



COMMENTARY

Virtual support groups in pediatric hematology/oncology during COVID-19: Lessons learned from the SickKids experience

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1 | INTRODUCTION

The 2019 novel coronavirus (COVID-19) respiratory illness pandemic caused by the coronavirus SARS-CoV-2 has redefined everyday life and medical care for people across the globe. Due to physical distancing, shelter-in-place, and stay-at-home orders, medical and psychosocial care for children with life-threatening illnesses has been significantly disrupted. Under normal circumstances, a diagnosis of cancer or a serious blood disorder can be one of the most difficult experiences a family can face. Processing feelings of shock, guilt, and sadness, while adapting to the major life changes that come with the diagnosis can be profoundly stressful. The COVID-19 pandemic, however, with its associated physical and social isolation, has made this experience infinitely more challenging. As a result, this patient population has been particularly vulnerable to both medical and mental health consequences of COVID-19.¹ Virtual group platforms are promising psychosocial strategies to help support patients and families facing serious medical illness.²

Virtual support groups can reduce stress, minimize feelings of isolation, and improve patients' and families' ability to cope with illness-related stressors. These groups connect individuals with

diverse diagnoses to age-appropriate resources³ and provide platforms for participants to support each other, engage in emotional expression, and share their distinct experiences in a safe, accessible space.⁴ In contrast with group psychotherapy, the emphasis in this modality is on coping with a shared burdensome experience, rather than targeting a specific psychological symptom or condition.

The Hematology/Oncology Program at The Hospital for Sick Children (SickKids) in Toronto, Canada, one of the largest pediatric hospitals in the country, has transformed its traditional psychosocial support programming to adapt to COVID-19 restrictions. This commentary outlines the transformation process, observed barriers, and lessons learned going forward postpandemic to maintain seamless care for patients and families.

2 | PROCESS AND PROGRAMS

Prior to March 2020, patient and family-centered support was primarily conducted on-site at the hospital. With the onset of the pandemic, this model needed reinvention within weeks, given limits on in-person interaction among patients, families, and psychosocial staff. The

SickKids mission to transcend geography and expand virtual health care during COVID-19 and beyond encouraged the psychosocial team to adapt to continue to support patients, siblings, and caregivers.

In preparing for the shift to virtual care, drawing from available literature and collective expertise, the psychosocial team carefully considered the many elements involved in best approximating a therapeutic in-person environment. These elements included the virtual impacts on participant recruitment, explaining confidentiality and ensuring privacy, collecting emergency contact information, creating a welcoming, safe environment, keeping participants engaged, monitoring for any signs of distress, and planning for group closure. Confidentiality and consent/assent were explained and obtained during participant recruitment and were reviewed again at the beginning of each group session. Groups involving physician facilitators were billed for and charted in the patients' medical record. The following virtual supports using Zoom for Healthcare were adapted and developed by the psychosocial team:

1. *Hemoglobinopathy and hemostasis programs*: Two closed (meaning all members began the group at the same time), 60-minute virtual groups were held once a week for 6 weeks for patients aged 8–15 years, focused on themes including the effect of the illness on school and family, peer relationships, and coping with challenging emotions.
2. *New oncology diagnosis sibling education*: Siblings of newly diagnosed patients were offered to join one 90-minute virtual psychoeducational session focused on increasing disease understanding and connecting with health care professionals. Sessions were offered monthly.
3. *Oncology caregiver workshops*: Sixty-minute, open (meaning new members could join at any time) virtual psychoeducational workshops for caregivers covered seven themes (one per workshop) including mindfulness strategies, fostering healthy nutrition and sleep habits during treatment, and supporting children with medications and medical procedures.
4. *Photovoice groups for teens on active cancer treatment and teenage siblings of cancer patients*: Separate virtual groups for teens and siblings provided the opportunity to meet, reflect, and share issues they faced about their own or their sibling's treatment journey using photography. Groups were closed, met once a week for 7 weeks, and sessions lasted 90 minutes.
5. *Teens4Teens*: A virtual open, drop-in community for teens at any stage in their cancer experience included psychoeducational and peer support components, the latter allowing teens to find commonalities and share coping strategies. Sixty-minute sessions were held once a week for 6 months.
6. *Camp Ooch & Camp Trillium*: Virtual camp-style programing connected children, teens, and families through activities including peer support, talent shows, and virtual campfires. Sessions were open, held multiples times per week, and ranged in duration from 60 to 90 minutes.

