

EXPLORING PSYCHOSOCIAL CHALLENGES AMONG ADULT SIBLINGS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES

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ABSTRACT

Adult siblings of individuals with intellectual disabilities deal with a complex system of psychosocial issues that have a significant impact on their well-being. Family system theory postulates the interconnectedness of family members, where each member's behavior influences others that shapes family dynamics. The present study aims to investigate the psychosocial challenges among Adult siblings of individuals with intellectual disabilities. Seven adult siblings of children with intellectual disabilities aged above 18 years were recruited by purposive sampling. Semi-structured interviews were used to investigate the challenges from siblings and the data was interpreted and analyzed using the interpretative phenomenological analysis. The major themes based on interpretative phenomenological analysis indicated that adult siblings face challenges includes; barriers in finding support, social impact, emotional impact, objective caregiver burden, family dynamics and coping strategies. It is found that having a sibling with an intellectual disability can make them experience increased caregiving role, emotional and social dynamics and impact on mental health.

Keywords: Adult siblings, emotional impact, family dynamics, intellectual disabilities, psychosocial challenges.

INTRODUCTION

An intellectual disability is defined by the American Psychiatric Association as a condition marked by significant limitations in both intellectual functioning and adaptive behavior that influences three major domains in life; the conceptual domain which includes memory, reasoning, knowledge, ability to read or write, the social domain which consists of communication skills, empathy, maintaining friendships, and the third one is the practical domain which includes organizing daily life tasks, taking care of oneself, attending job and managing finances (Jansen et al., 2023). Children who are diagnosed with

intellectual disability often have comorbidity with autism, attention deficit disorder (ADHD), Down syndrome, epilepsy, and anxiety (Krause et al., 2016). Intellectual disabilities include range of conditions, including autism, Down syndrome, cerebral palsy, fragile X syndrome, and global developmental delay in children under five years old. These conditions significantly impact cognitive and adaptive functioning. Around 1% (10.37 per 1000 population) of individuals globally are anticipated to experience intellectual disability, according to findings from a meta-analysis (Maulik et al., 2011). Intellectual

disabilities are generally manifested before the age of eighteen, that is based on Intelligence Quotient scores, intellectual disabilities are classified into four categories: Mild (50-70), Moderate (35-50), Severe (20- 35), and Profound (below 20) (Schalock et al., 2007).

Risk factors indicate a higher probability of a condition being present but they do not guarantee that it shall be present. Varied factors result in the development of intellectual disabilities: i) Genetic ii) Pre-natal iii) Post-natal and iv) Environmental. One of the causes attributed to intellectual disabilities is genetics such as Down's syndrome which is the most common disability. It occurs as a consequence of a mistake in the process of cell division leading to an abnormality of the person which we call trisomy 21, an extra copy of chromosome 21. For the same reason Intellectual disabilities can also be acquired through other variants including aneuploidies, copy number variations, and repeats in specific genes. Prenatal factors are any number of conditions and situations that have an impact on the growing embryo or fetus between the time the zygote is conceived and the infant is born. It has been discovered that prenatal factors that can cause symptoms of intellectual disabilities are the parent's age during the conception of the child, type of prenatal care, number and nature of previous pregnancies, maternal weight gain, fetal activity, maternal medical and obstetric difficulties, use of medications, drugs, and radiation exposure (Patel et. al., 2020). Post-natal factors are defined by World Health Organization as "The period of six weeks after the delivery of a child". During this time, a majority of maternal and neonatal deaths take place, making it crucial for both the mother and the infant. Post-natal factors include head injuries, exposure to environmental toxins, malnutrition, chronic health conditions, psychosocial deprivation, psychosocial stressors, and lack of access to healthcare.

Psychological Challenges

Psychological challenges are the difficulties related to mental and emotional well-being that influence one's thoughts, feelings, behavior, and overall

functioning. It can affect one's ability to cope with daily activities, maintain relationships, achieve personal goals, require support groups, and intervention. In this study, psychological challenges among adult siblings of individuals with intellectual and developmental disabilities would include heightened levels of anxiety and depression in comparison to the general population. Additionally, these challenges involve managing what may be viewed as complicated feelings toward the caregiving roles and the responsibilities, guilt and the balance, the struggles and conflicts between the individual's dreams and the family responsibilities.

Social Challenges

Social challenges can be defined as obstacles faced by individuals while interacting and communicating effectively. The studies reported in the current literature that social issues may result in isolation estrangement, communication, interpersonal problems, prejudice, and issues related to intimacy in a person's life (Troy et. al., 2007). Caring for a sibling may also lead to social isolation as the care receiver of the above family roles presses prominent duties on siblings that may hinder them from fully engaging in other social activities and stigma associated with intellectual disabilities. This isolation can be made worse by the fact that one often does not receive the type of acceptance that is granted to others by their friends and colleagues (Greenberg et al., 2019). The fundamental concept of positively focused thinking is based on cognitive theory and Wades worst-case cognitive appraisal theory. Adult siblings are individuals who have at least one parent in common and are of 18 years of age or above. It has been mentioned that siblings play a crucial role in each other's socialization and development, often being a child's first peer relationship (Conger et al., 2009). Siblings assist in developing basic social skills including conflict resolution, empathy, cooperation, and communication. Therefore, younger siblings develop healthy social relationships due to interactions with their adult siblings at home (Arnold & Heller, 2018).

Coping Strategies

The term "coping" describes the methods and techniques people apply to deal with stress and other obstacles in their lives. Coping strategies are the particular techniques one adapts to manage specific pressures and difficulties. These coping techniques can be categorized into three categories: behavioral, cognitive, and emotional (APA, 2010). Studies indicate that 70 percent of individuals with autism and 40 percent of individuals with intellectual disabilities engage in harmful behaviors, the most common are self-harm and physical attacks on others. Therefore, these behaviors often do not comply with the concept of violence or hostility. Early diagnosis of intellectual disability is essential as it enables timely intervention, which is necessary for optimizing the child's developmental potential. It helps in identification of the child's unique abilities and strengths, facilitating the establishment of realistic and achievable goals. Moreover, early diagnosis helps to alleviate parental anxiety by providing a clear understanding of the child's condition and the available support options (Cleary, 2022). It was also revealed that 60 percent of individuals with developmental impairments reside with their families, 25 percent of which are aged over 60 years (Braddock et al., 2011). As parental support diminishes with ageing, the role of adult siblings in the lives of younger siblings with disabilities becomes increasingly important. Adding to this, Hayden et al., (2019) found through empirical research that individuals with siblings who have intellectual disabilities might be more vulnerable to negative psychological effects compared to siblings belong from families without such challenges. When compared to siblings of individuals without disabilities, meta-analyses indicated that siblings of individuals with Neurodevelopmental Disorders and Conditions generally experience a modest yet significant negative impact on psychological and neurocognitive development and functioning. Siblings may commonly encounter increased levels of stress, anxiety, depression, and associated adjustment difficulties (Shivers et al., 2019). Hence, this study endeavors to investigate the

psychosocial challenges faced by adult siblings of individuals with Intellectual Disabilities, to understand their long-term psychological experiences. Additionally, it seeks to comprehend the siblings' perceptions and attitudes towards the disability. By emphasizing both psychological and social perspectives, this research aims to provide a comprehensive understanding that can facilitate the development of effective and inclusive interventions.

