


No increase in psychosocial stress of Dutch children with cancer and their caregivers during the first months of the COVID-19 pandemic

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Abstract

We studied the psychosocial impact of the start of the COVID-19 pandemic on Dutch children with cancer in outpatient care and their caregivers ($n = 799$) using regular monitoring and screening outcomes. No differences were observed between the pre-COVID-19 and early-COVID-19 periods in health-related quality of life and fatigue of children. Fewer caregivers were distressed during the COVID-19 period than pre-COVID-19. In conclusion, the additional stress of COVID-19 did not deteriorate psychosocial functioning of children with cancer and their caregivers. Results may be explained by alleviating daily life changes, experience in coping with medical traumatic stress, and appropriate care and support.

KEYWORDS

caregivers, childhood cancer, COVID-19, psychological distress, psycho-oncology, quality of life

1 | INTRODUCTION

In general populations, anxiety, distress, and preventative measures including social distancing during the COVID-19 pandemic seem to increase psychosocial stress.^{1,2} Children with cancer and their caregivers may be particularly affected^{3,4} as they often already experience high levels of stress.⁵ Additional psychosocial stress may reduce their quality of life and increase fatigue.⁶ To extend the limited available knowledge,^{2,7} we aim to compare psychosocial functioning of Dutch children with cancer and their caregivers during the first months of the COVID-19 outbreak to the period before COVID-19.

2 | METHODS

In the Princess Máxima Center, approximately 60% of families of children in outpatient cancer care participate in regular psychosocial

monitoring and screening with the KLIK patient-reported outcome measure portal.^{8,9} Assessment takes place every three to six months, combined with regular outpatient appointments. Patients and families provide written informed consent to use their clinical data for research. This study included assessments between January 1, 2020, and June 1, 2020; March 13, 2020, was considered the start of the COVID-19 outbreak, as national preventative measures were initiated at this time (i.e., homeschooling and the advice to stay at home). The following details were extracted from medical records: personal and medical characteristics (sex, age, diagnosis group [solid tumor, CNS tumor or hematological cancer], time since diagnosis, and treatment status [on or after treatment]).

2.1 | Outcomes

Health-related quality of life (HRQoL) and fatigue of children with cancer were assessed using the age-appropriate Dutch proxy- (2-7-year-olds) or self-report (age: 8-18-year-olds) pediatric quality of life inventory (PedsQL) generic and multidimensional fatigue scales.

Abbreviations: CNS, central nervous system; COVID-19, Coronavirus disease 2019; DT-P, distress thermometer for parents; HRQoL, health-related quality of life; PedsQL, pediatric quality of life inventory

Higher scores (scale: 0-100) indicate higher HRQoL (e.g., better emotional function or less fatigue). The PedsQL generic and fatigue scales have adequate psychometric properties.^{10,11} Cronbach alphas in this study ranged from 0.74 to 0.94.

Using the distress thermometer for parents (DT-P), caregivers self-reported their overall distress regarding physical, emotional, social, and practical issues on a thermometer with a range of 0-10; scores of 4 or higher indicated clinical distress.¹² In addition, caregivers reported the problems they experienced in six domains and these were summed to two total scores. Psychometric properties of the DT-P score are adequate.^{12,13} Cronbach alphas ranged from 0.65 to 0.91.

2.2 | Statistical analyses

Participant characteristics and outcomes were described for the pre-COVID-19 and early-COVID-19 periods. Scores between periods were compared using mixed-effect linear regression analyses, to correct for repeated measurements in a minority of participants. The occurrence of clinical distress was compared between periods using logistic generalized estimating equation modelling with an exchangeable covariance structure to correct for both caregivers filling out the DT-P. Models were corrected for the personal and medical characteristics and effect modification of treatment status was evaluated; an interaction term of period and treatment status was added to the model if it was statistically significant. To adjust for multiple testing, the level of statistical significance was set at 0.05 divided by the number of analyses conducted on (sub)scales of a questionnaire (e.g., for PedsQL generic: $0.05/6 = 0.008$).

3 | RESULTS

Approximately 75% of the regularly scheduled psychosocial monitoring and screening questionnaires in clinical care were completed between January and end of May 2020 (pre-COVID-19/COVID-19 period: 77%/74%). Informed consent was provided for 87% of the children-reported outcomes and 94% of the caregiver-reported outcomes. The total study sample included 799 (caregivers of) children with cancer (pre-COVID-19/COVID-19 period: $n = 494/438$, 17% completed questionnaires in both periods). Of these participating families, the mean age of the child was 9.4 (SD: 4.9) years, 55% was male, mean time since diagnosis was 2.6 (2.3) years, hematological cancer was the most frequent diagnosis group (45%) and 64% were after treatment. Because of differences in assessment frequency and respondents, samples differed per outcome (see Table 1 for characteristics).

Results on HRQoL and fatigue of children with cancer in outpatient care and caregiver distress in the pre-COVID-19 and COVID-19 periods are presented in Table 2 and Supporting Information Table S1. A smaller percentage of caregivers showed clinical distress in the COVID-19 period on the DT-P compared with the period pre-COVID-19 (OR [CI]: 0.59 [0.42-0.83], $P = 0.002$). No other statistically

significant differences and no effect modifications for treatment status were found.

