Siblings’ Experience of a Childhood Severe Illness Diagnosis: An Empirical Study

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Abstract: Siblings of children with a severe illness diagnosis experience childhood differently than their same-age peers. The purpose of this study was to explore and describe an adult’s understanding of their childhood experiences when their sibling was diagnosed with a severe illness. In prior studies, researchers engaged proxies, such as parents, to express the experience of the siblings living with an ill child. Few researchers waited until the siblings matured to adulthood to assess the impact on their lives. The sibling’s voice is needed to illuminate their unique experience. Findings from this study may help healthcare providers, social workers, and educators support siblings of ill children.

Keywords: sibling, childhood illness, development, adjustment, family system

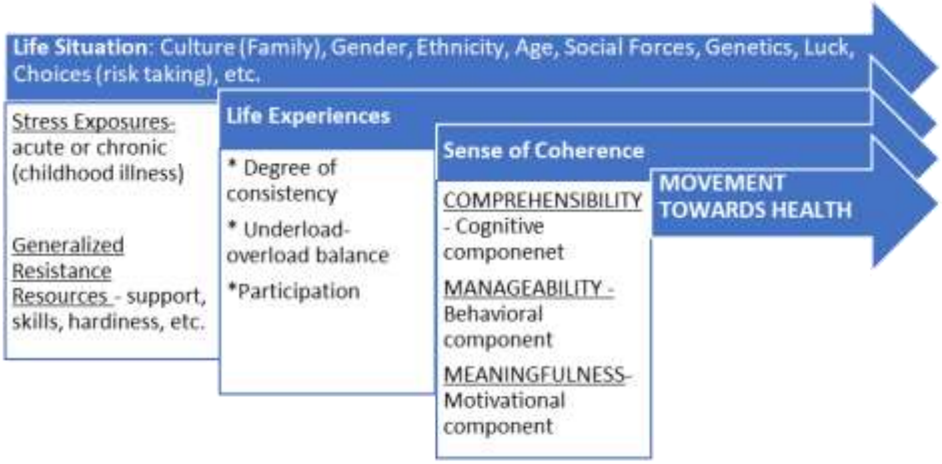
A childhood severe illness diagnosis impacts the entire family, yet siblings end up in the shadow that is created by the necessary and immediate focus on medical treatment for the ill child as well as keeping the parents medically informed (Heaton et al., 2022). “Sibling relationships are one of the most long-lasting and influential relationships in a human’s life” (Tay et al., 2022, p. 517). Siblings’ experience of a severe childhood illness has been primarily explored without directly talking to them. Consequently, conclusions drawn from existing data often include the perspective of parents, teachers, and healthcare professionals. Although useful, an adult bystander perspective does not adequately describe the healthy sibling’s experience.

Studies have assessed the experience of a severe illness from an ill child’s perspective (Clark, 2003; Nabors & Liddle, 2017) and reported the impact of childhood illness on family members in general (Patterson et al., 2003). Few published research studies specifically describe the effect of severe illness on an ill child’s siblings. Of these studies, most did not wait until the sibling had matured to adulthood for them to be interviewed. Most studies used surveys, questionnaires, or interviews with a proxy, such as a parent, to assess the sibling’s experience (Patterson et al., 2003). The purpose of this study is to explore and describe an adult’s understanding of their childhood experiences when their sibling was diagnosed with a severe illness. We spoke directly to the siblings and shared their voices in our findings.

Literature Review

We framed this research using Bowen’s Family Systems Theory (BFST) (Calatrava et al., 2021), the concept of salutogenesis, and a model of health (Antonovsky, 1979). Sociologist Antonovsky created the Salutogenic Model of Health (SMH) (Fig. 1) to understand why some people experience illness and others have good health after exposure to the same pathogenic agent or life stressor (Benz et al., 2014, p. 17). A core concept of the salutogenic model is Sense of Coherence (SOC), a disposition that makes some people more resilient when faced with life stressors (2014). Differentiation of Self (DoS) is the core concept in Family Systems Theory; it suggests that some people are better able to remain objective in the presence of intense family stress (Calatrava et al., 2021).

Figure 1. *Modified salutogenic model, based on Antonovsky (1979)*



Fleary and Heffer (2013) explored the effect of living with a sibling who was ill during childhood on healthy children's functioning during late adolescence (18-21 years old). They found that there are adverse psychological effects experienced by a healthy child when exposed to an ill sibling growing up. Knecht et al. (2015) conducted a comprehensive literature review aimed at gaining a broad overview of research related to siblings' life experiences with a childhood illness diagnosis and concluded that most available data on siblings' perspectives comes from a proxy and not directly from the siblings. The authors recommended further research concentrate solely on the siblings' perspective. Sibling's experience of a childhood severe illness diagnosis has been primarily conducted without directly talking with the affected sibling. In studies where the siblings were asked to self-report either by completing a questionnaire or in the setting of a focus group or a play interview, the data collected differed from that provided by their proxy (Lummer-Aikey & Goldstein, 2021).

