

Psychological impact of COVID-19 on parents of pediatric cancer patients

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November 27, 2020

Abstract

Background. The changes and general alarm of the current COVID-19 pandemic have amplified the sense of precariousness and vulnerability for family members who, in addition to the emotional trauma of the cancer diagnosis, add the distress and fear of the risks associated with infection. The primary objectives of the present study was to investigate the psychological impact of the COVID-19 pandemic on the parents of pediatric cancer patients, and to investigate the level of stress, anxiety, and the child's quality of life perceived by the parents during the Covid-19 epidemic. **Methods.** The parents of 45 consecutive children with solid and haematological tumors were enrolled. Four questionnaires (Impact of Event Scale-Revised - IES-R ; Perceived Stress Scale - PSS; Spielberger State - Trait Anxiety Inventory - STAI-Y ; Pediatric Quality of Life Inventory - PedsQL) were administered to the parents at the beginning of the pandemic lockdown. **Results.** 75% of parents exhibited remarkable levels of anxiety, with 60 subjects in state scale and 45 subjects in trait scale having scores that reached and exceeded the STAI-Y cut off. The bivariate matrix of correlation (Figure 1) found a strong significant positive correlation between the IES-R and PSS scores ($r = 0.55$, $P < 0.001$). There was a positive correlations between the PSS and PedsQL (emotional needs) scale ($P < 0.001$) and a negative correlation between IES-R and STAI-Y ($P < 0.001$). **Conclusion.** The results confirm that parents of pediatric cancer patients have a high psychological risk for post-traumatic symptoms, high stress levels, and the presence of clinically significant levels of anxiety.

INTRODUCTION

The COVID-19 pandemic has affected several aspects of lives all around the globe, and the unprecedented health crisis has put a strain on health services. Patients with cancer have been particularly affected, with a consequent high psychological impact¹ due to their vulnerability, immunosuppression, or need for cancer treatment². Among oncology patients, infants and children are at higher risk for medical or psychological complications. Their patients fear the consequences of infection on their child's already fragile state of health as well as potential treatment interruptions or delays. The type and intensity of antineoplastic treatments are known to have important psycho-evolutionary implications^{3,4,5}. These have been frequently noted in the literature^{6,7,8,9} framing pediatric cancer as a stressful and traumatic life cycle event^{10,11,12}.

Numerous studies have identified different interpretations of the concept of trauma^{13,14,15,16}; however, complex trauma, linked to the exposure to multiple traumatic events in childhood, shows more pervasive symptoms^{17,18}. Exposure to further traumatic experiences, such as pandemics, torture, war, imprisonment, or migration possibly leads to additional risks for chronic traumatization. The sum of these events could result in an elevated sense of threat levels for the patient's own life and that of their family members.

The risk of COVID-19 infection, and the unpredictability of relative potential emergencies, could exacerbate the emotional burden on patients and family members during oncological disease and treatment. The changes

and general alarm of the current pandemic have amplified the sense of precariousness and vulnerability for family members who, in addition to the emotional trauma of the cancer diagnosis, add the distress and fear of the risks associated with infection. In addition to the standard complex oncological clinical pathway, they require additional measures of self-protection, social distancing¹⁹, prolonged isolation, and new daily habits²⁰. Also, hospital rules have become more restrictive, requiring the suspension of some services and limitations to family visitation.²² These factors significantly affect the patients' and their family's quality of life both during hospitalization and afterwards upon discharge.

Families have a central role in preserving patients' psychological integrity. They represent a safe-harbour where children and adolescents can find psychic and psychological supplementary resources²². Families with a child with cancer are already under a great deal of stress and vulnerable to trauma induced by the diagnosis itself. It is reasonable to suppose that the added stress of the pandemic could undermine the psychological state and balance of the family.

The primary objectives of the present study was to investigate the psychological impact of the COVID-19 pandemic on the parents of pediatric cancer patients, and to investigate the level of stress, anxiety, and the child's quality of life perceived by the parents during the Covid-19 epidemic. Subsidiary objective of the study was to explore correlations between the results obtained and the variables investigated.

