

## Sibling Caregivers: A Mixed Methods Study and Family-Based Intervention Model in a Pediatric Hospital

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### Abstract

**Background:** Caregiving youth are minors providing significant assistance to relatives or household members who have chronic physical or mental illnesses and disabilities, yet in the US are relatively under supported.

**Objective:** We sought to introduce a hospital-based model for screening, referral, and intervention among a population of children who care for siblings with chronic and often complex medical conditions.

**Methods:** A descriptive, quantitative analysis was followed by a two-phase intervention (focus group and caregiver workshop) utilizing qualitative analysis in an academic children's hospital. Screening sites included the inpatient complex care team and three outpatient clinics.

**Results:** Sibling caregivers (N=21) spent an average of 2 hours a day on weekdays and 4 hours a day on weekends caring for a brother or sister with a chronic health condition. Common activities of daily living included: helping with mobility, bathing, dressing, and toileting. Advanced tasks included: giving medication, managing oxygen delivery, gastrostomy tube care, suctioning or medical interpreting. We applied the stress process and transition conceptual framework in analyzing emergent themes from dialogue with sibling caregivers and parents.

**Conclusion:** Key beneficial elements of our hospital-based intervention program identified by participants included: structured family-based dialogue, stress management techniques, and a peer-support environment. Interventions that target both the parent and caregiving sibling, with the goal of strengthening family communication, enhancing sense of community and understanding, and nurturing coping repertoires may help promote sibling caregiver resilience.

**Keywords:** Caregiver; Sibling caregiver; Young caregiver; Caregiving youth

### Introduction

Caregiving youth are minors providing significant assistance to relatives or household members who have chronic physical or mental illnesses and disabilities [1]. Responsibilities range from assistance with activities of daily living to sophisticated tasks including medication administration, management of medical devices and interpretation at health care visits. "Invisibility" remains a pervasive issue among young caregivers as they rarely identify their role to others. There remains a lack of wide demographic or surveillance data on caregiving youth in the United States, with the largest study reporting a national prevalence of 1.4 million based on surveys among 2,000 households [2].

### Impact of the caregiving youth role

Similar to the experience of adult caregivers, children are at risk for long-lasting psychosocial impacts associated with caregiving. Unfortunately, the population of caregiving youth in the US is relatively under-recognized, under-studied and under-supported, with only 22 published peer-reviewed articles, compared to more than 2,000 in the adult caregiving literature [3-5]. Negative impacts of early

caregiving have previously been categorized in three primary areas: school performance, mental health and family relationships [3]. Carrying the physical and emotional burden of early caregiving can lead to parentification, and its effects may remain influential into adulthood [6]. Subsequent studies found that the parentified child suppresses and defers his/her own needs in order to meet those of a care recipient, compromising normal development and transition into adulthood [7-11].

### Objectives

A subset of the caregiving youth population are sibling caregivers, who in particular care for a brother or sister suffering with a chronic and/or complex medical condition, often without any formal training. This mixed methods study characterizes sibling caregivers of patients in an academic children's hospital, and offers a model for intervention. The aims of the study were to:

- Describe home-based responsibilities of sibling caregivers.
- Investigate sibling caregiver and parent experience through focus groups and caregiver workshop.
- Identify key themes of the sibling caregiver experience using qualitative analysis.
- Offer an intervention model for a hospital-based sibling caregiver support network.

## Methodology

Quantitative data on caregiver tasks were derived from the descriptive study while a two-part intervention comprised of a focus group and caregiver workshop formed the basis of qualitative data (Figure 1). Research was approved by the Children’s Hospital Los Angeles (CHLA) Institutional Review Board. Informed consent procedures, assents, and waivers for recording were implemented.

