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RESEARCH

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Redefining closeness: Family resilience after sibling loss among individuals who had siblings with disabilities

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ABSTRACT

Objective: This qualitative study examined the experiences of individuals who had lost a sibling with a disability through a family resilience framework.

Background: Sibling relationships in families of individuals with disabilities are complex, with siblings often assuming caregiving roles and experiencing emotional strain. Yet, there has been very little research on sibling relationships when the death of a brother or sister with a disability occurs.

Methods: Forty-five individuals who had lost a sibling with a disability were interviewed. Participants were predominantly from the United States (n = 38), with seven international participants from six continents. Most identified as White/European (n = 39), having lost brothers (n = 23), sisters (n = 20), or multiple siblings (n = 2).

Results: Analysis revealed three primary themes: emphasizing adaptive changes, emotional coping mechanisms, and support networks. Participant narratives aligned with family resilience processes across three domains: belief systems, organizational processes, and communication and problem-solving processes.

Conclusion: The findings highlight the unique dynamics of post-loss sibling relationships in this context and demonstrate how families reconstruct their identities and relationships following such a significant loss.

Implications or Recommendations: Practitioners should recognize the complex grief experiences unique to losing a sibling with a disability and provide tailored support addressing adaptive changes, emotional coping needs, and support networks.

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KEYWORDS
caregiving; grief, loss, and bereavement; resilience; sibling relationships; stress and coping

Sibling relationships are fundamental to family life, shaping individual identity and contributing to emotional development. For families with children who have disabilities, these relationships often carry additional layers of complexity. Siblings may take on caregiving roles, adapt to shifts in parental attention, and shoulder significant emotional and practical responsibilities. These unique dynamics can be both enriching and challenging, setting these relationships apart from those in families without disabilities.

Siblings of people with disabilities experience a range of emotions and responsibilities that influence their perception of family life. A recent systematic review found that siblings view their family's quality of life as a mix of fulfilling and demanding experiences, although their perspectives are frequently overlooked in broader discussions (Múries-Cantán et al., 2022). Similarly, Hanvey et al. (2022) described siblings of individuals with disabilities as "hidden family members," highlighting their feelings of invisibility and emotional strain. These findings emphasize the importance of examining sibling experiences to better understand the dynamics of families with children who have disabilities.

The loss of a sibling with disabilities introduces profound changes to family life. Critchley et al. (2021) observed that in families with children on the autism spectrum, caregiving responsibilities often define roles and relationships. When a sibling passes away, families must grapple with grief while adjusting to an altered dynamic. Herberman Mash et al. (2013) noted that grief in these situations is often intensified by the depth of the sibling bond, leading to unresolved emotions and heightened psychological challenges. Sveen et al. (2014) further highlighted the role of support systems in helping families process such losses and rebuild their lives.

Much of the existing literature focuses on parental perspectives, with limited attention given to siblings. Studies such as Rossetti and Hall (2015) and Seltzer et al. (2001) underscore the need to explore how siblings process grief and adapt their roles within the family after a loss. Additionally, there is little research on how cultural and developmental factors shape resilience. Addressing these gaps is crucial for creating interventions that recognize and support the unique contributions and needs of siblings in these families. This research aimed to understand how families adapt, recover, and grow by focusing on how these processes manifest after the loss of a sibling with disabilities. The study also incorporates cultural and developmental perspectives, recognizing how these factors influence family resilience across diverse contexts.

INDIVIDUALS OF SIBLINGS WITH DISABILITIES AND FAMILY DYNAMICS

Presence of a child with disabilities within a family system often restructures roles and expectations among siblings, contributing to distinctive relational patterns before loss. Siblings of individuals with disabilities often grow up in environments shaped by heightened caregiving responsibilities and unique family dynamics. These roles can foster empathy, maturity, and a strong sense of purpose. However, they can also lead to emotional strain and feelings of neglect. Hanvey et al. (2022) noted that siblings often feel unseen in their contributions to the family, with societal and familial recognition primarily focused on the child with disabilities. These siblings often internalize caregiving responsibilities, emotional regulation, and family cohesion expectations. Despite these challenges, many siblings exhibit remarkable resilience, becoming pivotal emotional and practical supports within their families. Múries-Cantán et al. (2022)

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pointed out that these siblings frequently balance positive and challenging experiences, reflecting the complex nature of their roles within the family. Research by Bowman et al. (2017) underscores the duality of these experiences, where siblings reported both pride in their caregiving roles and the burden of increased responsibilities.

Positive meaning-making, as explored by Bayat (2007), can help siblings navigate these challenges by fostering a sense of purpose and connection. The importance of tailored interventions is evident, as highlighted by Hartling et al. (2014). Structured support systems, including counseling and peer networks, can alleviate emotional stress and equip siblings with tools to navigate their unique roles effectively. These findings emphasize the need to integrate the experiences of siblings into broader family support frameworks, ensuring their contributions and challenges are recognized and addressed.

The American Psychological Association (2020) has emphasized that meaning-making and access to social support networks are critical in processing grief and maintaining resilience after sibling loss. Despite growing awareness of bereavement in family contexts, limited research has focused on the specific challenges and adaptive processes experienced by families of individuals with disabilities. Understanding the role of siblings within the broader caregiving system is essential for comprehending how loss reverberates through the family dynamic.