METHODS

Participants

The parents of 45 consecutive children with solid and haematological tumors treated in the Pediatric Oncology, Pediatric Neurosurgery, and Radiotherapy Unit of Fondazione Policlinico Universitario A. Gemelli IRCCS in Rome were enrolled in the study. Criteria for selecting the subjects were: 1) parent of a patient with a cancer diagnosis; 2) parent of a patient who was in treatment or had completed their treatment regimen; and 3) parent of patients < 25 years of age. Parents with psychiatric or cognitive disorders or intellectual disability were excluded from the study.

This study was performed in accordance with the Helsinki declaration and approved by the Institutional Review Board. Written informed consent was obtained from all participants.

Measures

Four questionnaires were utilized for the study:

1. Impact of Event Scale-Revised (IES-R) is a 22-item, self-report measure (for DSM-IV) that assesses subjective distress caused by traumatic events²³. The scale had a high internal consistency ($\alpha = 0.96$).
2. Perceived Stress Scale (PSS) is a psychological instrument for measuring the perception of stress. The questions ask about feelings and thoughts during the previous few months²⁴. Internal consistency estimates using Cronbach's alpha range from 0.67 to 0.91.
3. Spielberger State - Trait Anxiety Inventory (STAI-Y) is a 40-item, self-completed questionnaire that aims to separately assess state anxiety (STAI-Y1, a temporary state influenced by the current situation) and trait anxiety (STAI-Y2, a general propensity to be anxious) with 20 items each²⁵. The internal consistency reliability ranges from 0.91 to 0.95 for the scale of state and from 0.85 to 0.90 for the scale of trait.
4. Pediatric Quality of Life InventoryTM (PedsQL) 4.0 Generic Core Scales is a parent proxy-report including Physical, Emotional, Social, and School Functioning Scales. It assesses parents' perception of their child's Health-Related Quality of Life²⁶. The scale has good internal consistency reliability for the total scale score ($\alpha = 0.90$ on parent report).

Procedure

The questionnaires were administered to the parents at the beginning of the pandemic lockdown. The researchers explained the purpose of the study to the parents. Their written informed consent to participate

in the study was obtained, and they were reassured about the confidentiality of the information they provided. Most parents preferred to be interviewed rather than to complete the questionnaires on their own. For each patient included in the study, the questionnaires were individually administered to the parents. The parents were informed that the IES-R scale referred to their child's cancer diagnosis, while the other questionnaires referred to the current phase of the pandemic.

Statistical analysis

Correlations between the scores of the 4 scales were analyzed. Subsequently, the correlation between the questionnaires (IES-R, PSS, STAI-Y, PedsQL) and the variable "months", the time between oncological diagnosis to starting the study, was determined. Comparisons between groups of parents were made using the Mann-Whitney U test for non-parametric samples. Statistical analysis was performed using R 4.0.3 version.

RESULTS

The study included the parents of 45 patients (32 with solid tumors and 13 with malignant hematological diseases). They were divided into 2 groups, those who had completed their treatment regimen (off-therapy group, $n = 27$) and those who were still receiving treatment (in-treatment group, $n = 18$). There were 18 females and 27 males.

One father had died, 1 father had psychiatric disorders, and 5 parents (1 mother and 4 fathers) did not fill in the questionnaires. Therefore, a total of 80 parents (44 mothers and 36 fathers) were included in the study. All parents agreed to participate and provided written informed consent. Demographic characteristics of the participants are summarized in Table 1.

A total of 87.5% of the parents had a moderate ($n = 20$) or high ($n = 50$) risk for traumatic disorder (IES-R, $x = 41.68 \pm 16.72$), and 83.7% had a moderate ($n = 54$) or high ($n = 13$) presence of stress symptoms (PSS, mean = 19.25 ± 5.33). In our sample 75% of parents exhibited remarkable levels of anxiety, with 60 subjects in state scale and 45 subjects in trait scale having scores that reached and exceeded the STAI-Y cut off. The mean values were Y1 (state), $x = 42.48 \pm 4.32$ and Y2 (trait), $x = 41.15 \pm 4.56$.

