Pediatric psychosocial oncology in the COVID 19 era: Patterns of use, challenges, and lessons learned

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The practice of pediatric psycho-social oncology underwent dramatic changes as healthcare resources shifted to respond to the COVID 19 pandemic. Although children are less affected by severe illness, systems rapidly adjusted to delivering all types of healthcare remotely, creating opportunities for virtual access for some, and highlighting the challenges of serving our most vulnerable children with cancer and their families.

1 | RAPID TRANSITION TO REMOTE WORK

Based on public health recommendations for social distancing and stay-at-home work, on March 16th our pediatric oncology clinic implemented a rapid transition to remote visits for all patient services that did not require onsite care. Our clinic typically sees about 80 outpatient oncology visits per day. It maintained inperson visits for chemotherapy and transfusion visits, while all other routine follow-up and support services were delivered by telehealth. The oncology clinic had a 22% decrease in medical visit volume, and our multidisciplinary psychosocial team went from seeing 520 unique patients and 1050 inperson visits in the 6 weeks prior, to 376 unique patients (28% decrease) and 622 remote visits (41% decrease) between March 16th and April 30th.

2 | TIERED CARE

Our model of psychosocial care is based on the Pediatric Psychosocial Preventative Health Model (PPPHM) that outlines three tiers of family psychosocial risk: Universal (low), Targeted (medium), and Clinical (high), and provides a rubric through which to deliver behavioral and psychosocial care. In unpublished data, the DFCI patient population has a distribution of risk levels (low: 58%, medium: 32%, high: 10%) that is very consistent with published risk stratification in other pediatric oncology settings as measured by the well-validated Psychosocial Assessment Tool.1 We do not have psychosocial risk data for patients for the current time period, in part due to limits on inperson screening during the pandemic. However, our clinical experience providing remote pediatric psychosocial oncology visits during the COVID pandemic fits well within this tiered theoretical model and underscores priorities for care as we adapt to the public health environment beyond the acute response.

Our multidisciplinary team of social workers, psychologists, psychiatrists, and resource specialists moved quickly to provide phone visits, then added a video platform for outpatients and their families. We are working to establish online teen and parent support groups.

2.1 | Low risk

Clinicians found that families with low psychosocial need were less interested in virtual visits and had the internal and external resources to manage stay-at-home life without support services.

2.2 | Medium risk

Patients and families with identified behavioral or mental health needs, and with the organizational and socioeconomic capacity to make use of phone or video telehealth, are able to be well served in these platforms. These include adolescent and young adult patients, and parents seeking guidance and support for identified mental health needs or specific difficulties coping with cancer care. Focused assessments such as pre-stem cell transplant or psychiatric evaluations are readily scheduled and implemented virtually. The remote platform has
also allowed for more flexible scheduling of psychosocial care separate from oncology visits. The exceptions are younger children with behavioral health needs, and children with developmental delays who may have difficulty sustaining engagement remotely.

2.3 | High risk

Families with significant material hardship, multigenerational psychiatric illness, and language barriers are the most difficult to serve through remote platforms. Issues such as lack of access to consistent internet, care of multiple children at home, crowded living situations, and concerns about privacy or domestic violence create barriers to remote psychosocial oncology care. These challenges may also fall along racial lines due to historical systemic inequality. Higher levels of psychosocial risk can also create challenges to adherence to cancer treatment and increased susceptibility to COVID infection, further complicating medical care.

3 | COLLABORATION WITH ONCOLOGY TEAMS

The psychosocial team working remotely relies on well-established multi-disciplinary collaborations to stay in touch with care activities in clinic. However, onsite nursing, oncology, and child life services are stretched with fewer staff and the need to adhere to new infectious disease control protocols. Using email, phone, and team video conferences provides partial replacement for multi-disciplinary integration. Our presence and casual liaison activities are sorely missed. Remote processes to identify and make initial contact with newly diagnosed families are important and sometimes challenging. When nursing and oncology teams identify high psychosocial need, barriers can sometimes but not always, be mediated with concrete facilitation of virtual contact while in clinic, for example, clinic staff bring a tablet to a family with a clinician logged on. Regular communication with oncology teams can proactively identify families with unmet needs.

4 | CONCRETE RESOURCE SUPPORT FOR FAMILIES

Our team of resource specialists/case managers are extremely busy as families struggle with the financial consequences of unemployment and loss of school/childcare. We make referrals to community and foundation support and are fortunate to have philanthropic funds to provide additional financial assistance. Having at least one onsite staff person to deliver gift cards and assistance checks has proven essential. Our Spanish speaking population is well-served by a designated bilingual clinician who collaborates closely with Spanish-speaking resource specialists to support families who may also face concerns about immigration status and lack of access to unemployment or relief benefits.

Key points

- Pediatric Psycho-oncology visit volume decreased with the shift to remote work in response to the COVID 19 pandemic.
- Recognition of a tiered psychosocial risk distribution can inform the model of care.
- Some clinical populations are able to make good use of telehealth services to receive targeted psychosocial services.
- Families with the highest psychosocial risk and limited resources may have the most difficulty accessing remote services.
- As teams move into a hybrid onsite/remote work plan, they should prioritize in-person care for those at highest risk.

5 | TEAM MEETINGS AND SUPPORT

As a psychosocial team, we hold weekly staff meetings to review logistics and share challenges and best practices. Smaller disease team meetings and individual check ins with leadership provide opportunities for collegial social support and problem solving. Joining remote pediatric oncology meetings provides updates on medical policies and demonstrates our continued presence. Shared remote social experiences with our larger department maintain cohesion and morale, and resuming academic meetings is enriching and stabilizing.

6 | LOOKING FORWARD TO PHASED RE-OPENING

As we transition from completely remote psychosocial services to a phased re-opening along with oncology practice, and prepare for longitudinal changes to the healthcare delivery system, we can learn from our experience and the gaps in remote care delivery. Implementing standardized electronic psychosocial screening to identify high risk families at diagnosis becomes even more essential. Individual telehealth for adolescents, young adults and parents, and virtual groups for facilitated peer support will continue to be useful. We anticipate being able to care for more families as staff and patients adjust to a hybrid model of remote and in-person care. However, as clinicians gradually return to onsite work, we will need to identify and prioritize the care of high need populations who may continue to have barriers to telehealth visits. Families with the greatest psychosocial risk and fewest resources need to be a focus of in-person care to address growing healthcare and social inequities and ensure that all children receive appropriate oncology and psychosocial care.
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DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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