4 | DISCUSSION

The psychosocial functioning of children with cancer in outpatient care and their caregivers is assessed as part of regular monitoring. For this reason, we were able to compare HRQoL and fatigue of children and distress of their caregivers during the COVID-19 period to the months directly preceding COVID-19 in a large sample. Surprisingly, the only observed difference was a decrease in the proportion of distress in caregivers. Previous studies that examined COVID-19-related stress found that youth with cancer and their parents were concerned about COVID-19 illness and severe complications,^{14,15} and that adolescents and young adults with cancer were at high risk for psychological distress during the COVID-19 outbreak.¹⁶ Our population may have been less concerned about COVID-19, because healthcare professionals shared reassuring information from pediatric oncology centers in other countries from an early time point (i.e., information that suggested that children with cancer seemed relatively unaffected by COVID-19).

In line with our results, recently published longitudinal studies in clinical adult populations also found signs of psychosocial resilience during the COVID-19 period.¹⁷⁻¹⁹ In women with breast cancer, small but significant improvements were found in HRQoL during the COVID-19 period compared with before COVID-19.¹⁷ Furthermore, no differences were found on most domains of HRQoL and depressive symptoms during the COVID-19 period compared with before COVID-19 in Italian and Serbian patients with multiple sclerosis.^{18,19} One study explained these results by their population being accustomed to experiencing (medical traumatic) stress,¹⁸ which can change perspectives and tolerance. Similarly, because of their experience with medical traumatic stress, children with cancer and their parents may have appropriate adaptive styles or strategies to cope with stress caused by COVID-19.^{20,21}

Furthermore, the care that children with cancer and their caregivers received may have helped to maintain healthy psychosocial functioning. Outpatient care at our center (diagnostics and treatment) was completely continued during the crisis, although some doctor consultations were performed online or by phone in accordance with the parents. In addition, care at our center includes specialized professionals of the comprehensive psycho-oncology department that are readily available. The availability of these healthcare professionals may have contributed to families feeling well supported. Also, some caregivers mentioned that changes in daily life due to COVID-19, such as working from home and less traveling for medical appointments, reduced the challenge of managing appointments in family life. Additionally, because children with cancer sometimes miss school and hygiene can be important during and after treatment, the preventative measure of homeschooling and increased societal awareness of hygiene decreased feelings of being different from others.

TABLE 1 Participant characteristics for the samples of each outcome

Questionnaire and sample size	Pre-COVID-19 or COVID-19 period	Age child in years; mean (SD)	Gender child girl/boy; n (%)	Time since diagnosis in years; mean (SD)	Diagnosis group: solid tumor/CNS tumor/hematological cancer; n (%)	In/after treatment; n (%)
PedsQL generic proxy report (n = 364, 60 repeated reports)	Pre-COVID-19 (n = 213) COVID-19 period (n = 211)	5.1 (1.6) 5.0 (1.6)	91/122 (43/57) 89/122 (42/58)	2.1 (1.4) 2.1 (1.4)	86/34/93 (40/16/44) 78/39/94 (37/19/45)	78/135 (37/63) 87/124 (41/59)
PedsQL fatigue proxy report (n = 230, 31 repeated reports)	Pre-COVID-19 (n = 136) COVID-19 period (n = 125)	5.4 (1.6) 5.3 (1.5)	57/79 (42/58) 50/75 (40/60)	2.7 (1.4) 2.7 (1.3)	61/21/54 (45/15/40) 59/19/47 (47/15/38)	0/136 (0/100) ^a 0/125 (0/100) ^a
PedsQL generic self-report (n = 359, 56 repeated reports)	Pre-COVID-19 (n = 219) COVID-19 period (n = 195)	13.6 (3.0) 13.2 (3.0)	97/122 (44/56) 94/102 (48/52)	2.9 (2.9) 2.9 (2.7)	57/67/95 (26/31/43) 49/53/93 (25/27/47)	70/149 (32/68) 71/124 (36/63)
PedsQL fatigue self-report (n = 241, 36 repeated reports)	Pre-COVID-19 (n = 151) COVID-19 period (n = 126)	13.6 (3.1) 13.2 (3.1)	67/84 (44/56) 66/60 (52/48)	3.6 (3.1) 3.5 (2.7)	35/56/60 (23/37/40) 36/42/48 (29/33/38)	0/151 (0/100) ^a 0/126 (0/100) ^a
Questionnaire and sample size	Pre-COVID-19 or COVID-19 period	Age caregiver in years; mean (SD)	Gender caregiver female/male; n (%)	Time since diagnosis in years; mean (SD)	Diagnosis group: solid tumor/CNS tumor/hematological cancer; n (%)	In/after treatment; n (%)
DT-P (n = 681 caregivers, of 530 children)	Pre-COVID-19 (n = 376) COVID-19 period (n = 309)	41.6 (7.3) 41.4 (7.0)	247/129 (66/34) 206/103 (67/33)	2.9 (2.2) 2.9 (2.0)	117/88/171 (31/23/46) 104/83/122 (33/27/40)	110/266 (29/71) 88/221 (29/71)

Abbreviations: CNS: central nervous system; DT-P: distress thermometer for parents; PedsQL: pediatric quality-of-life inventory; SD: standard deviation.