The World Health Organization states that intellectual impairment can develop on its own or in conjunction with other medical or psychological disorders. Intellectual impairment is far more common in underdeveloped countries than in affluent ones; two to eight times as many instances have been reported in the former. With an estimated 160 million people living there, 45% of whom are under the age of 18, the prevalence of intellectual impairment in Pakistan exceeds expectations (Pakistan Bureau of Statistics, 2011). A study was conducted to compare the siblings of individuals with mild intellectual disabilities and mental illness to a normative sample, revealing that siblings of individuals with mild intellectual disabilities were more likely to reside nearby and maintain regular family contact, yet reported lower levels of emotional intimacy. The study emphasized for the protection of the rights of persons with intellectual disabilities and proactively develop resources/ networks for preparing the siblings implied with the required information and materials to be able to advocate and support in such domains. The eight-dimensional quality of life model by Schalock and Verdugo may be proposed for use in persons with mental illness cohesive approach to flesh out these rights, for enhanced quality of life for persons with intellectual disabilities and to their families (Pérez-Curiel et al., 2023).

Family System Theory

According to Constantine (1986), a system is characterized as a bounded collection of interrelated elements that behave consistently. It can also mean an arrangement of things that are connected to one another by regular interactions or dependencies. The family systems approach, or

family systems therapy, was created in the 1950s by psychiatrist Murray Bowen. The family systems approach's basic tenet is that families are emotional units. They are a network of interrelated, mutually dependent people. Their psychology cannot be comprehended in isolation from the system as a whole since they impact one another. There are the eight principles of family system theory that focuses on interconnectedness of family and shifts the focus from an "individual" to other variables and external factors that influences the family relationships: i) Triangles ii) Differentiation of self iii) Nuclear family emotional process iv) Family projection process v) Multigenerational transmission process vi) Emotional cutoff vii) Sibling position viii) societal emotional process. Out of these eight principles, some find implications in the present study such as nuclear family emotional process, sibling position, and emotional cutoff.

Rationale of the study

Based on epidemiologic studies, estimates of the frequency of intellectual disability among children in the US vary greatly, ranging from 8.7 to 36.8 per 1,000. While the frequency of moderate ID varies from as low as 2 to more than 30 per 1,000 children, significant ID (IQ <50 with deficiencies in adaptive behavior) is generally found to be in the range of 2.5 to 5 per 1,000 children in the United States and other industrialized countries. Children from lower socioeconomic backgrounds have a higher chance of moderate intellectual disabilities (Boat et. al., 2015). Previous studies reveal that parents and caregivers play an important role in children having any disability yet they go through a lot of stress, social adjustment and societal pressure. It has been established that parents and siblings of individuals with intellectual disabilities often experience higher levels of anxiety and depression than those of parents and siblings of normal developing children. While there is an increasing gap in understanding the unique challenges and experiences faced by the siblings of individuals who have intellectual disability. In reviewing research literature, it is noted that a child's disability can have a variety of effects on other

siblings, including role changes within the family, a reduction in parental interest, an increase in sibling care responsibilities, and exposure to pressure

Objectives

The purpose of the present study is to explore and understand the psychosocial challenges among adult siblings of individuals with intellectual disabilities.

□ To understand the psychological challenges of adult siblings of individuals who are diagnosed with intellectual disabilities.

□ To understand the social challenges of adult siblings of children who are diagnosed with intellectual disabilities.

□ To explore the coping strategies adapted by adult siblings against challenges.

Research Questions

- What are the psychological challenges faced by adult siblings of individuals with intellectual disabilities?
- What are the social challenges faced by adult siblings of individuals with intellectual disabilities?
- What are the coping strategies utilized by adult siblings of individuals with intellectual disabilities against psychosocial challenges?

Methodology

Research Design

Qualitative research design was used in this study. It is a type of research that focuses on how people interpret and make sense of their experiences in order to understand each person's social reality and obtain a greater understanding of the situations around them. Further, a study also indicated that qualitative research design consists of open-ended interviews, participant's observation, ethnography, discourse analysis, case studies, and logic (Muzari et. al., 2022).

In this study phenomenological framework is utilized. Phenomenology requires the researcher to elaborate lived experiences of the participants by using own words referred to as voice in the text. In the process of phenomenology, the researcher is

interested in the participants' interpretations, assertions and descriptions of their familiarities and acquaintances. It has been shown that qualitative research yields a descriptive data that the researcher interprets using rigorous and systematic procedures of transcribing, coding, and analyzing of trends and themes. Phenomenological research investigates living events to learn more about how individuals interpret those experiences (Delve et al., 2022). Interpretative phenomenological analysis is applied in this study. It advocates the use of theoretical assumption, the act of interpretation while remaining closer to the data. It also focuses on participants words used as verbatim to ensure that their voice remains integral to the telling of stories (Smith et al., 2009).

Sampling Strategy

The eligibility criteria for the selection of participants in this study were purposive homogeneous sampling. Purposive sampling aims to address research questions by focusing on specific aspects of a population that are of interest. Homogeneous sampling means the sample which consists of people or cases having similar characteristics such as age, gender, background and occupation. The selected participants were assumed to reflect the incidents and events, personal experiences, values, beliefs, perceptions,

challenges they had been facing due to sibling of intellectual disability (Rai & Thapa, 2015).

Sample

The sample was comprised of 7 adult siblings above age range 18 years and having minimum qualification of intermediate. All participants had younger siblings diagnosed with Intellectual disability, Down's syndrome, Cerebral Palsy etc. The data was collected till saturation point. The sample was collected from different cities of Pakistan such as Lahore, Islamabad, Sialkot, and Narowal. In this present study, siblings above age 18 years were included and they had minimum intermediate qualification. Participants had siblings who were diagnosed with intellectual disabilities. The participants fulfilled the relationship criteria, such as full siblings rather than half-siblings, or adopted siblings. In this study, siblings of individuals with intellectual disabilities below 18 years of age or minor were excluded. Participants who themselves were diagnosed with any psychological disorder including intellectual impairment or any other neurodevelopmental disorder was excluded. Siblings of individuals diagnosed with the medical or psychiatric conditions not related to intellectual disabilities were excluded. 34

