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#### PSYCHOSOCIAL AND SUPPORTIVE CARE: BRIEF REPORT



# Psychosocial function of Dutch children with cancer and their caregivers during different phases of the COVID-19 pandemic

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#### Abstract

We compared psychosocial functioning of children with cancer and their caregivers in several phases of the coronavirus disease 2019 (COVID-19) pandemic to before COVID-19. One or more questionnaires on health-related quality of life (HRQoL) or fatigue of children or distress of their caregivers was available from 1644 families. In children with cancer, HRQoL was stable throughout the COVID-19 pandemic. Fatigue was slightly lower and sleep somewhat better during the pandemic than before. Caregiver distress was lower in the first pandemic phase, but increased to pre-COVID-19 levels in later phases, indicating that the length and consequences of the pandemic may be weighing on them.

#### KEYWORDS

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

#### 1 INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic and consequential massive adjustments in everyday life seem stressful on general populations,<sup>1</sup> including Dutch children.<sup>2</sup> Children with cancer and their parents were suggested to be vulnerable for psychosocial problems because of already increased stress levels due to their cancer diagnosis and treatment,<sup>3</sup> because of worries about the potential impact of COVID-19 illness<sup>4</sup> and consequences of the pandemic on their treatment.<sup>5</sup> However, in the first months of the pandemic, psychosocial stress of Dutch children with cancer and their parents was not increased compared to the months before.<sup>6</sup> The duration of the pandemic and alternating phases of more and less restrictive preventative measures may have impacted psychosocial functioning differently. Thus, we revisit this subject and aim to compare psychosocial functioning of children with cancer and their caregivers in several phases of the COVID-19 pandemic to before the pandemic.

Abbreviations: COVID-19, coronavirus disease 2019; DT-P, distress thermometer for parents; HRQoL, health-related quality of life; PedsQL, Pediatric Quality-of-Life Inventory.

#### 2 | METHODS

All childhood cancer care in the Netherlands is concentrated at the Princess Máxima Center for Pediatric Oncology. Care includes psychosocial monitoring and screening linked to outpatient cancer care appointments using the KLIK patient-reported outcome measure portal. Families are informed regarding the use of this data for research purposes and patients ( $\geq$ 12 years) and caregivers are asked for informed consent as they create an account for the portal. At the time of study, over 2000 families of children with cancer in the Princess Máxima Center for Pediatric Oncology had active KLIK accounts.<sup>7</sup>

Health-related quality of life (HRQoL) and fatigue of children with cancer were assessed every 3 months using the Dutch proxy-report (2–7-year olds) or self-report (8–18-year olds) Pediatric Quality-of-Life Inventory (PedsQL) generic and multidimensional fatigue scales. The questionnaires include generic (e.g., not cancer related) statements on children's general perceptions or concerns. Fatigue was only assessed for children who had completed active treatment. Higher scores (scale: 0–100) indicate higher HRQoL (e.g., better emotional function) or less

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fatigue. Psychometric properties of the PedsQL generic and fatigue scales are good.<sup>8,9</sup> Cronbach's alphas of scale scores in this study ranged from .73 to .94.

Caregivers self-reported their distress (thermometer score range 0–10,  $\geq$ 4 indicates clinical distress) and problems regarding physical, emotional, social, and practical issues every 6 months using the distress thermometer for parents (DT-P).<sup>10</sup> Psychometric properties of the DT-P are good.<sup>10,11</sup> Cronbach's alphas of the total and subscale problem scores in this study ranged from .64 to .92.

#### 2.1 | Statistical analyses

Outcomes were described for the phase preceding the COVID-19 pandemic (January 1, 2020 to March 12, 2020) and several COVID-19 phases based on preventative measures in the Netherlands (see Figure S1). These were the first lockdown (March 13, 2020 to May 31, 2020), release of most restrictions (June 1, 2020 to October 13, 2020), the second "partial" lockdown (October 14, 2020 to December 14, 2020), the second "strict" lockdown (December 15, 2020) to January 19, 2021), and the lockdown with a curfew (January 20, 2021 to March 12, 2021). Psychosocial outcomes during the COVID-19 phases were compared to pre-COVID-19 using linear mixed effects regression analyses to account for repeated measurements, with domains of HRQoL, fatigue, and caregiver distress as dependent variables and the COVID-19 phases as independent dummy variables. Clinical distress during the COVID-19 phases was compared to pre-COVID-19 using logistic generalized estimating equation modeling with an exchangeable covariance structure. Models were corrected for demographic and medical variables (age, sex, time since diagnosis, treatment status [on or off active treatment], and central nervous system [CNS] tumor diagnosis). A p-value of .05 divided by the number of analyses conducted on (sub)scales of a questionnaire (e.g., for PedsQL generic: .05/6 = .008) was considered statistically significant.

#### 3 | RESULTS

Approximately 75% of the scheduled psychosocial monitoring and screening questionnaires were completed during the study period. Informed consent was provided for 94% of completed questionnaires. In total, 1644 families of a child with cancer (33% during treatment) filled out one or more questionnaires. Sample size differed per phase because of differences in timeframe, and sample characteristics differed per outcome (Table 1).