IMPACT OF THE LOSS ON FAMILY DYNAMICS

The loss of a sibling with a disability profoundly affects family dynamics, often disrupting established roles and routines. Families face the dual challenge of processing their grief while restructuring responsibilities and relationships. These changes often require surviving family members navigate complex shifts in roles, responsibilities, and relationships (Keser & Işıklı, 2022; Rostila et al., 2012; Stroebe & Schut, 1999; Walsh, 2007). Shifts in relationships may be especially pronounced when the deceased sibling required significant care due to their disability.

The grief experienced by surviving siblings is often compounded by the intense emotional bonds they shared with their deceased sibling. Research by Herberman Mash et al. (2013) highlights the heightened risk of complicated grief, depression, and anxiety among siblings, particularly when the deceased sibling had disabilities. Parents, too, may struggle with their grief, sometimes unintentionally neglecting the emotional needs of surviving siblings. This can lead to feelings of isolation and guilt, as surviving siblings may suppress their grief to avoid burdening their parents further (Sveen et al., 2014). Furthermore, the grief of surviving siblings, particularly when the deceased sibling had a disability, can often be characterized as "disenfranchised grief"—a loss that is not openly acknowledged, publicly mourned, or socially supported (Doka, 1999). This lack of validation can compound feelings of isolation and complicate the grieving process, a challenge this study seeks to explore.

The grief experienced by surviving siblings is not only intense but can also have profound long-term developmental consequences. Foundational work by Fanos (1996) shows how losing a sibling with a disability shapes the survivor's identity and relationships over their entire life course. A key adaptive process in this experience is the formation of "continuing bonds," where siblings actively preserve a psychological connection to the deceased through memories and rituals (Packman et al., 2006). This integration of the deceased sibling's presence is central to understanding post-loss family adjustment.

The loss of a sibling often disrupts family communication. Families may find it difficult to discuss their grief openly, leading to misunderstandings and emotional distancing (Bosticco & Thompson, 2005; Cacciatore et al., 2021). On the other hand, some families report that shared grief fosters deeper emotional connections and strengthens communication, as they rely on each other for support. Open discussions about the sibling's life and legacy can serve as a unifying

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force, promoting resilience and healing. Over time, the loss can influence family cohesion in different ways. In some families, the shared experience of grief and the memory of the deceased sibling become central to their identity, fostering a sense of unity. For others, however, unresolved grief and the absence of adaptive coping mechanisms can lead to strained relationships and emotional fragmentation (Burke & Neimeyer, 2013; Lobb et al., 2010; Walsh & McGoldrick, 2013).

Cultural context also plays a significant role in shaping how families adapt to sibling loss. Cacciatore and DeFrain (2015) emphasized that cultural norms surrounding grief, mourning practices, and expressions of emotional pain critically affect how families process such loss. Similarly, Rosenblatt (2017) underscored the importance of attending to cultural diversity in bereavement responses, noting that what constitutes resilience or appropriate grieving is deeply shaped by sociocultural frameworks. This broader context underscores the importance of analyzing family resilience through ecological and culturally sensitive lenses. A study by Seake-Kwawu (2020) addressed the idea that families from collectivist cultures may draw strength from extended networks of relatives and community members, while those in individualistic cultures may rely more heavily on formal support systems. Stigma surrounding disability can also influence help-seeking behaviors and the mobilization of resources differently across cultures (Kayama et al., 2020). Understanding these cultural nuances is essential for developing interventions that address the specific needs of bereaved families (Cacciatore & DeFrain, 2015; Rosenblatt, 2017).

PROCESSES OF FAMILY RESILIENCE AMONG FAMILIES OF INDIVIDUALS WITH DISABILITIES

Family resilience refers to the ability to adapt and thrive in the face of adversity. For families of individuals with disabilities, resilience involves not only managing everyday challenges but also recovering from significant disruptions, such as the loss of a family member. Patterson (2002) emphasized resilience as both a process and an outcome, shaped by the family's ability to adapt through shared emotional expression, problem-solving, and connection. Bayat (2007) identified factors such as family cohesion, resource mobilization, and positive meaning-making as central to fostering resilience. These elements are particularly important for families navigating the loss of a sibling with disabilities because they provide a foundation for understanding and responding to profound emotional and structural changes.

The role of open communication is central to this process, as it is the primary vehicle through which families co-construct meaning from their experience of adversity. As Nadeau (1998) described, families engage in collaborative storytelling to create shared narratives that explain the death and redefine their identity. This process reflects a core principle of the family systems perspective: that loss is a family-wide transition requiring the renegotiation of roles and relationships across the life cycle (Walsh & McGoldrick, 2013).

Resilience in these families must also be understood within a unique life course context. Longitudinal research shows that sibling relationships in families affected by disability evolve into adulthood with high levels of closeness and lifelong caregiving commitments, with non-disabled siblings often central to future planning (Greenberg et al., 1999; Orsmond & Seltzer, 2007). Therefore, the death of a sibling with a disability is profoundly disruptive, representing not just a personal loss but the collapse of an established caregiving system and a core part of the survivor's identity.

Without adequate support, feelings of isolation and helplessness can compound the emotional burden of loss. The reorganization of a family can strain familial relationships, particularly when grieving individuals struggle to communicate or align their coping strategies. Shared rituals and traditions often serve as anchors during periods of adjustment, however, helping

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families honor the memory of the lost sibling while reinforcing their connections (Caldwell et al., 2018). Open communication can foster resilience, enabling families to navigate these challenges together (Bayat, 2007; Bosticco & Thompson, 2005; Cacciatore et al., 2021). Empowerment, the active engagement of families in decision-making and resource management, also plays a critical role in resilience, enabling families to regain a sense of control and purpose.

