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Original Paper

Siblings of Childhood Cancer Survivors: How Does This "Forgotten" Group of Children Adjust after Cessation of Successful Cancer Treatment?

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Siblings of childhood cancer patients are labelled the "forgotten children" because they experience significant psychosocial distress and are isolated from support systems inside and outside the family. This study investigates the late consequences of the cancer experience for siblings. 60 siblings of cancer survivors were compared with control subjects on measures of psychosocial adjustment. No differences were found between siblings of cancer survivors and controls on emotional and behavioural problems and competence, suggesting that siblings adjust well to the period after cessation of treatment. The effect of demographic, family and disease-related characteristics on the siblings' psychosocial adjustment was limited. Whereas during treatment many psychosocial problems for siblings have been reported, this does not result in a heightened risk of psychological disturbance for siblings as a late effect. The implications for patient care are discussed.

Keywords: psychosocial functioning, childhood cancer, siblings, long-term adjustment
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INTRODUCTION

PROGRESS IN the field of paediatric oncology has drastically improved the rate of survival in childhood malignancies. As more children survive their disease, the focus is now on the quality of this survival. Studies on the long-term consequences of cure should include the late effects for patients, parents and siblings because cancer and its treatment not only affect the patient, but also other members of the family. Information on long-term sequelae for patients is accumulating, and to a lesser extent this is also the case for parents, but studies on siblings are sparse. Some studies have investigated siblings' retrospective experience of the illness [1–3]. However, to date, no studies exist on the current psychosocial functioning of siblings of childhood cancer survivors.

Siblings of childhood cancer patients are considered to be vulnerable to psychosocial problems. Before diagnosis, the prevalence of psychosocial problems among siblings is similar to the general population, but after diagnosis, siblings experience significantly more emotional and behavioural distress than controls [4]. Problems frequently noticed by parents are feelings of jealousy and guilt, academic underachievement, somatic problems and acting out behaviour [5, 6]. It has been found that, during treatment, there are striking similarities in the emotional distress between siblings and paediatric cancer patients, including anxiety, social isolation, vulnerability to illness, and feelings of low self-esteem [7]. In some areas, siblings showed even more signs of distress than the patient [7]. The major theme in discussing the sibling's concerns is the disruption they experience in interpersonal relationships, especially with their parents [8, 9]. Siblings of leukaemic children more frequently felt a lack of a close relationship with their parents than siblings of other chronically ill children. It has been shown that within the family, the needs of the sibling are met least of all [10]. Simultaneously, they felt isolated from supportive systems outside the family [11]. As a result, siblings of cancer patients have been labelled as the "forgotten children" [11].

Summarising these findings, the question arises of what the long-term consequences are for healthy siblings after being exposed to prolonged periods of family disequilibrium. The first aim of the study was to investigate the psychosocial functioning of siblings of childhood cancer survivors by comparing their functioning to that of healthy peers. Studies on siblings of childhood cancer patients have been criticised for the use of non-

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standardised instruments and for the lack of multiple informants because most previous work is based only on parents' reports [2, 12]. Therefore, we used parents' and siblings' reports on standardised measures.

The second aim of our study was to investigate which factors affect the siblings' psychosocial adjustment. It has been observed that individual differences and family variables, such as age of the sibling, gender, birth order and family size, contribute to adjustment, but these variables have rarely been examined in relation to the sibling's psychosocial functioning [13, 14]. Also, disease-related characteristics, which are a possible indication of the disease-related stress, are seldomly considered. Consequently, the impact of demographic, family, and disease-related characteristics on the sibling's psychosocial adjustment was explored in the present study.

