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Original Articles

Child Life Services for Siblings of Chronically Ill Children

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Objective:
Siblings of children with chronic illnesses are at high risk of adverse psychosocial and developmental outcomes, yet limited sibling-specific services are available at most pediatric healthcare facilities. Child life specialists are often the professionals most focused on and available to provide education, emotional support, and therapeutic play to support sibling coping needs in this context; however, little is known about the scope and availability of child life services for siblings of children with chronic illnesses. Therefore, the purpose of this survey-based study was to examine the type and frequency of child life services available to siblings in pediatric healthcare settings in North America, and to identify barriers to sibling support provision.
Method:
Survey-based study, across the 76 participants.
Results:
A variety of sibling support frequencies and service types were identified, as well as barriers related to lack of clinical staffing, hospital-imposed visitation restrictions, and limited sibling support referrals from multidisciplinary team members.
Conclusion:
Noting these opportunities and limitations, it is crucial that healthcare administrators and institutions invest monetary and staffing resource to better meet the needs of siblings of hospitalized children.
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Nearly 250,000 children today are living with a sibling who has a chronic illness (Mooney-Doyle et al., 2022). Whether the condition is newly diagnosed or a long-known and integrated aspect of family life, siblings who are healthy are impacted by this experience in developmental and psychosocial ways (Meyer & Vadasy, 2007; Thompson, 2018). Additionally, given the high caregiver burden associated with having a child with chronic illness (Khanna et al., 2015), the social-emotional needs of siblings can often be unrecognized or are unable to be prioritized by parents and other family members (Pearson, 2017). Thus, having a child with a chronic illness – defined as any condition lasting three months or longer (Hockenberry et al., 2018) – affects the way caregivers interact with and care for all children in the family.

In a recent survey, parents of children with a life-threatening illness commonly described themselves as feeling frustrated, overwhelmed, afraid, exhausted, guilty, and torn (Mooney-Doyle et al., 2018). This can leave little “mental bandwidth” or emotional energy available for siblings who are healthy, despite the parent’s best efforts and intentions. For example, parents of children with cystic fibrosis or cancer self-report having less patience for their children who are healthy than they did before the diagnosis (Jankovic et al., 2018).

The effects of these parenting strains may look different for children at various ages and developmental and care needs. For instance, parents in one study reported feeling fairly dedicated to maintaining normal routines of a toddler who is healthy as much as they can, whereas they tended to spend less energy and effort on meeting the coping needs of their adolescent children (Mooney-Doyle et al., 2018). Additionally, family size may moderate these effects and impacts. In the case of a larger family system, when parents are unable to be physically or emotionally present, siblings may step in to care for one another to the extent they are

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able (Seymour, 2017). Although instrumentally helpful, this phenomenon (known as "parentification," per Masiran et al., 2022), can have significant adverse effects on the child's psychological well-being, interpersonal relationships, and behavioral difficulties, including toxic stress, disrupted development, and loss of boundaries – some of which may not surface until years later (Masiran et al., 2022).

Existing studies have also demonstrated an array of psychosocial impacts directly on siblings of children with chronic illness, though balanced in both positive and negative directions. Some of the most commonly reported emotional responses among siblings who are healthy include feelings of survivor's guilt, anxiety, jealousy, insecurity, and intense pressure to achieve; at the same time, these children also self-describe benefits such as maturity, pride in their sibling's growth and abilities, increased advocacy skills, and early exposure to vocational opportunities related to their sibling's chronic illness and treatment (Dinleyici & Sahin Dagli, 2019; Meyer & Vadasy, 2007). These interpretations, however, do appear to vary by age and developmental level, with the most outwardly negative effects seen in siblings between the ages of four and 11 years old (Pearson, 2017) – signaling a need to prioritize these age groups for sibling support services in and beyond the hospital setting.

Certified Child Life Specialists (CCLS) are in a unique position to provide these needed supports to siblings. Several different services have been correlated with positive effects on siblings, all of which correlate with the roles and responsibilities of child life practitioners. One particularly critical point of intervention is hospital visitation, especially in the intensive care environment. Siblings who have visited the Intensive Care Unit during a child's hospitalization have demonstrated improved coping compared to those who did not visit; additionally, those who visited often recall the memories of this experience positively even several years later (Sandler et al., 2013; Thompson, 2018). When visiting, siblings identify concerns specific to the unfamiliarity and anticipated stress of the healthcare environment, the appearance of the child with a chronic illness, and not knowing what will happen (Abela et al., 2022). With sufficient stress-point preparation and help processing their experiences through play during and after the visit, these negative effects can be lessened or eliminated through intervention from a CCLS (Thompson, 2018).

