The Parents' Acceptance of Their Children with Intellectual Disability: A Phenomenological Study

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Abstract

This study explores the lived experiences of parents regarding the acceptance of their child with an intellectual disability. Intellectual disability possesses unique challenges for parents requiring them to navigate various, emotional, social, and practical dimensions of accepting their child's condition.

The study adopts a qualitative approach, utilizing semi-structured interviews to gather data from a purposive sample of six parents who have children diagnosed with Intellectual disabilities. Thematic Analysis was employed to identify and interpret the patterns' themes and meaning emerging from participants. Moreover, findings revealed that the process of accepting a child with an Intellectual disability is complex and multifaceted. It includes parents' experiences, challenges, coping mechanisms, and insights of parents in the acceptance process towards their children having an Intellectual Disability.

The study highlights the impact of societal attitudes, stigma, and misconceptions on parental acceptance and the well-being of both the child and the family. This paper advises future researchers to provide a comprehensive understanding of parental acceptance and shed light on the nuanced experiences that parents navigate when embracing their child's intellectual disability.

Keywords: Acceptance; Intellectual Disability; Multifaceted; Journey; Resilience; Experience

1. Introduction

Life of children with intellectual disabilities may experience a wide range of challenges in their daily lives. They may struggle with academic tasks such as reading, writing, and math. They may also have difficulty communicating their needs and emotions effectively, which can lead to frustration and behavioral challenges. They are individuals with unique personalities, interests, and strengths. As the day along they deserve the same opportunities as any other child to learn, grow and achieve their goals, and it is important to provide them with the support and resources they need to do so. Few people realize how difficult it is to be a parent until they themselves become the parents. It is even more difficult to be a parent of a child with special needs. Families with children with disabilities want the same things as other families. They want to see their children reach their full potential, they want to be included and accepted by their community and they want to enjoy things together and have fun.

A study by Poulson and colleagues (2016) in Australia examined the experiences of parents of children with intellectual disabilities, highlighting the importance of providing adequate information and support to parents to promote acceptance and positive attitudes toward their child's disability. Parental acceptance of children with intellectual disabilities emphasizes the importance of providing parents with knowledge, resources, and support to help them accept their child's condition and provide appropriate care and assistance. Future research could focus on developing effective interventions and programs to promote parental acceptance and support for families of children with intellectual disabilities.

In the Philippines, parental acceptance of children with intellectual disabilities is also an important issue that has

been studied by researchers. For instance, a study by De Jesus and colleagues (2018) found that parents of children with intellectual disabilities faced significant challenges in accepting their child's condition, including feelings of guilt, blame, and shame. The authors also identified societal and cultural factors that contributed to the stigmatization of disability in the Philippines, which in turn affected parents' attitudes toward their child's intellectual disability.

However, Lumacad and colleagues (2020) in Cagayan de Oro City, Mindanao, aimed to explore the experiences of parents of children with intellectual disabilities in accessing health conditions and support. In the study of Lumacad who had greater knowledge and understanding of their child's condition were more accepting of their child's disability and more actively sought out support and resources. The study emphasized the importance of providing parents with accurate information and support to help them accept their child's disability and navigate the healthcare system.

This study is to enlighten the minds of parents and help children with disability in acceptance. Moreover, the study provides insights into the psychological, emotional, and social dimensions of parent/child relationships and families where a child has intellectual disabilities. It can help us identify the factors that affect parent-child interactions and the ways in which each parent can support the development and well-being of their children with disabilities. However, we conduct the study to help the parent realize that Intellectual Disability is not a shameful situation but rather to understand that is remediable if the parents know how to handle the situation with the help of the people around them.

1.1. Purpose of the Study

The purpose of the study on the parental acceptance of their child with intellectual challenges is to gain a deeper understanding of the experiences of parents with a child with an Intellectual Disability and their families to factors affecting the parental acceptance process and how parents cope with challenges and barriers to the parental acceptance. By improving our understanding of the acceptance process of parents with a child with an Intellectual Disability, the study can contribute to promoting acceptance and inclusion in society and addressing the unique challenges faced by parents with a child with Intellectual Disability. This can lead to improved well-being for parents with a child with Intellectual Disability and their children and can help to promote the rights and dignity of individuals with intellectual disability.

1.2. Review of Related Literature

In a study conducted in Israel, Landesman-Dwyer, and colleagues (2019) examined the experiences of 11 parents with ID. The findings of the study highlighted the importance of social support, self-esteem, and parenting skills in shaping the acceptance process for these parents.

According to (Riess 2017) Intellectual disability provided an emotional bridge to promote prosocial behavior in them as an exquisite interplay of neural networks, and understanding people's emotions could be addressed to distinguish between their own and others' distress.