Table 1. Demographic, family, and disease-related characteristics of the sample (n = 60)

	n	%
Demographic characteristics of siblings		
Sex		
Boys	34	57
Girls	26	43
Age at investigation		
Median: 10 years 6 months		
Range: 5–16 years		
Age at diagnosis		
Median: 4 years and 1 month		
Range: 0–11 years		
Unborn: 4 siblings		
Family characteristics		
Socioeconomic status		
Unskilled employees	5	8
Skilled manual employees	20	33
Minor professionals	9	15
Owners small business	7	12
Professionals	9	15
Major professionals	7	12
Housewife	1	2
Missing	2	3
Number of siblings		
One sibling	36	60
More than one sibling	24	40
Birth order		
Older than survivor	28	47
Younger than survivor	32	53
Concurrent stresses		
Yes	25	42
No	35	58
Chronic disease		
Yes	15	25
No	45	75
Disease characteristics of survivors		
Diagnosis		
Leukaemia	50	83
Non-Hodgkin's lymphoma	5	8
Rhabdomyosarcoma	5	8
Survival probability		
⩽ 50%	30	50
> 50%	30	50
Intensity of treatment		
Less severe	43	72
Very severe	17	28
Duration of treatment		
< 3 years	50	83
⩾ 3 years	10	17
Surgery		
Yes	10	17
No	50	83
Radiation		
Yes	29	48
No	31	52
Time off treatment		
< 5 years	45	75
⩾ 5 years	15	25
Visible impairment		
Yes	16	27
No	44	73
Invisible impairment		
Yes	12	20
No	48	80
Weight problems		
< 90th percentile	37	62
⩾ 90th percentile	23	38
School problems		
Yes	25	42
No	35	58

PATIENTS AND METHODS

Subjects

Siblings of childhood cancer survivors between 4 and 16 years of age were selected from families with a childhood cancer survivor. The childhood cancer survivor had to meet the following criteria: (a) the child was diagnosed with leukaemia, non-Hodgkin's lymphoma (NHL) or rhabdomyosarcoma (RMS); (b) the child had successfully completed cancer treatment; (c) used Dutch as their native language; and (d) was between the ages of 8 and 12 years inclusive at the time of the study. Childhood cancer survivors meeting these criteria were diagnosed between 4 November 1976 and 23 December 1987. During this time 473 patients were diagnosed with a malignancy at the Sophia Children's Hospital/University Hospital, Rotterdam, The Netherlands (one of the four paediatric cancer centres in The Netherlands). According to the patient selection criteria, 231 patients were eligible with respect to diagnosis. Of this group, 53 patients died of their disease. Of the remaining 178 patients, 10 patients were excluded because Dutch was not their native language. In addition, 90 patients were excluded because their age was outside the required range. In total, 78 survivors were eligible with regard to all selection criteria. Of this group, 73 children were approached to participate in the study, representing all children with leukaemia and NHL, and 5 children with RMS. The latter patients resembled the children with lymphoproliferative diseases with respect to prognosis, treatment protocol, difficulty of treatment, length of treatment, and late medical sequelae.

Of the 73 families approached, three families refused to participate because they felt that participation in the study would be too distressing for themselves ($n = 2$) or the sibling ($n = 1$). In seven families, the patient was the only child. In three families, the sibling fell outside the age range. From each family, one sibling was selected to control for patient and family characteristics. Preference was given to the sibling closest in age to the former patient. In total, 60 siblings were enrolled in the study.

Demographic, family, and disease-related variables

Demographic, family and disease-related characteristics are presented in Table 1. Socioeconomic status (SES) was rated according to Dutch standards on a six-step scale of occupational level (highest level = 6) [15]. Family stressors unrelated to the disease were rated as concurrent stresses. Chronic disease was scored if one of the family members other than the former patient had a chronic disease or a chronic condition.

Characteristics related to disease, treatment, and late sequelae are also summarised in Table 1. The survivor's statistical probability of survival at diagnosis was rated by an oncologist, based on the diagnosis, symptoms at presentation, and the success rates for the treatment protocols at that time. The intensity of chemotherapy was rated by the oncologist according to treatment protocol. Visible impairment was partly measured by the residual physical impairment index [3], consisting of the sum of ratings of current visibility and interference with daily living. Invisible impairment included invisible medical problems such as organ damage and endocrine problems. Weight problems were defined as the survivor's weight being at or above the 90th percentile corresponding to Dutch standards [16]. School problems were rated as present if the survivor received remedial teaching or was not able to attend a regular school.

Comparison groups

Parent reports on the sibling's behaviour were compared with those of children matched for sex, age, and SES from a representative sample of the general population ($n = 2033$; see [17] for sample selection and data collection procedure). Child reports were compared with randomly selected healthy children ($n = 300$) from two local elementary schools and matched for sex (see [18] for sample characteristics and data collection procedure).