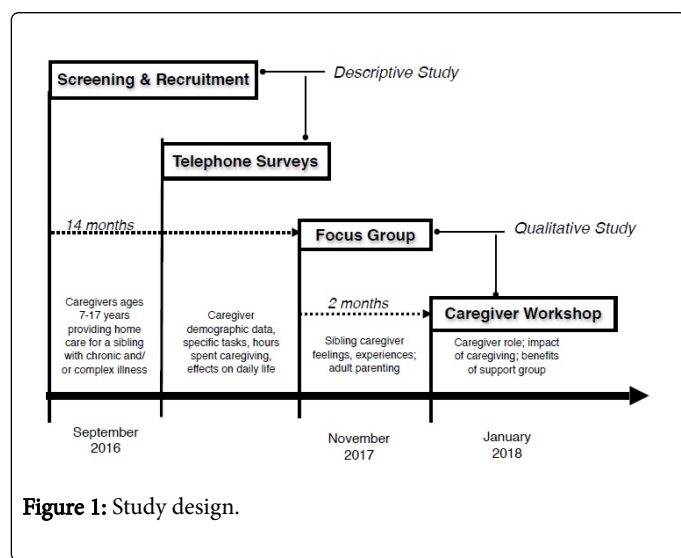


Figure 1: Study design.

### Identifying and recruiting caregiving youth

Recruitment took place from September 2016 through October 2017 in inpatient and outpatient sites of CHLA, a pediatric tertiary care center. Seventy families were screened via convenience sampling in clinics with a high incidence of children with medical complexity, including: spina bifida, complex care coordination, palliative care, and the inpatient complex care team. A physician and social worker research personnel integrated a two-question screening tool (Figure 2) into the standard patient home environment assessment. Exclusion criteria included 1) absence of a sibling in the home, and 2) sibling aged younger than 7 or older than 17 years of age.

- 1) Is there any child between age 7 to 18 years in the home?
- 2) Only if you answered YES: does that child help care for someone living in your home who needs special care because he/she is sick, has a disability or can no longer care for him/herself?

Figure 2: Caregiver screening tool.

### Descriptive study of caregiver responsibilities

Parents screening positive (those answering “yes” to both questions) consented to participate in a telephone-based scripted survey with the purpose of collecting quantitative data. A total of 21 caregivers in 16 different households participated. Parents were asked to self-report demographic information including family ethnicity, primary language spoken at home, as well as current family financial needs and the age

and diagnosis of the care recipient. Caregiving youth gave assent to participate and were asked about specific tasks performed at home, time spent caregiving and effects of caregiving on daily life. Telephone surveys and data collection were conducted by the project’s principal investigator, a physician with significant knowledge of caregiving youth.

### Focus groups

All telephone survey participants were invited to partake in a focus group, completed by nine sibling caregivers and six parents. Those siblings who did not participate either declined (3) or were unavailable (9) during the focus group. A facilitator’s focus group guide (Appendix A) was developed to better understand the feelings and experiences of sibling caregivers and to identify parenting beliefs and challenges in a household with sibling caregivers.

Parents and sibling caregivers were divided into two separate focus groups, each lasting two hours. Parent groups were conducted in both English and Spanish with an interpreter, and sibling groups in English. Two child psychologists facilitated the sibling caregiver focus group while a pediatric nurse facilitated the parent group. All facilitators were briefed in interviewing questions and exploring responses, including perceived challenges and rewards of caregiving.

### Caregiver workshop

A total of six sibling caregivers and four parents went on to participate in a three-hour-long caregiver workshop. Design of the workshop began with review and coding of focus group transcriptions to identify challenges shared by sibling caregivers and parents. These were encompassed by the following themes: 1) family communication; 2) caregiver role recognition; and 3) future plans for caregiving. The first half of the workshop was organized by alternating small (family-based) and large group-based dialogue exploring the above themes (Appendix B).

The second half of the workshop addressed home emergency preparedness and offered group yoga targeting stress reduction. Families completed written emergency communication plans and disaster checklists, including a guide to preparation of basic home supplies. A three-month follow up telephone survey was performed with these families to assess continued benefit from the intervention.