Table 1

Demographics Table

Sr. No	Age	Gender	Birth Order	No. of Siblings	Occupation	Qualification	Marital Status	Family system	Living status	City
1.	31 years	Female	3 rd	Six	Teacher	MBBS	Married	Nuclear	Together	Lahore
2.	25 years	Female	1 st	Three	Student	Undergraduate	Single	Nuclear	Together	Narowal
3.	21 years	Female	1 st	Five	Student	Undergraduate	Single	Joint	Together	Islamabad
4.	45 years	Male	1 st	Five	Businessman	Intermediate	Married	Joint	Separate	Islamabad
5.	29 years	Female	2 nd	Four	Professor	Graduate	Married	Nuclear	Separate	Islamabad
6.	25 years	Female	2 nd	Five	Student	Undergraduate	Single	Nuclear	Together	Sialkot
7.	20 years	Male	1 st	Four	Student	Intermediate	Single	Joint	Together	Lahore

Interviews

In this study, semi structured interviews were conducted to collect the data. The literature revealed that when the researcher's goal is to gain a greater understanding of the participant's distinct viewpoint rather than a more broad comprehension of a phenomenon, semi-structured interviews are the best approach for gathering data, while other methods of data collection have their place in qualitative research, one of the main advantages of semi-structured interviews is their ability to be focused while enabling the investigator to explore relevant ideas that may arise during the interview. Further it can improve understanding of the pharmacy service being evaluated (Adeoye-Olatunde & Olenik, 2021). In this study, total 17 questions were developed on the basis of psychosocial challenges considering the inclusion criteria.

Procedure

The data was collected by using purposive sampling technique. The participants were briefed about the main purpose of study and confidentiality was assured about their opinions and their consent was taken. Further, semi structured interview was conducted to collect the data from the participants. Collected data was recorded in audio form and was transcribed later. Interpretative phenomenological analysis was utilized in this study for conducting analysis. There are six steps of phenomenological analysis proposed by Smith et al., in 2009. The initial step was the immersion of the researcher in the reading and rereading of the original data and checking the transcripts for accuracy against audio recordings. The second step which Smith et al described as the most detailed and time consuming involves making initial notes which explore semantic content and language. During the third theme, emergent themes were noted and the fourth step was a search for connections across emergent themes was collated within a table. At step 5, it was proposed that process was repeated by moving onto the next case. The final step 6 involves looking for patterns in all nine cases. It is important to find out the means of paying

particular attention to the uniqueness of experience. Interpretative phenomenological analysis is concerned with the convergence and divergence and not to just find the shared experiences. Interpretative phenomenological analysis basically promotes the use of available theoretical knowledge to help interpret the findings (Bartoli, 2019).

Ethical Considerations

First of all, approval for data collection was taken from the university research committee. After taking the informed consent from all the participants, semi-structured interviews were conducted. All the guidelines and protocols were followed. Furthermore, the purpose, strategies, advantages of the study was explained in detail. Privacy and confidentiality were ensured to the participants. Any type of harm such as physical, psychological and emotional harm was minimized and appropriate support was provided. Accurate and comprehensive results of the research were shared with the participants.

Results

The goal of this study was to investigate psychosocial challenges among Adult siblings of individuals with intellectual disabilities. This chapter provides a detailed exploration of psychological and social difficulties experienced by Adult siblings. Results were analyzed through the interpretative phenomenology approach (IPA). IPA initially developed by Smith (1996), aims to understand how individuals make sense of their experiences regarding self, relationship, health and well-being. Six major themes have been emerged using IPA along with their subthemes and codes. A total of seven extended interviews were conducted. Five of the participants were female and two participants were male following inclusion and exclusion criteria along with ethical considerations.

The six major themes are introduced in this chapter are Barriers in finding support, Social Impact, Emotional Impact, Objective Caregiver burden, Family Dynamics and Coping strategies.

Table 1 *Three major themes and subthemes and their relevant codes*

	Theme 1	Theme 2	Theme 3
Major theme	Barriers in findingsupport	Social Impact	Emotional Impact
Subtheme	Lack of awareness	Limited support system	Negative states
	Internalized stigma	Unavailability of treatment	Low mood
Codes	Non-acceptance	Joint family's concerns	Hurt
	Lack of insight	Ageing of parents	Embarrassment
	Role Conflict	Absence of parents at home	Discomfort
	Parents as primary caregiver	Working mothers	Jealousy
	Siblings as secondarycaregiver	Social relationships	Worry
	Age gap with siblings	Early exposure to social interactions	Helplessness
	Fear of negativeevaluation	Constant pressure	Guilt
	Criticism from society	Limited social interaction	Anxiety
	Fear of mocking by others	Societal expectations	Frustration with lack ofprogress
	Lack in social invitations	Seeking a confidant	Emotional Dysregulation
	Impact of society	Victims of social isolation	Overwhelming emotions
	Fear of Judgment		Suppression
			Excessive rage
			Irrational anger
			Inferiority Complex

Major theme: Barriers in finding support

In this study, barriers in finding support emerged as first major theme. These are the barriers an adult sibling can experience in finding any support to decrease their experiences of challenges. These barriers can be self-imposed due to individual perceptions or fears, or forced by the society and or availability of various services. To adult siblings of individuals with intellectual disabilities, these barriers cause a lot of discomfort and reduce their chances of getting solutions desperately needed. In the present study participants had variety of hurdles that could not let them approach towards targeted support or themselves and also for their siblings with disability. In this study, this major theme includes three subthemes which are as Lack of awareness, Role

conflict and Fear of Negative Evaluation. These themes are also interconnected with each other such as lack of awareness can increase the fear of negative evaluation because individuals might not know how to steer support system and or confirm the reliability of support. Similarly, stigma might stop them to seek for support groups and individuals may avoid to invest in support services due to perceived social judgment. Further, these subthemes also enfold codes developed from semi-structured interviews. The first subtheme Lack of awareness includes these codes: internalized stigma, non-acceptance and lack of insight. The second subtheme Role conflict includes these codes: parents as primary caregiver, siblings as secondary caregiver, age gap with siblings. Similarly, third

theme fear of negative evaluation includes these codes:

criticism from society, fear of mocking by others, lack in social invitations, impact of society.

“When we were a little older, my parents advised us that it is not good. You cannot tell this to people.” (P, 1).

“Then he told her that the treatment of these children is not available in the whole world. They will be recognized wherever they are. (P,3).

“There is a parent role”. (P,1). “With adult siblings, they do play a vital role, but they're still not the primary caregiver if the parents are still around”. (P, 5).

“Adult siblings are always the secondary caregiver to younger siblings no matter what the conditions are”. (P,5).

The participant stated that parents may feel pressure to keep certain issues private, potentially due to stigma. This can create a barrier in finding

external support, as families might be reluctant to share their struggles with others. In the second verbatim participant stated that the necessary treatment or support for these children might be rare or unavailable globally. It may make it difficult for families to find appropriate care or resources, contributing to their sense of isolation. In the third verbatim it is stated that the central role parents play in caregiving, which can be overwhelming if adequate support is not available. Even if adult siblings are involved, they are often not the primary caregivers while the parents are still around, which may lead to stress on the parents. Participant also mentioned that adult siblings, while important, are typically not considered as the primary caregivers. This can limit their ability to influence care decisions or seek support independently, thus relying mostly on the parents.



