

Sa Ugoy ng Duyan: Mothers Raising a Child with Down Syndrome

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ABSTRACT

One of the most prevalent neurodevelopmental disorders in the country is Down syndrome. Raising a child with this disorder is not an easy feat for the parents or caregivers. This descriptive phenomenological study intends to explore the experiences of mothers in Lucena City in raising a child with Down syndrome. Ethical clearance was granted by the ethical review board. Trustworthiness and

rigor were also ensured. Data thickness and rich descriptions were achieved through the five (5) participants who were chosen through criterion sampling with the help of key informants from the SPED department. The narratives were gathered through the unstructured interview. Transcribed narratives were analyzed through the use of Collaizi's (1978) method and result into three (3) themes namely: (1) Pakikipaglaro sa Tadhana: A Pleasant Controversy, (2) Paghehele sa Problema: Guts and Glory and (3) Pag-aakay sa Kinabukasan: Stronger till the end. The outcome unveils the world of these mothers not only with a glimpse of their adversaries but mostly features this as a blessing in disguise. Their child's condition has helped bring community awareness and perspective on people in the same situation. Their experiences have also inspired other parents who likewise struggle with having a child with different abilities.

Keywords — Social Science, Down syndrome, Qualitative, Lived experiences, Philippines

INTRODUCTION

Everyone is vulnerable to any abnormalities. Chances of encountering pessimistic feedbacks from the society can be easily foreseen by the individual who suffers a certain type of an unusual condition. They may come in different types and may also come with various anomalies. Down syndrome turns out to be one of the most prominent of all disability-related cases. In our country alone, according to Down Syndrome Association of the Philippines, Inc. (DSAPI), a child with Down syndrome is born every 4 hours and is present in 1 out of 800 Filipino children causing widespread discussions of their inclusion to the society (Punay, 2015).

Down Syndrome (DS) or trisomy 21 mainly features physical or aesthetic issues and defects. DS individuals have a variety of physical characteristics like a small chin, slanted eye, low-set ears, poor muscle tone, a flat nasal bridge, a single crease of the palm and a protruding due to a small mouth and large tongue. Other features may include big toe, an abnormal pattern of fingerprint and short fingers (Asim, Kumar, Muthuswamy, Jain & Agarwal, 2015). Just as the downside of having a grotesque appearance, the cognitive or intellectual feature is also refined in having delayed or inherent abnormalities and is considered as the most common cause of intellectual disability (Cohen, 2005). Research conducted in finding the cause dates to 1886 wherein various conclusions had

been made including uterine exhaustion in older women as they grew older. Hence, increasing the risk of giving birth to a child with DS which is then narrowed down as a catalyst of frequent meiotic non-disjunction, a chromosomal abnormality (O'Connor, 2008).

Meanwhile, an intellectual disability which is also referred to as general learning disability or mental retardation is commonly known as an impairment of intellect and cognitive state of a person. Interaction, as well as their way of adaptation, is altered, resulting in isolation and difficulties of adjusting oneself in every situation like common engagements to hardships in living a normal life. Just as this case is multi-factorial, this disability is subdivided into two which is a syndromic intellectual disability, referring to medical or behavioral signs (e.g. Down syndrome, Fragile X syndrome), and non-syndromic or idiopathic intellectual disability, which then occurs without other abnormalities. Unfortunate as it is, problems related to this are incurable and can only be aided by professional or relational backgrounds whose expertise realms around psychopathology with concerns to perceived social or network support (Cicchetti & Cohen, 2006).

According to Samaniego (2015), such factors include genetic disorders, congenital hypothyroidism and environmental factors (e.g. alcoholism, nutritional deficiency, physical trauma, and medications). Moreover, this can be manifested by an indication of unusual temperament, self-injurious and hyperactivity or inattentive behaviors observed during their initial stages of development. However, it was still diagnosed using mental status examination which is usually taken when a child starts to study and go to school. Results from the test with lower than average intelligence support the fact that one is suffering from intellectual disability.

These cases were predominantly discovered in the stage of prenatal or early childhood by their guardians or gynecologist. Even though considered incurable and prescribed as having various alterations such as short attention span, poor judgment, impulsive behavior and slow learning, some skills can still be attained yet it only takes more time in developing compared to those without it. Professionals under health, social services, and education play a significant role in providing support for it is beneficial to the development of one with learning disabilities and as well as the intensity of relationship of the individuals within that family (Ward, 2001).

