

Short Communication

Child Life Specialist Videoconference Support of Siblings of Pediatric Stem Cell Transplant Recipients: A Pilot Study

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Abstract

Objective: To offer child life services conducted by certified child life specialists (CCLS) to siblings of children undergoing hematopoietic stem cell transplantation (HSCT) through videoconferencing.

Methods: The study focused on the 100 days following transplant, during which non-donor siblings engaged in virtual sessions with a CCLS. Interviews were conducted with siblings and parents post-intervention to assess its effectiveness. Qualitative analyses of the interviews were done.

Results: Families expressed contentment with the intervention (64%) and an interest in maintaining or expanding the program. Sixty percent of siblings found the intervention helpful, emphasizing the value of 1-on-1 support and sharing crucial medical information. Positive outcomes included increased empowerment, engagement in therapeutic activities, coping mechanisms, and improved communication. Privacy concerns led to limited parental involvement, but both parents and siblings acknowledged the importance of the intervention in conveying necessary information. Challenges such as connectivity issues and scheduling conflicts were noted, suggesting potential areas for improvement.

Discussion: The study underscored the significant impact of remote interventions in offering vital support and information to siblings during the intensive HSCT process. The study also emphasized the negative impact on siblings without focused services and stressed the importance of providing inclusive support mechanisms, especially when access to such resources is restricted at home.

ABBREVIATIONS

HSCT: Hematopoietic Stem Cell Transplantation; CCLS: Certified Child Life Specialist

INTRODUCTION

Siblings of children facing chronic illnesses constitute a population at heightened risk for psychosocial distress, compromised psychological well-being, reduced engagement in peer activities, and lower cognitive development scores [1-3]. Notably, siblings of children undergoing hematopoietic stem cell transplant (HSCT) are at risk [4]. This paper focuses on siblings of pediatric cancer and sickle cell patients undergoing HSCT, a population with distinct unmet needs and concerns.

HSCT is an invasive treatment requiring extended hospital

stays for both the patient and at least one caregiver, leaving an indelible mark on the entire family [4,5]. Our previous work revealed that these siblings of HSCT patients experience difficult emotions, negative effects of separation from the patient and caregiver(s), additional responsibilities, and, particularly with the non-donor siblings who do not typically interact with the healthcare team, lack of information about the medical situation [6]. Importantly, siblings themselves have articulated that their needs frequently go unaddressed and have voiced valuable suggestions regarding how healthcare teams could provide more effective support [5].

Despite the prevailing paradigm of family-centered care and the endorsement of supportive measures for siblings by organizations such as the American Academy of Pediatrics [7], a critical gap exists in understanding the tangible strategies

families employ to assist siblings during this complex and demanding medical journey. In response, our study aims to address this gap by exploring targeted interventions to support these siblings during HSCT. We provide child life services through videoconferencing to address the siblings' needs and concerns and offer insights into the potential effectiveness of remote interventions for supporting siblings during the challenging HSCT process.

MATERIALS AND METHODS

All phases of the study were approved by the institutional review boards of participating institutions and consent/assent was obtained from all participants.

To address the needs of non-donor siblings during hematopoietic stem cell transplant (HSCT), child life services conducted by a CCLS was extended to fifteen non-donor siblings of patients undergoing HSCT, representing fourteen families with nineteen parents and fifteen siblings. These siblings participated in video-conferencing sessions with the CCLS during the 100 days following the transplant. The CCLS's three goals in conducting their sessions with siblings were: building rapport, providing developmentally appropriate education, and providing therapeutic interventions to assist the sibling in coping. After the 100-day period, the effectiveness of the pilot intervention was evaluated through interviews conducted with both the siblings and their parents. Qualitative analysis of the themes that emerged from these interviews was done. These themes included usefulness, impressions, parent involvement, outcomes, activities, information sharing, difficulties, feasibility, and areas for improvement.

RESULTS AND DISCUSSION

In this study, the Certified Child Life Specialists (CCLS) implemented a comprehensive approach to provide remote support and interventions to siblings of pediatric patients undergoing hematopoietic stem cell transplant (HSCT). In total, 34 family members, 19 parents, and 15 siblings were involved. The age range of the siblings was 9-17, with an average age of 12.

Overall, 60% of the siblings found the intervention helpful and 87% expressed that it went well. 63% of parents expressed that the intervention was enjoyable for the siblings. Notably, 47% of siblings mentioned that sessions were conducted in locations other than their homes, often due to primary caregivers being at the hospital with the patient. A significant proportion of parents (42%) were not actively involved in the intervention, reporting that they did not know the exact session details, ensuring a level of privacy between the CCLS and sibling. 11% of parents mentioned advising CCLS on the content of sessions, giving suggestions on what to do or tell their child.

