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The Lived Experiences of Siblings of Individuals with Special Needs: A Qualitative Study

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Abstract

This study explored the lived experiences of siblings of individuals with special needs, guided by Bowen's Family Systems Theory. This study, conducted in Cabuyao, Laguna, Philippines, adopts a qualitative phenomenological approach and uses semistructured interviews. This study aimed to uncover the essence of these experiences, examine family dynamics, identify opportunities for personal growth, and develop themes from participants' narratives. Additionally, this study recommends programs beneficial for researchers and participants. In this study, five participants were selected through purposive sampling based on the inclusion criteria of having siblings with special needs. Data were collected through semi-structured interviews and analyzed to identify ten emergent themes. Key findings include family conflict in child care, highlighting emotional tension and misunderstandings; caregiving involving parentallike responsibilities and long-term support; and personal growth characterized by emotional maturity and shared happiness. Other themes identified were emotional boundaries, family adaptability, and balancing family priorities, which reflect the complexities siblings face in managing their relationships and roles. The study revealed that participants presented both challenges and opportunities for growth. Based on the results, the study recommends developing program focused on enhancing emotional support, fostering family education, and promoting flexibility to optimize sibling roles and strengthen famil dynamics.

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1. Introduction

The experiences of having a sibling with special needs are often deep; shaping the emotional, social, and psychological dimensions of an individual's life. Sibling relationships are among the most enduring familial bonds, beginning in childhood and evolving through various stages of life. However, having a sibling with special needs introduces unique challenges and opportunities for personal growth. This study explores the lived experiences with special needs, focusing on their responsibilities, family dynamics, and emotional complications.

Using Bowen's Family Systems Theory as a framework, this research examines how family dynamics influence the roles and relationships of siblings with special needs. The theory highlights the interconnectedness of family members, where the experiences of one-member impact the entire system. The study review the challenges that siblings experience, their coping strategies, and the personal growth that emerges from these experiences.

The significance of this study is rooted in addressing the gap in literature, particularly in the Philippine context, where cultural values such as "pakikisama" (social harmony) and familial obligations shape caregiving roles. While previous research focuses on the experiences of parents of individuals with special needs, this study emphasizes the perspectives of siblings, who play critical yet often unacknowledged caregiving roles.

The study employs a qualitative phenomenological approach, utilizing semi-structured interviews to gather data from five participants in Cabuyao City, Province of Laguna. The research seeks to answer the following questions:

What is the essence of the lived experiences of individuals with siblings who have special needs?

How do family dynamics shift in response to these unique roles?

What themes emerge from these narratives, and what recommendations can be made to support these individuals?

2. Methodology

A. Research Design

This study employed a qualitative phenomenological approach to explored the lived experiences of siblings of individuals with special needs in Cabuyao City, Laguna. A phenomenological design was used to gain deeper insights into how participants perceived and made sense of their experiences. Semi-structured interviews were conducted to allow participants to express their thoughts openly, while also giving researchers the flexibility to ask follow-up questions for clarification and deeper understanding. This approach aligned with Van Manen's (1997) [2] framework, which emphasizes understanding human experiences from the perspective of those who lived them. By focusing on the participants' narratives, the study aimed to uncover meaningful themes that reflected their unique realities.

B. Research Locale

The study was conducted in Cabuyao City, Laguna a location chosen due to its relevance to the research focus. Based on statistical data, Cabuyao City had 387 enrolled individuals with special needs who had siblings, making it an appropriate setting to examine sibling experiences. The city's accessibility also facilitated data collection, ensuring that researchers could engage with participants effectively. Conducting the study in this locale provided valuable insights into the familial and social dynamics that shape the experiences of siblings of individuals with special needs.

C. Population and Sampling

This study involved five (5) individuals from Cabuyao, Laguna, who were siblings of people with special needs. Participants were selected using purposive sampling to ensure they met specific criteria, such as being both a sibling and a caregiver.

This method enabled the researchers to focus on individuals whose experiences were directly relevant to the study's objectives, providing meaningful insights into family dynamics and personal growth. Purposive sampling was particularly useful for this research, as it prioritized participants with unique and relevant lived experiences.