External support systems, including professional counseling, community groups, and educational resources, are essential for resilience-building. Rosanblatt (2017) and Sharp et al. (2020) highlighted the importance of culturally tailored interventions that address the unique needs of families. By recognizing and supporting the specific roles siblings play within the family, these interventions can enhance the family's overall capacity for resilience.

CONCEPTUAL FRAMEWORK

To provide a more comprehensive understanding of family resilience, this study incorporates an ecological systems perspective (Bronfenbrenner, 1979). Grounded in Bronfenbrenner's ecological model, this approach conceptualizes the family as embedded within multiple interrelated systems from the individual and family levels to community and sociocultural contexts. These layers interact dynamically and influence how families respond to adversity, including the death of a sibling with disabilities (Cheng et al., 2024; Tang et al., 2023; Walsh, 2016). Recent research emphasizes that family resilience is a function not only of internal dynamics but also of external environmental supports, such as extended family, community networks, and accessible services (Tang et al., 2023). A systemic-ecological perspective helps capture how families mobilize resources beyond the immediate household to cope with the death of a sibling with disabilities.

This ecological framing is complemented by Walsh's family resilience model, which emphasizes belief systems, organizational patterns, and communication processes that enable positive adaptation in times of stress (Walsh, 2016a, 2016b). Together, these frameworks situate resilience as both a product of internal family processes and contextual influences. Grounded in systems theory, family resilience emphasizes the interdependence of family members and can explain how the entire family unit is influenced by serious crises, including the loss of a sibling with disabilities (Walsh, 2003, 2016b). Family resilience is supported by three key processes: belief systems, organizational processes, and communication (Walsh, 2016b).

Belief systems help families find meaning in adversity, maintain a positive outlook, and connect to a larger purpose. Organizational processes include flexibility within a family system, connectedness and mutual support, and mobilizing external support and resources to help families adapt in difficult situations. Communication or problem-solving processes encompass open emotional sharing through clear communication and collaboration to support families in recovering and experiencing growth from serious life challenges. Transactional processes within the family, such as shared coping strategies, emotional support, and proactive problem-solving, are critical in determining effective family functioning and positive adaptation (Walsh 2016a, 2016b). The family's approach to crises plays a critical role in determining whether the family system rebounds and grows stronger or dysfunction is created. By exploring changes in their family dynamics, belief systems, and communication patterns after the loss, the current research aims to provide a deeper understanding of how individuals of a sibling with disabilities adapt and reestablish their relationships and roles to be more capable in the process of grieving.

A developmental perspective further enriches the understanding of family resilience by considering the lasting impact of losing a sibling with disabilities that affect individuals and family processes at different stages of their life cycle (Walsh, 2016b). This insight can guide interventions and support mechanisms to help these individuals and families navigate their grief and maintain healthy dynamics.

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By combining these theoretical lenses, this study moves beyond static understandings of adaptation to highlight how families actively negotiate challenges and reconstruct meaning following the death of a sibling with disabilities. This integrated perspective allows for a deeper examination of the reciprocal interactions between family systems and the sociocultural environments in which they are embedded.

THE CURRENT STUDY

Individuals of siblings with disabilities face a distinct grieving process that may differ from those who lose typically developing siblings as they often play a critical role in the lives of their brothers or sisters with disabilities, such as caregivers, guardians, and another active role (Coyle et al., 2014; Dorsman et al., 2024). Although much research has been conducted on the experiences and perspectives of parents, the voices of siblings remain underrepresented, and many experience feelings of isolation and guilt, and misunderstanding (Rossetti & Hall, 2015; Seltzer et al., 2005). In addition, the loss of a sibling with disabilities can lead to significant changes in family dynamics and relationships (Funk et al., 2018; Sharp et al., 2020). Existing literature highlights the importance of family resilience and adaptive processes in situations of adversity (Walsh, 2016). There is limited research specifically on how family functioning and the roles of family members change, however. To address the gaps in the literature, this study began with the following research question: How do individuals with a sibling who had disabilities experience family resilience after the loss of their sibling? Exploring changes in family dynamics, the meanings of the loss, and emotional sharing within the family can provide insights into the specific needs of individuals who have lost their siblings with disabilities, thereby facilitating the development of more inclusive support mechanisms for them.

METHODS

Participants

Participants were recruited via three social media groups made up of siblings of people who have disabilities. The social media group sizes ranged from approximately 150 to more than 6,000. Two of the groups are affiliated with a large nonprofit that supports siblings of people with disabilities. The third and much smaller group was a spinoff group specific to siblings whose brothers or sisters had died. Research flyers were distributed twice in each group, and potential participants were asked to call or email the principal investigator if they were interested in participating. Inclusion criteria included (a) having lost a brother or sister to death, (b) the brother or sister who died had a disability either from birth or acquired later, and (c) any type of sibling relationship (e.g., biological, step, adoptive). Additionally, participants needed to be over age 18 years at the time of the interview and able to speak English for participation in the interview. If the potential participant met the criteria for study, an electronic consent from was sent via SoftDocs. During the later part of the study, the researchers also conducted some word-of-mouth snowball sampling to increase the diversity in the sample by recruiting more men to participate.