Both parents and siblings highlighted two essential aspects of the intervention: the 1-on-1 support provided and the sharing of critical information about the patient's medical situation and transplant process (Table 1). Table 2 describes positive outcomes

reported by family members from the intervention. According to the siblings, these positive outcomes included feeling empowered to ask questions (33%), receiving advice and coping mechanisms from the CCLS (73%), gaining medical information (93%), engaging in focused 1-on-1 interactions (47%), enjoying visual engagement through videoconferencing (13%), finding an outlet to discuss non-treatment-related issues (33%), and feeling included within the family dynamic (40%). Siblings also expressed enjoyment in participating in activities with the CCLS, including therapeutic workbooks and games.

All fourteen families acknowledged that the CCLS shared an appropriate level of information with the siblings. Among the siblings, 87% indicated that important information was effectively conveyed, and 60% reported that they received novel and valuable information. Notably, neither the siblings nor the parents expressed any regrets or concerns about the information that was shared during the interventions.

Table 3 describes difficulties encountered by family members during the intervention. For siblings, these included internet connection issues (53%), interruptions due to sibling moving locations (13%), scheduling challenges (40%), shy sibling had difficulty connecting with CCLS (13%), and sibling already knowledgeable about details surrounding patient's treatment forcing CCLS to adapt their plans (13%). Table 4 describes potential areas of improvement suggested by family members. Overall, 64% of families indicated that they would not change anything about the intervention and wished to maintain it, while 29% mentioned a desire to expand the program for children of adults undergoing surgery or treatment. 16% of parents suggested a pre-intervention meeting between parent(s) and CCLS to discuss content and information that would be shared. Other areas of improvement offered by family members included increased scheduling flexibility (15%) and text message reminders prior to sessions (9%).

Finally, based on a usefulness scale, both siblings and parents found the videoconferencing, information shared, and suggestions offered by the CCLS to be highly valuable. These findings highlight the positive impact of the intervention in providing valuable support and information to siblings during the challenging HSCT process.

GOALS OF THE CCLS INTERVENTION

Assessment

The initial session was pivotal for the CCLS in gathering essential baseline information about the siblings. They delved into various aspects, such as family dynamics, living arrangements, communication with the hospitalized sibling, and the sibling's interests and educational background. This comprehensive assessment allowed the CCLS to tailor their interventions to each sibling's specific situation. For example, understanding their level of engagement with the hospitalized sibling helped them gauge their emotional connection and adapt their support accordingly.

Table 1: CCLS Approaches to Rapport Building, Education, and Therapy In-Person vs. Virtually

Child Life Goal	In Person	Virtual
Assessment / Rapport Building	1. Collecting baseline information: who is sibling staying with? How often do they talk to or visit hospitalized child? What does sibling like to do, grade in school, etc. 2. Check- in at beginning of each interaction (emotional identification and building rapport)	1. Collecting baseline information: who is sibling staying with? How often do they talk to or visit hospitalized child? What does sibling like to do, grade in school, etc. 2. Similar check-in virtually, virtual can impact the flow of the conversation
Education: providing developmentally appropriate education	1. Utilizing dolls and real medical equipment to teach sibling about diagnoses and procedural information	1. Send home photocopies of medical equipment, books about procedures/treatment, and provide education via virtually
Coping/therapeutic interventions:	1. In person therapeutic art activity - in person, therapeutics are more collaborative and hands on. We typically follow the child's lead, for example if a child brings up a certain topic like self-esteem, we could easily gather materials directed towards that	2. We utilized therapeutic workbooks often virtually. The activities were set up more like asking the sibling to take a few minutes to work on a specific activity/journal page, then talk together after

Abbreviations: CCLS: Certified Child Life Specialist

Table 2: Positive Outcomes of Intervention Reported by Family Members

Positive Outcomes	INDIVIDUALS, n=34 n (%)	Parents, n=19 n (%)	Siblings, n=15 n (%)
Able to ask questions	11 (32)	6 (32)	5 (33)
Advice	14 (41)	3 (16)	11 (73)
Medical information sharing	27 (79)	13 (68)	14 (93)
1-on-1 interaction	18 (53)	11 (58)	7 (47)
Video calling for visual engagement	5 (15)	3 (16)	2 (13)
Provide release	8 (24)	3 (16)	5 (33)
Sibling felt comfortable with CCLS	7 (21)	4 (21)	3 (20)
Made sibling feel important	7 (21)	6 (32)	1 (7)
Inclusion within family	17 (50)	11 (58)	6 (40)
Allows for remote CCLS support	4 (12)	4 (21)	0 (0)

Abbreviations: CCLS: Certified Child Life Specialist

Table 3: Difficulties Encountered During Intervention Reported by Family Members

Difficulties	Individuals, n=34 n (%)	Parents, n=19 n (%)	Siblings, n=15 n (%)
Trouble utilizing iPad	2 (6)	2 (11)	0 (0)
WiFi connection	11 (32)	3 (16%)	8 (53)
Sibling moves location Interruption	4 (12)	2 (11)	2 (13)
Scheduling	11 (32)	5 (26)	6 (40)
Summer/breaks from school	1 (3)	1 (5)	0 (0)
Shy sibling	5 (15)	3 (16)	2 (13)
Trouble remembering sessions	3 (9)	3 (16)	0 (0)
Preexisting behavioral challenges	2 (6)	2 (11)	0 (0)
Sibling already knowledgeable	4 (12)	2 (11)	2 (13)