Outside of the intensive care environment, siblings who received educational interventions focused on the diagnosis and treatment not only experienced fewer behavioral problems, but also demonstrated higher levels of self-respect, understanding of the illness, perceived social support, and psychological well-being compared to control groups (Dinleyici & Sahin Dagli, 2019; Prchal et al., 2012). Additionally, in community settings, siblings who are involved in peer support groups and workshops report decreased isolation, improved coping, and feelings of self-worth (Deavin et al., 2018; Meyer & Vadasy, 2007). Thus, there are benefits associated with child life care for siblings of children with chronic illnesses both in healthcare settings and the larger community, by increasing understanding, promoting coping and self-esteem, and creating opportunities to express feelings through play and socialization.

Although 90% of pediatric hospitals report offering some form of sibling support (Mooney-Doyle et al., 2022), siblings are at high risk of being overlooked and underserved by both families and providers. Few sibling-specific tools exist, and services are typically administered reactively rather than proactively because of this (Davis et al., 2022). Only 26% of hospitals report receiving funding for sibling-focused programming (Newton et al., 2010). In fact, psychologists, social workers, psychiatrists, and CCLS all report this same barrier, which may be pushing siblings towards the bottom of the priority list for these pertinent practitioners (Brosnan et al., 2022). In child life specifically, when asked which groups they spend the most time with, CCLS ranked siblings below patients, parents, grandparents, and healthcare workers (Lookabaugh & Ballard, 2018).

As the literature to date highlights, siblings have significant psychosocial and developmental needs because of living and coping with a sibling who has a chronic illness in their family system. Although these needs are somewhat recognized across providers and professionals, there are limited resources available for supporting this population, despite evidence of the benefit of these services for children and families. CCLS are well-positioned to meet these needs; however, little is known about the scope and availability of child life sibling support services at this time. Therefore, the purpose of this study was to examine the scope and availability of sibling support services provided by CCLS in pediatric healthcare settings, and to identify barriers to more effective and robust intervention offerings for this vulnerable population. The research questions included:

Q1: What types of child life services are provided for siblings, and with what frequency?

Q2: What barriers to child life sibling support provision do participants identify?

Method

As the purpose of this study was to capture a specific moment in time and service delivery across a varied participant group, a survey-based study was most appropriate. To meet the aims of this study, eligible participants included 1) CCLS working in pediatric healthcare settings who 2) spoke English as their primary language and 3) provided consent to participate. Sixty-two participants completed the study in full; an additional 14 participants provided partial responses but did not fully complete the survey and thus are not represented in Table 1. Of the full sample of 76 participants, 72 (94.7%) lived and worked in the United States, and the remaining four (5.3%) lived and worked in Canada at the time of participation.

Procedures

Eligible participants were recruited from several social media sources: 1) the Association of Child Life Professionals (ACLP) Connect internal professional networking platform, 2) Facebook groups entitled Certified Child Life Spe-

Table 1. Participant Demographics

Variables	Frequency	Percentage (%)
Gender		
Male	2	3.3
Female	59	96.7
Age		
20-29	19	30.6
30-39	33	53.2
40-49	5	8.1
50-59	3	4.8
60+	2	3.2
Race		
White or Caucasian	57	91.9
Asian	3	4.8
Two or more races	1	1.6
Other	1	1.6
Ethnicity		
Hispanic or Latino	4	6.5
Not Hispanic or Latino	57	91.9
Declined to answer	1	1.6
Education Level		
Bachelor’s degree	21	34.4
Master’s degree	40	65.6
Experience		
Less than 1 year	4	6.5
1-2 years	8	12.9
3-5 years	14	22.6
6-10 years	19	30.6
11-14 years	10	16.1
15 years or more	7	11.3
Position Type		
Full time	56	90.3
Part time	3	4.8
PRN (per diem)	3	4.8
Current Role		
CCLS with no supervisory responsibilities	18	29
CCLS with student supervisory responsibilities	35	56.5
CCLS with staff supervisory responsibilities	2	3.2
Child life manager or director	5	8.1
Other	2	3.2
Primary Work Environment		
Free-standing children’s hospital	32	52.5
Children’s hospital within an adult hospital	18	29.5
Pediatric service within an adult hospital	4	6.6
Outpatient clinic or treatment center	2	3.3
Other healthcare environment	1	1.6
None of the above	4	6.6

Variables	Frequency	Percentage (%)
Primary Work Setting		
Inpatient acute care	18	29
Critical care	20	32.3
Outpatient clinic	7	11.3
Emergency department	4	6.5
Radiology	2	3.1
Pre-Surgery	1	1.6
Hospice or palliative care	4	6.5
Private practice	1	1.6
Other*	5	8.1
Number of Full-Time Child Life Staff		
1	7	11.3
2-4	6	9.7
5-9	10	16.1
10-19	19	30.6
20-29	10	16.1
30-39	5	8.1
40 or more	5	8.1

* Denotes both inpatient and outpatient units (n=2), pediatric oncology day camp (n=1), all settings except private practice (n=1), and all brain tumor patients (n=1).

cialists, Canadian Child Life Specialists, The Child Life Connection, and The Child Life Connection Student Forum, and 3) the personal social media profiles used by the research team. Interested participants entered the study using a provided REDCap (Harris et al., 2009, 2019) link and QR code; the survey instrument consisted of three parts: a study information sheet (consent form), a screening form to verify eligibility, and a survey of sibling support service provision with an embedded demographic information section. All data were collected between September and October 2022.