The small, targeted sample size allowed for an in-depth exploration of their perspectives. This approach also aligned with the study's goal of understanding the nuanced challenges and roles that siblings faced within the family system in Cabuyao, Laguna.

D. Research Participants

The participants of this study were siblings of individuals with special needs from Cabuyao, Laguna, who also served as their secondary caregivers. To ensure relevance to the study's objectives, specific inclusion criteria were established. Participants had to be at least (1) 18 years old to

provide informed consent and effectively share their lived experiences. Additionally, (2) they needed to have lived with their siblings with special needs or spent a significant portion of their lives with them. The study focused on exploring their unique challenges and perspectives.

Participants were excluded if they did not provide informed consent or were unable to fully comprehend the study's requirements. Those experiencing severe psychological or emotional distress, which could have been exacerbated by discussing their experiences, were also excluded. Furthermore, siblings with minimal interaction with their siblings with special needs or those involved in the research process, including research team members or their relatives, were not included in the study.

E. Research Instrumentation

The researchers of this study consulted three (3) psychometricians who had extensive knowledge and expertise in the relevant field to ensure the methodological rigor of the study's instrument. The data collection tool underwent a comprehensive validation process, which included several key steps such as revisions, modifications, and the removal of certain items.

These adjustments were made to enhance the clarity, relevance, and precision of the instrument. It also underwent content validation, during which the validators assessed whether the interview questionnaires effectively represented the constructs and variables under investigation. This content validation ensured that the items were both relevant and representative of the study's objectives.

Furthermore, the instrument was tested to confirm its ability to produce consistent and replicable results across different contexts and participants. Through these rigorous validation procedures, the researchers sought to strengthen the overall integrity and validity of the data collection process, thereby ensuring that the findings were credible.

F. Data gathering procedure

The researcher gathered data after the interview questionnaires were validated by the research validators. Once the approval letter was received from the research professor or adviser, in accordance with university guidelines, the researcher began data collection.

The study specifically targeted siblings of individuals with special needs. The researcher ensured that the participants clearly understood the study's purpose before their inclusion. To identify suitable participants, the study employed purposive sampling, a method widely

used in qualitative research to select individuals who met specific criteria directly aligned with the research objectives (Crossman, 2020) ^[1]. This approach was particularly advantageous for the study, as it focused on a sensitive topic that required participants with relevant experiences to provide meaningful insights.

Interviews were conducted face-to-face, with each participant answering one question at a time until all prepared questions were addressed. After collecting the necessary information, the researcher analyzed and clustered the data for interpretation. Based on the gathered data, conclusions and recommendations were formulated.

G. Ethical Consideration

This study strictly adhered to ethical guidelines to protect participants' rights and well-being. Informed consent forms were provided, and a briefing was conducted before interviews to ensure participants fully understood the study. They had the right to withdraw at any time if they felt uncomfortable.

To maintain confidentiality, a personal information sheet was attached to the consent form, following Republic Act 10173 (Data Privacy Act of 2012). The researchers acknowledged potential risks, such as emotional distress, and took measures to minimize discomfort. As a token of appreciation, participants received benefits for their time and contributions. Recognizing that personal backgrounds could have

influenced interpretations, the researchers engaged in selfreflection and discussions to minimize bias. The study aligned with the guidelines of the Research Ethics Review Committee, ensuring credibility and ethical integrity.

3. Results and Discussions

The study identified ten major themes with twenty supporting sub-themes that explain the lived experiences of siblings of individuals with special needs. These themes reveal the challenges, personal growth, and family dynamics that shape the caregiving journey of these siblings.

Table 1: Detailed Illustrations on the Challenges Faced by Siblings of Individuals with Special Needs

Participants	Participant Responses	Researcher's Observation
Participant 3	"Since yung brother ko nga po clinically diagnosed with ASD mahirap siyang I control po kapag hindi pasok sa routine niya yung nangyayari so kailangan mo siyang pag sabihan parang for her hayaan nalang po eh ang side naman po namin is kapag hinayaan lang siya magtutuloy tuloy possible na maka sakit pa siya ng ibang tao."	Participant 3 illustrates the conflict between prioritizing a sibling's needs and addressing safety concerns, showing the challenges of balancing family perspectives.
Participant 4	"Kapag may gusto siya naiinis yung ulo niya, minsan hindi pa sapat ganon parang meron parin siyang gusto dalawa kasi yung inaalagaan ko, isang senior at isa isang down syndrome."	Participant 4 highlights the additional strain of caregiving two individuals with different needs, emphasizing emotional exhaustion and the difficulty of meeting conflicting demands.