Table 4: Strategies Suggested by Family Members to Improve Intervention

Strategies to improve intervention	INDIVIDUALS, n=34 n (%)	Parents, n=19 n (%)	Siblings, n=15 n (%)
Nothing to change	15 (44)	8 (42)	7 (47)
Pre-intervention meeting between parent(s) and CCLS	3 (9)	3 (16)	0 (0)
Better wifi connection	1 (3)	0 (0)	1 (7)
Technology explanation	1 (3)	1 (5)	0 (0)
Text message reminders	3 (9)	2 (11)	1 (7)
More Flexible timing	5 (15)	2 (11)	3 (20)
Expand program	4 (12)	3 (16)	1(7)
More writing/drawing activities	2 (6)	0 (0)	2 (13)

Abbreviations: CCLS: Certified Child Life Specialist

Additionally, the CCLS implemented ongoing assessments throughout the sessions. The “highs and lows” exercise not only built rapport but also provided insights into the siblings’ emotional states. This continuous evaluation was crucial in identifying stressors and adapting interventions to address their evolving needs.

Rapport Building

Building rapport with siblings was a fundamental aspect of the remote interventions led by the CCLS. They employed various techniques to foster a sense of trust and connection with the siblings, even in a virtual setting. Activities like the “Get to Know You” game and sharing “3 things” helped create a supportive environment where siblings felt comfortable expressing themselves.

Developmentally Appropriate Education

One of their primary goals was to provide education to siblings about the diagnosis and treatment processes of their hospitalized siblings. They utilized concrete visual tools and engaging activities to ensure that the information was accessible and comprehensible. For example, using picture copies of “Medikenz” for teaching about bone and cells allowed siblings to have visual aids at home, reinforcing their understanding of complex medical concepts.

Coping/Therapeutic Intervention

Coping with the challenges of having a hospitalized sibling required a targeted and individualized approach led by the CCLS. They employed a variety of therapeutic activities aimed at helping siblings navigate their emotions and responsibilities. These activities, such as the “Map of My Brain,” “Iceberg Therapeutic,” and “Stress Less Therapeutic,” provided valuable tools for siblings to manage stress and express their feelings.

Moreover, the CCLS recognized the importance of maintaining engagement in a virtual setting, where distractions could be prevalent. To address this challenge, they utilized incentives, sticker charts, and activities tailored to the siblings’ interests. This approach ensured active participation and enhanced the effectiveness of the interventions.

Challenges and Differences from In-Person Interventions

The CCLS's had to take on unique approaches to attain their goals of building rapport, educating, and providing coping strategies in a virtual format. Their contrasting approaches to attain these goals in person vs virtually are described in Table 1 with successes and challenges identified. The remote interventions led by the CCLS faced several unique challenges compared to traditional in-person sessions:

Supplies: Providing necessary supplies to participants became more complex over time, as many siblings would misplace the materials given at the beginning of the 100-day period. Adapting activities to utilize common household items was essential to ensure the continuity of therapeutic interventions.

Modifying Games: Traditional games and activities often used for rapport building needed modification in the virtual setting. For instance, they adapted games like "Therapeutic Uno" to be played remotely, maintaining their therapeutic value.

Scheduling: Flexibility in scheduling became paramount, as siblings' availability was influenced by various factors, including caregiving responsibilities, school, and healthcare appointments. The CCLS sent text reminders and provided "homework" to accommodate their ever-changing lifestyles.

Internet Connection: Internet connectivity issues sometimes posed challenges. To mitigate this, the CCLS helped participants find optimal locations for sessions and offered phone calls when video calls were not feasible.

Participant Engagement: Ensuring participant engagement in virtual sessions required creative strategies, including the use of incentives and activities aligned with their interests.

Communicating with Caregivers: Communication with caregivers was essential, especially when siblings disclosed important information during sessions. In these cases, the CCLS relied on emails or phone calls to keep caregivers informed.

CONCLUSION

Siblings of patients undergoing HSCT are negatively impacted

without focused services to offer support, share information, and help the sibling feel included. The findings from our pilot study indicate that virtual interventions hold significant value in providing essential CCLS support to siblings, especially when access to such resources at home is limited. By addressing their unique needs through assessment, rapport building, education, and coping interventions, the CCLS aimed to enhance their ability to navigate the challenges posed by their sibling's hospitalization. While remote interventions presented distinct challenges, the adaptable approach allowed the CCLS to effectively support these siblings during a critical and demanding period in their lives. Further research and refinement of remote interventions in this context can contribute to improved psychosocial support for siblings of pediatric HSCT patients.

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