Procedure

Parents were approached during regular appointments at the follow-up outpatient clinic. They were asked to inform the sibling about the study and to explore the sibling's willingness to participate. If the sibling agreed, written informed consent was requested. Siblings were interviewed at home in an open, in-depth way about their experiences with the illness. After the interview, the instruments were administered. Instruments were only administered if they were appropriate for the sibling's age. Mothers were asked to complete a questionnaire while their child was being evaluated. Although 2 siblings refused to participate, their parents' reports were included. In one family, the mother did not complete the questionnaire because of clinical considerations, but information from the sibling was available.

Measures

The Child Behaviour Checklist (*CBCL*) [19] for ages 4–18 years is a standardised procedure to obtain parents' reports of their child's behavioural and emotional problems. The CBCL has excellent psychometric properties, which have been replicated in Dutch children [17]. The problem section of the CBCL consists of 120 items. Parents are requested to circle a 0 if the problem item is not true for the child, and a 1 or a 2 if it is sometimes true or very true, respectively. High scores reflect a high degree of problems. Total problem scores are computed by summing the scores on each item. Achenbach [19] has empirically constructed eight syndromes: withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent problems, and aggressive behaviour. Five of these syndromes could be grouped under two broad band scales: internalising and externalising. Internalising problems reflect internal distress, whereas externalising problems reflect conflicts with other people and their expectations of the child. The internalising group consists of the following syndromes: anxious/depressed, somatic complaints, and withdrawn. The externalising group consists of aggressive behaviour and delinquent behaviour.

The Self-perception Profile for Children (*SPPC*) [20] is a 36 item questionnaire measuring self-concept or perceived competence in children 8–12 years of age. The SPPC contains six subscales, on (1) scholastic competence; (2) social acceptance; (3) athletic performance; (4) physical appearance; (5) behavioural conduct; and (6) general self-worth. Each subscale contains six items on which the child is asked to rate its competence on a 4 point Likert scale. Subscale scores range from 6 to 24 and a higher score is associated with higher perceived competence. The reliability and validity of the SPPC has been established for Dutch children [18].

The Amsterdam Biographic Questionnaire for Children (*ABV-K*) [21] is a forced choice (yes/no) personality questionnaire for children 9–17 years of age measuring (1) neurotic complaints; (2) somatisation; (3) extroversion; and (4) testing attitude. The "neurotic complaints" scale measures psychoneurotic complaints with descriptive statements such as "I worry a lot" and "Deep down I am scared of many things"; the "somatisation" scale measures somatisation of neurotic complaints, with items such as "I often have a headache" and "My belly often aches"; the "extroversion" scale measures the child's position on the dimension introversion–extroversion with descriptive statements such as "I feel self-conscious" and "When with other children, I stay in the background"; and the "testing attitude" scale measures social desirability with items such as: "I lie sometimes", "I only have good thoughts about other people". The total scores on each subscale reflect the individual's position on a continuum ranging from 0 to 100. Satisfactory internal consistency and test–retest reliabilities have been reported [21, 22].

The Children's Depression Scale (*CDS*) [23] is a well-established measure of the presence and severity of depressed mood in children of 9–15 years of age. Children sort 63 cards with descriptive statements on a 5 point Likert scale. Scores range from 63 to 315. High scores indicate a higher degree of depression. Reliability and concurrent validity have been established [24].

Statistical analysis

To test differences between siblings and comparison groups, analyses of covariance (ANCOVA) were performed with age at investigation as a covariate. The total group of siblings and boys and girls separately were compared with children from the general population. The impact of demographic, family and disease characteristics (Table 1) on psychosocial problems was assessed by comparing the mean CBCL, ABV-K, SPPC, and CDS scale scores of siblings with and without a characteristic present in a series of one way analysis of variance (ANOVA). Non-dichotomised variables were categorised as follows: age of sibling at investigation (< 11 years old, $\geqslant 11$ years old); age of sibling at diagnosis (< 4 years old, $\geqslant 4$ years old); socioeconomic status (skilled manual employee or lower, minor professional or higher).

