

Primipara: Advanced Maternal-Age Mother Dealing with A Child with Congenital Anomalies

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Abstract -The rising number of pregnancies among women over 35 reflects a global trend of delayed motherhood. Advanced maternal age, defined as 35 years or older, increases the risk of pregnancy complications, including congenital defects that impact both the child's and parents' well-being. While medical research on congenital defects is extensive, little is known about the lived experiences of older first-time mothers. This phenomenological study explored how these mothers cope with raising a child with a birth defect through unstructured interviews with five primiparous women of advanced maternal age. Data were analyzed using Van Manen's lifeworld existential: lived body, reflecting emotional and behavioral responses; lived time, capturing the journey from diagnosis to advocacy; lived space, revealing daily challenges; and human relations, emphasizing the importance of support networks. Despite significant difficulties, the study found that the mother-child relationship was marked by deep love, resilience, and personal growth. Ultimately, it highlights how adversity can strengthen family bonds and underscores the need for supportive environments to help these mothers navigate their complex realities.

Keywords: *primipara, advanced maternal age, congenital anomalies, phenomenology, lifeworld existential.*

Introduction

Childbirth is a great transformative experience that signifies the upbringing of a new life. However, childbirth is a delicate phase for primiparous women in advanced maternal age (AMA), who are at risk of having a child with congenital anomalies and may face significant challenges in raising their child. This study has focused on the lived experiences of primiparous women in their advanced maternal age dealing with a child with congenital anomalies.

Previous studies delved into the real-life experiences of mothers who have children with congenital abnormalities. According to Bonanno, Bennett, and Pitt (2013), some parents with a child with congenital abnormalities may have different experiences and challenges. Abbasi et al.

(2016) stated that mothers often exhibit high levels of stress, anxiety, negative emotions, self-blame, and apprehension toward anticipated future issues in their children, which may suggest that motherhood is a complex and multifaceted experience that can be emotionally and psychologically challenging. These concerns need to assist and help mothers maintain their well-being and that of their children.

A recent study in the Philippines revealed the influence of advanced maternal age associated with adverse birth and child outcomes that result in an inconvenient situation for a child wherein the mother experiences twice these sufferings and more (Barona et al., 2013). The research involved examining how 2 Filipino mothers perceive their experiences with children born with an anomaly using the 7D Prism Eidetic. The findings revealed seven dimensions of their experiences: disbelief, defensiveness, drama, dismay, determination, devotion, and dismissal. These dimensions reflect the stages of adjustment the participants underwent upon discovering their child's condition. Disbelief is the initial reaction to unexpected news or events. It involves denial or shock, often as a defense mechanism to cope with sudden change. Defensiveness is the response to perceived criticism or threat. They are characterized by protecting oneself through justification, counterattacks, or resistance to change. Drama is an exaggeration or emotional reactions to situations. It often involves heightened emotions, conflicts, and attention-seeking behavior. Dismay is the feeling of disappointment or distress. Arises from unfavorable outcomes or situations that did not meet expectations. Determination is the firmness of purpose and resolve. Involves persistent effort and commitment towards achieving goals despite obstacles. Devotion is strong dedication and loyalty. Often seen in personal relationships, careers, or causes that one is passionate about. Lastly, dismissal is rejecting or disregarding ideas, feelings, or people. It can be an intentional decision not to engage or an unintentional oversight. Varona, Reyann, et al. (2013) Although mothers may experience mixed feelings of acceptance and unacceptance, a recent study found that their love for their children is undeniable and unconditional.

Moreover, in some countries, the percentage of mothers giving birth at the age of 35 years old and above is prominently higher compared to previous years. For instance, opening up education, employment, and other career opportunities for women have fundamentally changed the temporal pattern of reproductive behavior by providing alternative roles that compete with motherhood (Van de Kaa and Goldin, 1987, 2006). Longitudinal research has illustrated many benefits of postponement, including better family functioning, greater family stability, and more stable financial situations for the parents. Delaying parenthood, therefore, strongly influences women's income and promotion at work, especially for those women graduating from college (Taniguchi and Miller, 1999, 2010).

Researchers recognize the profound influence of a child born with abnormalities on a mother's welfare. Understanding the mother's lived experiences enables the researchers to conceptualize their daily lives with all the complexity and intricacy. The study will allow the researchers to unravel the complex phenomena of this subject to promote awareness regarding the situation and foster a supportive environment for mothers dealing with a child with congenital anomalies.

Methods and Materials

This study employs a hermeneutic phenomenological design, a qualitative approach used to explore and interpret the lived experiences of primiparous women of advanced maternal age raising children with congenital anomalies. By capturing participants' detailed narratives, the study

seeks to uncover the profound meanings behind their shared experiences. Through empathetic, open-ended, and in-depth interviews, researchers analyze how these mothers navigate the challenges and sources of strength in their unique circumstances.

The study includes five primiparous women aged 35 and older with children diagnosed with congenital anomalies. Participants were selected using snowball sampling, a method that relies on referrals from existing participants to identify others who meet the study criteria. This approach facilitated trust-building and ensured the inclusion of individuals with relevant lived experiences. Data saturation was reached after interviewing five participants, as no new themes emerged.