Individuals diagnosed with Autism Spectrum Disorder (ASD) often exhibit challenges in emotional regulation and social communication which can significantly impact family dynamics. In this situation, it exemplifies Bowen's Family Systems concept of triangulation, where sibling becomes mediator between two conflicting family members. The

participant's experience reflects the complex interplay of patience, resilience and emotional exhaustion, which are common in caregiving roles. Their narrative underlines the necessity of support systems to ease the burden of such responsibilities.

Table 2: Detailed Illustrations on Responsibilities Associated with the Sibling Role

Participants	Participant Responses	Researcher's Observation
Participant 2	"Since. nabanggit ko naman na deaf siya and late narin siya nakapag aral mahirap Makipag intindihan. Kumbaga may times na meron siyang hindi gusto na hindi ko maintindihan? At may gusto akong sabihin sa kaniya. na hindi niya rin naiintindihan so parang nagkakaroon siya ng barrier on communication"	Participant 2 highlights the difficulty of bridging communication gaps with a sibling who is deaf, reflecting the emotional strain and patience required in daily interactions.
Participant 5	"bilang panganay po, yung mag aalaga po sa kaniya especially po ganun po yung kondisyon niya."	Participant 5 expresses the sense of duty inherent in being the eldest sibling, especially in caring for a sibling with special needs.

The participants highlighted distinct yet interconnected aspects of caregiving responsibilities for siblings with special needs. Their experiences underscores the emotional labor and patience required to navigate such barriers while fostering a meaningful relationship. It emphasizes the cultural and familial expectations tied to their position, balancing personal goals with the demands of caregiving. The researcher notes

that caregiving responsibilities, such as managing communication barriers, are influenced by the nuclear family emotional system of Bowen's concept, which reflects patterns of interaction within the immediate family. These challenges underscore emotional connections and stresses inherent in the sibling relationahip when one member has special needs.

Table 3: Detailed Illustrations on Personal Growth and Challenges

Participants	Participant Response	Researcher's Observation
	"May times na nagkakaroon ng. parang jealousy kase mas napapansin	Participant 2 shares feelings of jealousy but
Participant 2	yung kapatid mo, mas nakakabilibre ng gusto niya. Pero andon parin	also reflects on the deep understanding and
	talaga yung understanding na mas kailangan niya kase"	acceptance that developed over time.
	"sabi ng doctor niya masarap merong ganyian sa bahay kasi forever	Participant 4 expresses joy and fulfillment in
Participant 4	baby. Yon masaya parang pag wala siya sa bahay kulang ang	having a sibling with special needs, describing
_	maghapon namin."	them as a constant.

The participants shared a unique emotional dynamic in having siblings with special needs. Their perspoective illustrates how caregiving can nurture profound love, gratitude, and purpose, transforming challenges into

meaningful connections. Siblings often develop differentiation of self, learning to manage and separate their emotional responses from the family system. This skill fosters personal growth, emotional maturity, and adaptability. In the context of special needs families, this differentiation enables siblings to balance feelings of jealousy

or competition with a deeper understanding of their sibling's unique needs.

Table 4: Detailed Illustrations on Values and Beliefs About Family Roles

Participants	Participant Responses	Researcher's Observation	
Participant 1	"Ako kase pinalaki ako ng parents ko naaa, parang itrato yung mga tao	Participant 1 underlines the importance of	
Participant 1	na equally, parang ahh parang regardless ng inakita sayo na"	treating everyone equally.	
Doutisiment 5	"Vyma ana na ia kailanaan aa namikya ay tuhunaan aanyu na "	Participant 5 shares a belief in mutual	
Participant 5	"Yung ano po, is kailangan sa pamilya ay tulungan, ganun po."	support as essential to family dynamics.	