Figure 1 and Table S1 describe the results on HRQoL and fatigue of children with cancer in outpatient care and caregiver distress in the pre-COVID-19 and COVID-19 phases. HRQoL was not different in any of the COVID-19 phases compared to pre-COVID-19. Children after treatment for cancer between 8 and 18 years reported less fatigue in all phases of the pandemic than pre-COVID-19, except during the strict lockdown, with the largest differences on the sleep subscale ( $\beta = .24$ -

.32, p < .013). Caregivers had lower distress in the first lockdown than pre-COVID-19 ( $\beta = .23$ , p < .007), but the difference dissipated as the pandemic progressed.

#### 4 DISCUSSION

We found no difference in HRQoL in children with cancer throughout the COVID-19 pandemic. This may seem surprising because of reports of decreased psychosocial function in general populations and expected vulnerabilities of children with cancer and their caregivers.<sup>1,2,12,13</sup> However, other studies also found that psychosocial function of children with chronic illness and cystic fibrosis were less affected by COVID-19 than general population peers during the pandemic.<sup>14,15</sup> The lower negative impact of COVID-19 on clinical pediatric populations may be explained by being accustomed to stress<sup>15</sup> and isolation<sup>16</sup> because of their treatment and decreased feelings of being different because of generalized hygiene measures and home schooling.<sup>6</sup> In addition, because of contact with health care professionals at our center, children with cancer may have been informed better regarding COVID-19 risks and prevention, and had access to psychosocial support if necessary.<sup>17</sup> Also, the disruption of care during COVID-19 may be worrisome,<sup>18,19</sup> but outpatient care was continued completely at our center.

Although effect sizes were modest, we found that fatigue decreased and sleep improved during the pandemic in children who had completed active treatment for cancer. In adults with insomnia, improvements in sleep have also been observed during COVID-19, but worse sleep has been found in adults without pre-existing problems.<sup>20</sup> Because sleep problems are common in children with cancer.<sup>21-23</sup> our results may align with these. Furthermore, our results may be explained by children being homeschooled in some phases, thereby not having to get up early. This may fit better with their sleep schedule, especially that of adolescents,<sup>24</sup> and have improved sleep and reduced fatigue.<sup>25</sup> In line with this, an Italian study suggested that the sleep changes of adolescents during COVID-19 did not disturb their sleep, as the changes were compliant with their physiological sleep needs.<sup>26</sup> Finally, clinical observations indicated that children benefitted from being exposed to less stimuli during COVID-19, which may have reduced fatigue and improved sleep.

Notably, compared to published general population norms of the PedsQL generic in Dutch children in several age groups, children with cancer had worse HRQoL and experienced more fatigue.<sup>27-30</sup> This difference was around 10 points on all domains. Thus, although the COVID-19 pandemic did not negatively impact HRQoL and fatigue of these children, HRQoL should continue to receive appropriate attention in pediatric oncology care.<sup>3</sup>

As in our previous report,<sup>6</sup> we found that stress of caregivers was decreased during the first lockdown. Throughout the duration of the pandemic, stress gradually increased to pre-COVID-19 levels. In addition to having developed adaptive strategies to cope pre-existing