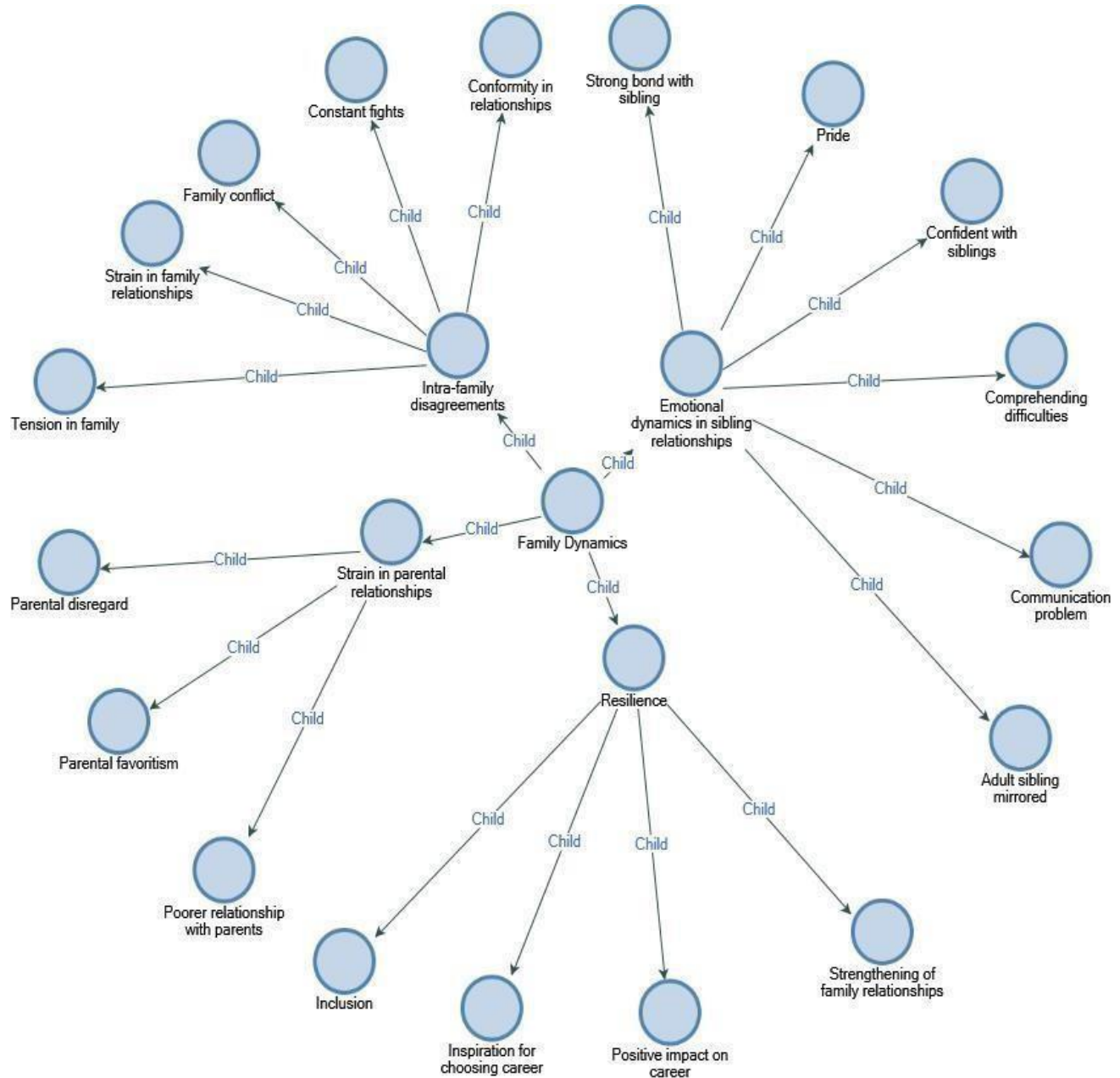


Figure 1

Hierarchy of subthemes of fourth major theme and codes of themes respectively after NVivo 14.

Major theme: Social Impact

In this study, social impact emerged as second major theme. An individual experience a lot of difficulties due to influence of society. Social implications can be defined as the manner in which an individual's conditions or behavior influences or affects their social context or relations. This can comprise anything from interpersonal level to the community level in the

broad sense of the word. Based on specific cultural norms, siblings have experienced a need of motivation, confidant, close friend to share their experiences. In the present study, siblings might undergo the social impact due to sibling's condition that can affect themselves and their younger sibling too. In this study, this major theme includes two subthemes which are as Limited support system and Social Relationships. Further,

these subthemes also enfold codes developed from semi-structured interviews. The first subtheme: Limited support system includes these codes: Unavailability of treatment, Joint family's concerns, ageing of parents, Absence of parents at home and Working mothers. The second subtheme Social relationships includes these codes: Early exposure to social interactions, Constant pressure, Limited social interaction, societal expectations, Seeking a confidant and Victims of social isolation.

Participants stated that, "Look, now we live in a joint family and the parents who are able to take care of their siblings, their brother, their child, the rest of the people don't do that." (P,6).

Participants has stated that, "But there were some family gatherings where we couldn't go. Because we knew that if there will be food noise during the wedding, it would trigger him." (P,2).

In the context of social impact, the participant is highlighting the challenges faced by families living in a joint family system when dealing with a member who is having intellectual disability can be triggered by certain environments, like loud noises or certain types of food. Adult siblings may sometimes feel unsupported by other family members. The participant also mentioned that there were instances where the family had to avoid attending certain social events, such as weddings, because they knew these events could potentially influence the condition of the family member they were caring for. This may lead to feelings of isolation or exclusion from the broader social circle. The social impact here refers to how the condition of a single sibling can influence the entire family's ability to engage in social activities, affecting their social life and interactions within the community.

Major theme: Emotional Impact

In this study, emotional impact emerged as third major theme. Emotional impact is described as effect of any event, interaction, or experience that

can influence one's emotions and feelings. It can be positive and negative both depending on individual's response and nature of the stimulus. It also encompasses the ways that occurrence in the life and some aspects of these occurrences influence the psychological state of a person. This comprises of different emotional effects together with the performance of psychological well-being. In this study, this major theme includes two subthemes which are as Negative states and Emotional dysregulation. Further, these subthemes also enfold codes developed from semi-structured interviews. The first subtheme Negative states includes these codes: Low mood, Hurt, Embarrassment, Discomfort, Jealousy, Worry, Helplessness, Guilt, Anxiety and Frustration with lack of progress. The second subtheme Emotional Dysregulation includes these codes: Overwhelming emotions, Suppression, Excessive rage, Irrational anger and Inferiority Complex.

"But when he was born, one of neighbors said this is a punishment from God to us. I was hurt that time and cried a lot." (P,3).