The sample size of this study was not large, limiting the statistical power of the tests. To obtain insight into the exact power of each analysis to detect differences that do exist but fail to reach statistical significance ($P < 0.05$), and thus avoid type II errors, we performed *ad hoc* estimations of power and effect size. According to Cohen [25], group differences of approximately 0.20, 0.50 and > 0.80 standard deviation are considered to be small, medium, and large effects, respectively. The sample size in this study was not large enough to detect small effects (power ranges from 0.09 to 0.20). Estimation of power showed that with an α of 0.05, there was a 80–100% probability of finding large effects in the total group of siblings and for each sex separately, and 73–85% probability of finding medium effects in the total group of siblings. Thus, for these analyses, the power is adequate (> 0.70) to excellent (> 0.90). However, in comparing male and female siblings with their controls, the power to detect medium effects was inadequate (range: 0.33–0.61). Differences that showed a medium effect, but failed to reach statistical significance due to low power, will be mentioned in the Results section, but should be interpreted with caution.

RESULTS

Differences between siblings and comparison groups

Results of the comparison between siblings and children from the general population are presented in Table 2. Comparison between the total group of siblings and the comparison groups yielded 22 non-significant differences and one significant difference: on the ABV-K somatisation scale, siblings of cancer survivors ($M = 44.8$) reported less problems than controls ($M = 58.2$) at $P < 0.05$. Analyses of each sex separately showed one significant difference for the boys and two for the girls. Male siblings had a lower mean score on the ABV-K extroversion scale ($M = 50.0$ versus $M = 71.9$ at $P < 0.05$) and female siblings had a lower mean score on the ABV-K somatisation scale ($M = 38.4$ versus $M = 61.1$) and a higher mean score on the SPPC social acceptance scale ($M = 19.4$ versus $M = 16.2$) both at $P < 0.05$. In addition, two medium effects for girls were found that did not reach statistical significance due to low power. Female siblings had higher scores on the SPPC behavioural conduct scale and on the SPPC total score. Finally, no significant differences for the CBCL or for the CDS were found.

Effect of demographic, family, and disease-related variables on adjustment

Significant differences at $P < 0.05$ and percentages of explained variance are presented in Table 3. Sex and age at diagnosis of the sibling had an effect on four self-report scales. Male siblings had a lower ABV-K extroversion score ($M = 50.0$) than girls ($M = 68.3$) and a lower SPPC social acceptance score

Table 2. Mean for age-adjusted scale scores for sibling and control groups

Scale	Total			Boys			Girls		
	Sibling	Control		Sibling	Control		Sibling	Control	
CBCL	$n = 59$			$n = 34$			$n = 25$		
Withdrawn	1.9	1.8		2.0	2.2		1.6	1.3	
Somatic complaints	0.9	0.8		1.0	0.8		0.8	0.7	
Anxious/depressed	2.3	2.5		2.4	2.9		2.0	2.0	
Social problems	1.4	1.6		1.5	2.1		1.1	0.8	
Thought problems	0.5	0.2		0.6	0.2		0.3	0.2	
Attention problems	3.1	3.2		3.7	3.8		2.3	2.4	
Delinquent behaviour	1.0	1.4		1.0	1.5		1.0	1.2	
Aggressive behaviour	5.6	6.6		6.7	8.4		4.1	4.2	
Internalising behaviour	5.0	5.0		5.4	5.7		4.5	4.0	
Externalising behaviour	6.6	8.0		7.7	9.9		5.2	5.4	
Total problems	18.6	21.1		21.1	25.0		15.1	15.7	
SPPC	$n = 46$			$n = 26$			$n = 20$		
Scholastic competence	17.5	16.1		18.0	17.1		16.7	14.7	
Social acceptance	18.1	17.8		17.1	19.0		19.4	16.2	**12.4***
Athletic competence	17.1	18.0		17.6	19.3		16.3	16.6	
Physical appearance	18.3	17.0		19.4	18.5		17.0	14.8	
Behavioural conduct	16.3	16.3		15.8	16.8		17.1	15.4	
General self-worth	19.6	18.7		20.2	19.7		18.8	17.5	
Total score	106.9	103.8		108.2	110.5		105.3	95.2	
	$n = 46$			$n = 25$			$n = 21$		
ABV-K									
Neurotic complaints	47.2	47.5		47.1	41.3		47.8	54.4	
Somatisation	44.8	58.2	**4.9***	50.1	55.7		38.4	61.1	14.5*
Extroversion	59.0	63.5		50.0	71.9	12.5*	68.3	54.8	
Testing attitude	48.4	45.6		47.3	50.7		49.7	39.4	
CDS	$n = 44$	$n = 30$							
Total score	151.2	147.1							