The sibling support provision survey was composed primarily of open response, multiple choice, and rating questions using a six-point Likert-type scale of frequencies. For the Likert-type items, “almost never” was defined as a support provided less than 10% of the time; “rarely” provided was defined as being given between 10 and 25% of the time; “sometimes” providing a support meant performing 25 to 50% of the time; and “usually” meant it was provided between 50 and 75% of the time. If something was “almost always” given, this indicated it was done more than 75% of the time. These ranges were chosen with respect to situations where it is impossible to serve siblings for reasons outside the CCLS’s control (such as when a child does not have siblings, or the sibling is at an age where they would not reasonably be expected to take part in a particular intervention). Participants were also given the option to indicate that they did not provide a certain service.

Table 2. Overall Sibling Support Frequency

Sibling Support	Frequency	Percentage
Almost never	2	2.6
Rarely	14	18.4
Sometimes	30	39.5
Usually	15	19.7
Almost always	15	19.7

Results

A range of sibling support frequencies were reported by the 76 participants, with results approximating the shape of a normal curve (see Table 2).

The majority of these participants (81.6%; n = 62) proceeded to the rest of the survey and offered more specific information about the scope of their sibling support services. The most frequently reported support (i.e., the support with the highest mean, M = 4.10) was education for parents on sibling needs (see Table 3). On the converse, the least commonly provided (i.e., lowest mean, M = 2.37) was referrals to counseling or support groups. The highest standard deviation (SD = 1.59) concerned engagement in special events or hospital programming, suggesting some degree of consistency across participants, while the lowest standard deviation (SD = 0.94) was for education about the illness and treatment, indicating a higher degree of variance in provision practices across participant respondents.

A total of 21 participants provided write-in responses regarding other supports not listed. These included legacy and memory making interventions when a child is at end of

Table 3. Descriptive Statistics for Different Support Types

Support Type	*M*	*SD*
Education for parents on sibling needs	4.10	1.00
Assessing sibling's psychosocial needs	4.02	1.02
Education about the illness and treatment	3.76	.94
Teaching coping skills	3.34	1.14
Bedside visit preparation/support	3.24	1.43
Therapeutic play	3.11	1.16
Medical play	2.89	1.19
Engagement in special events or hospital programming	2.76	1.59
Referrals to counseling or support groups	2.37	1.32

Table 4. Common Barriers to Access

Barrier Type	Frequency	Percentage
Limited visitation policy for siblings	46	78
Lack of child life staffing	35	59.3
Facility staff neglects to contact child life	28	47.5
Lack of funding/resources for siblings	22	37.3
Parents/caregivers decline child life services	14	23.7
Not enough training in how to provide sibling support	6	10.2

Note. N = 62; participants were able to select all responses that applied.

life (n = 8), coordinating on-site sibling visits (n = 3), connecting families with resources such as books or camps especially for siblings (n = 3), facilitating virtual visits when a sibling could not visit in person (n = 2), personally made photo story books (n = 2), sibling-only events (n = 1), teaching siblings how they can engage with the sick child (n = 1), and the use of artwork to facilitate bonding (n = 1).

Concerning the specific provision of sibling support groups, a small number of participants (n = 7; 11.3%) indicated their facility provided such a group. There were 30.6% (n = 19) who reported their facility does not provide its own support groups, but specialists refer children to outside support group offerings. Half of participants (n = 31) belonged to a facility that neither provided a group nor referred children to an outside support group source, and five (8.1%) were unsure what their facility did in this regard.

When asked to indicate barriers to sibling support provision, the majority of participants reported limitations due to sibling visitation policies (n = 46; 78%) and a lack of child life staffing (n = 35; 59.3%;see Table 4).

When given the opportunity to write in additional barriers, 24 participants elected to do so. It was noted by a total of 11 participants that a variety of factors restrict sibling presence. Those listed include family not being local to the area, siblings residing with a different caregiver than the child with a chronic illness, lack of familial resources, school schedules, parental reluctance to bring siblings into high-intensity environments such as the intensive care unit, and siblings not being in a space where they are emotionally safe to visit the patient. Other barriers listed included ongoing visitation restrictions due to the coronavirus pandemic (n = 6), low child life staffing during evenings and weekends when siblings are most likely to visit (n = 2), healthcare staff lacking appropriate understanding regarding the role of child life services (n = 2), parents not identifying siblings as having unique needs (n = 2), and language barriers (n = 1).