"Sometimes, adult siblings do not have words to others' criticisms, and feels inferior in front of everyone." (P,4).

In the first verbatim it is mentioned by the participant that there is a profound emotional impact of insensitive and hurtful remarks from others, such as being told that a child's condition is a "punishment from God." This reflects the broader societal stigma that families might face. In the second verbatim the participant highlighted the emotional burden carried by adult siblings, who may feel powerless or inadequate in the face of external criticism. It reflects that participants are unable to respond such criticism suggests a deep sense of vulnerability and inferiority, contributing to feelings of emotional distress and low self-esteem. Overall, the participant has conveyed how external judgments and societal stigma can lead to significant emotional suffering for both parents and siblings, contributing to feelings of hurt, inferiority, and helplessness.

Table 2 *Three Major themes, subthemes with their relevant codes*

Theme 4	Theme 5	Theme 6
Objective Caregiver Burden	Family Dynamics	Coping strategies
Time constraints	Intra- family disagreements	Adaptive coping strategies
Regular supervision	Family conflicts	Constructive view of disability
Reduced personal time	Tension in family	Insight
Limited leisure time	Strain in family relationships	Religious help
Limited parental contact	Conformity in relationships	Blood relationship with sibling
Puberty adjustments	Strain in parentalrelationships	Empathetic attitude
Cost burden on caregiver	Empathy for disabled sibling	Seeking support
Financial strain	Comprehending difficulties	Education
Limited independence	Strong bond with sibling	Focus on solutions
Career deferment	Confident with sibling	Maladaptive Coping strategies
Family Dynamics	Pride	Frustration
	Communication problem	Denial
	Adult sibling mirrored	Delay of career
	Resilience	Difficulties in coping
	Strengthening familyrelationship	Inarticulate
	Inspiration for choosing career	
	Inclusion	
	Positive impact on career	

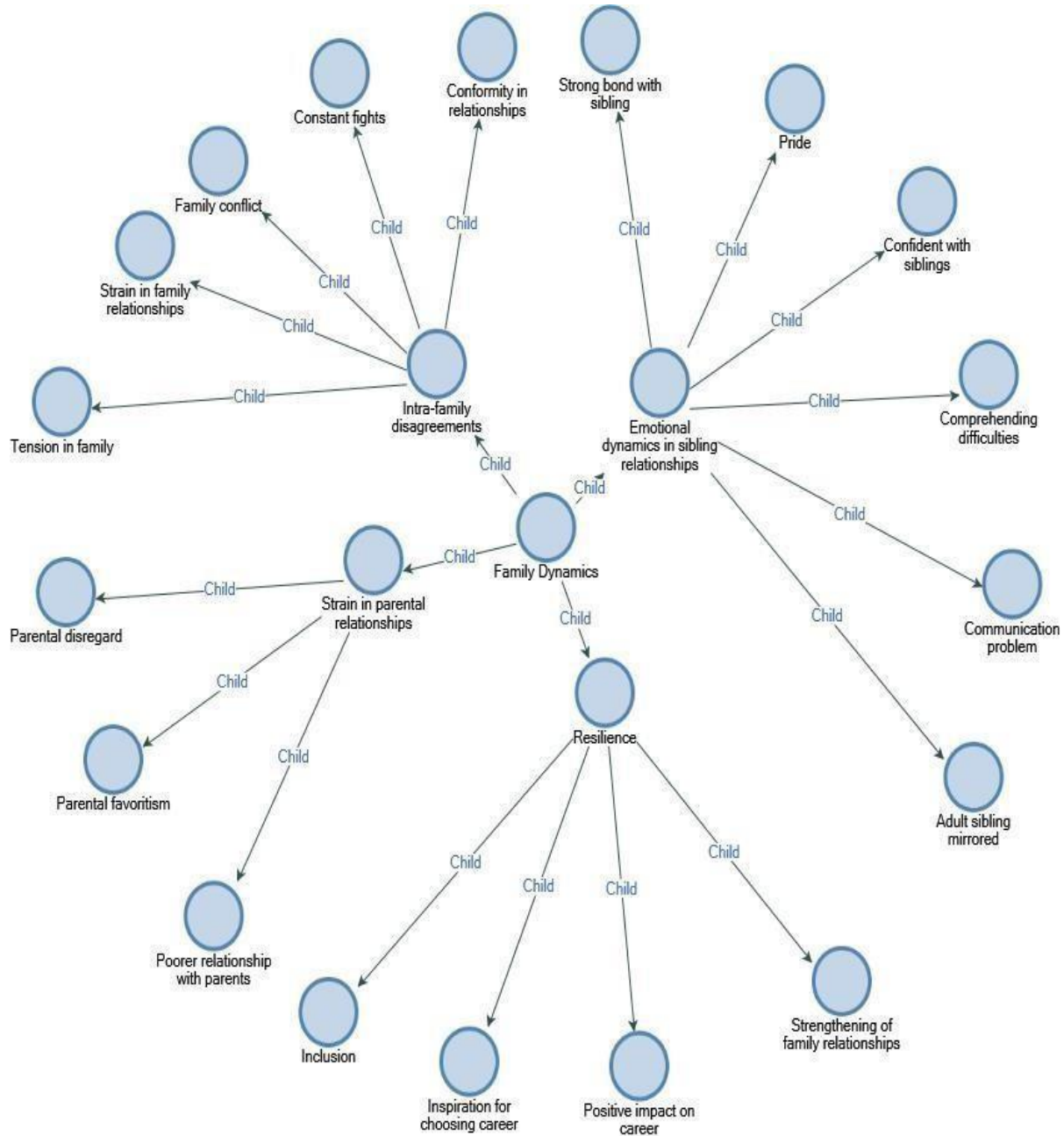


Figure 2 Hierarchy of subthemes of fifth major theme and codes of subthemes respectively after NVivo 14.

Major theme: Caregiver Burden

In this study, “objective caregiver burden” emerged as fourth major theme. Objective caregiver burden is described as difficulties or pressure an individual face while taking care of someone with chronic illness, disability or other long-term health conditions. It refers to the tangible, measurable aspects of caregiving that can

place a strain on the caregiver. These burdens typically involve direct impacts on the caregiver’s resources, such as time, money, and physical energy. These burdens often involve direct impacts on the caregiver’s time, financial resources, and overall well-being. There can be many sub aspects in objective caregiver burden such as including all the external factors that can lead to negative

consequences regarding any individual. In a present study, this major theme includes two subthemes which are as Time constraints and Cost burden on caregiver. Further, these subthemes also enfold codes developed from semi-structured interviews. The subtheme Time Constraints includes these codes: Regular supervision, reduced personal time, Limited leisure time, limited parental contact and Puberty adjustments. The second subtheme Cost burden on caregiver” includethese codes: financial strain, Limited independence and Career Deferment.

“But if he is not happy or he is worried or he is being stubborn, then it becomes a challenge for all of us. So, the role of a caregiver alsodepends on the state of the sibling.” (P,2).

