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Health-Related Quality of Life in Children and Emotional Reactions of Parents Following Completion of Cancer Treatment

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Background. Completing therapy is one of the major transitions in care in the practice of pediatric oncology and, therefore, deserves special consideration. The purpose of the study was to investigate health-related quality of life (HRQOL) of pediatric patients, and emotional reactions of their parents, shortly after the end of successful treatment. ***Methods.*** HRQOL of 126 patients, aged 1–15 years, on average 2 months after the end of successful treatment, was assessed with the TNO-AZL Pre-school Quality of life Questionnaire and the TNO-AZL Children's Quality of life Questionnaire. Emotional adjustment of 124 mothers and 111 fathers was assessed with the General Health Questionnaire and the Situation Specific Emotional Reaction Questionnaire. The outcomes of the patients and parents were compared with norm data by means of one sample *t*-tests, one sample sign-tests or binomial tests. ***Results.*** All age groups, except patients aged 8–11 years, experienced worse HRQOL than the norm with respect to motor functioning. In addition, pre-school patients were rated worse on sleeping, appetite, stomach, skin, problem behavior, anxiety, and liveliness, and patients aged 6–7 years on autonomy and cognitive functioning. Parents reported more psychological distress than the norm. Compared to parents whose children were 1–5 years after cancer treatment, they suffered more from feelings of loneliness, helplessness, and uncertainty. ***Conclusions.*** A few months after the end of successful cancer treatment, both patients and parents appeared to experience worse well-being than the norm to a clinically relevant extent. Supporting patients and parents should not stop when treatment ends. Pediatr Blood Cancer 2006;47:312–319.

Key words: neoplasm in childhood; psychological adaptation; quality of life

INTRODUCTION

Approximately 400 children are diagnosed with cancer in the Netherlands every year [1]. The diagnosis of childhood cancer has an enormous impact on the child and his family. They are confronted with a life-threatening disease mostly implying extensive treatment with negative side-effects and the risk of negative long-term consequences. Considerable literature has been devoted to the long-term adjustment of the child [2–4]. It can be concluded that dealing with childhood cancer is a dramatic event that could influence physical and psychosocial functioning long time after termination of the treatment [2,5,6]. In addition, post-traumatic stress symptoms appeared to be common in families of childhood cancer; among survivors of childhood cancer, as well as among their parents [7–10]. Nevertheless, many long-term survivors of childhood cancer turned out to function well [11,12](see reviews by Langeveld et al. [3] and Stam et al. [4]). This appeared also to be true for their parents; overall, most of them did not experience more emotional disturbances than healthy controls [13–16]. However, if illness related concerns were taken into account, parents of survivors of childhood cancer seemed to experience feelings of uncertainty and loneliness [17,18].

Less is known about what happens in the years immediately after successful treatment. During treatment, patients and their families may have struggled for life, living day by day, supported intensively by the medical staff and social support networks. After termination of treatment, concerns about the further course of the disease as well as the child's education and employment can take the place of treatment-related worries [2]. The social and emotional support also often decrease when active treatment ends. Families have to integrate their experiences in normal daily life and have to face future challenges relating to issues surrounding the diagnosis and treatment of cancer. These first years following the end of treatment can be considered as an important phase of adjustment to the cancer experience. A longitudinal study was designed in order to gain insight into this process of adjustment.

The results presented here concern the first assessment of the longitudinal study among the childhood cancer patients and their parents, 2 months after the termination of the cancer treatment. We considered this moment of assessment to be interesting because it represents the transition from active treatment to "normal daily life." The aims of the current study are the assessment of (1) health-related quality of life (HRQOL) 2 months after the end of treatment, using comprehensive instruments that measure physical, cognitive, social as well as emotional aspects of HRQOL, and (2) the emotional adjustment of the parents 2 months after the end of treatment of their child.

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PATIENTS AND METHODS

Procedure

The results presented here concern the first measurement of the longitudinal VOLG-study (Vragenlijsten kinderOncologie Latere Gevolgen), a Dutch study on the late psychosocial consequences of cancer in childhood. It started in 2000 and will end in 2006. The respondents of the VOLG-study were recruited from the The Emma Children's Hospital/Academic Medical Center in Amsterdam (from March 2000 until the end of 2002) and the Radboud University Nijmegen Medical Center (from June 2002 until the end of 2002). Inclusion criteria were: (1) age 1–18 years, (2) complete first remission, (3) end of successful treatment at most 2 months before, and (4) being able to complete Dutch questionnaires.