Forty-five individuals who have lost their siblings with disabilities participated in the study: 40 women and five men. Table 1 presents the participants' demographics and basic information about the nature of their brothers' and sisters' diagnoses related to disabilities. Names in Table 1 are pseudonyms. Their ages ranged from 23 to 74. Thirty-eight participants resided in the United States, while the remaining seven were from Argentina, Australia, Canada, Italy, Ireland, Kenya, and Sweden. Thirty-nine participants identified as White/European, three were Africans, one was Latina, and two did not disclose their races. Twenty-three of the participants

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TABLE 1 Participant demographics.

Pseudonym	Part. gender	Part. race	Part. age	Sibling age @ death	US Region or Country	Sibling diagnoses
Alex	F	White	<30	12	Northeastern US	Autism, seizures
Alicia	F	White	30–39	38	Northeastern US	CP, heart defect, ID
Ashley	F	White	<30	18	Northeastern US	CP
Annie	F	White	30–39	32	Midwestern US	ADHD, LD, heart defects
Alexis	F	White	40–49	12	Western US	Hemiplegic CP
Alexandra	F	White	50–59	48	Italy	Muscular dystrophy
Beth	F	White	50–59	55	Western US	Down syndrome with Alzheimer disease
Benjamin	M	African	<30	19	US immigrant from Africa	Blindness
Bella	F	White	30–39	32	Western US	Cognitive impairment unknown
Christa	F	White	>70	58	Southern US	Down syndrome and autism
Cecelia	F	White	>70	80	Northeastern US	TBI and paralyzed
Carol	F	White	60–69	Unknown	Midwestern US	ID, scoliosis, schizophrenia
Catherine	F	White	>70	60	Midwestern US	ID, autism, physical disability
Erica	F	White	30–39	38	Midwestern US	Paralyzed, seizures
Ella	F	White	60–69	55	Midwestern US	Down syndrome, dementia
Gianna	F	White	<30	32	Midwestern US	Spina bifida, hydrocephalus
Hannah	F	White	<30	29	Northeastern US	Turner syndrome, epilepsy
Jenna	F	White	40–49	54	US and Sweden	Moderate ID
Leslie	F	White	40–49	49	Argentina	Quadriplegic
Kayla	F	Unknown	<30	13	Midwestern US	Trisomy eight mosaic
Melissa	F	White	60–69	69	Australia	Autism and OCD
Tammy	F	White	40–49	40	Midwestern US	CP, ID, muscular dystrophy
Kristina	F	White	<30	30	Northeastern US	Autism (low functioning)
Karyl	F	White	40–49	25	Western US	ID, brain tumor
Bethany	F	Hispanic/ Mexican	<30	12 and 8	Midwestern US	Metachromatic leukodystrophy
Kayelyn	F	White	40–49	30	Northeastern US	Autism and ID
Katie	F	White	60–69	52	Northeastern US	CP and ID
Khloe	F	White	30–39	24	Southern US	Congenital heart defect, autism, ID
Kira	F	Unknown	50–59	47	Western US	Developmental disability
Lily	F	White	30–39	35	Midwest and West US	CP, hydrocephalus
Mary	F	White	<30	16	Ireland	Seizures, brittle bones
Michelle	F	White	60–69	69	Northeastern US	Down syndrome
Marissa	F	White	30–39	25	Western US	Dravet syndrome
Natalie	F	White	50–59	<60	Midwestern US	Autism, bipolar, Crohn disease

(Continues)

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TABLE 1 (Continued)

Pseudonym	Part. gender	Part. race	Part. age	Sibling age @ death	US Region or Country	Sibling diagnoses
Paxton	M	White	>70	54	United Kingdom	ID
Parker	M	White	30–39	27	Western US	CP, ID, epilepsy
Pamela	F	White	50–59	46	Europe and US	Epilepsy
Sophia	F	White	40–49	35	Southern US	ID, hydrocephalus
Beverly	F	White	30–39	26	Canada	Autism, multiple disabilities
Charles	F	African	<30	8	Kenya	Bipolar
Janessa	F	White	40–49	40	Southern US	Autism, ADHD, depression
Jessica	F	White	40–49	41	Midwestern US	Brian tumor, epilepsy
Joyce	F	White	>70	63	Northeastern US	Down syndrome
Simon	M	White	40–49	12	Southern US	Hydrocephalus
Terry	M	African	<30	19	Western US	Vision impairments

Note: ADHD = attention-deficit/hyperactivity disorder; CP = cerebral palsy; F = female; ID = intellectual disability; LD = learning disorder; M = male; OCD = obsessive compulsive disorder; part. = participant; TBI = traumatic brain injury.

had lost a brother, and 20 had lost a sister. Two participants had lost multiple family members: one who had lost two brothers, and one who had lost two sisters. Seventeen participants had lost siblings who were nonverbal due to disabilities.

Procedures

The research team included four faculty members and two doctoral-level students in the field of social work. The team created an interview protocol with 23 questions for a semistructured interview guide (Appendix A in the supplemental materials). The interview questions aimed to explore the participants' understanding of their sibling's disability, their relationship with a brother or sister with disabilities as well as with the rest of the family, the support and resources available to the family, and their experiences at the end of their sibling's life and after the loss. The questions also included suggestions for what they would like people in general, and specifically helping professionals, to know about their experiences with their siblings with disabilities. A member of the Sibling Leadership Network reviewed and provided feedback on the proposed questions, leading to minor modifications in the interview protocol. The study was reviewed and approved by the first author's university institutional review board before recruitment.