It plays a key role in intimate relationships, or in the situation with more complexity than it would appear at first according to (Bloom 2017). In the study conducted by Bloom (2017), the role of emotions in intimate relationships and complex situations was examined. Emotions, contrary to their often-underestimated significance, were found to play a pivotal role in shaping the dynamics of intimate relationships and navigating situations that may initially seem straightforward but possess underlying complexities.

Another statement given by (Gusrianti et al. 2018) that intellectual and developmental disability makes it possible for parents to reduce the negative feelings and behavior of their children, it elicits different responses in their parents, e.g., denial or neglect. (Ashori et al. 2019). Gusrianti et al. (2018) explored the impact of intellectual and developmental disability on parents and found that it can lead to a reduction in negative feelings and behavior exhibited by their children. Parents of children with intellectual and developmental disabilities often develop unique coping mechanisms and adaptive strategies to address the specific challenges they face. Despite the initial difficulties associated with the disabilities, parents tend to demonstrate resilience and display a range of responses to the situation.

Attitude and acceptance rate of the parent, knowledge rate and parenting skill, self-confidence, and interactional and multi-layer of parent-children relationship are some factors originating from the mental health of mothers. Furthermore, in a qualitative study within a Swedish context, Aspelin, Östlund, and Jönsson, (Citation2020) showed that special educators considered trusty relationships with students to be fundamental to successful professional work with students with special needs. It has been determined in many ways through research that children with ID need persons in their close environment to be tentative and flexible to achieve successful learning opportunities (Dunst et al. Citation2001).

Other factors related to parenting a child with an ID that may negatively impact parents' mental health may include disappointment that their child will not reach the career ideals they had envisioned or feelings of embarrassment, shame, and isolation. In this study, a higher risk for a psychiatric diagnosis of anxiety, depression, and anxiety and depression together was associated with the gender of the parent. (Russell, 1986).

Parents of people with disability are often referred to as 'carers. This 'carer' labeling devalues parents' roles and responsibilities and diminishes the relationship between mothers and their adult/child with a disability (Nolan, Grant & Keady 1996). Indeed, as Beckett (2015) asserts, the stigma of labeling and stereotyping a person with a disability spread to family members and close others. However, most parents do not identify themselves as in the carer category and argue the clear distinction between 'caring for' and 'caring about someone (Kelly 2016: 17–24). Having a child with ID often requires a reorientation and re-evaluation of family goals, responsibilities, and relationships. (Gohel, Mukherjee, & Choudhary, 2011; Karmanshahi et al., 2008.)

1.3. Research Questions

This study sought to answer the following questions:

1. What are your experiences of having a child with an intellectual disability?

    1.1 How do you feel after finding out that your child has an intellectual disability?

    1.2 How old is your son and what condition does he suffer from?

    1.3 What special times or accomplishments did your child with an intellectual handicap have?

2. What are the struggles encountered by the denial and acceptance of the parents of their child with an intellectual disability?

    2.1 How do you usually react when your child's intellectual disability is diagnosed or confirmed?

    2.2 What difficulties or worries do you frequently encounter when adjusting to your child's intellectual disability?

3. What insights can be gained from the experiences of the learner and parents?

    3.1 What would you like people to know and understand about children with special needs?

    3.2 What insights have been obtained from this process and how has the path of embracing and supporting their children with an intellectual disability influenced the parents' values, priorities, and beliefs?

2. Methods

2.1. Research Design

This study used a qualitative research design utilizing a phenomenological method. The word "phenomenon" is defined as an observable fact or event. A series of extraordinary or unusual things are called "phenomena" (Proofed, August 2022). Phenomenological research is a qualitative research approach that seeks to understand and describe the universal essence of a phenomenon (DELVE-March 16, 2022).

It also helps us understand what is like to experience a specific situation or life event. This approach 'studies the structure of various types of experience ranging from perception, thought, memory, imagination, emotion, desire, and volition to bodily awareness, embodied action, and social activity including linguistic activity" (Smith, 2016).

2.2. Key Participants

The study may involve purposive sampling to recruit participants who have experience with accepting a child with an intellectual disability. Participants may be recruited from disability support organizations, schools, or online support groups.

2.3. Data Collection

The researcher will use one or more data collection methods, such as in-depth interviews (IDI). In-depth interviews are a common method for phenomenological research because they allow participants to explore their experiences in detail. The researcher may use purposeful sampling to encourage participants to share their experiences and perspectives.

This study selected descriptive phenomenology as the research paradigm for the proposed study because the research questions were concerned with gaining insight into the lived experiences of parents who have very young children with intellectual disability.