Parents of children with cancer, and children with cancer aged 8 years or older were informed about the VOLG-study by letter. After informed consent was obtained, the parents were telephoned and an appointment was made for completion of questionnaires anonymously in the hospital or at home. The children and parents were instructed to complete the questionnaires independently. The assistance of the researcher was restricted to reading questions out loud and to explaining the meaning of difficult words. Some parents and some patients aged 15 years or older filled in the questionnaires without the assistance of the researcher, at home. The respondents were asked to complete the questionnaires, yearly, four to six times, depending on the year of inclusion. The results of the first assessment were used in this study. The self reports of the patients aged 16 years or older were not included in this study because of the small number of eight patients in this age group. A unique patient number made it possible to gather medical information, from the respondents as well as from the non-respondents. The Medical Ethic Committee of the Academic Medical Center in Amsterdam and the Radboud University Nijmegen Medical Center has approved the study protocol.

Measures

Health-related quality of life. HRQOL of the childhood cancer patients was assessed with the *TNO-AZL Preschool Quality of Life* questionnaire for children aged 1–5 years (TAPQOL) [19,20], and with the *TNO-AZL Children's Quality of Life questionnaire*; Parent Form for children aged 6–11 years (TACQOL-PF) [21] and Child Form for children aged 8–15 years (TACQOL-CF), [22,23]. These questionnaires are generic Dutch instruments that measure health status problems weighted by the impact of the health status problems on well-being. It offers the respondent the possibility of differentiating between their functioning and the way they feel about it. Most of the items consist of two questions linked to one another. On the first one, the respondent can rate whether or not a specific problem occurred in the past few weeks. The second one is about the possible negative emotional responses to the problems. The respondent can indicate how he (or his child) felt about this problem on a four point Likert scale: fine, not so good, quite bad, bad. The items are clustered into multi-item scales with higher scores indicating better quality of life. Norm data from the general Dutch population were available. The instruments measure HRQOL on group level in a reliable and valid way [19–24].

The *TAPQOL* assesses the child's functioning on 12 domains: sleeping, appetite, lungs, stomach, skin, motor functioning, social functioning, problem behavior, communication, anxiety, positive mood, liveliness. The raw scales scores of the TAPQOL are converted to a 0–100 scale. The Cronbach alphas in our study population were moderate to good. Norm data were collected via a sample from the general population of children visiting well-baby clinics in the Netherlands in 1997. Periodically, almost all children aged 0–5 years in the Netherlands visit well-baby clinics [19].

The *TACQOL* for children aged 6–11 years (PF) or aged 8–11 years (CF), assesses functioning on seven domains: physical complaints, motor functioning, autonomy, cognitive functioning, social functioning (in relation to parents and peers), positive emotions, and negative emotions. The *TACQOL* for adolescents, aged 12–15 years, assesses functioning on six domains: physical complaints, motor functioning, cognitive functioning, social functioning (in relation to peers), positive emotions and negative emotions. The Cronbach alphas, in our study population, were moderate to good. Norm data were collected via the Centers for Preventive Youth Health Care all over The Netherlands, via stratified random sampling [21–23,25].

Medical data. Medical data were obtained from the medical record of the ill child. Prognosis was based on the oncologist's rating of the child's survival chances at diagnosis, that is, <25%, 25–75%, >75%.

Parental distress. Parental distress was measured with the *General Health Questionnaire-30* (GHQ-30) [26,27], a 30-item self-report measure. The raw total scale score can be used as an overall index of psychological distress, ranging from 0 to 30 with higher scores indicating more distress. According to Goldberg et al. [26], scores ≥ 5 indicate clinically elevated levels of psychological distress. The validity of the 30-item version is well documented and internal reliability is highly satisfactory [26]. Cronbach alpha in the current study is high ($\alpha = 0.92$).