After obtaining consent from the participant, a Zoom session was scheduled at the participant's requested time. The virtual interviews were recorded and lasted between 45 and 90 minutes. Participants received a $15 gift card as compensation for their participation. The recorded interviews were submitted to Otter AI to generate initial transcripts, which were then reviewed by the research team to correct any errors or typos. Nonverbal cues not captured in the transcripts were also added to convey nuances in the participants' experiences and meanings. NVivo was used for the analysis of the reviewed interview transcripts. Names were replaced with pseudonyms, and any mentions of the brother or sister with disabilities by name were also removed.

Data analysis

This study focuses specifically on positive examples of family resilience, which emerged as a significant theme during the coding process of a larger study originally examining unaddressed

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grief among individuals who had lost siblings with disabilities. Given that family resilience was not the original focus of the broader investigation, instances where resilience processes did not occur are outside the scope of this analysis and were not systematically explored. This methodological approach enables a focused examination of how families successfully demonstrate adaptive processes following the loss of a sibling with disabilities.

A theory-informed thematic analysis was employed, using two-cycle coding (Vanover et al., 2021). In the first coding cycle, the research team employed elemental coding methods to conduct an initial review of the transcribed interviews. The researchers reviewed the transcripts, collaboratively, generating a total of 55 nodes that reflected recurring concepts across interviews. Each transcript was then coded by pairs of team members using the identified set of nodes. Through ongoing discussions in regular meetings, the team continued to explore themes emerging from the coding and reviewed coding consistency. The second cycle of coding was guided by family resilience theory integrated a developmental systems framework (Walsh, 2016). During this phase, the research team focused on capturing the adaptive processes families engaged in following the loss of a sibling with disabilities. Discussions centered on resilience-related dynamics, particularly how families experienced adaptive change and renewed connections. Through continued team discussion and interpretive memoing, the following five thematic areas were identified (Supplementary Material 1): family relationships, extended family, family becoming closer, family secrets and lack of communication, and open communication. Additional coding further distinguished three overarching themes derived from Walsh's framework: (a) belief systems, (b) organizational processes, and (c) communication and problem-solving processes. These components served as a guiding analytic framework for categorizing and understanding the adaptive strategies described by participants. Participants' narratives under each theme were organized by subthemes. Under belief system, three subthemes were identified, including (a) making meaning of adversity, (b) a positive outlook, and (c) the elements of transcendence and spirituality (e.g., faith, rituals, and continued bonds with the deceased). The component of organizational processes encompassed (a) flexibility in caregiving roles and routines, (b) connectedness through sustained family support and shared responsibilities, and (c) the ability to mobilize social and economic resources through external support networks or services. Lastly, communication and problem-solving processes included (a) clarity in expressing roles and needs through consistent communications, (b) open emotional sharing among family members, and (c) collaborative problem-solving that facilitated mutual decision-making and emotional support. Taken together, this framework provided an in-depth understanding of the perspectives and experiences of individuals with siblings with disabilities on how their families adaptively reorganized and supported one another after the passing of their siblings.

RESULTS

The study participants' discussions provide deep insights that align with the family resilience processes across three domains, including belief systems, organizational processes, and communication and problem-solving processes. Belief systems reflect how they perceive their relationships and challenges after their sibling's passing, organizational processes demonstrate their collective efforts to cope and support each other, and communication and problem-solving processes reflect their approaches to navigating grief and care.

Belief systems

Participants' reflections highlighted their normalization of caregiving roles, engagement in memory about their siblings, and pursuit of positive meaning-making. Their experiences and

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perspectives align with core principles of family resilience, particularly within the dimension of family belief systems, which emphasize making meaning of adversity, maintaining a positive looks, and fostering family identity (Walsh, 2003).

Making meaning of adversity

Participants' reflections highlighted resilience in the family through acceptance and normalization of their quasi-parental role for their siblings with disabilities. Such normalization reflects their ability to see family as cohesive and demonstrates a shared commitment to support all family members despite the challenges. Marissa described how an acceptance and normalization of her caregiving role shaped her lifelong identity as a supportive figure within her family:

> All three of us got the attention we needed for different reasons. And yes, my sister demanded a lot of it, but it never felt off balance. I think one day I hope to be a parent. And I'm like, I know it's not going to be boring, but I'm like, wow, it is gonna be interesting to see and sit at a dinner table with a different dynamic.

Marissa's discussion reflected on her family, where caregiving demands for her sibling with disabilities were integrated into everyday life. While she acknowledged her sibling's high care needs, she did not view it as a burden. Given this, Marissa anticipated her future parenting as interesting because it would involve a different dynamic. Alexis also reflected on her caregiving roles as an ingrained part of her personality shared by her family dynamic:

> So it's hard for me to parse out how much of my, like, not-falling-apart caretaker tendencies were related to Eleanor, and how much were just, like, that was, those were that was the family I was born into, and that was the situation from my whole life.

The normalization process reduces emotional distress and promotes a sense of purpose. By reframing their caregiving roles as natural responsibilities, participants demonstrated adaptive coping strategies that reinforced familiar bonds and their sense of identity.