This correlates to the topic of how parents of those who have that condition cope with this type of situation. Primarily of how they react and inducement of

chronic sorrow due to impending realizations of being in a tragic situation was only an initiative to the occurrence of the situation (Lindgren, Burke, Hainsworth & Eakes, 1992). Parents may feel distressed, grieved, confused and angry as an effect (Einfeld & Emerson, 2009). May even sought for a formidable choice like consideration to religion or various beliefs to encourage each faith and somehow deduce confrontations due to the consequence faced but may end up thinking about the consequences that they possibly face in the future.

Parents entering the world of having a responsibility to a child with DS often encounter a confusing array of treatment options and opportunities which means determining where to focus will always be an onerous task. Physical therapies as an example play a critical role in providing long-term functional outcomes to the prevention of abnormal movement patterns which is known to be an essential onset for the task of learning in the child (Winders, 2001).

Furthermore, Kishore (2011) stated that the fountainhead of stress and negative emotions to mothers and caregivers are derived from a child's sense of needs to accomplish optimal maintenance of health and maximal security for his or her future. This includes problems related in nurturing a disabled child in terms of financial prospect and significantly on the behavioral aspect considering that children possessing that case bring adept distraction to parents and teachers whenever they feel challenged in a difficult task. Contrary to the negative outcomes, parents may acquire new opportunities when undergone to adjustment processes like personal growth and tangible gains. Conflicting emotions such as jealousy, embarrassment, and anger could be reciprocated in such profits like increased empathy, patience and sensitivity when having a child with DS (Levine, 2002). Therefore, positive perception does exist in the latter part of childhood and serves as a compliment in minimizing marginalization among the development and assured future for the child (Cohen et al., 2011).

After a long and in-depth research about Down syndrome, it provides the parents with perceptive clarification of the condition of the child that takes a sensible expectation about what will happen in the future, hence, it concludes less stress and worries about the future (Fidler, Hodapp, & Dykens, 2002). For mothers, the primary caregivers, stress levels were strongly related to their child's self-sufficiency. When children with disabilities can walk alone, handling and physically caring for them becomes easier for their parents. Despite changing the gender roles, mothers still tend to have primary responsibility and essential obligation for child care and are, thus, most subjected to the challenges associated to their child's disability (Gray & Holden, 1992).

This study aims to discern the experiences of the mothers in raising a child with Down syndrome and intellectual disability in relation to their psychological related perceptions and as well as determining the coping mechanisms or strategies that they used in trigger events, circumstances. Garnered data were then analyzed and interpreted with the aid of using Colaizzi's Method as accurately applied to studies with a descriptive phenomenological approach.

METHODOLOGY

Research Approach

A qualitative research method is found useful in deciphering the output of the study as it was relatable to a phenomenological study.

The study aimed to analyze the experiences of mothers raising a child with Down syndrome whereas a phenomenological approach was utilized. Derived descriptions from the co-researchers were improvised and concluded by means of finding the familiarity with it. Lopez and Willis (2004) argued that singularity of information among the lived experience of an individual or a group of people do exist with precise and accurate definitions. Therefore, generalizing this phenomenon relates as indisputably applicable for any occasion within this type of study.

Phenomenology

Wojnar and Swanson (2007) citing Lopez and Willis (2004) eloquently stated that phenomenology is a way of understanding the people's everyday lived experience. The aim of phenomenology is to convey the experiences by using Colaizzi's (1978) strategy of descriptive phenomenological data analysis in a qualitative research.

Descriptive Phenomenology

A descriptive phenomenological approach helped the researchers in analyzing the phenomena occurring in the field of raising a child with Down syndrome. Descriptive phenomenology is found as the most reliable source to the development of findings on a universal aspect.

Descriptive phenomenology is the philosophical foundation of Husserlian Phenomenology that follows a five-step system of the method of researching. In doing so, Giorgi's (2009) five-step system gives the precise thoroughness of "science" while not being reductionistic in its treating of the people contemplated.

Moreover, the strategy is disclosure situated instead of check arranged. Descriptive phenomenology clarified that it is more helpful for a systematic investigation to pinpoint the general aspects of the phenomenon that were never conceptualized or deficiently conceptualized in a research (Wojnar & Swanson, 2007).