## Results

### Descriptive study

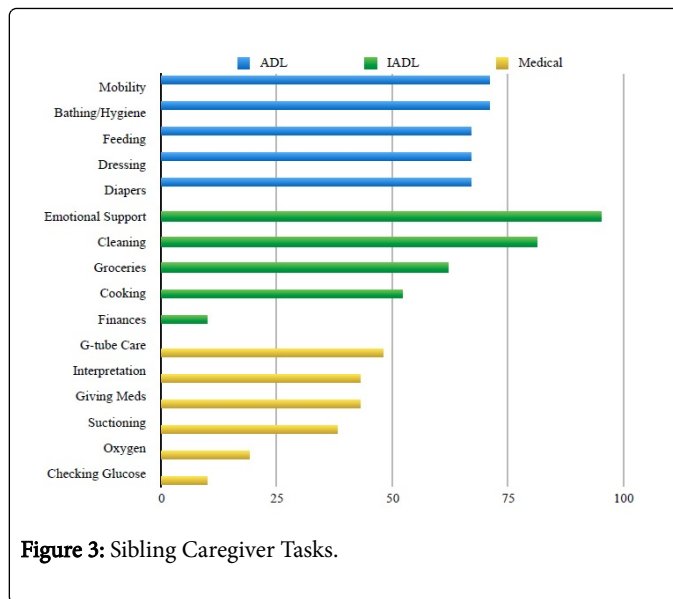
Sibling caregiver demographic information along with care recipient characteristics is displayed in Table 1. Regarding unmet financial needs among 16 surveyed households, four (25%) parents reported needing help with financial assistance, three (19%) with housing maintenance and two (13%) with employment.

Sibling Caregiver Characteristics	
Mean age in years	13 (9-17)
<b>Gender</b>	
Male	52%
Female	48%

Race/ethnicity	
Hispanic/Latino	67% (14)
Caucasian	23% (5)
African American	5% (1)
Other	5% (1)
Primary language spoken at home other than English	62% (13)
Number of siblings for whom child provides care	
1	90% (19)
2	10% (2)
<b>Care Recipient Characteristics</b>	
Mean age of care recipient sibling (range)	11 years (5 months-21 years)
<b>Primary diagnosis of care recipient sibling (N=17)</b>	
Spina bifida	29% (5)
Cerebral palsy	23% (4)
Autism	12% (2)
Mitochondrial disorder	12% (2)
Encephalopathy	6% (1)
Leukodystrophy	6% (1)
Extreme prematurity	6% (1)
Severe asthma	6% (1)

**Table 1:** Sibling caregiver demographics.

Siblings reported providing a mean of 2 hours of caregiving per day during weekdays and 4 hours of caregiving per day during both weekend days and summer recess. Figure 3 displays home-based caregiving tasks performed by siblings, arranged by frequency reported. The majority of caregivers performed various Activities of Daily Living (ADLs) and Independent Activities of Daily Living (IADLs). Two sibling caregivers (10%) reported using funds from a part-time job to help provide for household finances. Medical responsibilities included gastrostomy tube care (48%), interpretation at healthcare provider visits (43%), giving medications (43%), airway suctioning (38%), and managing an oxygen device (19%). Sixteen siblings (76%) reported regularly feeling worried about their brother or sister's health, on average 13 days per month. Six siblings (29%) reported missing at least one school day per month due to caregiving responsibilities.



**Figure 3:** Sibling Caregiver Tasks.

### Theme 1: The caregiver role

**Lack of recognition:** Sibling caregivers of all ages were concordant on their personal reservation in discussing their caregiving role with peers because of a perceived difficulty in peers' comprehension or stigmatization with potential for bullying. Multiple caregivers stated that they "had no need" to talk with others, citing that "it's not something they would understand."

**Caregiver perceived role:** Siblings commonly described their caregiving role as simply an extension of being a brother or sister. Conviction as a caregiver did not stop with caring for a sibling, but many described their role in alleviating parents' stress at home. Caregivers across age groups discussed their reservation toward special rewards for caregiving, rather discussing their service as "the right thing to do."

Reconciliation of future plans with caregiving responsibility. Sibling caregivers were generally in agreement that they envision themselves continuing to provide care during the next stage of their schooling or career. However, they seemed somewhat conflicted on how to continue providing in-home services while balancing future plans, a source of personal stress:

*I want to go out of state for college and my mom wants us to stay home because she needs a lot of help and it'd be difficult to not have one of her children with her. If I were to do what I wanted it might seem selfish. Who's going to take care of my brother?(16 year-old).*

**Shared stress:** Sibling caregivers were introduced into their role at home from a young age, often as young as five years. Parents elaborated on long-term approaches to raising their family by adapting to the needs of the child with chronic illness:

*The kids have learned that when their sister feels good, that's when we need to take advantage and go outside. We found that if we didn't give them something to do, they're going to break.*

During times of hospitalization, parents felt particularly divided amongst their children.

