cancer, the patient is less likely to be bullied by his classmates [37]. Perceived social support by peers has also been found to be critical for long-term psychological adjustment among adolescent cancer patients [37].

The biggest problem that came up in this study was bullying—the patients reported approximately 3 times as much bullying as the healthy children did. Our results of bullying among healthy pupils paralleled the numbers of a larger Finnish sample from secondary schools [39]. The teachers estimated the extent of the bullying quite accurately, although it is possible that they had kept an exceptionally good eye on these students. In most cases, the bullying was due to appearance. In previous studies, children with a physical disability have been shown to be victimised more than healthy children [40]. The same has been shown concerning pupils with a short stature [41]. We found that those who fell ill at school-age were bullied less than those who fell ill earlier. This may implicate that once the children learn to know the patient as a normal, healthy child, they are less likely to bully him/her later even though the treatment has affected his/her appearance. Usually, mobbing is thought to be more common among boys, although indirect mobbing, such as isolation and ignoring, seems to be more frequently used by girls [42]. In this study, no difference was observed between genders as bully victims.

In general, bullying is a major problem that may have serious long-term consequences for the victim and should never be accepted or neglected by those in authority. Bullied children often suffer from a low self-esteem, poor well-being and many common health problems such as stomach aches, headaches, difficulties in sleeping, bed wetting and general sad mood [43,44]. Bullying adds to the social and educational problems that a cancer patient has to face when returning to school and makes the school re-entry all the more difficult. It is therefore crucial that the parents, the teacher and the

Table 3
Some proposals for improving the psychosocial support of childhood cancer patients at school:

1)	New information material to school personnel (e.g. by the National Cancer Societies).
2)	Individual educational plans (''home school''and hospital school should participate in planning).
3)	Social worker from hospital visits ''homeschool'' before the patient's entry.
4)	Continuous practice of communication between school and hospital team.
5)	*However, one must keep in mind: school is a place where children with cancer look forward being as normal members of their class, not any special cases.*

medical team work together to create supportive instructional practices and, thus, facilitate the patient's adjustment and give him/her a possibility to go to school in a tolerant, friendly environment where his/her needs are taken into account.

Some proposals are presented in Table 3. In our department, the social worker of our team visits the school of the patient before she/he re-enters it. The hospital teacher works in close contact with the patient's own teacher, but quite often the visits at the hospital are so short that the role of the hospital teacher remains suboptimal. We also have decided to start using a questionnaire for the patients when they come to their out-patient visits. One part of the questionnaire will be dealing with various aspects of psychosocial well-being, e.g. bullying. The questionnaire used in this study was constructed on very basic issues and it dealt with them on quite a general level. It could be possible to gather more detailed information by interviewing patients, albeit using a questionnaire as a guide, during their hospital visits.

In conclusion, the cancer patients seem to need extra tutoring significantly more often than their siblings or healthy controls. The patients themselves regarded the given amount of extra tutoring as too little. Arrangements for home and hospital teaching were also requested more than they were offered. In the group of cancer patients, there was a tendency to having poorer remarks in mathematics and in foreign languages. However, only the marks in the physical education of the leukaemia/lymphoma patients were significantly lower than those of the other patients and of the control subjects. Surprisingly, nearly half of the patients did not know whether their classmates were informed about their illness or not. In addition, a majority of the patients thought that the information should come from the hospital team or from their teacher, not from their family members. School is a place where children with cancer look forward to being accepted as normal members of their class, and not as special cases. This may be the reason for these children not being willing to talk so much about their illness at school. The biggest problem faced by the cancer patients in this study was bullying—the patients reported approximately 3 times as much bullying as the healthy children did. It seems that despite many improvements in psychosocial supportive care of the childhood cancer patients, there still are several aspects which need to be reconsidered when these children and adolescents return to school or start their school-life as survivors of childhood cancer.

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Appendix

A) A QUESTIONNAIRE ABOUT ATTENDING SCHOOL (CANCER PATIENTS)

Background:

Date of birth: _____

Gender: 1 girl 2 boy

Diagnosis: _____ Age at diagnosis _____

The year you started school: _____

Normal school 1 yes 2 no (what kind: _____)

Your grade at the moment: _____

Issues dealing with school attendance:

Did you start your school:

1. at normal age 2. later 3. earlier than normally

Have you had to repeat a grade 1. no 2. yes (why: _____)

If you were already at school when your cancer was diagnosed, for how long (school hours) did you have to stay out of school.

In the beginning of treatment _____

During the first school term _____

For how many school hours have you been absent during the autumn term of 1997? _____

Do you think that you have had difficulties in some school subjects?

1. no 2. yes (which kind _____

_____

Have you got some extra tutoring?

1. no 2. yes (what _____)

Have you got enough extra tutoring?

1. no 2. yes 3. I have not needed any

Have you got tutoring at home if needed?

1. no 2. yes 3. I have not needed any

(Who was your tutor: _____)

Have you got tutoring at hospital (by hospital teacher)?

1. no 2. yes 3. I have not needed any

About your school reports:

Were any of the marks in your school report worse during the last term?

1. no 2. yes (in which subjects: _____)

Did some of the marks improve during the last term?

1. no 2. yes (which: _____)

Marks in your report before the cancer diagnosis:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

Marks in your first report after the cancer diagnosis:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

Marks in your latest (which grade ____) report:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you have already finished your secondary school, which were your marks in the final report:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you have had some problems in learning, what kind they have been? Describe in your own words:

_____

_____

Issues dealing with your school community:

Do you have good friends at school? 1. no 2. yes 3. I can't say

Have you been bullied at school? 1. no 2. yes

If you have been bullied, please describe it in more detail:

1. because of your illness 2. for another reason

1. in the beginning of your illness 2. further

1. at school 2. on your way to/from school 3. elsewhere

Please describe in your own words _____

_____

_____

Did your schoolmates keep in contact with you when you were absent/at hospital for longer periods?