The values such as equality and mutual support which re passed down through the family projection process. Parents transmit their beliefs and expectations to their children, shaping how siblings perceive and interact with their family members. In Bowen's Family Theory, the family projection process refers to the tendency of parents to project their

anxieties and expectations onto their children, which subsequently shapes how children interact with each other. Both perspectives reflect a shared commitment fostering understanding, unity, and solidarity in their sibling relationships.

Table 5: Detailed Illustrations on Balancing Personal Goals and Family Responsibilities

Participants	Participant Responses	Researcher's Observation
Participant 4	"Nag asawa ako 38 na kasi inuuna ko sila May baby na ko so na nito lang Forty-four na ko nito lang ako nagkababy kasi sila nga yung inuuna ko."	Participant 4 conveys the sacrifices made for family, delaying personal milestones.
Participant 5	"Kapag po kase may kulog or may loud sounds po uhhh, nagwawala po siya so kailangan po, andun ka at aware ka sa surroundings at the same time di mo po magagawa yung kinakailangan mo pang gawin, like kunyare po sa pag-aaral o sa OJT ko po ganun."	Participant 5 shares the constant struggle to balance caregiving with academic and professional demands.

Balancing family responsibilities with personal aspiration often leads to emotional cut off, where individuals must temporarily distance themselves emotionally or physically to manage their own goals. These challenges highlight the tension between individuality and family obligations. In

Bowen's theory, this often a coping mechanism for maintaining personal emotional stability while juggling familial obligations. Their accounts reflect the sacrifices and adjustments required in families with special needs.

Table 6: Detailed Illustrations on Strategies for Balancing Needs

Participants	Participant Responses	Researcher's Observation
Participant 1	"Binabalanse? ang ginagawa ko kase, ngayon na naranasan ko na, uhh siyempre tignan yung schedule ko, so tapos if ever, ang ginagawa ko, ahead of time, a week before, kapag andyan yung nanay namin at kaya niya naman bantayan sa school pinapasamahan ko na lang siya sa isa ko pang pinsan kung wala namang pasok."	Participant 1 demonstrates effective time management and delegation to balance caregiving responsibilities.
Participant 5	"Adjusting lang po sa needs ng kapatid ko, at the same time po, pano po ko makakawork o makaka study sa bahay habang inaalagaan ko siya."	Participant 5 underscores the constant need for adjustments to address both personal sibling-related duties.

The participants showcases the importance of flexibility and teamwork in managing dual responsibilities. Balancing personal and sibling needs reflects the multigenerational transmission process, where patterns of caregiving,

prioritization, and responsibility are learned and replicated across generations. Siblings often adapt these patterns to find balance in their own lives.

 Table 7: Detailed Illustrations on Family Support Dynamics

Participants	Participant Responses	Researcher's Observation
Participant 3	"nila, pinapasok po nila sa sped school so doon pa lang po, nakikita namin growing up yung support nila sa brother namin so pati kami aysumuporta rin." "Although may kapatid ako at cousin na may special needs, 'di nila tinuring na iba ba?"	Participant 3 shares how parental acceptance and proactive efforts shaped a supportive environment within the family.
	"Bata palang po kami na kwento po sa amin na hindi talaga aware yung parents namin na maymay ASD youngbrother ko pero over the time parang nauna po nilang tanggapin at parang hindi nila tinago, tinerapy."	

Family's emotional support system is strengthened through shared caregiving experiences. Bowen's nuclear family emotional system illustrates how emotional bonds arte reinforced, even challenging circumstances, leading to greater resilience within the family unit. Their perspective illustrate how collective efforts foster resilience and understanding among family members.

Table 8: Detailed Illustrations on Conflicts Between Family Expectations and Aspirations

Participants	Participant Responses	Researcher's Observation
Participant 3	"Before po ako mag college sinasabi na sa akin ng mother ko na mag take ako ng parang SPED related or yung Psychology related na course para maka tulong daw sa brother ko."	Participant 3 shares how familial expectations influenced their educational choices.
Participant 5	"Pressure po siguro kase gusto po nila na, grumaduate po ko on time at the same time po wala pong magbabantay dun sa kapatid ko."	Participant 5 reflects on the dual pressure of fulfilling family responsibilities and personal aspirations.