Methodology

We explored how siblings of a child with a severe illness experienced events that unfolded during the diagnosis, treatments, and the years that followed using a descriptive narrative approach, specifically interpretive description (ID). According to Connelly and Clandinin (1990), "The study of narrative is the study of ways humans experience the world" (p. 2). As the data was collected, narrative inquiry allowed for emerging aspects of the study design (Bruce et al., 2016).

The primary researcher received IRB approval before recruiting the participants using purposeful convenience sampling. All participants were adults at least eighteen years old who were children when their child sibling received a severe illness diagnosis. We contacted previous beneficiaries of an annual event that raises awareness of severe childhood illness called Jacey's Race (Lawson & Scott, 2022) by email to participate in the study. The first five respondents who met the selection criteria were interviewed using a semi-structured interview format. The five participants interviewed represented four families, all identified as female and ranging in age from 19 to 30 years. The severe illnesses represented were cancer (2) and congenital malformation (2). Data analysis was iterative, using constant comparison and thematic analysis to analyze the data looking for core narratives and themes across all transcripts. The data was classified inductively using the integrated code structure described by Dr. Leslie Curry and others (Bradley et al., 2007).

The ID methodological framework was used to examine the subjective experience of siblings of children with a severe illness to identify themes and patterns among the siblings' subjective perspectives and recognize variations between individuals. "ID is grounded in an interpretive orientation that acknowledges the constructed and contextual nature of human experience" (Burdine et al., 2021). The interviews lasted up to sixty minutes and were conducted virtually over Zoom. Researchers used Otterai to transcription the audio recordings verbatim. All identifying information was removed from the transcripts, and each participant was assigned a unique pseudonym. Individual codes were collected on a cumulative Excel sheet where themes, categories, and narrative blocks were identified. The cumulative Excel code sheet was additionally color-coded. The five themes or narrative blocks identified in this study are: shrinking safety net- lack of attention and missing parents, developmentally inappropriate roles - contributing to confusion/fear, children are still human- helpful and unhelpful adult behaviors, sense of support- the importance of choosing a compassionate response and, tune into humanity- awareness of personal challenges relative to other humans.

Findings

As noted above, five themes emerged from our data worth in-depth discussion: shrinking safety net, developmentally inappropriate roles, children still being human, sense of support, and tune into humanity.

Shrinking Safety Net- Lack of Attention and Missing Parents

Adults were understandably distracted by necessities brought on by their child's severe illness. The disruption of family routines contributed to the children feeling anxiety. Max stated, "We were very stressed and trying to put pieces together on our own." Avery revealed that because the family was at the doctor's office so much for one child's illness, their own diagnosis was delayed because neither the parents nor the medical staff was focused on the healthy sibling. All their attention was focused on the already identified ill child. Avery said, "I thought it was just normal to be going to the doctors all the time." Cameron expressed anxiety about knowing the adults were keeping information to themselves, "There was just a lot of fearfulness in the unknown. What was happening?" All participants acknowledged the seriousness of their sibling's diagnosis and could identify specific times in their lives when a childhood illness in the household made life more stressful.

Developmentally Inappropriate Roles- Contributing to Confusion/Fear

The first narrative block identified was confusion/fear, which led to the synthesis of the theme of developmentally inappropriate roles. Max confided, "We would try to help out more. I would go put the baby to bed and stuff like that." One of the siblings was the oldest in the family and, at eight years old, was responsible for preparing meals for their father and other siblings when their mother was at the hospital with their ill sister.

Children are Still Human – Helpful vs Unhelpful Adult Behaviors

Grandparents and other family members were identified as helpful. Max stated, "I remember my dad's parents, my grandparents. When [my sibling] was having surgery, and we flew to a different state for the surgery, they came over to hang out with us while he was in surgery, and my parents were busy." "I think when my grandparents [arrived, I knew] that they would be there to help me through this," explained Cameron. The community was also seen as supportive, "In our church, some members would bring us meals that they had made, which was helpful," recalled Carter of her memory of the experience. Avery stated, "There were a lot of people in our community willing to step up and help."