* Percentage of explained variance. CBCL, Child Behaviour Checklist; SPPC, Self-perception Profile for Children; ABV-K, Amsterdam Biographic Questionnaire for Children; CDS, Children's Depression Scale.

Table 3. Percentages of variance accounted for by significant ($P < 0.05$) *effects of demographic, family and disease-related characteristics on psychosocial problems**

	Characteristics						
	Demographic		Family		Disease		
	Sex	Age at diagnosis	Chronic disease	SES	Radiation	Time since treatment	School problems
CBCL							
Withdrawn							
Somatic complaints						11.6††	
Anxious/depressed			7.4‖				
Social problems			11.6‖				
Thought problems							
Attention problems							
Delinquent behaviour			7.0‖				
Aggressive behaviour							
Internalising behaviour							
Externalising behaviour							
Total problems			10.8‖				
SPPC							
Scholastic competence		9.6§					
Social acceptance	8.9†			10.5¶			
Athletic competence							
Physical appearance	10.1‡						
Behavioural conduct							
General self-worth					11.1**		
Total score							
ABV-K							
Neurotic complaints							
Somatisation				8.9¶			
Extroversion	12.0†						
Testing attitude					8.9**		
CDS							
Total score					18.2**		10.4**

* Only those characteristics with at least one significant result are listed; † Higher problem scores for male siblings; ‡ Higher problem scores for female siblings; § Higher problem scores for older siblings (≥ 4 years at diagnosis); ‖ Higher problem scores for siblings with characteristic present; ¶ Higher problem scores for siblings from lower SES, ** Lower problem scores for siblings with characteristic present; †† Higher problem scores for siblings of survivors ≥ 5 years off treatment. CBCL, Child Behaviour Checklist; SPPC, Self-perception Profile for Children; ABV-K, Amsterdam Biographic Questionnaire for Children; CDS, Children's Depression Scale; SES, socioeconomic status.

($M = 17.1$ versus $M = 19.4$), but a higher score on the SPPC physical appearance scale ($M = 19.4$ versus $M = 17.0$). The mean SPPC scholastic competence score was lower for siblings who were older than 4 years when the disease was diagnosed than for siblings who were younger ($M = 16.2$ versus $M = 19.3$).

With respect to family characteristics, we found that parents of siblings coping with a chronic disease in another family member reported more psychosocial problems. The mean CBCL total problem score was 28.3 for siblings from these families versus 15.3 for siblings from other families. The mean CBCL syndrome scores that were elevated were, respectively, anxious/depressed ($M = 3.6$ versus $M = 1.8$), social problems ($M = 2.7$ versus $M = 0.9$), and delinquent behaviour ($M = 1.9$ versus $M = 0.8$). Furthermore, siblings from lower SES families had higher ABV-K somatisation scores ($M = 54.0$ versus $M = 36.0$) and reported lower social acceptance on the SPPC ($M = 17.0$ versus $M = 19.6$) than siblings from higher SES families.

The impact of disease-related factors on the siblings was restricted to an effect of radiation and time since cessation of treatment and whether the survivor had school problems. Siblings of survivors who were radiated during treatment, scored themselves higher on SPPC general self-worth ($M = 20.5$ versus $M = 17.9$), higher on the ABV-K testing attitude scale ($M = 55.0$ versus $M = 37.0$), and had lower depression scores on the CDS ($M = 142.0$ versus $M = 162.0$). Siblings whose brother or sister had school problems as a late effect also reported lower depression scores on the CDS ($M = 142.0$ versus $M = 157.4$). For siblings whose brother or sister had been off treatment for longer than 5 years, parents reported more somatic complaints ($M = 1.4$ versus $M = 0.5$).