3 | OBSERVATIONS

3.1 | Barriers removed

We noted that several barriers were removed with the pivot to virtual group psychosocial care, including geographical, socioeconomic, and socioemotional. Participants who would not have previously been able to attend in-person sessions shared that they were now able to join from homes in remote locations, cars, or hospital beds. The need to take time off work and school, incur costs associated with transportation and parking, and arrange childcare were largely eliminated. Siblings who were unable to visit the hospital due to COVID-19 restrictions could still benefit from supportive and educational interactions with the multidisciplinary team. Many participants were observed to be, and reported themselves to be more comfortable physically and emotionally and less distracted as compared with the hospital setting. Teens were particularly amenable to building social bonds by maximizing the technological features of the Zoom platform, such as chat boxes and reactions.

3.2 | Barriers introduced

The rapid virtualization of supports also introduced certain barriers. While technological innovations in health care are generally designed to improve access, we were cognizant of disproportionately poor access to reliable high-speed internet and electronic devices for people from racial or ethnic minorities, lower socioeconomic backgrounds, lower digital literacy, or those with limited English proficiency.

Another added barrier involved lack of private space from which to join groups. This was of particular concern to teens as well as caregivers, both of whom often want to protect the other from their own emotional disease-related concerns. The use of headphones and a space away from others helped but did not fully guarantee a confidential environment.

The increased distance between providers and patients, and between patients themselves, prevented opportunities for more organic formation of social connections found with in-person interactions, like walking into the room early, sharing refreshments, and exiting the building together. Finally, signs of online fatigue were noticed in some groups, with many participants joining after hours of school or work in front of a screen. A minority reported feeling tired or restless as a result, though this was not widely observed across groups.

4 | LESSONS LEARNED AND NEXT STEPS

Though legitimate concerns about equity of access, privacy, and engagement remain, the COVID-19 pandemic has highlighted the advantages and potentially substantial clinical impact of virtual psychosocial care. The groups were feasible to develop, in terms of observations of referral numbers, attendance rates, facilitators' time, and

financial costs. Based on informal participant feedback during sessions, groups were well-received by patients and families and were smoothly tailored to meet the specific needs of younger children, teens, siblings, and caregivers. As an example, the culminating exhibition of the Photovoice Group for Teens, a public showcase of the photographic works and narratives of the participants developed across 7 weeks of the group, was held virtually this year for the first time. Attendance at its peak was well over 150 attendees, a record for the event. Invited guests including oncologists, nurses, allied health professionals, and administrators, as well as the group facilitators, teen participants and their families, uniformly described a deeply captivating and profound experience. This case, along with countless others since the start of the pandemic, has demonstrated to us the opportunity to permanently shift elements of group psychosocial care virtually in caring for the pediatric hematology/oncology population.

Moving forward, we must consider the unique characteristics and needs of our patients and families, including social determinants of health, digital literacy, and linguistic diversity. Health care providers and the hospital share a responsibility to advocate for equitable access to virtual care and inform patients and families about virtual group opportunities. Furthermore, given this population's high proportion of immunocompromised individuals, frequency of hospital visits, and number of missed days of school and work due to treatment, virtual care may offer distinct benefits to this group. New virtual programs should be developed, and old ones modified with the above considerations in mind.

Existing guidelines on the responsible provision of virtual medical and mental health care are helpful frameworks and may be adapted specifically for use in pediatric psychosocial hematology/oncology care. Future research is needed to create evidence-based virtual programming; for example, as an adjunct to the Standards of Psychosocial Care for Children with Cancer and Their Families.⁵

The team at SickKids has formed groups transcending geographical location to provide psychoeducation, peer support, and skill-based

interventions. Patients and families have connected with others going through similar experiences in a period of communal isolation. Leveraging technology to foster virtual connections has shown that psychosocial support groups can be integrated into routine psychosocial care long into the future.

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REFERENCES

1. Bandinelli L, Ornelli F, Von Diemen L, Kessler FHP. The sum of fears in cancer patients inside the context of the COVID-19. *Front Psychiatry*. 2021;12:557834.
2. Ferrari A, Patriccioli A, Silva M, Casanova M, Signoroni S, Massimino M. Looking out to see within: a photography project developed by adolescents with cancer during the COVID pandemic. *Pediatr Blood Cancer*. 2021;68(5):e28948.
3. Hong Y, Peña-Purcell NC, Ory MG. Outcomes of online support and resources for cancer survivors: a systematic literature review. *Patient Educ Couns*. 2012;86(3):288-296.
4. Love B, Crook B, Thompson CM, et al. Exploring psychosocial support online: a content analysis of messages in an adolescent and young adult cancer community. *Cyberpsychol Behav Soc Netw*. 2012;15(10):555-559.
5. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the psychosocial care of children with cancer and their families: an introduction to the special issue. *Pediatr Blood Cancer*. 2015;62(5):S419-S424.

How to cite this article: Kaka A, Shama W, Lucchetta S, et al. Virtual support groups in pediatric hematology/oncology during COVID-19: Lessons learned from the SickKids experience. *Pediatr Blood Cancer*. 2021;68e29378 <https://doi.org/10.1002/pbc.29378>.