

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

Marloes van Gorp¹, Heleen Maurice-Stam¹, Layla Teunissen¹, Wietske van de Peppel - van der Meer¹, Maaike Huussen¹, Antoinette Schouten-van Meeteren¹, and Martha A. Grootenhuis²

¹Princess Máxima Center for pediatric oncology

²Princess Máxima Center for Pediatric Oncology

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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 COVID-19 era in health-related quality of life and fatigue of children. Fewer caregivers were distressed during the COVID-19 era 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.

Introduction

Anxiety and distress caused by the coronavirus disease 2019 (COVID-19) pandemic and preventative measures including social distancing seem to increase psychosocial stress in general populations.^{1, 2} Because children with cancer are vulnerable and they and their caregivers often already experience high levels of stress and anxiety,³ they may be affected in particular.^{4, 5} To extend the very limited available knowledge,^{2, 6} we aim to compare psychosocial functioning of Dutch children with cancer and their caregivers in the first months of the COVID-19 era to the pre-COVID-19 era.

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.^{7, 8} Assessment takes place every three to six months, combined with their outpatient appointments, and families are asked to provide informed consent to use their clinical data for research. This study used assessments between 01-01-2020 and 01-06-2020 and considered March 13 as the start of the COVID-19 era with national preventative measures, including social distancing and advice to stay at home. Personal and medical characteristics of children (sex, age, diagnosis group [solid tumor, CNS tumor or hematological cancer], time since diagnosis and treatment status [currently in or after treatment]) were extracted from medical records.

Outcomes

Health-related quality of life (HRQoL) and fatigue of children with cancer were assessed using the age-appropriate Dutch proxy- (age: 2-7 years old) or self-report (age: 8-18 years old) pediatric quality of life inventory (PedsQL) generic and multidimensional fatigue scales. Higher scores (scale: 0-100) indicate higher

HRQoL or better functioning (e.g.: better emotional function or less fatigue). The PedsQL generic and fatigue scales have good psychometric properties.^{9, 10} Cronbach's alphas in this study ranged from 0.74-0.94.

Using the distress thermometer for parents (DT-P), caregivers self-reported their overall distress regarding physical, emotional, social and practical issues on a 0-10 scaled thermometer, scores of 4 or higher indicating clinical distress.¹¹ In addition, experienced problems were assessed for 6 domains and summed to 2 total problem scores. Psychometric properties of the DT-P score are good.^{11, 12} Cronbach's alphas in this study ranged from 0.65-0.91.

Statistical analyses

Participant characteristics and outcomes were described for the pre-COVID-19 and COVID-19 era. Pre-COVID-19 and COVID-19 era scores were compared using mixed effect linear regression analyses, to correct for repeated measurements in a minority of participants and both caregivers of a child filling out the DT-P. The occurrence of clinical distress was analyzed using a logistic generalized estimating equation model with exchangeable structure. To adjust for multiple testing, the level of statistical significance was set at .05 divided by the number of analyses conducted on (sub)scales of a questionnaire (e.g. for PedsQL generic: $0.05/6=0.008$). Models were corrected for the personal and medical characteristics and effect modification of treatment status was evaluated.

Results

Roughly 75% of the regularly proposed psychosocial monitoring and screening questionnaires in clinical care were completed between January and end of May. Informed consent for research purposes was provided for 87% of the children-reported outcomes and 94% of the caregiver-reported outcomes. Finally, 799 (caregivers of) children with cancer (pre-COVID-19/COVID-19 era: $n=494/438$, 17% in both era) participated in this study. 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 era are presented in Table 2. A smaller percentage of caregivers showed clinical distress in the COVID-19 era on the DT-P compared to the pre-COVID-19 era (OR [CI]: 0.59 [0.42; 0.83], $p=0.002$). No other statistically significant differences or effect modification for treatment status were found.

Discussion

Because of regular monitoring of psychosocial functioning of children with cancer in outpatient care and their caregivers, we were able to compare HRQoL and fatigue of children and distress of their caregivers during the COVID-19 era to the months directly preceding in large samples. Surprisingly, the only observed difference was a decrease in the proportion of distressed caregivers. Previous studies specifically asking for COVID-19-related stress found that youth with cancer were worried of getting ill and having severe complications¹³ and that adolescents and young adults with cancer were at high risk for psychological distress during the COVID-19 era.¹⁴ Our population may have been less worried about COVID-19, since healthcare professionals shared reassuring information from pediatric oncology centers in other countries with them early on, suggesting 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 resilience of psychosocial function during the COVID-19 era.¹⁵⁻¹⁷ In women with breast cancer, small but significant improvements were found in quality of life, physical functioning and role functioning during the COVID-19 era compared to before.¹⁵ Furthermore, no differences were found on most domains of HRQoL and depressive symptoms during the COVID-19 era compared to before in Italian and Serbian multiple sclerosis patients.^{16, 17} One study argued that the resilience of their clinical population may be explained by being accustomed to experiencing (medical traumatic) stress,¹⁶ 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.^{18, 19} We recommend future studies to compare the pre-post COVID-19 results of clinical populations to

the general population to study possible differences in coping.

Furthermore, the care that children with cancer and their caregivers received may have helped maintaining psychosocial functioning. Outpatient care at our center was almost completely continued (partly digitally) during the crisis and physicians and specialized healthcare professionals of the comprehensive psycho-oncology department were readily available, as per usual. The availability of these healthcare professionals may have caused a continuous feeling of support. Also, some caregivers mentioned that changes in Dutch daily life due to COVID-19 such as home schooling, increased societal awareness of hygiene, working from home and less traveling for medical appointments decreased feelings of being different from others and reduced the challenge of managing appointments in daily family life.

We did not find different effects of COVID-19 stress on psychosocial functioning between families with a child during or after treatment for cancer. It should be noted however that we exclusively included 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, on the longer term, COVID-19 consequences such as financial problems or loss of employment may increase the risk of psychosocial problems in all families in pediatric oncology,²⁰ and should be taken into account in future research and care.

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

Conflict of interest statement

The authors declare that they have no conflicts of interest.

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