*Many times my son has expressed that 'Mom, I feel like you don't love me, because you spend too much time with my brother' and it's really hard to hear that from your son, right? I visit my son, but I cannot sleep at home knowing that my other son is in the hospital.*

## **Theme 2: impact of caregiving**

**Caregiving vigilance and effect on mobility:** Caregivers discussed stress due to the logistic difficulty of vacations and the long preparation time involved in regular commutes or leisurely activity. They also gave examples of sibling emergency events in the car, including choking. A younger caregiver expressed her discomfort around inviting friends to her home:

*My mom says that she wants to know my friends, but I think they're going to be a bit confused. I get scared if they might start playing with the machine belonging to my sister (11 year-old).*

**Guilt:** Nearly all sibling caregivers across various ages described experiences of feeling guilty during times of personal illness or injury. There was a strong desire to avoid bringing excessive attention to themselves at the perceived cost of taking attention away from their sibling, or adding to the parent's stress. For example:

*I just try to not let my mom notice or sometimes I might tell her I'm sick but not that sick. It kind of gets worse but then I hold it in (9 year-old).*

One teenager elaborated on what other caregivers had described in their own accounts:

*I feel like having a sibling who needs more attention requires us to become a little bit more independent than other people so I feel like it's common in all of us to try and take care of ourselves (16 year-old).*

**Parentification:** It was commonly noted that the child was the primary source of physical and emotional support in the household, often greater than a spouse or even a nurse. One mother noted the following of her eleven year-old daughter:

*She helps me in everything. I call her my little nurse. She's my other hand...and I might be tired or feel depressed and she says 'I'll do it. Don't worry, just take a break and sit down.'*

Parents in the room shared a similar respect and pride for their caregiving children.

*She's practically the biggest help that I have. I don't have a home nurse now, and I leave my child with my daughter. My child requires a ventilator and it's necessary to know how to suction him, how to change a trach, how to react in an emergency, but she learned all this on her own. These children are our angels, and all this has made us stronger.*

**Maturity:** Parents consistently identified maturity as a unique characteristic of the caregiving child. Even mothers of younger caregivers aged nine to eleven years of age shared a common remark in describing their child: "He doesn't think like a nine year old." Parents of older caregivers reflected on how their children became even more responsible and grew in unique ways when they helped their sibling. One thirteen year-old caregiver expressed his desire to get a job soon with a plan "to leave my mom with some money to help out with her needs."

**Empathy:** When asked about some of the rewards derived from caregiving, sibling caregivers as a group directly referred to empathy and compassion, drawing a contrast to non-caregiving peers:

*I like the open mindedness that I get from it. There are a lot of special kids at my school and with my friends I feel like they're not understanding or not accepting (14 year-old).*

Parents were also asked to reflect on some of the qualities they were most proud of in their caregiving child, and again empathy and compassion were identified.

*I'm very proud to hear him talk and some of the things he says in a way shows me that he's going to grow up to be a caring person, that he has good principles. He doesn't like other people suffering.*

## **Theme 3: benefits of caregiver support group**

**Recognition by peers and family:** Sibling caregivers of all age groups found recognition of their role as one of the most important features of the support group. A mother also reaffirmed the impact of simply recognizing the sibling caregiver, stating that "The program helped my son understand that what he's doing is not going unnoticed, that what he does for his brother is very important."

**Group support:** Prior to attending the workshop, no sibling caregivers had participated in activities specifically targeting their needs. At the end of the workshop, a seventeen year-old caregiver reflected:

*I think it's a good way for others to express how they feel and talk to somebody who could relate to them and have a little bit more moral support than when they're on their own, isolated from everybody it's like a moment of a little freedom.*

Parents also noted the importance of having a space to hear and relate to the experience of others, allowing the exchange of ideas and experiences. One mother expressed:

*I was able to relate with other parents and I realized that we had the same scenarios. Although the conditions of our kids might be different, we have the same questions, the same doubts, the same worries, the same concerns.*

**Improved family relationships and communication:** Parents reported that their children were able to "open up" about the personal impact of caregiving, while also reflecting on their own improved ability to express themselves with their children. Many sibling caregivers found that they were able to speak about their brother or sister's condition with their parents in ways they had not before.