1. no 2. yes 3. there was no need

Has there been problems with organising your transportation to school?

1. no 2. yes 3. no need for transportation

what kind of problems: _____

Have you had any problems with your teachers?

1. no 2. yes (what: _____)

Did somebody tell your classmates about your illness before you returned to school?

1. no 2. yes 3. I don't know

(Who told them? _____)

What is your opinion on who should tell your classmates about one's severe illness and the facts related to that illness?

1. physician 2. nurse 3. parents 4. the patient

5. teacher 6. somebody else: _____

Should illnesses, like your own, be discussed more at school?

1. no 2. yes

Please write down here your own opinions, proposals and wishes

_____

_____

_____

Thank you!

B) A QUESTIONNAIRE ABOUT ATTENDING SCHOOL (SIBLINGS OF CANCER PATIENTS)

Background:

Date of birth: _____

Gender: 1 girl 2 boy

The name of your sister/brother who is our patient at the moment: _____

Your school: _____ Your grade at the moment: _____

Do you have any illnesses? _____

Issues dealing with school attendance:

Did you start your school:

1. at normal age 2. later 3. earlier than normally

Have you had to repeat a grade?

1. no 2. yes (what: _____)

For how many school hours have you been absent during the autumn term of 1997? _____

Have you got some extra tutoring?

1. no 2. yes (what _____)

Have you got enough extra tutoring?

1. no 2. yes 3. I have not needed any

About your school reports:

Do you think that you have had difficulties in some school subjects?

1. no 2. yes (which kind _____

_____)

Were any of the marks in your school report worse during the last term?

1. no 2. yes (in which subjects: _____)

Did some of the marks improve during the last term?

1. no 2. yes (which: _____)

Marks in your latest (which grade ____) report:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you are older than your sister/brother who is our patient, please give here your marks on that grade which your sister/brother last has attended

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you have finished your secondary school, what were your marks in the final report?

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you have had some problems in learning, what kind they have been? Describe in your own words:

_____

_____

_____

Issues dealing with your school community:

Do/did you have good friends at school? 1. no 2. yes 3. I can't say

Have you been bullied at school? 1. no 2. yes

If you have been bullied, please describe it in more detail:

1. at school 2. on your way to/from school 3. elsewhere

Please describe in your own words _____

_____

_____

Thank you!

C) A QUESTIONNAIRE ABOUT ATTENDING SCHOOL (CONTROLS)

Background:

Date of birth: _____

Gender: 1 girl 2 boy

Your school: _____ Your grade at the moment: _____

Do you have any illnesses? _____

Issues dealing with school attendance:

Did you start your school:

1. at normal age 2. later 3. earlier than normally

Have you had to repeat a grade

1. no 2. yes (what: _____)

For how many school hours have you been absent during the autumn term of 1997? _____

Have you got some extra tutoring?

1. no 2. yes (what _____)

Have you got enough extra tutoring?

1. no 2. yes 3. I have not needed any

About your school reports:

Do you think that you have had difficulties in some school subjects?

1. no 2. yes (which kind _____

_____)

Were any of the marks in your school report worse during the last term?

1. no 2. yes (in which subjects: _____)

Did some of the marks improve during the last term?

1. no 2. yes (which: _____)

Marks in your latest (which grade ____) report:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you have finished your secondary school in the Spring of 1997, what were your marks in the final report:

mother tongue _____ mathematics ____ I foreign language ____

natural science ____ physical training ____ handiwork ____

mean (all marks) ____

If you have had some problems in learning, what kind they have been? Describe in your own words:

_____

_____

Issues dealing with your school community:

Do you have good friends at school? 1. no 2. yes 3. I can't say

Have you been bullied at school? 1. no 2. yes

If you have been bullied, please describe it in more detail:

1. at school 2. on your way to/from school 3. elsewhere

Please describe in your own words _____

_____

_____

Thank you!

D) A QUESTIONNAIRE ABOUT ATTENDING SCHOOL (TEACHERS OF CANCER PATIENTS)

Background:

Your age: _____

Gender: 1 female 2 male

The name of your pupil who/has been is our patient: _____

For how many years have you been working as a teacher? _____

Have you had any cancer patients among your pupils before? 1. no 2. yes

Issues dealing with school attendance:

Did the pupil start his/her school:

1. at normal age 2. later 3. earlier than normally

Has she/he had to repeat a grade?

1. no 2. yes (what: _____)

Has the pupil been put on some special education?

1. no 2. yes (what _____)

Has the pupil needed extra tutoring? 1. no 2. yes

Has the pupil got enough extra tutoring?

1. no 2. yes 3. has not needed any

Have the parents wanted more extra tutoring for their child than you have considered appropriate?

1. no 2. yes 3. I can't say

About school reports:

Do you think that the pupil has had difficulties in some school subjects?

1. no 2. yes (which kind: _____

_____)

Has the pupil done worse during the illness?

1. no 2. yes (any reasons? _____)

Has the pupil done better during the illness?

1. no 2. yes (any reasons? _____)

Did any of the marks in his/her school report get worse during the last term?

1. no 2. yes (in which subjects: _____)

Did some of the marks improve during the last term?

1. no 2. yes (which: _____)

Issues dealing with the school community:

Does/did the pupil have good friends at school? 1. no 2. yes 3. I can't say

Has the pupil been bullied at school? 1. no 2. yes 3. I can't say

Please describe in your own words _____

_____

_____

If you have any comments, suggestions or wishes dealing with the theme 'a child with cancer at school', please write them down in you own words: _____

_____

_____

Thank you!

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