“My study time is compromised. If I have to go with a friend, he comes with me. I have to take care of him even during games.” (P,7).

In the first verbatim, the participant stated that how the caregiver's role is heavily influenced by the emotional or behavioral state of the sibling. If the sibling is unhappy, worried, or stubborn, it creates additional challenges for the entire family, particularly for the caregiver. This highlights the unpredictable and demanding nature of the caregiving role, where the caregiver must constantly adapt to the sibling's need. In the second verbatim the participant illustrated the personal preferences that the caregiver must make, such as compromising study time, social activities, and even leisure activities like games. The participant is emphasizing how caregiving responsibilities intervene upon and limit their own life, underscoring the significant burden that comes with balancing caregiving with personal interests and needs. Overall, the participant is emphasizing the practical and measurable impact of caregiving on their daily life, including the challenges of adapting to the sibling's needs and the personal sacrifices made in the process.

Major theme: Family Dynamics

In this study, “family dynamics” emerged as fifth major theme. Family Dynamics can be described as interrelationships between and among individual members, and the forces or circumstances that produce particular behaviors. It pertains to the

arrangements that are present in the family in regards to interactions with other family members. These dynamics involve individual actions, positioning, and the ways that the family members use to interact with each other and outside entities, and these play a very crucial role in determining the whole functioning of the family and the wellbeing of the persons involved. In this study, family dynamics includes four subthemes which are as, Strain in parental relationships, Emotional dynamics in sibling relationships, Intra-family disagreements and Resilience. Further, these subthemes also enfold codes developed from semi-structured interviews. The first subtheme Strain in parental relationships includes these codes; Poorer relationship with parents, Parental Disregard and Parental favoritism. The second subtheme Emotional Dynamics includes these codes; Comprehending difficulties, Strong bond with sibling, confident with sibling, Communication problem, Adult sibling mirrored and Pride. Similarly, the third subtheme Intra-family disagreements includes these codes; Constant fights, family conflicts, Tension in family, Strain in family relationships and Conformity in relationships. And the fourth subtheme resilience includes these codes; strengthening of family relationships, Inspiration for choosing career, inclusion and Positive impact on career.

“The second reason is that all my time goes to them and sometimes I feel that my parents do not love me and own me, that's why they do not listen me.” (P,7).

“Arguments can last for long hours due to the disabled sibling”. (P,4).

“I personally think that it didn't lead to social isolation for me because I would include her in everything and I took pride in being her sister.” (P,5).

“I am also teaching at special school and having sibling at home motivates me and makes me realize that it is important for every child to be managed by teachers and therapists”. (P,2).

The first verbatim highlighted the participant's feelings of being neglected by their parents, who they perceive as prioritizing the sibling with special needs over them. This suggests that the participant feels emotionally distant and unloved, which can create tension and strain within the family

dynamic. The second verbatim points to how the sibling's condition can lead to prolonged arguments within the family. This reflects the heightened stress and conflict that can arise as family members navigate the challenges of caregiving and managing the sibling's needs. The third verbatim offers a contrasting perspective, where the participant takes pride in including their sibling in all aspects of their life. This indicates a positive and inclusive approach to family dynamics, where the sibling's condition strengthens the bond between them and fosters a sense of responsibility and pride. The fourth verbatim showed how the experience of having a sibling with special needs has positively influenced the participant's career and outlook. It highlights how family dynamics can lead to personal growth, motivating the participant to contribute to the care and education of other children with similar needs. Overall, the participant is focusing on the complex and varied ways in which a sibling with special needs affects family relationships, from

feelings of neglect and conflict to pride, inclusion, and motivation.

Major Theme: Coping Strategies

“Coping strategies” emerged as a sixth major theme in this study. Strategies or techniques that an individual use to manage any difficult situation, stressor or trauma. It can be adapted consciously or unconsciously. Coping mechanisms are techniques by which a person attempts to confront or deal with stress and other pressures. It is possible to divide them into two types: positive, which contribute to decrease of the stress level and increase of the overall well-being, and negative, which are counterproductive in this aspect. Adult siblings have mentioned their coping strategies they have applied to encounter the difficulties they face while dealing with younger sibling having disability. This major theme is also divided into two further subthemes based on interviews which are “Adaptive coping strategies” and “Maladaptive coping strategies”.