**Stress management:** Caregivers discussed having a "different perspective" on their personal strengths as caregivers. Many children and parents felt yoga was an effective way to target and relieve stress. Providing prompts and structure to promote dialogue about specific issues between parent and the caregiving child were also regarded as sources of stress relief.

**Nurturing positive and protective values:** Gaining confidence in self-expression, communication skills, and empathy were cited by both sibling caregivers and parents as the most common values fortified by the intervention. For all, the focus group and workshop were the first types of environments that allowed them to process feelings and thoughts, to have questions answered and to normalize the caregiving experience with other similar individuals, all contributing to perceptions of enhanced coping.



### Three-month follow up survey

Participants who completed the caregiver workshop took part in a telephone survey three months later to assess continued benefit from the intervention. Sibling caregivers were asked about how the workshop may have affected their ability to manage challenges of caregiving and as well as their relationship with a parent, familial care recipient and/or health care providers. Commonly cited benefits included: continued utilization of self-calming techniques to combat stress, growing personal patience, and increased confidence in discussion of their caregiving role with peers, parents and medical providers. Parents were asked about how understanding of their child's caregiving role may have changed and how, if at all, the workshop may have affected communication with their children. Parents shared an improved awareness of the complexities and stressors of the sibling caregiver role including personal guilt, the child's conviction behind caregiving, and life balance challenges. Parents also reported an overall renewed outlook, with less stress and feeling more capable of encouraging their caregiving children. One parent commented: "My son plays a big role as a caregiver and it is very important for me to understand how he feels. This program gave me the tools to be able to talk and help my child as a caregiver to understand that he is loved and appreciated."

### Discussion

The responsibilities of caregiving youth are diverse, time intensive, and commonly without formal training, recognition or support. We present a descriptive study and hospital-based intervention model among sibling caregivers caring for individuals with chronic, complex medical conditions. Screening and recruitment were integrated into social work assessment of the home environment allowing a feasible strategy that may be replicated in other health care sites. Distinct from existing literature, this study expands the knowledge base of the context in which sibling caregiving occurs, offering both quantitative and qualitative data on caregiver advanced medical tasks and family participant data rather than focusing on the caregiver alone [12,13]. Findings from scripted surveys and focus groups demonstrate the complex interplay of positive and negative psychosocial effects of caregiving on a developing child. Furthermore, results of a caregiver workshop suggest that similar interventions may fortify sibling caregiver coping and resilience primarily by strengthening caregiver recognition, stress management, communication skills and family relationships.

We found a similar breadth of caregiving activities among a comparably aged population of 396 caregiving youth enrolled in the Florida-based American Association of Caregiving Youth (AACY) [1]. However, reported caregiving hours were greater during both weekdays and weekends in our population of sibling caregivers: compare median 2 hours and 3 hours to median 1.6 hours and 2.3 hours, respectively [14]. A key difference in the studies is the care recipient population: in the AACY study, care recipients were primarily adults. The actual reported frequency of each performed caregiving task is markedly higher in our population, which may reflect the complex needs of pediatric care recipients as well as the inherent differences in caring for a child instead of an adult.

The transition and stress process conceptual model may provide a framework to analyze the persistent hardship of caregiving as a challenge to the child's adaptive capacity [15]. Specifically, the concept of stress proliferation-whereby a chronic hardship leads to exposure of

secondary stressors-may be applied to mapping interactions between different types and sources of stressors [15]. A second concept called the out-of-sequence transition describes the risk of exposure to chronic hardships with the non-normative timing of transition into or out of a role [15]. Its application may further the understanding of a caregiving child's coping mechanisms, particularly in the absence of peer role recognition. Analysis of the sibling caregiver in the context of the above concepts may contribute to an effort in designing targeted, proactive interventions among this vulnerable population.