Positive outlook

Participants held strong beliefs in the importance of remembering and honoring their sibling's memory through open communication and shared activities within the family. They viewed the loss of their sibling with disabilities as something that should be acknowledged and honored to keep the sibling's influence present in their family lives. Jenna described her dedication to maintaining her sibling's memory by incorporating meaningful items and activities into family life, such as his Halloween and Christmas decorations, to pass on these memories. She elaborated the meanings of such activities:

> So just little things that I can try to do to keep his memory alive and to make sure that my son doesn't forget him, I think is the most important thing, because they were quite close when he was alive, and I don't want him to lose that.

This routine reflects resilience within her family by highlighting their belief system, which values active remembrance and the honoring of her brother.

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Transcendence and spirituality

The shared understanding and participation in honoring sibling's memories go further to strengthen family bonds and shape personal growth because it indicates a shared effort in understanding their experiences with the loss and navigating their grief together. Alex described their active initiative to pursue positive meanings of having a sibling with disabilities and a shared sense of purpose and pride in her family:

> We started a little bit of like a charity for a while. But we realized that, we were more impactful if we were just kind of contributing to already existing things. So, my parents were really involved with autism [in their region], my mom started this special education group at the church as well to allow kids [with disabilities] to be able to make first communion and get their sacraments. So, she would teach that a lot. And I would often volunteer there as well. So, it was just trying to find a combination of like little ways as well, it's kind of like the big ways to remember him.

Alexi's family viewed the loss something that should be acknowledged and his life honored, indicating their commitment to keeping her brother's influence present in their lives. This shared sense of purpose enhances resilience by fostering mutual support and recognition of the sibling's impact on family life.

Organizational processes

How participants described their siblings as central to their family dynamics reflects the organizational processes within family resilience (Walsh, 2016). They discussed how the loss of their siblings deeply affected their family roles and structure, leading to changes in how family members supported each other. They adjusted their roles and found new ways to stay connected, which is a core component of family resilience. Their support system also extended beyond immediate family members, as they worked to bring extended family members together. These efforts helped them cope with their loss by creating a sense of stability and navigating grief collectively.

Flexibility

First, participants' reflections on the family relationships after their sibling's passing demonstrated how families reorganize and adapt to maintain resilience. While grieving the loss of the sibling, they felt a stronger sense of closeness within their family. Their family adapted to the loss by becoming more interconnected. This adaptation demonstrates resilience through flexibility and the reorganization of family relationships, where members rely more on each other for support. Beverly described the shared experiences within her family that brought them closer together since the loss of her sibling:

> I have a better relationship with my parents and my other brother than I [did before], because we can do things as a family that we could never do before because we just weren't able to. And sometimes in those moments, I'm like, "Oh, this is really special." Kind of a new family unit almost. But we still learned, much like you're grieving that loss, it's different. And you're still missing your family member. Same time, there are still like, silver linings, I guess, and I'm fine to acknowledge that.

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Beverly's discussion reflected how her family adapted and reorganized after the loss of her sibling, developing new patterns of interaction that were previously constrained by caregiving demands for her sibling.

Connectedness

Some participants further discussed commitment and mutual support within the family that encourage their adaptive responses to loss. To keep their sibling's memory alive, their families created special traditions and rituals, such as celebrating important dates and sharing memories or meaningful items in their daily lives. Alex reflected on how actively engaging in rituals honoring her sibling's memory within her family helped her family cope with the loss and rebuild their support systems to maintain connection and continuity:

> We used to always take off the anniversary of his death … we'd go to daily mass, visit the cemetery, walk through a park we always went to with him, and watch a video of pictures my dad put together. We also celebrate his birthday with neighbors, sharing cupcakes my mom would make and gathering in a garden where we'd share memories about him.

These activities help redefine roles, maintain family cohesion, and support each other's grieving process (Walsh, 2016). By participating in these rituals, families found comfort in each other and maintain a sense of unity even after their loss.

Mobilize social and economic resources

Participants also shared how their relationships with extended family played an important role in helping their family stay strong after losing their sibling. They discussed how family members can mobilize and manage support and resources by turning to extended family after the loss of their sibling. They became more connected with their extended relatives, finding comfort in their presence and assistance. Cecilia shared receiving support from her extended family after the passing of her sibling:

> She [cousin] flew up for which I was incredibly grateful because my family is so small and I think this is not something you haven't heard before, but siblings can feel so isolated with this kind of loss because nobody really knew our siblings and, and the grief of the family for me anyway was so private and so not shared. … So my point is, I was very grateful that this cousin came and her daughter took the day off of work and, and came too so the six of us went to the funeral.

Cecilia's discussion reflected her gratitude when a cousin and her cousin's daughter traveled to attend her sibling's funeral, showing their support. She further reflected on the feelings of isolation in grieving her sibling as not everyone fully understood the depth of that loss among siblings. These experiences highlight how families can reorganize their support systems while also recognizing the unique challenges that come with their grief.

Communication processes

The participants' reflections highlight the importance of open communication and shared problem-solving in enhancing family resilience following the loss of a sibling with disabilities.

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Many participants noted that honest discussions with their family members, especially their parents, about their sibling's disability and passing not only helped them process their grief but also deepened their family bonds. Open communication about caregiving responsibilities fostered a sense of collective responsibility and reinforced the family's ability to adapt and provide support during both the caregiving and grieving processes. These findings underscore the significance of open communication and problem-solving in strengthening resilience in the face of loss.