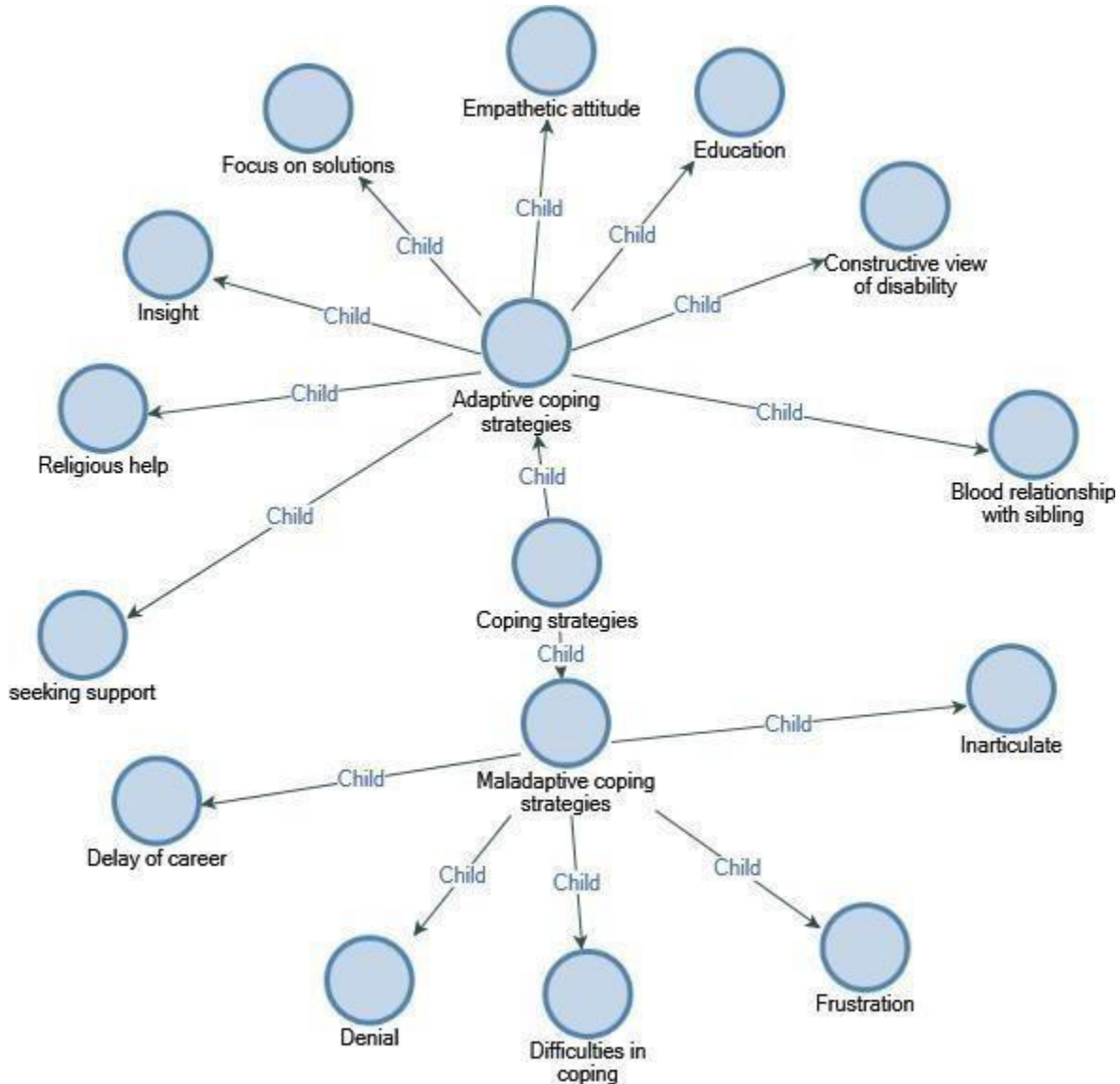


Figure 3

Hierarchy of subthemes of sixth major theme and code of subthemes respectively after NVivo 14.

The subtheme “Adaptive coping strategies” has following codes: “Seeking support”, “Religious help”, “Insight”, “focus on solutions”, “Empathetic attitude”, “Education”, “Constructive view of disability” and “Blood relationship with sibling”. The subtheme “Maladaptive coping strategies” also has these mentioned codes: “Inarticulate”, “Frustration”, “Difficulties in coping”, “Denial” and “Delay of career”.

“We do not feel sad. We accept that he has this disease. So, we treat him like this.” (P,2). “But now I realized that he had a need. So, it was okay.” (P,2).

“For the first three to four years I used to deny him as my brother, and used to cry secretly”. (P,7).

The participant stated in the first verbatim as a shift towards acceptance as a primary coping strategy. The participant expressed that they no longer feel sad but have accepted the sibling's condition as a reality. By embracing the situation, the family treats the sibling accordingly, which shows a practical and emotionally better approach

as adaptive coping strategy. The second verbatim emphasized the participant's realization that their sibling's behavior originates from an unmet need. It allowed the participant to feel more at peace, recognizing that it was "okay" to handle those needs, which signifies a coping strategy of empathy and understanding as a way to navigate challenges.

The third verbatim illustrated an earlier stage of coping, where the participant initially struggled with denial and shame, rejecting their sibling and crying in secret. This shows the emotional difficulty of accepting the situation early on and how denial was part of the initial coping mechanism before progressing to acceptance.

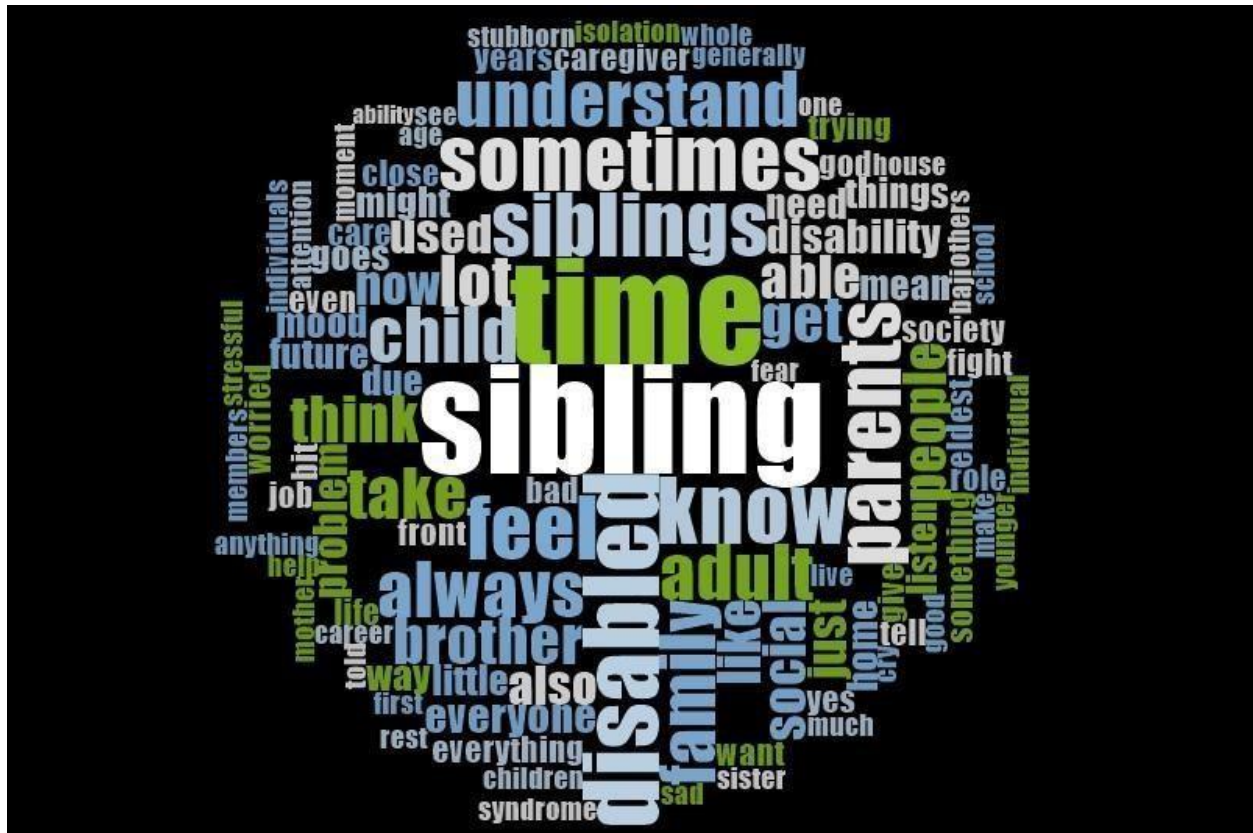


Figure 4
 Representation of word cloud after NVivo 14.

