

Survey of Healthcare Delivery and Distress in Pediatric Cancer Patients and Caregivers during the COVID-19 Pandemic at a Single Institution

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Abstract

During the COVID-19 pandemic, pediatric oncology patients, caregivers, and providers were required to adapt to changes in healthcare delivery to minimize the risk of COVID-19 exposure. This study evaluated the impact of the pandemic on oncologic care and patient and caregiver distress by surveying patients actively followed for cancer treatment or on surveillance. Adherence to therapy and access to the oncology team was largely maintained with increased virtual visits. Due to concern for exposure and disruptions to work, social stressor screening and support are warranted. Continuing access to up-to-date information about COVID-19 is critical as the pandemic continues to evolve.

INTRODUCTION

The Coronavirus Disease 2019 (COVID-19) pandemic brought unprecedented challenges to the delivery of pediatric oncology care. Patients, caregivers, and providers had to balance increased concern for infection with timely delivery of oncology care. Experiences from international pediatric oncology centers showed varying degrees of treatment delays during the pandemic.^{1, 2} Psychosocial and financial stressors became more prominent during this time among this population.^{3, 4} This study reports the results of an institutional survey of patients or their caregivers about the oncologic care and factors associated with increased distress during the initial stages of the COVID-19 pandemic.

METHODS

After obtaining IRB approval, patients due for cancer treatment or surveillance between January 1, 2020 and June 30, 2020 were identified using the electronic medical record (EMR). Deceased patients were excluded. A brief electronic survey (Appendix 1) was developed, and an introductory letter containing the link was distributed via mail and at clinic visits. Anonymous responses were voluntarily collected between July and December 2020.

Results were analyzed using descriptive statistics and comparisons of patient distress using demographics, clinical characteristics, and psychosocial factors. For independent predictors that were two-level categorical variables, Mann-Whitney U-test or student t-test was used. For the independent predictors that were more than two-level categorical variables, Kruskal-Wallis test or one-way ANOVA were used. When the

independent predictors were continuous variables, Pearson correlation or Spearman correlation were used. All statistical analysis was completed using SAS 9.4 (SAS Institute Inc., Cary, NC, USA).

RESULTS

There were 78 partial or complete responses to the survey. Median age was 13 years (range 22 months – 24 years), 43% identified as female, and 71% identified as Caucasian (Table 1). Of the 24 patients receiving therapy, 8% reported a delay. More participants reported a delay in surveillance scans (18%) and scheduled appointments (24%). No patients surveyed chose to delay treatments or surveillance against provider’s recommendations.

Sixteen percent used our EMR to send messages, and 59.4% had video visits using Epic© EMR or Zoom. Five percent of participants reported difficulty getting in touch with the oncology team.

Other care-related questions revealed 22% of participants endorsed fear about going to the emergency department. A majority of patients/caregivers (89.7%) felt the institution’s visitor policy helped keep them safe, and 93.2% felt it helped keep others safe.

Characteristics related to increased distress (Table 2)

Patients scheduled to receive cancer-directed therapy rated their distress higher on a five-point Likert scale than those off therapy (3.42 vs 2.59, $p<0.05$). Level of distress was not associated with malignancy type.

During the study period, 10.3% of families indicated a household member had symptoms or diagnosis of COVID-19. Patients and families exposed to a household member with COVID-19 symptoms/diagnoses had increased distress compared to families without exposure (3.86 vs 2.77, $p=0.03$).

Patients/caregivers noted disruptions to school and work during the pandemic. Thirty-six percent of college students planned to defer classes. A household member in 36% of households stopped working due to the risk of exposure. Families with someone that worked outside the home were notably less distressed than those who did not (2.53 vs 3.33, $p<0.05$).

Most participants reported following guidelines for mask-wearing and social distancing. The majority of participants reported using a government website as their source for COVID-19 information, but they relied more on their healthcare providers for cancer-specific information. Participants who used healthcare providers as a resource for general COVID-19 information (3.25 vs 2.56, $p<0.02$) as well as for cancer-specific COVID-19 information both rated their distress higher than those who did not (3.27 vs 2.07, $p<0.01$). Increased distress was also reported by patients/caregivers that called or sent a message to the oncology team compared to those that did not (3.60 vs 2.76, $p<0.05$).

DISCUSSION

The COVID-19 pandemic changed all aspects of healthcare delivery across the globe including pediatric oncology care.⁵ Psychosocial measures related to the pandemic have been studied in caregivers of pediatric cancer survivors.^{3, 6} This study additionally found increased distress amongst patients who are actively receiving therapy.

Here, treatment delays were found to be uncommon, and those delayed did not endorse more distress. However, being on therapy was associated with increased distress for both the patient and for their family. This may be related to fear of increased exposure during visits to healthcare facilities. The institutional visitor policy for pediatric patients allowed one visitor for clinic and infusion appointments and hospitalizations, consistent with Center for Disease Control (CDC) recommendations and other institutions across North America.⁷ During hospitalizations, visitors were limited to patients’ rooms and asked to wear masks. Shared spaces such as playrooms were closed. Some participants expressed stress from having decreased caregiver support and other typical coping mechanisms, especially if there was bad news, though overall, the rationale of the policy was understood. Similar to other centers, exceptions were granted in end-of-life situations for pediatric patients.⁸

Due to risk of COVID exposure, a member in a third of surveyed households stopped working, and those not working outside the home reported significantly more distress than households with someone working outside the home. Further investigation would be valuable to elucidate the cause of increased distress, which may include lack of income or feelings of isolation.

Some college students surveyed planned to defer classes due to COVID-related changes, such as the challenges of virtual classes or the risk of exposure during in-person learning. Patients who receive cancer therapy are more likely to have learning disabilities,⁹ which may contribute to difficulties in this novel online environment. In a French survey of parents of children with attention deficit hyperactivity disorder (ADHD), parents expressed concern that inattention was worse with at-home schooling, and decreased accommodations were available during COVID-19.¹⁰

While there were many changes to hospital, home, work, and school environments, treatment timelines were largely preserved, which is similar to a Latin American study.² Although early studies from the Middle East, Northern Africa, and Europe demonstrated delays in therapy due to risk of COVID-19 concerns,^{1, 11} the severity of COVID-19 infections in children with malignancies now appears to be similar to their healthy peers.¹²⁻¹⁶ The benefit of continuing therapy during the pandemic likely outweighs the possibility of COVID-19 exposure in most cases and is supported by international pediatric oncology groups.¹⁵

In regard to delayed appointments, patients/families surveyed in this study reported that virtual visits were helpful substitutes, and participants overall felt positively about their convenience. The use of telemedicine has increased since the pandemic and will likely continue to play a role in pediatric oncology care, even beyond the pandemic.¹⁷⁻²⁰

Other strategies to improve care in this population includes ensuring support during a pandemic, especially when patients or their caregivers are 1) receiving active therapy, 2) exposed to a household member with COVID symptoms/diagnosis, 3) unable to work outside the home, or 4) reaching out for information, which were all associated with increased distress. When these stressors are present, social work, psychology/psychiatry, and child life services should be consulted to provide additional support. As providers, we can also support patients asking for more information by remaining current on COVID-related evidence and providing consistent recommendations.

Limitations of the study include risk for recall bias. Although this survey was not validated, it provided valuable input that can be incorporated into practice to improve the oncology patient and caregiver experience during the COVID-19 pandemic.

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