		Age of child in years	Sex of child male	Time since diagnosis in years	<b>CNS</b> tumor	In treatment
Questionnaire	Phase (sample size)	Mean (SD)	n (%)	Mean (SD)	n (%)	n (%)
PedsQL generic proxy	Pre-COVID-19 (n = 191)	5.1 (1.6)	108 (57%)	1.9 (1.2)	32 (17%)	75 (39%)
report; 1201 reports from parents of 507	First lockdown ( $n = 185$ )	5.1 (1.6)	102 (55%)	1.9 (1.2)	34 (18%)	82 (44%)
children	Release of restrictions ( $n = 363$ )	5.1 (1.6)	204 (56%)	1.9 (1.1)	59(16%)	137 (38%)
	Partial lockdown ( $n = 212$ )	5.2 (1.6)	117 (55%)	2.1 (1.3)	42 (20%)	74 (35%)
	Strict lockdown ( $n = 97$ )	5.1 (1.6)	54 (56%)	1.9 (1.1)	11(11%)	30 (31%)
	Curfew added ( $n = 153$ )	5.3 (1.6)	81 (53%)	2.1 (1.3)	36 (24%)	54 (35%)
PedsQL fatigue proxy	Pre-COVID-19 ( <i>n</i> = 115)	5.4 (1.6)	66 (57%)	2.4 (1.1)	20 (17%)	Oa
report; 751 reports from parents of 425 children	First lockdown ( $n = 107$ )	5.3 (1.5)	61 (57%)	2.3 (1.2)	17 (16%)	Oa
	Release of restrictions ( $n = 224$ )	5.3 (1.6)	124 (55%)	2.4 (1.1)	37 (17%)	Oa
	Partial lockdown ( $n = 136$ )	5.5 (1.6)	76 (56%)	2.6 (1.2)	29 (21%)	O <sup>a</sup>
	Strict lockdown ( $n = 68$ )	5.2 (1.6)	40 (59%)	2.3 (1.0)	5 (7%)	Oa
	Curfew added ( $n = 101$ )	5.5 (1.6)	55 (55%)	2.5 (1.3)	29 (29%)	Oa
PedsQL generic self-report;	Pre-COVID-19 ( $n = 224$ )	13.7 (3.3)	129 (58%)	1.6 (1.1)	65 (29%)	60 (27%)
1575 reports from 908 children	COVID-19 era ( $n = 197$ )	13.8 (3.6)	99 (50%)	1.9 (1.2)	49 (25%)	65 (33%)
	Release of restrictions ( $n = 490$ )	13.9 (3.4)	269 (55%)	2.0 (1.3)	129 (26%)	131 (27%)
	Partial lockdown ( $n = 280$ )	14.3 (3.6)	148 (53%)	2.0 (1.3)	86 (31%)	76 (27%)
	Strict lockdown ( $n = 165$ )	14.3 (3.5)	95 (58%)	1.9 (1.2)	41 (25%)	41 (25%)
	Curfew added ( $n = 219$ )	14.0 (3.6)	108 (49%)	2.1 (1.2)	56 (26%)	44 (20%)
PedsQL fatigue self-report;	Pre-COVID-19 ( <i>n</i> = 165)	13.7 (3.5)	94 (57%)	1.9 (1.1)	57 (35%)	Oa
1156 reports from 726 children	COVID-19 era ( $n = 133$ )	14.2 (3.8)	64 (48%)	2.2 (1.1)	38 (29%)	0 <sup>a</sup>
	Release of restrictions ( $n = 359$ )	14.0 (3.6)	181 (50%)	2.4 (1.3)	105 (29%)	Oa
	Partial lockdown ( $n = 200$ )	14.5 (3.7)	102 (51%)	2.4 (1.2)	66 (33%)	Oa
	Strict lockdown ( $n = 124$ )	14.6 (3.6)	73 (59%)	2.3 (1.1)	32 (26%)	Oa
	Curfew added ( $n = 175$ )	14.1 (3.5)	81 (46%)	2.4 (1.1)	48 (27%)	Oa
		Age of caregiver in years	Sex of caregiver male	Time since diagnosis in years	CNS tumor	In treatment
	Phase	Mean (SD)	n (%)	Mean (SD)	n (%)	n (%)
DT-P 2613 reports from	Pre-COVID-19 ( $n = 325$ )	41.4 (7.1)	113 (35%)	2.0 (1.2)	80 (25%)	94 (29%)
1977 parents of 1274 children	COVID-19 era ( $n = 274$ )	41.5 (7.1)	93 (34%)	2.1 (1.2)	75 (27%)	83 (30%)
	Release of restrictions ( $n = 877$ )	41.9 (7.5)	367 (42%)	1.9 (2.3)	191 (22%)	219 (25%)
	Partial lockdown ( $n = 411$ )	42.0 (6.9)	165 (40%)	2.2 (1.4)	133 (32%)	73 (18%)
	Strict lockdown ( $n = 277$ )	42.2 (8.2)	112 (40%)	2.1 (1.3)	42 (15%)	63 (23%)
	Curfew added ( $n = 449$ )	42.2 (7.3)	191(43%)	2.1 (1.3)	103 (23%)	120 (27%)
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 TABLE 1
 Participant characteristics for the samples of each outcome



100 900 FT5 50 50 25 0 Pre-COVID First Release of Partial (n= 115) lockdown restrictions lockdown lockdown added (n= 107) (n= 24) (n= 16) (n= 68) (n= 101) Phase









**FIGURE 1** Bar charts of the mean total scores with standard deviations of health-related quality of life (HRQoL) and fatigue of children of and proportion of distressed parents. Stars indicate significant differences compared to pre-COVID-19

stress, we previously explained this result through alleviating daily life changes, and increased understanding and hygiene awareness of others during the COVID-19 pandemic.<sup>6</sup> Item scores from the DT-P suggested that problems with transportation and lack of understanding from the environment seemed to be experienced less often during all phases of the pandemic than before (results not shown). Thus, the increase of distress may be attributed to more general stressors, such as sleep problems<sup>20,31</sup> and homeschooling while working from home<sup>32</sup> due to the sustained crisis.

#### 4.1 | Limitations

Although it was a great advantage that we were able to use regular care data to study psychosocial function during the COVID-19 pandemic, this also came with some limitations. Our results were limited to generic questionnaires, and we did not assess specific COVID-19-related distress or problems, such as the impact of COVID-19 on income. At the start of the study period, 60% of families participated in regular care monitoring and screening.<sup>6</sup> We were unable to compare characteristics of participants to nonparticipants, so conclusions about the representativeness of the results could not be drawn. Results came from questionnaires that were offered linked to outpatient appointments, but we did not register hospitalizations in between assessments. As a consequence, we cannot rule out bias due to hospitalization.

In conclusion, in this population-based study of children with cancer in outpatient care, we found stable levels of HRQoL and small reductions in fatigue throughout the COVID-19 pandemic. An initial decrease in caregiver distress increased to pre-COVID-19 levels, suggesting that the length and consequences of the pandemic may be weighing on them.

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#### CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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#### SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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