The bivariate matrix of correlation (Figure 1) found a strong significant positive correlation between the IES-R and PSS scores ($r = 0.55$, $P < 0.001$). There was a positive correlations between the PSS and PedsQL (emotional needs) scale ($P < 0.001$) and a negative correlation between IES-R and STAI-Y ($P < 0.001$).

It was not possible to make comparisons between the parents of patients diagnosed during and before the pandemic due to the inhomogeneity between the groups. However, the 8 parents interviewed whose children were diagnosed during the pandemic had an average IES-R of 50.28. Since there was a weak correlation ($P > 0.05$) between the time from diagnosis to completing the IES-R, the sample was further divided according to the time from diagnosis, < 24 , $24 - 48$, and > 48 months. In figure 2 the trend line shows a decrease over time, but the difference between the groups is not significant, and in the third group ($x > 48$ months) there is also a large dispersion of scores. Comparisons between the groups were also made separating parents into those with and without high trait anxiety (divided according to the STAI-Y2 cut-off). Even this group of patients did not have significant differences in any of the test variables.

Separating the groups into those off and on therapy found that this variable had a significant impact on the outcome of IES-R ($P < 0.001$; off-therapy, $x = 36.60 \pm 4.84$; on-therapy, $x = 49.55 \pm 16.23$) and PSS ($P < 0.001$; off-therapy, $x = 18.10 \pm 4.84$; on-therapy, $x = 21.03 \pm 5.64$). Subsequent comparisons between groups found a significant difference between the scores of mothers and fathers only on the PSS ($P < 0.001$; mothers, $x = 20.89 \pm 4.90$; fathers, $x = 17.20 \pm 5.21$).

DISCUSSION

The diagnosis of cancer in the pediatric age group is widely described as a traumatic event for the parents, and may result in experiences, emotions, and even symptoms of psychopathological conditions such as post-traumatic stress disorder²⁷⁻²⁹. There are different approaches to investigate these phenomena and

any discordant results^{30,31}. Generally, parents' high levels of anxiety and distress following their child's diagnosis^{24,26} decrease over time with a decline already present three months after diagnosis^{34,35}.

The principal objective of the present study was to explore the influence of the impact of a pediatric cancer diagnosis on parents, particularly during the health emergency caused by the COVID-19 pandemic. We were interested in determining if, unlike a period without a socio-sanitary emergency, the influence of past traumatic experiences might exacerbate the challenges or symptoms, such as anxiety or stress, or place parents at a new or additional risk of psychological suffering. This supposition is supported by evidence showing that COVID-19 has great emotional impact, even on the general population, with or without specific medical conditions.³⁶

Consistent with our hypothesis, our sample's parents showed high levels of post traumatic symptoms related to the oncological diagnosis of their child. They also had an elevated perception of stress symptoms referable to the pandemic, much higher than the general population's during COVID-19.^{37,38} The average level of state anxiety, measured with STAI-Y1, indicated the presence of a considerable number of anxiety symptoms.

The correlation matrix (2-tailed) showed that parents recording a higher traumatic impact level on the IES-R also perceived higher stress levels measured with the PSS. This suggests the presence of an increased risk condition and a probable need for support from the family. It also suggests the possibility of identifying populations at risk for experiencing sequelae and consequences on child well-being. Studies have shown that parents experiencing greater stress find it more difficult to understand their child's needs and respond in a sensitive manner^{39,40}.

The results of this study show that parents who exhibit symptoms of post-traumatic stress related to their child's diagnosis appear to be more vulnerable to stress symptoms perceived during the pandemic lockdown. The parents' symptom states do not appear to be related to the individual characteristics of anxiety traits. In fact, comparing the scores of "anxious" and "non-anxious" parents, there were no significant differences on all questionnaires except for the form of state STAY-Y 1.