Parental situation-specific emotional reactions. Parental situation-specific emotional reactions were assessed with the *Situation Specific Emotional Reaction Questionnaire* (SSERQ). This is a Dutch questionnaire that consists of 30 items, divided in four subscales, which describe feelings that can be considered situation-specific for parents of children with cancer. It concerns feeling of (1) loneliness, 11 items, for example, "I have the feeling that nobody understands what I am going through," (2) helplessness, 7 items, for example, "I feel helpless that I can't do anything about the situation," (3) uncertainty, 6 items, for example, "I am uncertain about the course of the disease," and (4) positive feelings, 6 items, for example, "I have the feeling that I can enjoy small things more tremendously." Parents were asked to indicate whether they experienced an emotional reaction on a 4-point scale: never, sometimes, often, almost all the time. The higher the scores the more often parents experienced the emotional reactions. The validity and reliability turned out to be satisfactory in former studies [28]. The Cronbach alphas in the current study were also satisfactory, ranging from $\alpha = 0.71$ to $\alpha = 0.85$.

Statistical Analyses

The Statistical Package for Social Sciences (SPSS), Windows version 11.5, was used for all analyses. Before conducting the final analyses several preparation analyses were conducted. First, scales were constructed and missing data imputed on the basis of the guidelines of the questionnaires used. Second, the reliability of these scales was calculated. Third, descriptive statistics were used to describe the demographic and medical characteristics of the participants. Finally, binomial tests were performed in order to test whether the distribution by gender in the several patient groups (1–5, 6–7, 8–11, and 12–15 years) differed from that in the age-matched norm groups.

HRQOL of the childhood cancer patients. One sample *t*-tests, or, if the sample size was smaller than 20, non-parametric equivalents (one sample sign-test or binomial test), were performed to test whether the mean score, the median, or the binomial distribution of the several HRQOL-scales scores of the childhood cancer patients differed from the norm data available. A significance level of $P < 0.005$ was used in order to compensate for multiple testing. Effect sizes (d) were calculated by dividing the difference in mean score between the childhood cancer patients and the norm group by the standard deviation of the scores in the norm group. According to Cohen, effect sizes of up to 0.2 were considered to be small, effect sizes of about 0.5 to be moderate, and effect sizes of about 0.8 to be large [29].

Patients' self-reports were used for analysis unless the self-report was not available due to the young age of the patient. Separate analyses were conducted for (1) patients aged 1–5 years, using the TAPQOL, (2) patients aged 6–7 years, using the TACQOL-PF, (3) patients aged 8–11 years, using the TACQOL-CF for children, and (4) patients aged 12–15 years, using the TACQOL-CF for adolescents.

Separate analyses by gender were performed in the age group 8–11 years because the distribution of gender in this patient group differed from that in the norm group. This was not the case in the other age groups.

Parental emotional reactions. Parental psychological distress was compared with the Dutch norm by conducting one sample *t*-tests on the mean total GHQ-score, and binomial testing on the percentage "clinically elevated levels of psychological distress," that is, GHQ-scores ≥ 5. Analyses were performed for mothers and fathers separately. Effect sizes could not be calculated because the standard deviations of the mean scores among the norm group were not available. The mean items scores on the subscales of the SSERQ, computed for mother and fathers separately, were compared to the mean items scores of mothers and fathers of children who were off cancer treatment for 1–5 years [28]. One-sample *t*-tests were conducted and effect sizes were calculated.

RESULTS

Participants

A total of 164 consecutive childhood cancer patients who completed treatment successfully at most 2 months before, and their parents, were approached for the longitudinal part of the VOLG-study; 150 patients from The Emma Children's Hospital AMC and 14 patients from the Radboud University Nijmegen Medical Center. The response rate was 81.7 per cent (N = 134). Of the 30 families who did not participate, 9 did not want to be confronted with cancer any longer, 8 did not return the informed consent form, and 5 did not return the questionnaires. Other reasons of refusal were: recurrence of the disease (N = 3), multiple family problems (N = 3), not being able to complete Dutch questionnaires (N = 2). No significant differences were found ($P < 0.1$ at *t*-tests or χ^2-tests) between the participants and non-participants with respect to age, gender, and several medical variables (Table I).

The final study sample of the VOLG-study consisted of 134 patients, 124 mothers, and 111 fathers. Their socio-demographic and medical characteristics were presented in Tables I and II. A total of 60 patients were old enough to complete questionnaires themselves. The self reports of eight patients aged 16 years or older were not included in this study. The 52 patients aged 8–15 years filled in the TACQOL-CF; 25 patients aged 8–11 years, and 27 patients aged 12–15 years. The researchers assigned the parent-form of the HRQOL-questionnaires at random to the father or the mother of the patients aged 1–7 years. The TAPQOL for children aged 1–5 years was completed by 35 mothers and 19 fathers. A total of nine mothers and nine fathers of children aged 6–7 years filled in the TACQOL-PF. All parents filled in the questionnaires about their own emotional well-being.