Post-hoc Analyses and Findings

A chi-square test of independence was run to determine a possible relationship between primary work setting and reporting "limited visitation policy for siblings" as a barrier to access. The relationship between these variables was significant, χ^2 (2, N = 62) = 11.86, $p < .01$. Therefore, there appeared to be a significant relationship between areas with restricted visitation policies and provision of sibling services in those settings.

Discussion

Findings from this study suggest that the majority of siblings are not receiving child life services. Of the participants in this study alone, 60.5% stated they provide sibling support for fewer than half of their patients. Past research has shown positive correlations between receiving child life services and improved coping (Thompson, 2018); additionally, the coping ability of healthy siblings is also reflected in the anxiety and distress levels of the larger family unit (Gill, 2020).

The most significant barrier to access noted by participants was limited sibling presence in the healthcare environment. Approximately 78% of respondents stated visitation policies made it difficult to serve siblings, and 18% of the sample discussed other common reasons why siblings could not be present, such as living too far away to visit. Psychosocial care providers may be able to reach greater numbers of siblings by utilizing asynchronous methods, such as telemedicine platforms. A small number of participants in this study indicated using supports such as bibliotherapy, personally made photo story books, and art. Expanding the reach of these interventions would allow for siblings and families to benefit even when they are not able to visit the hospital.

Siblings may also benefit from supports such as the SuperSibs Comfort and Care Mailing Program, or the Beads of Courage Sibling Program (Sibling resources, n.d.; Supporting siblings, n.d.), neither of which were mentioned by participants in this study. Caregivers could be provided with kits they can then bring home to siblings, or if this is not feasible, caregivers may prefer to be presented with the option to sign up for appropriate resources themselves. If a parent or other family member is traveling back and forth to the hospital, a CCLS may also encourage the creation of artwork or handwritten messages to be passed between the siblings. This has been shown to benefit siblings who are healthy, promote bonding, and allow for self-expression (Pearson, 2017).

Of supports offered, the two most frequently provided – educating parents about sibling needs and assessing a sibling's psychosocial needs – may be feasible to implement through intentional, often-brief dialogue with a parent or other family caregiver. In this case, the sibling need not be physically present. Many services (e.g., teaching coping skills) can be offered remotely using videoconferencing technology. For those that are less optimal on a digital platform (e.g., therapeutic play), the most practical suggestion may be a referral to psychosocial care providers in the family's home community. Despite this, referrals to counseling or support groups were the single least commonly provided support offered by participants in this study. To meet this need in an efficient and accessible way, CCLS can partner with social workers and other care providers to offer caregivers lists of providers such as mental health counselors in the local area, or encourage them to consult with their child's school, outpatient pediatrician, or insurance company to locate local and accessible care.

Although research demonstrates that the majority of siblings of children with chronic illness desire more contact with peers (Joosten et al., 2019), fewer than 50% of participants reported that sibling support groups are available in their facility. Although support groups may be challenging and time intensive to organize and facilitate, CCLS may help meet this need by providing sibling-only or sibling-focused special events in the healthcare settings or connecting families with local sibling social groups such as Sibshops (Meyer & Vadasy, 2007). When CCLS are familiar with the peer support options offered in the local area, they are better able to serve siblings and families.

Although this study is the first to document sibling service provision type and frequency across CCLS and highlights key barriers to more expansive service offerings, it is not without limitations. Despite the robust sample size, the participants in this study were quite homogeneous in terms of gender and race; however, this is a known and high-priority issue in the child life profession. When considering barriers to providing sibling support, 78% answered that limited visitation policy for siblings played a role. Factors such as funding, the COVID-19 pandemic, and hours of operation could impact visitation policies, and future research should explore contributing factors and how to combat the barrier. Additionally, further research is warranted regarding sibling support when a child is at end of life – a time siblings are generally prioritized (Thompson, 2018) – as noted by several participants in this study. Finally, survey-based studies are subject to reporting bias, which may make these results less reliable than direct observation of sibling support services and interventions as they are provided in real time – making direct, systematic observation an opportunity for further empirical study.

Conclusion

Children who are healthy and have a sibling with chronic illness remain an underserved group, despite demonstrating risk factors for adverse developmental and psychosocial outcomes. Respondents in this study highlight that primary challenges to providing these supports include visitation restrictions imposed by the healthcare facility, which may render in-person sibling supports difficult or inaccessible altogether. Child life specialists may be able to better serve siblings by providing caregivers with information about or referrals to supports that can be utilized outside the healthcare setting, partnering with other psychosocial providers and community organizations, and facilitating virtual visits where they can offer psychosocial interventions to siblings.

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