Overall, the methods used in a phenomenological study of parents' acceptance of their child with an intellectual disability will be focused on gaining an in-depth understanding of participants' experiences and perspectives. The study will use

qualitative research methods to explore the subjective experiences of parents and develop an understanding of the meaning they construct around their child's disability.

Moreover, these were the things to be considered before, during, and after the conduct of the interview. Bracketing was done before the conduct of the interview. This was intended to avoid researchers' biases toward the process and result of the research. The participants were given prior consent to be signed as per the agreement. During an interview, the purpose of the study was explained to the informant as the interview process. These include consent, time allocation for an interview, and audio or video documentation. In addition, the safety health, and interview guide protocols were also observed by the researchers. Maximum of forty-five (45) minutes for interview per informant. The recorded answers were transcribed and translated after the conduct of the interview.

2.4. Data Analysis

The researcher will analyze the data collected using Conceptual Map or other qualitative analysis methods. The Conceptual map is a diagram or graphical tool that visually represents relationships between concepts and ideas to organize the data and identify key themes.

2.5. Ethical Considerations

Prior consent was given to the participants. This form contains relevant information about the study. We respect the privacy of the respondents and maintain the standards of honesty, responsibility, competence, and credibility. All the data are kept with secrecy between the researcher and the participants.

3. Results and Discussion
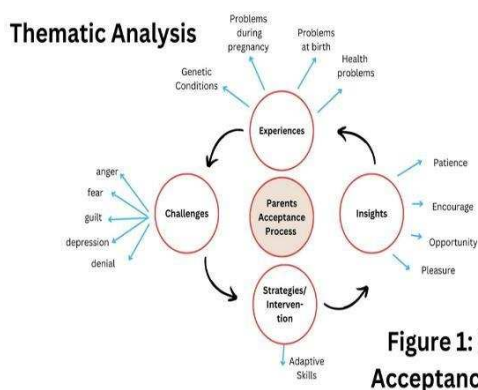
Fig. 1. Parents' acceptance process

The diagram shows four (4) categories in the n acceptance process of parents: experiences, challenges, strategies/Interventions, and insights of parents of children with Intellectual Disabilities.

3.1. Findings

Experiences of Parents' Acceptance Process

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and enormous challenges.

a.   Genetic conditions. Sometimes an intellectual disability is caused by abnormal genes inherited from parents, errors when genes combine, or other reasons. Examples of genetic conditions are Down syndrome, fragile X syndrome, and phenylketonuria (PKU)

During our conversation, some parents mentioned that they have relatives who have intellectual disabilities. There is a parent who inherited from their family bloodline.

b.   Problems during pregnancy. An intellectual disability can result when the baby does not develop inside the mother properly. For example, there may be a problem with the way the baby's cells divide as it grows. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability.

As we discussed with our participants, many of them acknowledged that the stress, anxiety, and traumatic events they experienced because of the phenomenon known as "Super Typhoon Pablo" had a significant impact on their pregnancy with a child who had an intellectual disability.

c.   Health problems. Diseases like whooping cough, measles, or meningitis can cause intellectual disabilities. They can also be caused by extreme malnutrition (not eating right), not getting enough medical care, or being exposed to poisons like lead or mercury.

Mothers also experience health problems and extreme malnutrition based on their statements during the in-depth interview.

Challenges of the Acceptance Process

A quotation from Sensory Processing Parent Support: "Having children with special needs can be challenging. Getting people to understand can be the hardest part."

This study recognized the acceptance of parents' experiences of their child with a disability. It states that parents encounter or undergo an event or occurrence to their child with ID. Let's look more closely at these emotional reactions and how they might fluctuate over time.

It plays a key role in intimate relationships, or in the situation with more complexity than it would appear at first according to (Bloom 2017). In the study conducted by Bloom (2017), the role of emotions in intimate relationships and complex situations was examined. Emotions, contrary to their often-underestimated significance, were found to play a pivotal role in shaping the dynamics of intimate relationships and navigating situations that may initially seem straightforward but possess underlying complexities.

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Some parents of children with disabilities that we interviewed they experience or deal with the loss of their original hopes and dreams for their child. We found out that the following mentioned above play a part in the parent experiences having a child with disabilities. The parent did not expect that her child is diagnosed with an Intellectual disability. They taught that their child is just normal like their siblings. The parents were alarmed when the teacher calls-out to have a face-to-face conference regarding the child and some of her co-teachers joined our conference and give an explanation about the academic performance of the child. The teacher asked permission they will allow the daughter to have a psychological

assessment. From that time, the parent rejects the offer because they cannot afford to send their daughter to have a psychological assessment, but the teacher insists and promise that the Department of Education (DepEd) with the Special Education Fund will shoulder the assessment of their child. The teacher and the child go to Davao City specifically to Fapia General Hospital room 108 to conduct the assessment. They waited for two (2) weeks to hand in the result. From the confirmation of the teacher and confirmation from the psychologist, the parent did not reclaim the result. They accepted their child and support them in every way. Most of the parents challenge the following emotions: fear, guilt, depression, denial, anger.