Family expectations often mirror societal pressures and cultural norms, as reflected in Bowen's societal emotional process. These expectations can conflict with the individuals personal aspirations, leading to tension as they strive to

balance familial roles with their own identity. The expectation to prioritize family needs over personal dreams highlights the struggle to reconcile individual identity and family responsibility.

Table 9: Detailed Illustrations on Emotional Boundaries

Participants	Participant Responses	Researcher's Observation
Participant 2	"Yung understanding lang talaga. Yun yung pinaka-point don. Kailangan mong maintindihan yung situation ng nandon ka. Kase hindi puwedeng lagi mong sasabihin lang sa sarili mo na ako nalang lagi, lagi nalang ganito, lagi nalang ganyan. Pero, hindi mo kinoconsider na yung kapatid mo is, same lang din yung naiisip niya."	Participant 2 illustrates a family-centered approach to caregiving, where collaboration and shared goals help maintain balance within the household.
Participant 4	"Pag yung kailangan namin na kami lang nung asawa ko at ang baby ko, dun lang sa kwarto"	Participant 4 reflects a strong emotional need for personal bonding time with their spouse and baby, emphasizing love, sacrifice, and the importance of maintaining close family connections despite caregiving challenges.

Managing emotional boundaries is a core component of differentiation of self, a concept from Bowen's Family Systems Theory. Siblings must learn how to maintain their emotional health by finding a balance between emotional closeness and personal autonomy. This allows them to support their sibling while also preserving their own wellbeing.

Table 10: Detailed Illustrations on the Impact of Social Events

Participants	Participant Responses	Researcher's Observation
Participant 1	"For example, meron kaming unexpected na challenge or event na nangyari sa life namin, so, syempre, pag-usapan namin., uhh parang mag b brainstorming kami, uhh yung kaniya kaniyang perspective kung pano namin sosolusyunan yung gantong bagay, di kami, di kami mag a act sa isang problem naaa., kaniya kaniya, we make sure na, 'pag may problema si ganto, nagtutulungan kami."	Participant 1 describes a collaborative problem-solving approach within the family.
Participant 5	"Mas naging strong po yung bond namin, yung communication po namin."	Participant 5 highlights how challenges have strengthened family unity and communication.

The participants shared an experience where an unexpected societal challenge led the family to work together in a collaborative problem-solving effort, with everyone contributing their ideas and strategies. External events or societal trends influence family dynamics through the societal emotional process, prompting families to adapt and strengthen their bonds. This adaptability reflects the family's resilience in facing external challenges together, it strengthened family bonds and communication highlighting the importance of teamwork in overcoming challenges.

4. Discussion

The findings reveal that siblings of individuals with special needs navigate an interplay of caregiving responsibilities, personal aspirations, and family expectations. While these roles build personal growth, emotional maturity, and resilience, they also come with significant sacrifices, including compromises in education, career, and personal goals.

Participants highlighted the importance of family values,

such as patience, respect, and shared responsibility, in managing caregiving roles. Emotional support within the family was important in overcoming challenges, with siblings often stepping into parental roles to ensure their sibling's well-being. However, societal stigma and bullying added another layer of difficulty, emphasizing the need for greater public awareness and support.

Despite these challenges, participants expressed pride and joy in their sibling's achievements, which strengthened family bonds. The study underscores the need for targeted support systems, including counseling, community programs, and educational resources, to help siblings balance their caregiving roles with personal aspirations.

To address these challenges, this study proposes a structured support program titled "The Sibling Compass: Navigating Care, Empowering Growth." This program aims to provide caregiver siblings with the knowledge, strategies, and emotional support needed to navigate their roles confidently and compassionately. It emphasizes balancing caregiving responsibilities with personal growth, helping participants

prioritize their well-being while fostering resilience and empowerment.

By implementing this program, we hope to create a more supportive environment for caregiver siblings, ensuring they receive the necessary resources and recognition to thrive in both their caregiving and personal lives.

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