DISCUSSION

The aim of the study was to investigate how siblings of cancer survivors adjust after cessation of treatment. The results of the present study show that the psychosocial functioning of siblings of childhood cancer survivors is comparable with that of children in the comparison groups. Although small differences between groups may exist, which could not be detected due to limited statistical power, no major differences in psychosocial functioning has been found. On all measures of emotional and behavioural problems and competence, the total group of siblings fared the same or even better than those to whom they were compared, showing that childhood cancer does not result in a heightened risk of psychological disturbance for siblings as a late effect. Depending on the informant, estimates of the frequency of siblings' adjustment problems may vary. The fact that in our study parents and siblings reports coincided, emphasises that the stresses associated with cancer and its treatment have no serious late psychosocial sequelae for the sibling of the survivor.

Although clinical experience and research demonstrates that during diagnosis and treatment siblings have serious problems [4–11, 26–28], after completion of treatment, siblings adjust well. The absence of long-term sequelae in siblings is in sharp contrast to the late effects of cancer experience on the survivors themselves and their parents. In comparing childhood survivors and siblings with their matched controls on the CBCL, siblings showed significantly fewer problems than the survivors. In the survivor group, 21.1% of the children had serious adjustment problems versus 6.8% in the siblings ($P = 0.01$; z-test two-tailed probability) (J.E.W.M. Van Dongen-Melman, unpublished results). Moreover, childhood cancer has distinct and persistent late effects on parents that even tend to increase over time [29]. Whereas it has been reported that during treatment siblings are less adjusted than other family members [10], after termination of treatment this situation seems to be reversed. It might be hypothesised that after termination of treatment, siblings are able to distance themselves from the cancer experience, whereas for survivors and parents the confrontation with the disease, the concerns and anxieties over the recurrence of the disease and its long-term medical consequences, continue.

Few demographic, family and disease-related factors were found to affect the siblings' adjustment. This finding can be attributed to the overall good adaptation of the sibling because these factors have to discriminate between well adapted and better adapted siblings. In the literature, several factors are considered to be important in explaining the differential adaptation in siblings of chronically ill children [13, 14, 30]. However, the situation is different for siblings of childhood cancer survivors than for siblings of children with cancer undergoing cancer treatment. After completion of cancer treatment, the direct medical stresses subside whereas siblings of children undergoing cancer treatment are continuously confronted with the illness. The fact that a chronic disease in another family member did increase adjustment problems for siblings may lend support to this supposition.

Interestingly, siblings of a survivor who received cranial radiation or who had school problems showed significantly lower depression scores and higher scores on general perceived competence. Simultaneously, they gave more socially desirable answers that might explain these favourable scores. Cranial radiation is associated with neuropsychological deficits that negatively affect academic achievement. Because one would expect that long-term sequelae in a survivor would increase problems, the question is why do these siblings need to present themselves more favourably. A possible explanation might be that they do not want to show their concerns or problems which might enhance their parents' burden or worries [28]. Siblings may feel the need to excel to compensate for the survivor's problems and thus make a valuable contribution to family life. Alternatively, these siblings may feel jealous towards the survivor and thus like to overemphasise their adequate adjustment in contrast to that of the survivors.

The fact that childhood cancer does not result in an increased risk of major psychological disturbance does not signify that siblings may not have undergone alterations in psychosocial functioning or do not experience distress. The individual sibling may have lingering concerns and problems that do require attention. From the interviews with children, we found that if there were lingering concerns, they focused on the relationship with the parents and their position within the family. Short-term counselling sessions were developed to help parents to initiate communication about these issues with their children. Parents reported back that addressing the disadvantaged situation of the sibling was very effective in alleviating these problems. Recent data suggest that siblings who reported more communication about the illness perceived their lives to be less affected by the cancer experience [2]. Even though siblings fare well, their quality of life can be enhanced by well attuned communication.

Our study shows no major differences in psychosocial functioning between siblings of cancer survivors and controls, suggesting that childhood cancer does not result in a heightened risk of psychological disturbance for siblings after the cessation of treatment. Although potential reassurance can be given to parents about the long-term outcome for siblings, simultaneously efforts to facilitate communication between parents and siblings should be made. Our study provides information to develop adequate support strategies for families of childhood cancer survivors. It may help the health care team to direct care to those family members who are in need of support.

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