Discussion

The purpose of this study was to inquire the psychosocial challenges among Adultsiblings of individuals with intellectual disabilities. The data provided in this study is enriched with the challenges at both psychological and social level, they have experienced. This study makes several contributions to the literature as adult siblings have reported different experiences related to their own sibling with intellectual disabilities After conducting semi interviews from the participants, six major themes were established, including subthemes of codes. The first theme “Barriers in finding support” was emerged in the meaning of

hurdles siblings have experienced and were not able to seek support. The subthemes ofthis major theme as lack of awareness, role conflict and fear of negative evaluation highlighted as the reason’s siblings had difficulties to find support for themselves. Boelsma et. al., (2017) also stated that, siblings who could not find support from immediate family and local society where they were living, their quality of life was negatively affected. Some of the siblings reported that they considered themselves as secondary caregiver, whereas parents as primary caregiver. Though it led them to non- acceptance of their caregiver role as an Adult sibling. A study also found that when

siblings reported their difficulties in accepting their brother or sister's disability because of the related difficulties, it can be inferred that this might stay as confusion in sibling's life (Muries et. al., 2022). Siblings have also reported that fear of negative evaluation caused variety of challenges as not being able to discuss openly, discussion regarding experiences, lack in invitations from the relatives. This is also in line with the qualitative analysis, which has pointed out that siblings are often exposed to stress due to social prejudices they face and are rejected by their peers (Avieli, 2019). The second major theme emerged in this study was a "Social Impact" on Adult siblings of individuals with intellectual disabilities. Siblings reported that their social interactions were limited and they could not find trustworthy friend for sharing their difficulties. It was also found that siblings whose parents were ageing or had working mothers, they had to face more obstacles. A scoping review based on the theory of trauma explains that siblings of individuals with intellectual disabilities or autism experience various stressors such as balancing between the care giving role and one's own life and lack of support from parents who are aging and are not able to provide care for the sibling (Rocheffort et. al., 2023). The third major theme emerged in this study was "Emotional Impact". Siblings have reported that they had low emotional states while facing all the challenges such as low mood, helplessness, hurt and guilt etc. Adult siblings mentioned that they felt jealous because of attention given by parents to the younger sibling with disability. It is also mentioned in the recent study that siblings often face emotional challenges such as jealous, and become frustrated because all the attention is provided to the disabled sibling. Further, these feelings may cause embarrassment in social settings as friends or social circle as they may not understand the need (Sommantico et. al., 2020). Siblings have also experienced intense emotional responses leading to emotional dysregulation such as suppression, irrational anger, inferiority complex etc. A study has also discovered that these emotional difficulties may be due to the elevated and persistent affectivity, resulting to unfavorable consequences, such as,

persistent thinking about the subject an extreme sensitivity to social exclusion. It is therefore implied that when emotional dysregulation is treated through psychological therapies, one can effectively manage such difficulties and enhance his/her quality of life and social adjustment (Dell Osso et. al., 2023). The fourth major theme established in this study was "Objective caregiver burden". It includes financial cost to caregiver burden, time commitment, physical demands, lifestyle disruption. Siblings reported that they had to compromise their time for sibling with disability as regular supervision was required. They also mentioned that they had less time for themselves, fun and leisure. A quantitative research study conducted in year 2023 focused on the caregiver burden issues in adult siblings of individuals with intellectual disabilities. It included basic personal care, health and other therapies, medical care, and overseeing of services. The study also established that the impact of this burden results in emotional stress, financial strain and effects on the siblings' own personal and professional lives (Arnold & Heller, 2018). Few siblings have also reported that as their younger siblings grew up and faced puberty, it has also caused stressful situation for them because they had to handle every condition. Further, their career plans were also delayed due to increased caregiving responsibilities. The investigation also discovered that several adult siblings had to postpone or make modifications to their employment intentions so that they could provide care for their brothers or sisters. Such siblings developed strict ethical responsibilities towards the family members with disability affecting their life decisions and career choices (Arnold & Heller, 2018).

The fifth major theme found in this study was 'Family Dynamics'. This major theme indicated interpersonal relationships between family members and on individual basis. The subthemes established under this major theme were strain in parental relationships, emotional dynamics in sibling relationships and resilience. A review was conducted on the experiences of siblings of children with disabilities, various themes were discussed such as psychological adjustment, family dynamics and the long-term impact on sibling

relationships (Stoneman, 2005). A study has also found that caregiving responsibilities develops a resilience in family relationships. The challenges and experiences faced by adults due to younger sibling having a disability also create strong bonds, lasting memories. Younger siblings having disability have been a great inspiration in their life was also mentioned by few participants. It has also been mentioned in a study that raising a child with disability causes some challenges but many families adapt positive caregiving patterns and consider their child as a positive aspect to their family and to their quality of life (Woodman & Hauser, 2012). The sixth major theme developed in this study was "Coping strategies". This major theme included two subthemes as adaptive coping strategies and maladaptive coping strategies. Adaptive coping strategies utilized by Adult siblings included constructive view of disability, focusing on solutions and seeking support. It has been discovered that problem-focused strategies have been linked to improved psychological well-being and decreased levels of pessimism, subjective burden, and depressive symptoms among families with children having developmental disabilities (Woodman & Hauser, 2012). Similarly, maladaptive strategies were the patterns adapted by adult siblings that had negative consequences later such as frustration, denial, delay of career and inarticulation. It has been discovered in recent study that siblings often develop maladaptive coping mechanisms including denial, frustration to adjust with the difficulties temporarily but it led them to long term issues such as anxiety and depression (Rocheft, 2023).

Conclusion

The main purpose of the study was to investigate psychosocial challenges among Adult siblings of individuals with intellectual disabilities. Six major themes have been originated from this study which are as 1) barriers in finding support, 2) social impact, 3) emotional impact, 4) objective caregiver burden, 5) family dynamics and 6) coping strategies respectively. All of these themes had further subthemes of codes developed by semi-structured interviews. Research also highlighted that adult siblings living together with a sibling

having disability faced higher psychological issues than siblings who are living separately. This study has also found that there is less investment on the interventions and target support groups for adult siblings of individuals with intellectual disabilities. This study also gives us the future directions to advance research on the siblings of disabled individuals and to improve the wellness of adult siblings of people with intellectual disabilities.

Limitations

This study had some limitations. While collecting the data from participants we may have taken only eldest siblings having first birth order rather than second and third birth order siblings. In addition, we could have considered the marital status of Adult siblings as singles and married both have different experiences. Similarly, we have involved both criteria of siblings who had been staying together and separately from a sibling with disability, differentiating them might have brought different results. Moreover, the participants as adult siblings could have been categorized as their parents were alive or not. As this might have increased or decreased the responsibilities of Adult siblings leading to different results of the studies. Also, by categorizing the siblings having joint family system and nuclear system might have distinguished the results. It is also noteworthy that most of our participants were female which could have further biased the results as previous study found that sisters of individuals with intellectual disabilities are more involved in caretaking than brothers (Dorsman et. al., 2023).

Implications

This study highlights the importance of well-being of Adult siblings of individuals with intellectual disabilities and there should be practical implication of support groups based on this purpose. Future research should explore strategies and methods to develop support groups for Adult siblings of individuals with disability, moreover a scale should be developed specifically related to siblings of individuals with intellectual disabilities. This study has focused on adult sibling's role in the life of sibling with disabilities, thus it requires

maximum support to entail. Furthermore, it explored that parents are primary caregivers consequently future studies may focus on experiences of parents related to Adult siblings. Similarly, a guideline can be provided to parents to develop equality between all children having disability or not. This study has also emphasized on the basis of family system theory, having a member with disability at home affects other family member.

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