Health-Related Quality of Life of Childhood Cancer Patients Off Treatment

Patients aged 1–5 years. The HRQOL of the pre-school patients appeared to be significantly worse ($P < 0.005$) than the HRQOL of age-matched children from the general Dutch population, on eight out of the twelve scales of the TAPQOL:

TABLE I. Socio-Demographic and Medical Characteristics of the Participant and Non-Participant Patients

	Participants				Non-participants			
	M	SD	Range	N	M	SD	Range	N
Age at study (years)	8.3	4.6	1.1–18.2	134	8.4	4.9	1.7–17.7	30
Age at first diagnosis (years)	7.1	4.7	0.3–17.2	134	7.8	5.2	0.6–17.2	30
Time since first diagnosis (months)	13.6	8.3	2.0–29.7	134				
Time since end of last treatment (months)	2.2	1.0	0.1–5.7	134				
Duration of treatment (months)	11.4	8.3	0.6–26.0	134	12.5	9.5	0.5–26.1	29
Days of admission in Emma Children's hospital	44.9	30.2	2–141	120	45.7	30.6	5–127	27
	%		N		%		N	
Age categories								
1–5 years	40.3		54		40.0		12	
6–11 years	33.6		45		26.7		8	
12–15 years	20.1		27		26.7		8	
16–18 years[a]	6.0		8		6.7		2	
Gender								
Female	43.3		58		38.7		12	
Native country								
The Netherlands	96.2		128					
Diagnosis								
Leukemia/lymphoma	47.8		64		53.3		16	
Solid tumor	47.8		64		40.0		12	
Brain tumor	4.5		6		6.7		2	
Treatment[b]								
Chemotherapy	95.5		128		89.7		26	
Radiotherapy	18.7		25		17.2		5	
Surgery	47.0		63		44.8		13	
Autologous bone marrow transplantation	2.2		3		3.4		1	
Other	2.2		3		3.4		1	
Prognosis								
<25%	5.2		7		6.9		2	
25–75%	41.0		55		31.0		9	
>75%	53.7		72		62.1		18	
Visible consequences of the disease[b]								
None	68.8		86					
Amputation	4.8		6					
Moon-faced	6.5		8					
Bald	37.1		46					
Scars	21.8		27					
Wheel chair	4.0		5					
Other	27.2		34					

[a] The self reports of this patients were not included in the present study.
[b] More than one answer is possible per patient.

sleeping T(1,53) = −4.4, appetite T(1,52) = −4.2, stomach T(1,53) = −6.2, skin T(1,53) = −3.0, motor functioning T(1,50) = −6.1, problem behavior T(1,53) = −3.4, anxiety T(1,52) = −6.5, liveliness T(1,52) = −3.6. These differences were moderate to large: effect sizes (d) ranged from d = 0.4 for skin to d = 3.7 for motor functioning. No significant differences were found on the following scales: lungs, social functioning, communication, positive mood (Table III).

Patients aged 6–7 years. According to the results of non-parametric testing, the parent-reported HRQOL of the patients aged 6–7 years was significantly worse ($P < 0.005$) than that of age-matched children from the general Dutch population with respect to motor functioning, autonomy, and cognitive functioning. The differences were large: effect size (d) = 3.2 for motor functioning, d = 2.7 for autonomy, and d = 1.0 for cognitive functioning. The patients did not differ from the general population on the other TACQOL-PF scales: physical complaints, social functioning, positive emotions, and negative emotions (Table IV).

Patients aged 8–11 years. On the basis of the TACQOL self-reports, the patients aged 8–11 years seemed not to differ from the general Dutch population of 8–11 aged children, at a significance level of $P < 0.005$ (Table V). However, the cancer patients tended to score worse than the general population on motor functioning (T(1,23) = − 2.3; $P = 0.03$) and autonomy (T(1,22) = −2.2; $P = 0.04$). The

TABLE II. Socio-Demographic Characteristics of the Participating Parents

	M	SD	Range	N
Age mother (years)	37.8	5.0	26.0–50.0	124
Age father (years)	39.8	5.2	29.0–54.0	108
	%		N	
Family				
Father and mother, and child(ren)	94.0		125	
Father or mother, and child(ren)	4.5		6	
Other	1.5		2	
Eductional level[a] father				
Low	21.8		24	
Middle	34.6		38	
High	43.6		48	
Educational level[a] mother				
Low	43.1		53	
Middle	30.8		38	
High	26.0		32	

[a]Highest level completed: Low: primary education, technical, and vocational training, Lower and middle general secondary education; Middle: middle vocational education, higher general secondary education, pre-university education; High: higher vocational education, university.

effect sizes were moderate to large: d = 0.7 and d = 0.9 for motor functioning and autonomy, respectively. The non-parametric analysis by gender revealed no significant differences between the cancer patients and the general population, although the cancer patients scored worse on all scales of the TACQOL-CF.