^aPedsQL fatigue was only assessed in children after treatment.

TABLE 2 Quality of life and fatigue of children with cancer and distress of their caregivers in the pre-COVID-19 and COVID-19 periods

Caregiver about child (proxy report)				
	Pre-COVID-19 (n = 213)	COVID-19 period (n = 211)	Difference ^a	
<u>PedsQL generic; range 0-100</u>	Mean (SD)	Mean (SD)	Std. beta (SE)	P value
Total	75.1 (16.3)	77.1 (16.2)	0.16 (0.07)	0.032
Physical function	74.9 (21.4)	76.6 (20.6)	0.11 (0.08)	0.167
Emotional function	69.3 (19.2)	71.4 (18.9)	0.13 (0.08)	0.098
Social function	80.8 (17.7)	83.5 (17.6)	0.15 (0.08)	0.063
School function	76.3 (20.9); missing n = 14	78.7 (21.3); missing n = 48	0.16 (0.08)	0.049
Psychosocial function	75.2 (15.6)	77.6 (15.6)	0.17 (0.07)	0.014
Caregiver about child (self-report)				
	Pre-COVID-19 (n = 136)	COVID-19 period (n = 125)	Difference ^a	
<u>PedsQL fatigue; range 0-100</u>	Mean (SD)	Mean (SD)	Beta (SE)	P value
Total	76.8 (15.7)	77.2 (17.8)	0.06 (0.10)	0.566
Child about child (self-report)				
	Pre-COVID-19 (n = 219)	COVID-19 period (n = 196)	Difference ^a	
<u>PedsQL generic; range 0-100</u>	Mean (SD)	Mean (SD)	Std. beta (SE)	P value
Total	73.2 (16.6)	72.0 (18.2)	0.04 (0.07)	0.523
Physical function	71.7 (24.0)	70.0 (25.6)	0.11 (0.07)	0.117
Emotional function	73.1 (19.7)	73.6 (20.3)	0.05 (0.07)	0.480
Social function	81.8 (15.9)	78.8 (19.4)	-0.13 (0.08)	0.087
School function	67.0 (20.3)	66.6 (21.3)	-0.002 (0.09)	0.983
Psychosocial function	74.0 (15.3)	73.0 (17.0)	-0.03 (0.07)	0.706
	Pre-COVID-19 (n = 151)	COVID-19 period (n = 126)	Difference ^a	
<u>PedsQL fatigue; range 0-100</u>	Mean (SD)	Mean (SD)	Std. beta (SE)	P value
Total	69.3 (16.7)	70.6 (18.1)	0.15 (0.08)	0.063
Caregiver about caregiver (self-report)				
	Pre-COVID-19 (n = 374)	COVID-19 period (n = 307)	Difference ^b	
<u>DT-P</u>	Mean (SD)	Mean (SD)	Std. beta (SE)	P value
Thermometer score; range 0-10	3.9 (2.8)	3.4 (2.9)	-0.20 (0.08)	0.010
Distress (DT-P ≥4); n (%)	192 (51%)	122 (40%)	OR (95% CI) ^d : 0.59 (0.42-0.83)	0.002 ^{c,*}

Abbreviations: CI: confidence interval; DT-P: distress thermometer for parents; PedsQL: pediatric quality-of-life inventory; SD: standard deviation; SE: standard error.

^aResults for linear mixed-effect regression analysis with random intercept, corrected for gender and age of child, time since diagnosis, diagnosis group, and in/after treatment.

^bResults for linear mixed-effect regression analysis with random intercept, corrected for gender and age of caregiver, time since diagnosis, diagnosis group, and in/after treatment.

^cResults of logistic GEE corrected for sex and age of the parent, time since diagnosis, diagnosis group, and in/after treatment.

*Significant according to $P < 0.05$ /number of analyses on scales of the questionnaire.

Generalization of results of this study is limited to families of children with cancer receiving outpatient care in the Netherlands. The COVID-19 pandemic may have had different impact on the psychosocial functioning of families with hospitalized children, due to visiting and leisure restrictions and increased health concerns, or in other countries. Also, COVID-19-specific consequences such as COVID-19 illness, financial problems or loss of employment were not accounted for in this study. However, these factors may increase the risk of psychosocial problems in all families in pediatric oncology on the longer term, and should therefore be examined in future

research and care.²² In addition, we recommend that the impact of COVID-19 be studied longitudinally with attention to possible differences in coping from the pediatric oncology population to the general population.

In conclusion, we found that the HRQoL and fatigue of children with cancer in outpatient care were not different during the early months of the COVID-19 pandemic, and their caregivers were less often distressed than before COVID-19. Results may be explained by alleviating daily life changes, experience with medical traumatic stress, and appropriate support from healthcare professionals.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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