Data from the few parents who received the oncological diagnosis of their child during the pandemic show a high level of PSS. Parents who received the diagnosis close to the onset of the COVID-19 pandemic were subjected to this potential acute stress event⁴⁰ and showed an increase in the already high risk^{27,31} of developing post-traumatic symptoms.

Therefore, it seemed worthwhile to investigate the correlation with temporal distance from the time of diagnosis to understand the role of time as a protective factor^{41,42}. Among this study's participants, the variable "months" from the time of diagnosis did not have a significant impact on the IES-R score. Moreover, this factor had even less of an impact on the development of stress symptoms during COVID-19. To understand this phenomenon, it is important to consider that the scores of most parents documented a significant presence of post-traumatic symptoms. In accord with the literature, traumatic psychological conditions can have long term consequences^{43,44}. The inclusion in the protocol of parents' perception of their child's quality of life (PedsQL - parent proxy-report version) made it possible to collect important information on the children's activities and behaviours during COVID-19 (physical, scholastic and social activity) as well as the degree of emotional needs or difficulties of children. This last variable showed a significant positive correlation ($P < 0.001$) with the tool on parental stress (PSS), highlighting a strong relationship between the psychological state of child and parent^{45,46,47,48}. Previous reports have found a significant difference between mothers' and fathers' scores on PSS ($P < 0.001$)^{31,49-51}. Additionally, there is a significant difference between the parents of patients "off therapy" and those still "on therapy" in the IES-R ($P < 0.001$) and PSS scores ($P < 0.001$).

Studies suggest that it is important to observe the stress of the parents of children with cancer, even long after the diagnosis^{52,30}, but in this particular emergency it seems to be very important to do so during treatment, when children are exposed to the risk of infection⁵³⁻⁵⁷.

CONCLUSION

Worldwide, data suggests that pediatric cases of COVID-19 are less severe than adults⁵⁶. However, the

possibility that their child might be infected creates worry and fear in parents, especially if the child has a pre-existing condition such as cancer where infection with COVID-19 might aggravate symptoms and pose an additional risk to the child's health. Preliminary results of our longitudinal study, which will continue to investigate parental symptoms and variables over the course of 9 months, show a significant positive correlation between parental scores of traumatic impact of their child's cancer diagnosis (IES-R) and parental stress perception during the COVID-19 outbreak (PSS).

The results of this study confirm that parents of pediatric cancer patients have a high psychological risk for post-traumatic symptoms, high stress levels, and the presence of clinically significant levels of anxiety. There were no significant differences among groups of parents depending on the amount of time since their child's cancer diagnosis; however, parents whose children were still receiving treatment experienced the most psychological distress.

This study confirms the importance of caring for the well-being of the parents, and that attention must also be paid to their needs throughout their child's entire disease process, even at a time remote from diagnosis^{52,30}. This is especially true in the case of a major health emergency such as the COVID-19 pandemic. During an emergency, where psychological problems might arise for the general population, the situation for parents caring for a child with a complex diagnosis could be aggravated by psychological consequences as well as infection control policies that have an impact on the quality of life⁵⁶.

It is therefore essential to continuously monitor the psychological state of this population. The COVID-19 pandemic has introduced new challenges for the organization of health services and multidisciplinary work⁵⁸. This study highlights the importance of integrating care for the parents with care for the child through continuous monitoring of their psychological state and the need for parent-oriented interventions.

The present study is limited by the absence of a comparison group of parents who have not experienced the pandemic, and there is no control group of parents whose children do not have a cancer diagnosis. We will attempt to increase the reliability of the investigation by making comparisons between subjects with the re-test that will be performed, according to the study's protocol, in the coming months.

Funding

This research received no external funding.

Conflict of Interest Statement

The authors declare no conflict of interest.

Acknowledgments

This study was technically supported by Fondazione per l'Oncologia Pediatrica, Rome, Italy.

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LEGENDS

TABLE 1 Demographic and clinical characteristics

Figure 1 Matrix of correlation (2-tailed)

Figure 2 Time from diagnosis and IES-R results

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