Patients aged 12–15 years. The cancer patients aged 12–15 years appeared to score significantly worse than the general population on motor functioning: T(1,24) = −1.0, $P < 0.005$, which is considered a large effect (d = 1.5). No significant differences were found on the other scales, and the corresponding effect sizes were small (Table V).

Emotional Reactions of Parents of Childhood Cancer Patients Off Treatment

Parental psychological distress. Mothers as well as fathers reported significantly more psychological distress ($P < 0.001$) than the general Dutch population: T(114) = 10.5 and T(107) = 7.3 for mothers and fathers, respectively. The mean level of distress of the mothers (M = 10.1) as well as that of the fathers (M = 8.2) was in the clinical range, that is, GHQ-total score ≥ 5. Moreover, the percentage of mothers and fathers who reported a clinically elevated level of psychological distress was significantly higher ($P < 0.001$)

TABLE III. Mean (M) and Standard Deviation (SD) of the Scores[a] on the TAPQOL-PF, Childhood Cancer Patients Aged 1–5 Years Versus the Norm[b]

	Cancer patients (1–5 years)			Norm	Effect size
Parent report	M	SD	N	M	d
Sleeping	67.9*	24.1	54	82.3	0.8
Appetite	74.7*	17.1	53	84.6	0.8
Lungs	94.0	14.6	53	93.6	0.0
Stomach	72.4*	23.2	54	91.9	1.4
Skin	87.5*	10.5	54	91.8	0.4
Motor functioning	81.9*	19.5	51	98.5	3.7
Social functioning	84.7	24.0	50	91.3	0.4
Problem behavior	55.6*	26.1	54	67.7	0.8
Communication	92.9	14.3	50	91.7	0.1
Anxiety	55.0*	26.1	53	78.3	1.3
Positive mood	92.1	17.2	53	98.7	1.0
Liveliness	87.4*	21.2	53	98.0	1.3

*$P < 0.005$ at one sample t-test: cancer patients versus norm.

[a]Scores range from 0 to 100, higher scores representing better HRQOL.

[b]General Dutch population of children aged 1–5 years [19].

TABLE IV. Mean (M)[a] and Standard Deviation (SD) of the Raw Scores[b] on the TACQOL-PF, Childhood Cancer Patients Aged 6–7 Years Versus the Norm[c]

	Cancer patients (6–7 years)			Norm	Effect size
Parent report	M	SD	N	M	d
Physical complaints	25.2 (78.8)	4.9	18	27.5	0.6
Motor functioning	24.0* (75.0)	6.6	18	31.0	3.2
Autonomy	25.6* (80.1)	6.2	18	31.0	2.7
Cognitive functioning	26.0* (81.3)	5.7	15	29.6	1.0
Social functioning	28.7 (89.6)	2.8	18	30.2	0.7
Positive emotions	14.4 (89.9)	2.4	18	15.0	0.3
Negative emotions	11.0 (68.8)	2.5	18	11.4	0.2

*$P < 0.005$ at non-parametric testing (sign-test or binomial test): cancer patients versus norm.

[a]Higher scores represent better HRQOL: range 0–32 for physical, motor, cognitive, social, autonomy; range 0–16 for positive and negative emotions.

[b]Transformed scores (0–100) are put between brackets.

[c]General Dutch population of children aged 6–7 years [25].