There is a parent who answered that they somehow blame for the disability of their child which may result in guilt. Two parents experienced a denial stage and anger in accepting their child with Intellectual Disability.

Coping Mechanism (Strategies/Interventions)

"The child's humiliation in the neighborhood, among friends and classmates, and another rumor spread by others around the youngster are the "eye-openers." Parents seek information on the disorder as an active way to cope.

This study found that social support from organizations is important and crucial for parents of children with developmental difficulties. Even while they offer priceless emotional support, family and friends frequently lack the expertise, experience, and understanding of raising a kid with special needs. Consequently, enlisting the aid of groups and developing connections with others.

According to information acquired from parents during the interviews, it is believed that to overcome obstacles, each person must develop their own strategy for handling criticism and other factors that may influence the acceptance process.

This study revealed the coping mechanism in handling children with Intellectual Disability. It is with the use of:

Adaptive skills. Many children with intellectual disabilities need help with adaptive skills, which are skills needed to live, work, and play in the community. Teachers and parents can help a child work on these skills at both school and home. Some of these skills include: communicating with others; taking care of personal needs (dressing, bathing, going to the bathroom); health and safety; home living (helping to set the table, cleaning the house, or cooking dinner); social skills (manners, knowing the rules of conversation, getting along in a group, playing a game); reading, writing, and basic math; and as they get older, skills that will help them in the workplace.

Some parents respond that they requested a tutor for their child. To aid in their child's socialization, several parents enrolled them in group play.

Insights of Parents' Acceptance Process

The more you know, the more you can help your child. Having a child with Intellectual difficulties plays a vital understanding and support of parents. Along the way, parents may experience challenges in handling their child and understanding the coping mechanism that helps to improve their child. Despite this, the Acceptance process is very important to face this positively.

Here below are some insights that the parents we interviewed shared:

Parents 1 and 2 stated, "Be patient, be hopeful." Parents' insight implies that the child has a whole lifetime to learn and grow. Never surrender and be hopeful for your child.

Parents 3 and 4 stated, Encourage independence in your child." For example, help your child to learn daily care skills such as dressing, feeding him or herself, and other practical things that they will be independent.

Some parents also stated that "Find opportunities in your community for social activities." Like, recreational activities, sports, and so on. Lastly, take pleasure in your beautiful one. Acknowledge that your child is a precious one. Learn from your child. Those with Intellectual disabilities have a special light within—let it shine.

In a study conducted in Israel, Landesman-Dwyer, and colleagues (2019) examined the experiences of 11 parents with ID. The findings of the study highlighted the importance of social support, self-esteem, and parenting skills in shaping the acceptance process for these parents.

3.2. Conclusion

This study emphasizes how parents embrace their children who have intellectual challenges. Parents' experiences can range from issues throughout pregnancy to issues with birth to health issues. However, parental experiences are acknowledged and verifiable. While accepting their child, parents may experience obstacles such as rage, anxiety, guilt, despair, and denial. With the application of adaptive skills, as described in the study, coping mechanisms are considerably more crucial when combined with the acceptance process. This study provided insights that will aid other parents in knowing how to embrace their children to develop an accurate and profound intuitive grasp of parents' acceptance.

Individuals with parental acceptance were able to overcome the experiences, challenges, coping mechanisms, and insights in the acceptance process in handling their children with intellectual disabilities.

4. Recommendation

Based on the researcher's framework. model of parent involvement and the findings of this study, future studies can build upon this study. For example, researching the specifics of how having a child with a severe intellectual disability impacts parent involvement would be further. the understanding of the choices of parents about involvement daily.

Additionally, the findings of this study can be used to strengthen the interactions between the school and home settings to increase parent involvement activities and provide opportunities to inform the school about the child's intellectual development.

The researcher also recommends that even though the parents in the research accepted and embraced their child's intellectual needs, the researcher further recommends exploring the need for interventions to facilitate parents in increasing their capacity in caring for a child with an intellectual disability.

Researchers in the future can improve upon this study. This study should be repeated with a larger sample size and in other parts of the Philippines. This study can also be replicated by using different disability categories (learning disabilities, emotionally disturbed, etc.) or different levels of severity.

For additional information on parent involvement, future research can include a study on how communication is perceived and received by parents and what types of communication is most effective in encouraging parent involvement.

Acknowledgements

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