Consistent communication

Many participants acknowledged in detail that open communication between their parents and them about the disability and death of their sibling with disabilities positively impacted their grieving process and strengthened family bonds after the sibling's passing. Terry explained how his family engages in open, regular communication shared their experiences and emotions, using these conversations to stay connected and strengthen their bond through their shared faith. For example:

> So anytime we want to talk about it, which is every time we just pray that so you know rest in peace and you know, anytime to say that I just feel so bad. Yeah, we do. We do. We do talk about her and we just pray that, you know, she's with God. And, you know, just, at least we do we do anytime we want to discuss about our family. We do include our in our discussions.

Participants' communications regarding their siblings with disabilities revealed that talking openly about their loss allowed them to face their emotions, fears, and uncertainties as a family, rather than dealing with them alone. This open communication fostered a supportive environment where family members felt heard and understood, making it easier to process their feelings in a meaningful way.

Open emotional sharing

Participants' discussions about the grieving process within their families further revealed various ways their families communicate and express emotions while grieving. Their stories demonstrated that each family has its own beliefs and traditions that help them remain connected during difficult times. Cecilia described a deeply personal and collaborative grieving ritual, such as reading religious books and bringing her brother's favorite snack. For example:

> There were a couple of readings that were more Christian oriented. And then I had a, I had a couple of more Buddhist readings and I had a quote from Winnie the Pooh, I felt like I found a really nice variety and there's a poem about you know, the caged bird has flown, you may have read it, but it's a poem it's very apropos if you, you know, just even try to look up funerals for disabled person that so each of us did a reading. And we brought chocolate pudding to the cemetery because that's what was his favorite at the snack. I would always bring him, and we all had a chocolate pudding.

Her discussion elaborated on her family's way of coming together and the shared experience and highlighted open emotional sharing as effective communication and problem-solving within the family as they navigate grief. Although religious readings played a role in this particular

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ritual, it is important to note that coping practices can be diverse and personally meaningful, incorporating both spiritual and secular elements.

Collaborative problem-solving

Participants' reflections on how they became involved in the caring process provided valuable insights into how their families adapted and built resilience. Open communication about the caring process among family members can foster a sense of agency and collective responsibility in the context of having a sibling with disabilities (Walsh, 2003). Sopia's discussion of her involvement in caring for her sister with disabilities described how caring for her sister brought her family closer, as they worked together with a sense of unity and shared commitment even after the passing of her sibling:

> So, the three of us got together. And, we planned [the service]. Abby died on a Tuesday and the service was on a Friday. So, we kind of just pulled it together really quickly. It was very beautiful and just right. And we just felt like we had good communication [as a family]. And my parents were really happy.

This experience not only helped her family navigate the daily challenges of caregiving but also prepared them to face the grieving process with emotional strength.

DISCUSSION

These findings reinforce key dimensions of Walsh's family resilience framework, particularly belief systems, organizational flexibility, and communication patterns. For example, families who attributed meaning to the life and death of the sibling tended to exhibit greater cohesion and long-term adaptation. In addition, intergenerational caregiving roles emerged as a cultural and relational factor that helped sustain continuity and identity following the loss. These findings demonstrate that resilience is not a fixed trait but an evolving family process influenced by cultural narratives and caregiving history. They suggest the importance of culturally responsive bereavement support that acknowledges extended caregiving structures and meaning-making pathways.

Siblings who had lost a brother or sister with a disability discussed various ways they used all aspects of family resilience to cope and navigate the change in family dynamics after the loss. Consistent with family resilience theory (Walsh, 2016, 2016b), losing a brother or sister with a disability was a significant life stressor that challenged family functioning. However, families were able to use the key processes in family resilience to maintain relationships and cope with the loss including making meaning out of the adversity, exhibiting flexibility and adaptation, connecting with each other, and using open emotional sharing about the loss. These processes observed in our participants offer a deeper look into the mechanisms of resilience theory. For instance, making meaning of adversity often manifested as a proactive cognitive reframing, where families, long before the loss, integrated the sibling's disability into their core identity. Similarly, the families' flexibility was not passive acceptance but an active systemic reorganization. To be specific, many participants described normalization of caregiving roles and the honoring of their siblings' memory as important pathways to family unity and personal growth. This aligns with the perspective of family resilience that resilient families can make meaning of adversity by viewing challenges as opportunities for transformation (Walsh, 2016). Participants' discussions also highlighted a core element of resilience in the face of disruption as they shared how their families adapted by reshaping routines, such as new rituals, and connections through

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ties with extended family. This flexibility enabled their families to support one another through collective grief. In addition, the findings of this study highlighted a critical role of open emotional communication among family members in the face of adversity. The efforts of participants' families to express grief, share stories, and engage in symbolic activities mirror the communication and problem-solving processes identified by family resilience theory (Walsh, 2016) as essential for fostering resilience because they promote honesty, joint decision-making, and mutual support. Furthermore, this study revealed that resilient communication is powerfully expressed through collaborative problem-solving. When families worked together on concrete tasks, such as planning a funeral service, they were building collective efficacy, a shared belief in their ability to handle challenges together, which is a vital implication for practice.

Taken together, the narratives of individuals who lost their siblings with disabilities highlighted that family resilience in the wake of profound loss is not solely about individual strength or external resources. Rather, family resilience is relational processes in which family members interact, communicate, and support one another, especially during times of crisis as the relational processes enable families to remain emotionally bonded.