TABLE V. Mean (M)[a] and Standard Deviation (SD) of the Raw Scores[b] on the TACQOL-CF, Childhood Cancer Patients Aged 8–11 Years Versus the Norm[c], 12–15 Years Versus the Norm[d]

	Cancer patients (8–11 years)			Norm	Effect size	Cancer patients (12–15 years)			Norm	Effect size
Child report	M	SD	N	M	d	M	SD	N	M	d
Physical complaints	26.4 (82.6)	5.3	24	24.9	0.3	22.7 (71.0)	4.8	25	23.7	0.2
Motor functioning	27.7* (86.5)	4.8	24	29.8	0.7	25.0** (78.3)	5.4	25	29.8	1.5
Autonomy	29.5* (92.1)	3.7	23	31.2	0.9	—	—	—	—	—
Cognitive functioning	28.5 (89.1)	3.2	23	28.4	0.0	28.6 (89.3)	3.3	26	27.6	0.2
Social functioning	29.8 (93.0)	3.5	24	29.7	0.0	30.8 (96.4)	2.6	26	31.1	0.1
Positive emotions	12.5 (78.3)	3.1	24	13.5	0.4	12.9 (81.2)	3.6	26	13.0	0.0
Negative emotions	11.3 (70.3)	2.6	24	11.6	0.1	11.2 (70.2)	2.9	26	11.6	0.2

*$P < 0.05$ at one sample *t*-test: cancer patients versus norm.
**$P < 0.005$ at one sample *t*-test: cancer patients versus norm.
[a] Higher scores represent better HRQOL: range 0–32 for physical, motor, cognitive, social, autonomy; range 0–16 for positive and negative emotions.
[b] Transformed scores (0–100) are put between brackets.
[c] General Dutch population of children aged 8–11 years [25].
[d] General Dutch population of children aged 12–15 years [23].

than the percentage in the general population. Almost three-fourths of the mothers (72%) fell in the clinical range versus 24% of the female Dutch population. Among the fathers, we found 60% to be in the clinical range versus 22% of the male Dutch population (Table VI).

Parental situation-specific emotional reactions. The results in Table VII indicated that a considerable part of the mothers as well as of the fathers often experience feelings of helplessness, on average 2 months after the end of successful treatment of their child. However, they also often experience positive feelings. Feelings of uncertainty appeared to be experienced sometimes, while feelings of loneliness were reported less frequently.

Compared to parents whose children were 1–5 years after cancer treatment [28], the parents in our study turned out to suffer significantly more often from feelings of loneliness, helplessness, and uncertainty, mothers (T(120) = 2.1, T(121) = 3.1, T(121) = 6.7) as well as fathers (T(108) = 3.0, T(108) = 8.5, T(108) = 6.7). Moreover, the mothers reported less positive feelings on average 2 months after termination of treatment than the mothers a few years after that: T(120) = −3.5.

DISCUSSION

This study focuses on well-being of children and parents at the transition from active treatment to normal daily life. As far as we know, multidimensional HRQOL of pre-school patients of childhood cancer, shortly after termination of successful treatment, has never been assessed before. The patients with childhood cancer appeared to experience worse HRQOL in the physical domain, namely motor functioning. A considerable part of the patients in almost all age groups reported difficulty with activities such as walking, running, and endurance. The youngest patients, aged 1–5 years, were also rated worse HRQOL on other physical scales than motor functioning: sleeping, appetite, lungs, stomach and skin. These physical aspects were measured more globally among the older patients very likely because the TACQOL take the complaints together in one scale. The older patients seemed not to differ from the norm on this scale of physical complaints.

Among the older children, very few psychosocial differences were found between patients and the normal control group. Patients appeared to function well emotionally

TABLE VI. Psychological Distress in Parents of Childhood Cancer Patients Versus the Norm[a]: Mean (M) and Standard Deviation (SD) of the GHQ-30 Total Scores, and Percentage Clinically Elevated Levels of Psychological Distress

	GHQ-total score[b]			GHQ-total score ≥ 5[c]	
	M	SD	Norm (M)	%	Norm (%)
Mothers (N = 121)	10.1*	7.5	3.0	72*	24
Fathers (N = 108)	8.2*	7.2	3.1	60*	22

*$P < 0.001$ at one sample t-test or binomial test: parents versus norm; [a] General Dutch population [27]; [b] Score range 0–30; higher scores indicate higher levels of psychological distress; [c] Scores ≥ 5 indicate a clinically elevated level.