Process Of Reflective Analysis

Colaizzi's method of analysis provides an active strategy in describing the lived experience of a person of a group people. This includes the extraction of data and to formulate significant meanings through the narratives. The level of data saturation was determined by the researchers in a process carried out in parallel with data collection. The expressions were deciphered and interpreted as a whole in consideration with a certain condition (Wojnar & Swanson, 2007).

Establishing Trustworthiness and Rigor

Trustworthiness to all of the information was given importance as this possesses a subjective viewpoint that should be kept in a confidential manner. Criteria for trustworthiness in subjective research are actually the same to the paradigmatic underpinnings in which a specific examination is directed. The researchers treated the interview with an in-depth consideration to avoid the exacerbation of negative feelings that will disorient the participants and the data.

Trustworthiness has been divided into confirmability, dependability, transferability, and credibility. Moreover, the researchers consistently utilized the technique to guarantee immaculate elucidation of garnered information.

Ethical Consideration

Containing the anonymity of the co-researchers, collecting the assets and liabilities of the research and acquiring the informed consent were the ethical constituents preferred for application to the study. The ethical clearance beforehand was reviewed by the research adviser which includes the procedures and research questions that are answered by the co-researchers. Ahead of the interview are the justification and clarification in the form of written explanations of the purpose and the essence of the study condensed into informed consent.

Potential co-researchers were contacted and were given a brief discussion on the coverage of the study, informed consent, and the recession of procedures and set a fixed date, time and place for the interview. The co-researchers were given a free will so that they may retreat whenever they feel ashamed or stress. Thereupon, the overall activity of the collection of data procedure, analysis, usage, and storage was tackled during the transaction of the researchers and co-researchers.

RESULTS AND DISCUSSION

Three (3) major themes were generated in the narratives namely: (1) Pakikipaglaro sa Tadhana: A Pleasant Controversy, (2) Paghehele sa Problema: Guts and Glory and (3) Pag-aakay sa Kinabukasan: Stronger till the end.

The theme Pakikipaglaro sa tadhana: A pleasant controversy initially descends after the thorough process of research analysis. Under these are the three subtopics namely (1) Searching for Enlightenment, (2) Social Dilemma: Blessing or loss of reputation and (3) Will of God. Which discusses how mothers embraced the climacteric changes of having a child with Down syndrome on the initial time onset like doubting of the occurrence of the child, receiving of degrading side comments or appraisals and consideration to the situation as a perfect planned by God. **Vilma** shared her experience about finding answers and how they found the answer regarding the situation.

“At first, we blame each other saying it’s your fault, my fault, why is he like that? When the Doctor explained to us that it’s no one’s fault, just pure accident, we just accepted it, cause it’s our child, we can’t give it to other people because it is our flesh and blood.”

Judy added:

“At first, their father asked why, why is he born like that? But we explained the situation. Before, my husband doesn’t want him to attend school, “What will he learn there?” he said. I’m the only one who is insisting it.”

In addition, the co-researchers experience social judgment that is either positive or negative criticism. **Judy** stated that:

“Of course, in a married couple it’s like you can’t accept it at first. Every time I would go to the health center, I feel humiliated. Sometimes other people tell that my child is a blessing.”

Vilma said that:

“I can see in their eyes that they are judging me. That’s why sometimes I pity myself.”

Some co-researchers regarded the situation as a planned of God where they whole-heartedly express their gratitude towards Him. **AiAi** said that.

("I would tell the Lord God if you take my life take my daughter's life too; if you take hers then take mine as well.")

Maricel further elaborated that:

("We don't want that to happen. It is beyond our control. That's why we say that it is a blessing from Lord God. We don't blame each other, we are thankful instead.")

Another theme unfolded in the process is Paghehele ng Problema: Guts and Glory. This is then divided into two subtopics which are the (1) Sacrificial Support and (2) Financial Stability and Standings. It addresses how mothers cope and how they handle the responsibility of having a child with Down syndrome like assessing how they handle tantrums, providing the child's wants and finally nurturing the child to the fullest along with an extra burden of balancing the needs or finances of the family. The co-researchers handled the responsibility and sacrificed everything for the sake of her child. According to **Vilma**:

("There is a time that when he takes a nap in the afternoon, he would still be up until 12 midnight or 1:00 am. He would get up, go upstairs and downstairs that's why I had to be awake as well since I'm the only one taking care of him.")