Caregiving-related stress may not simply be derived from the physical or emotional challenges of caring for an ill brother or sister, but may be strongly influenced by parental sources of chronic stress as well. Since the sibling and parent are conjointly tied in the role set of caregiver, the parent's lifetime hardship itself may lead to secondary stressors (or stress proliferation) in the sibling caregiver and vice versa [16]. In our cohort, especially among adolescents, we found that parental fear of medical emergency and dependence on their caregiving child's assistance limited their comfort with travel or even allowing their adolescent child time away from home. This stress in turn may influence sibling caregiver guilt around aspirations to leave home for education, play or work, or perhaps deprive them of opportunities to build the skills necessary to do so.

Commonly, the child's conviction behind caregiving was tied to both their sibling's health and easing parental stress. This was evident in pre-adolescent caregivers' reports of preoccupation with performing age-inappropriate caregiving tasks, such as lifting. Similar behavior has been described as parentification, leading to circumstances in which a caregiving child may suppress his or her own needs to satisfy those of a family member [7]. However, understanding the source of parentification as a caregiver role set between parent and the caregiving child may challenge the notion that parentification itself is simply a reversal of roles within the family system [17]. Rather, there may be a process of shared caregiving, where the child's caregiving experience appears to be both preceded and shaped by the parent caregiving experience. Additionally, social factors such as limited home resources likely influence the development of caregiving roles within the family system. Population data derived from the first study on caregiving youth prevalence in the US found that they are more likely to come from single parent low income households compared to non-caregivers [2].

The hardship created by early transition into a caregiving role-the unexpected career-is a process outside the child's control that may lead to personal maladaptive coping [18,19]. Siblings in our sample discussed strong convictions of their role as caregivers and as siblings being inseparable, creating a scenario in which children commonly anchored the aspiration of a "good brother" or "good sister" to first being a good caregiver. This perspective was reinforced by multiple parents' reference to their caregiving child as "little nurse." Ascribing a conjoint value to sibling and caregiver incurred exposure to personal distress when the role of caregiver conflicted with the desire to participate in activities away from home. In the literature, early caregiving itself has been associated with difficulty in establishing a separate and authentic sense of self in adult relationships and work [7,20]. For pre-adolescent caregivers, career plans were framed in ways that would allow or even integrate simultaneous caregiving. A strong intent for future caregiving was also demonstrated in a survey of 108 young adult caregivers of siblings with autism [21]. Guilt was described by both younger and older caregivers in times of personal illness or injury as many sought to avoid bringing attention to themselves at the

cost of their chronically ill sibling. Lastly, fearing stigmatization by peers, many caregivers completely avoided discussing their role with others at school. The long-term effects of such maladaptive coping may include social isolation, altered aspirations, and personal physical and mental health impacts, in addition to economic hardship [4].

This study had a number of limitations inherent in its study design. First, study recruitment occurred through convenience sampling in targeted outpatient and inpatient hospital sites. Due to the nature of the study, no control population was recruited. A small sample size may limit the generalizability of the study's findings. Participation rates in the caregiver focus group and workshop were less than half of the total recruited sample. During the intervention, participant responses may have been influenced by the presence of medical professional facilitators and audio recording instrumentation, as well as other peers and families. Additional studies are needed to expand screening sites to additional healthcare sites and/or schools, assess the efficacy of longitudinal support groups, and to apply validated tools for mental health assessment prior to and following interventions.

## Conclusions

Based on the findings of our descriptive study and focus groups, sibling caregiver interventions may benefit from targeting both the parent and caregiving youth rather than the child alone (the stress proliferation and role set), as well as caregiver coping repertoires (the out-of-sequence transition). While there is no standardized model for intervention, key beneficial elements in our program identified by participants included: strengthening family relationships and communication through structured family-based and group-based dialogue; targeting stress management techniques with yoga and meditation; and creating a peer-support environment that both normalized their mutual experiences and nurtured positive values of caregiving, including empathy and maturity. The benefits of a hospital-based screening and support model may include a theoretically higher prevalence of sibling caregivers compared to the general population, assembly of a cohort of caregivers with similar caregiving experience, and adaptation of psychosocial support resources already in place in the hospital or institution. Screening and intervention in this environment may lead to sustained support group opportunities that promote and mentor caregiver resilience skills.

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## Conflict of Interest

The authors report no conflict of interests.

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