TABLE VII. Situation-Specific Emotional Reactions of Parents of Childhood Cancer Patients on Average 2 Months After Termination of Successful Treatment, versus Parents of Childhood Cancer Patients 1–5 Years After Termination of Successful Treatment: Mean Items Score[b] on the SSERQ

	Mothers				Fathers			
	M (SD)	N	M[a]	Effect size (d)	M (SD)	N	M[a]	Effect size (d)
Loneliness	1.47 (0.38)*	120	1.40	0.2	1.33 (0.35)**	109	1.23	0.4
Helplessness	2.30 (0.56)**	121	2.16	0.2	2.27 (0.49)***	109	1.87	0.6
Uncertainty	2.03 (0.53)***	121	1.72	0.7	1.88 (0.47)***	109	1.58	0.8
Positive feelings	2.54 (0.52)***	120	2.71	0.4	2.40 (0.50)	109	2.38	0.0

*$P < 0.05$ at one sample *t*-test; **$P < 0.01$ at one sample *t*-test; ***$P < 0.001$ at one sample *t*-test; [a]Parents of childhood cancer patients 1–5 years after termination of succesful treatment [28]; [b]Item scores: 1 = never; 2 = sometimes; 3 = often; 4 = almost all the time.

in contrast to their parents who reported high levels of distress. It is imaginable that the pediatric patients look less into the future than their parents, whose treatment-related worries will be replaced by the uncertainty about the future course of the disease and concerns about their child's education and employment [2]. Another explanation could be that older pediatric patients would be able to understand what has happened. This could lead to feelings of happiness to have survived the disease and treatment. These positive feelings could result in under-reporting of problems and in improving of HRQOL. This phenomenon, already described among adults, is called "response shift." It means that the experience with cancer changes the internal standards of patients, resulting in changes in the meaning of their self-evaluation and hence in a possibly different experience of problems [30]. Data about pre-cancer perceptions are needed to assess response shift.

It is reasonable to question whether patients really functioned psychosocially as well as the norm group or whether that there were methodological explanations. Perhaps more differences between the patients and the norm group would have been observed if an instrument could have been used that assesses pediatric social and emotional HRQOL in a more sensitive or cancer specific way than the TAPQOL and the TACQOL do. However, HRQOL-questionnaires translated and normed for young Dutch children, other than the TAPQOL and the TACQOL, were not available at the start of the VOLG-study. Unfortunately, the reliability of the social functioning scale of the TACQOL was moderate. This is a very interesting domain in our opinion, because recent research revealed that the social development of young adult long-term survivors of childhood cancer was hampered [31].

Finally, the "proxy problem" should be taken into account, because the HRQOL in the younger patients was assessed by their parents while the HRQOL of the patients aged 8–15 years was assessed by self-report. Previous research on the correlation between the parent-reported and the child-reported HRQOL showed that, on average, children reported significantly lower HRQOL than their parents on five out of the seven scales of the TACQOL including the positive emotions scale [32]. The comparison of the parent report and the child report in the current study revealed no systematic difference (internal report). Based on those data, we believe that there is no indication of a serious "proxy problem" in our study.

The parents experienced more psychological distress than the general Dutch population, and they appeared to suffer from feelings of loneliness, helplessness, and uncertainty. This is not surprising given the enormous transition from active treatment to the "coming off treatment" period. The parents have to get used to live with the uncertainty about recurrence of the disease and possible long-term side-effects. Many parents report that they feel uncertain without the protection of the medical treatment and support from the hospital. However, the experience of cancer is not necessarily in negative direction. We found that the parents often experience positive feelings, such as "I have the feeling that I can appreciate things more." The results of research by Greenberg and Meadows [17] were in the same direction, which showed negative parental comments as well as positive outcomes including the acquisition of new values and attitudes, improved marital adjustment, and social support.

There are some limitations in the present study that should be mentioned. First, the conclusions are based on relatively small subgroups of patients, because different age groups need different questionnaires. Second, the HRQOL questionnaires used had some limitations, though the TAPQOL and TACQOL are acceptable and the best available at the start of the study. Third, it cannot be concluded definitely that the worse HRQOL of the patients was due to cancer or having any chronic disease, because of the lack of data about pre-cancer functioning.

In spite of the limitations of the study, we can conclude that a few months after the end of successful cancer treatment, both patients and parents experienced worse well-being than the general Dutch population to a clinically relevant extent. The effect sizes found on the HRQOL of the young children with cancer in comparison with the norm groups were large according to Cohen [29].

The results emphasize that supporting patients and parents should not stop when treatment ends. Completing therapy is one of the major transitions in care in the practice of pediatric oncology and, therefore, deserves special consideration [33]. It is of importance to identify patients and parents at risk for adjustment problems. This called for longitudinal research directed at the predictors of patient's and parental adjustment in order to enable health care providers to trace and support patients and parents at risk.

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