The participants felt that the travel time to treatments or hospital visits was not helpful. Max stated *We moved. We still lived about 45 minutes to an hour away from the hospital where my brother was.* Carter recognized that the negative of the hospital travel distance was lessened by having a nice place for the family to stay (Ronald McDonald House) when they needed to be close to the hospital. Other negative experiences included the absence of both parents, expressed by Carter, *That was the first time I had been away from my parents in my life*. The absence of one or both parents may have influenced the participants' statements surrounding the desire for more attention during their sibling's illness. *I think we felt like we were being emotionally neglected at some point, just because all of the attention was always on him*, was reflected by Max and shared by Cameron, who said, *I think I definitely rebelled and for reasons why I don't fully know but maybe it was to get attention or have more spotlight on myself even though it wasn't the kind of spotlight I would want*.

Sense of Support- Importance of Choosing a Compassionate Response

Mothers were seen as a universal source of support in this cohort of participants. Cameron stated, "I think it was definitely the support of my mom and her closest friends and relatives." Carter shared,

> *Because my mom is a physical therapist, she has a stethoscope. She would put it on my sister's heart. We would hear how it made a whooshing noise. It was different from my heartbeat and my mom's heartbeat. Therefore, it didn't feel scary to me. It was more just like, oh, this is interesting. This is like a fun fact.*

Additionally, three participants identified the dad's role as supportive. *I think my dad kind of explained it to me and my siblings*, Max recalled. Atlas remembers her dad intervening after she purchased a large bag of candy to help her sister gain weight, *and then my dad had to be like, hey, this is cool and everything, but this isn't for us. We need her to be a certain weight so that the surgery can go well*. Another type of support was identified through camp experiences. Summer camps designed to include other family members in addition to the ill child were described by Cameron and Avery as supportive, safe places to be and to express feelings.

Tune into Humanity- Awareness of Personal Challenges Relative to Other Humans

Participants gained a broader perspective. Again, Max shares, *Raise the siblings to [understand that] it can be exhausting for your siblings to always stand up for themselves. So, if you see someone like that, step in, show them, and teach them. Don't be cruel but educate them*. All participants expressed gratitude for the people who entered their lives because of their sibling's illness and greater empathy after their experience. Carter shared, *I think maybe the main thing is, it's made me more understanding of other people who have illnesses or a family with a major illness.* Avery conveyed, *I think that it also helps me to be a more compassionate nurse and know what people are going through. You see them in the hospital all the time.*

An unexpected finding was that many of the participants developed a severe illness themselves before the age of twenty-five. They recognized that their experience of living with an ill sibling influenced how they approached and managed their own illness.

Discussion

The study results indicate an impact on siblings when a child is diagnosed with a severe illness and build on previous work describing siblings' experiences in a family with a severe childhood illness diagnosis. Cancer is the primary severe illness studied in most research on siblings and childhood illnesses. A scoping review by Tay et al. (2022) acknowledged that of the studies they evaluated, approximately 30% explored self-reported experiences of siblings of children with a non-cancer diagnosis. In the study described in this paper, 50% of the severe illness diagnoses were non-cancerous. Another design element unique to this study is that the researcher asked the siblings interview questions after an expansion of time since diagnosis, allowing them to express their childhood experiences from their adult perspective.

Siblings of children with any severe illness must learn to manage stressors like the disruption of daily routine, physical changes in their ill sibling, fear of the unknown, and parental expressions of anxiety. Tay et al. (2022) suggested that additional research is still needed to gain more insight into the causes of distress expressed by siblings of children with severe illness. The current study helps to answer this call for more data by identifying confusion and fear as contributing factors to a sibling's distress. The suffering felt by healthy siblings in the absence of one or both parents created a need for additional attention and a perceived disparity of attention received between the healthy and ill siblings, as supported in the current literature (Hanvey et al., 2022).

A helpful behavior identified in this study and described by Moon et al. (2021) is treating each child in the family as unique. Moon et al. (2021) recommended that healthcare providers support the differentiation and individual identities of the child with severe illness and their siblings. "The difference between siblings can be considered meaningful" (p. 7). Inconsistent with the results from this study, Moon et al. (2021) also reported that sibling rivalry scores increased as the siblings aged and were associated with aggressive and coercive behavior. The participants in this study categorically expressed deep love and admiration for their ill siblings, presumably because maturation to adulthood allowed them to tune into humanity in a way that the children and adolescents interviewed in the Moon et al. study were not yet able to.

All but one participant developed what could be described as a severe illness before the age of 25. This finding was unexpected and should be explored in future studies. The additional knowledge gained from this study could lead to better systems for mitigating the negative impact of the disease on the siblings and more positive psychosocial outcomes for the entire family. Therefore, based on the results of this study, adults interacting with families with a child with a severe illness diagnosis need to engage directly with the siblings in the family to alleviate confusion by assessing their understanding of the diagnosis and answering any questions they have without inflaming fear. They also need to evaluate the support systems available for each unique family member, ensure that they are adequate, and increase awareness for potential significant illnesses occurring in siblings.

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