The body of literature on sibling loss is small, and the grief siblings experience is often unrecognized (Funk et al., 2018). This study adds to this small body of research and emphasizes that loss of a sibling with a disability to death is a significant life event causing disruption in family life (Critchley et al., 2021; Sveen et al., 2014). Siblings reported disruption and adaptation regardless of whether they experienced the loss early in childhood or much later in life. For siblings who experienced the loss in childhood or adolescence, the amount of time the parents had to invest in them after the loss of the other child often increased significantly. For siblings who experienced the loss in middle to late adulthood, many had assumed significant caregiving tasks for their brother or sister with a disability, and the loss shifted their daily tasks and responsibilities. In both cases, siblings had to make meaning of the loss, reorganize their family relationships, and communicate with other family members about the loss. Meaning-making, productive reorganization, and open communication appeared to contribute to better coping and better relationships with other family members.

By situating family resilience within ecological systems and cultural contexts, this study highlights the importance of both intrafamilial processes and external environmental factors. The integration of cultural sensitivity into resilience theory underscores the need for practice and policy approaches that are tailored to the unique values and structures of diverse families. These findings suggest that resilience should not be viewed solely as a family-internal process but as interplay among individual, relational, systemic, and cultural elements.

Limitations

The original study primarily focused on unaddressed grief among individuals who had lost siblings with disabilities. During the coding process, however, the researchers identified significant components of family resilience that warranted further in-depth exploration. Although the interviews provided valuable reflections on how families navigate challenges, the data may not fully capture the nuances of family resilience as it pertains to other contexts, such as coping strategies or long-term adaptation. In addition, this study explored family resilience from the perspective of a single family member whose sibling had a disability. It may limit the depth of insights gained in this specific area. This limitation could impact the conclusions regarding resilience because participants were not specifically asked about it, and their experiences may not have been thoroughly examined from a resilience perspective.

Next, in this study, information about the timing of their sibling's passing, types of disabilities, and sibling birth order was collected as contextual background for the analysis. No discernible patterns emerged indicating that this information influenced the themes, however. This

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may be partly due to a selection bias because the participants in this study were individuals who voluntarily chose to participate. The study participants were predominately English-speaking, White, educated women of European descent. They may have access to more resources, which could facilitate adaptive coping and articulated their experiences. Similarly, although a few study participants expressed unresolved grief or continued strain within family relationships after the loss of a sibling with a disability, these experiences were often embedded within narratives that also highlighted meaning-making or growth over time. This pattern may also reflect a selection bias as mentioned earlier. Many participants were highly articulate and well-engaged in educational or professional environments. As a result, negative cases like those who experienced persistent or severe family dysfunction may have been underrepresented. Future study explicitly centered on family resilience should further explore how family and disability-related contexts shape individual and family adaptation to loss.

Finally, the study participants were predominantly White individuals from Western countries. This limits the generalizability of the findings to people from other cultural contexts. In particular, people from Eastern cultures may have different experiences and perspectives on disability, caregiving, and family dynamics, especially when considering cultural factors influencing their attitudes toward disability. In many Eastern cultures, there may be a higher sensitivity to stigmatization, and stigma may outweigh the perceived benefits of disability services (Kayama et al., 2020). This cultural difference could shape how families approach caregiving, decision-making, and resilience. Another limitation is that the participants were predominately female, limiting our understanding of how male participants experience grief and contribute to or perceive family resilience. Given that gender may influence caregiving roles, emotional expression, and coping strategies, future research is needed to include a more gender-balanced perspectives for the comprehensive understanding of the findings.

Implications

This study has important implications for future research and practice. Future research could address diverse cultural perspectives by interviewing more people from Eastern cultures and interviewing in other languages than English. Future qualitative or quantitative studies could examine the interrelationships among family communication, caregiving, resilience, and emotional processing. Discussion of these elements in this qualitative study often overlapped, making it difficult to draw clear boundaries. For instance, emotional support provided by family members may contribute to both resilience and effective caregiving (Aivalioti & Pezirkianidis, 2020). In addition, communication within the family might play a role in both caregiving practices and resilience-building. Future research could examine these concepts in more depth and enhance the understanding of how they independently or collectively contribute to family resilience.

This study has important implications for mental health practitioners. Although resources for people with living siblings exist, such as the Sibling Leadership Network, Supporting Siblings organizations, and clinical guidance resources (Lobato & Kao, 2005; Stoneman, 2005), these resources primarily focus on ongoing caregiving relationships rather than addressing loss. Resources specifically for supporting siblings experiencing loss are notably lacking. This may make it harder for siblings to feel the connectedness and mutual support they need to recover from the loss and leave practitioners unprepared. Future work needs to focus on more written resources for siblings working through the loss, such as guides or manuals. Also, structured support groups for siblings could be beneficial. Loss is a natural part of the family life cycle that all families will eventually face; thus, integrating bereavement content into existing sibling support resources would provide more comprehensive care.

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Practitioners can support siblings who have had a loss by helping them find meaning in the life and death of their brother or sister with a disability; when appropriate to the individual's beliefs and preferences, this may mean connecting to spirituality, faith practices, or other meaningful coping strategies. For example, siblings may need help identifying strategies to reorganize and restabilize their lives after the loss, particularly when much of the sibling's life has been focused on caregiving. Practitioners can also encourage open communication and sharing between the siblings and other family members, including parents, other siblings, and extended family members. Open and clear communication will promote continuing relationships between the family members still living.

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SUPPORTING INFORMATION

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