Jaclyn added:

("Once he wants something, "ate I want that, ate" He will be accompanied to the mall. If he wants something, his sister must buy it immediately. Because if you don't buy it, he would stay on that spot and he wouldn't move there until you buy that thing. That's why if you bring him to the mall you must have money.")

Moreover, the co-researchers also experienced problems and challenges related to finding enough money to provide the needs of their child, especially the medical demands that is compulsory sometimes. **Vilma** expressed that:

("That's why his father works harder to provide finances because it is hard to earn money here in the Philippines, it is very insufficient. Especially that I want him to undergo OT and therapy...")

Sisa further added:

("I don't take her as a problem because my problem is money and where to get it that's why I'm striving...")

Judy further elaborated by sharing:

("At first, when he came, we need money, because he is always needed to be brought to the hospital that's where I have to spent all of our money.")

The last theme generated was the Pag-aakay sa Kinabukasan: Stronger Till The End which depicts two subtopics namely (1) Enriching Family Ties and (2) Source of Joy which then presents how their family established a stronger bond as well as the joy that the child brings to everyone. One of the co-researchers, **Vilma**, refurbished family connection:

("He helps me. Whatever it is you just need to accept it even though it is hard because they are only two. I'm not supposed to cry but, at least his brother, I see how he studies very well, his grades are good and he is always on the honor list...")

Jaelyn added that:

("His father loved him. Even his siblings, they love their brother. Yes, they accept their brother and give him whatever he wants. When he tells them that he wants to buy that, his siblings buy it immediately.")

Maricel elaborated that:

("She's close to her father. Her siblings love her very much. They take care of her just so much despite her condition.")

The joy of having the child in their life along with the happiness that they shed on the family is also experienced by the co-researchers. According to **Vilma**:

("There are times that he is always happy, he's clingy and sweet. It is okay because he is happy that is why we are happy.")

In addition, *Judy* stated that:

(“He is thoughtful and clingy, most of them are sweet, always clingy. Stay away from him because of back pain. His father would tell him to then he will still do something at his back even with my co-mothers and to his teacher. Then he kisses the hands of elders to show them respect.”)

CONCLUSION

The study determined the essence of mothers raising a child with a Down syndrome. The superiority of a descriptive phenomenological approach proposed by Edmund Husserl was shown throughout the study. The co-researchers were chosen through purposive criterion sampling and with the help of the SPED teachers under the unit of mental retardation serve as the key informant of the study. Five (5) co-researchers agreed to take part in this study. Wherein, they qualified on the following criteria: (1) Should be a female Filipino citizen living in Lucena City and may be legally married, widowed and may or may not have another child. (2) Should have a child with Down syndrome. (3) Should be willing to give information and genuine answers with regard to the topic.

Colaizzi’s Method was used in doing the reflective analysis. Garnering three (3) major themes from the data namely; (1) Pakikipaglaro sa Tadhana: A Pleasant controversy; (2) Paghehele sa Problema: Guts and Glory; and (3) Pag-aakay sa Kinabukasan: Stronger Till the end. Sustaining a careful reflection led to the understanding of the essence of the mothers raising a child with Down syndrome, as characterized by having faith, resilience, flexibility, submissiveness, and optimism.

The co-researches showed optimism which that takes part because they never let those negative thinking dominate their lives. They have become productive instead of being trashed and helpless by transforming negativities such as stress, grief, and anger into a positive one. Helping themselves see the bright side of having a child with Down syndrome in the family. The mothers fearlessly face the problems with raising their child. They were able to offer their own time for their child to give them better future and to secure their safety.

IMPLICATIONS

- ✓ Groundwork research about other façades or perspectives of mothers in raising a child with Down syndromes like on how they cope with the rising demands and adjust themselves from tantrums or other manic reactions.
- ✓ Endorsements of additional aides in finance or assistance on needed therapies on a phase of renewed and much faster distribution for the disabled patients like Down syndrome from the government.
- ✓ Provide or informed people of free consultations for the parents from a professional to expand their knowledge on how to handle provocative problems like pampering tantrums or even in the balancing of daily needs from various demands.
- ✓ Publicly informed the community about the case through the deployment of productive seminars, meetings or cultivating activities with a goal of establishing camaraderie among community people and families with a Down syndrome patient and other disabled.
- ✓ Establish organizations whose committed and imbued on assisting or launching innovative programs not only for the child with a disability but as well as to their parents.

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