

# 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 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.

## Introduction

The 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.

## 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. 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> Patients and caregivers were asked for informed consent to use KLIK data for research.

Health-related quality of life (HRQoL) and fatigue of children with cancer were assessed every three months using the Dutch proxy- (2-7 year-olds) or self-report (8-18 year-olds) pediatric quality of life inventory (Peds-QL) generic and multidimensional fatigue scales. 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 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 0.73-0.94.

Caregivers self-reported their distress (thermometer score range 0-10, [?]4 indicates clinical distress) and problems regarding physical, emotional, social and practical issues every six 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 0.64-0.92.

### *Statistical analyses*

Outcomes were described for the phase preceding the COVID-19 pandemic (01/01/20-12/03/20) and several COVID-19 phases based on preventative measures in the Netherlands (see Fig. 1). These were: the first lockdown (13/03/20-31/05/20), release of most restrictions (01/06/20-13/10/20), the second 'partial' lockdown (14/10/20-14/12/20), the second 'strict' lockdown (15/12/20-19/01/21), and the lockdown with a curfew (20/01/21-12/03/21). 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 modelling 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 CNS tumor diagnosis). A p-value of 0.05 divided by the number of analyses conducted on (sub)scales of a questionnaire (e.g. for PedsQL generic:  $0.05/6=0.008$ ) was considered statistically significant.

## **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 filled out one or more questionnaires. Samples differed per outcome (Table 1).

Table 2 describes 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 ( $\beta$ : 0.24-0.33,  $p<0.013$ ). Caregivers had lower distress in the first lockdown than pre-COVID-19 ( $\beta$ : 0.23,  $p<0.007$ ), but the difference dissipated as the pandemic progressed.

## **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> Since 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 since 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 stress, we previously explained this result through alleviating daily life changes and increased understanding from 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>20,32</sup> and homeschooling while working from home<sup>33</sup> due to the sustained crisis.

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.

### Conflict of interest statement

The authors declare that they have no conflicts of interest.

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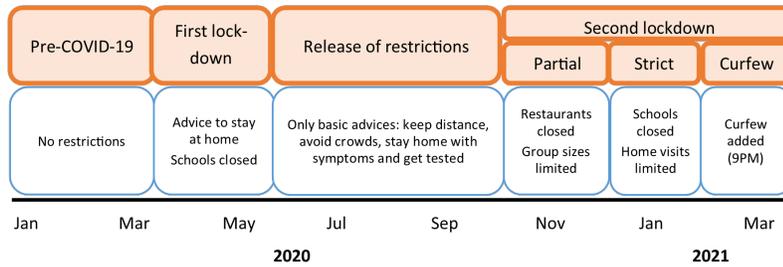
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Figure 1: Schematic overview of phases with different preventative measures during COVID-19



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