Data collection was conducted in Cebu, Philippines, with interviews held in the participants' homes to ensure a comfortable and familiar environment. The setting allowed mothers to openly share their experiences in a space where they felt safe and at ease. An unstructured interview method was used as the primary data collection tool. Open-ended questions encouraged free-flowing conversations, allowing participants to share their experiences in depth. This flexible approach enabled researchers to explore emerging themes while ensuring the consistency and relevance of responses.

Before conducting interviews, researchers obtained ethical approval from an institutional review board (IRB) and secured permission from the academic institution. Participants were provided with informed consent forms detailing the study's objectives, potential risks, benefits, and confidentiality measures. Interviews were audio-recorded with participants' consent, then transcribed for analysis. To maintain ethical integrity, participants' identities remained anonymous, and all collected data were securely stored.

Data was analyzed using Van Manen's four lifeworld existential: lived body, lived time, lived space, and lived human relations. NVIVO 10 software was used to organize and code interview transcripts. Thematic analysis was conducted to identify patterns and deeper meanings in participants' narratives. Each researcher independently transcribed and reviewed the data to ensure accuracy and minimize bias. To ensure the study's credibility and reliability, triangulation was employed by cross-referencing data from multiple participants. Prolonged engagement, persistent observation, and peer debriefing were used to enhance credibility, while audit trails and member-checking supported dependability. Confirmability was ensured by maintaining an objective approach in interpreting participants' experiences, and transferability was achieved through detailed descriptions of the study's findings.

Ethical principles guided every stage of the study. Informed consent was obtained from all participants, ensuring voluntary participation and strict confidentiality. Respect for persons was upheld by treating participants with dignity and allowing them to withdraw at any time without consequences. Beneficence was ensured by prioritizing participants' well-being, minimizing risks, and emphasizing the study's potential benefits in improving support systems for mothers of children with congenital anomalies. Justice was maintained by promoting fairness, inclusiveness, and ethical integrity, ensuring that all voices were respected and accurately represented. This methodological framework ensures a comprehensive and ethically sound exploration of the lived experiences of primiparous women of advanced maternal age, providing valuable insights into their challenges, resilience, and support systems.

Results and Discussion

The researchers utilize Van Manen's four lifeworld existential to understand, interpret, and analyze the collected data. By analyzing the obtained data, the researcher identifies two themes for each lifeworld existential. This employed storytelling techniques and vivid language to capture the essence of their experiences, allowing the participants to bring to life their own lived experiences and highlighting the struggles, resilience, and growth that emerged from their journey

Life Worlds	Themes
Lived Body	Affective states
	Handling a Delicate Butterfly
Lived time	Strength, Adaptability, and Challenges
	Embracing Resilience and Growth
Lived Space	Environment
	Societal Expectation
Lived Human Relations	Relational Nexus
	Unbreakable Bond

Lived Body

Van Manen (1997) stated that the lived body is one of the four lifeworld existential; it refers to the physical body or the bodily presence that we may encounter in everyday life, including all that we feel, conceal, reveal, and share through our lived body. Through the body itself, we are constantly present in the world; as such, it is through our lived body that we communicate, feel, interact, and experience the world.

Affective States

One of the common reactions for mothers after knowing the condition of their children; the effect can be devastating. As Blachar & Bakar, 2001; and Hill & Rose 2009 emphasize, the initial reaction of a parent would likely be negative, which is related to bereavement, especially if it is their first-born child. Then, a period of questioning will follow which may go on for months and years, as to why this should have been experienced.

“When the doctor told me my baby had a congenital anomaly, it felt like the air had been sucked out of the room. My hands went cold, and my heart was racing. I remember just staring at the ultrasound screen, not really understanding what I was seeing, but knowing that my life had just changed forever. I couldn’t sleep for nights afterward—I kept thinking, ‘Did I do something wrong during my pregnancy? Could I have prevented this?’ The guilt was overwhelming. My body felt drained, like all my strength had been taken away. I barely had the energy to eat or even hold conversations with people. I just wanted to be alone.”

In addition, parents may tend to blame themselves or each other (Scorgie & Sobsey, 2000). When their child's impairment is diagnosed, some parents may experience negative physiological and emotional reactions. The social lives of families that have a kid with a disability undergo substantial changes as a result of this transition. According to Heiman (2002), some people go through periods of extreme stress along with emotions, including despair, rage, shock, denial, guilt, and self-blame. The desires of families are the same as other families in children with special needs, wanting to see their children reach their full potential, to be included and accepted by their community, and to enjoy things together (Baker & Fenning, 2007). Professionals must perceive each child's potential rather than just their impairment; they also need to acknowledge the value and expertise of the parents.

According to Dandy et al. (2023), it is not surprising that these parents experience shock, shame, sadness, and anger after learning of the diagnosis. They may also have a higher chance of developing anxiety, depression, and post-traumatic stress disorder. In addition, Lemacks et al. (2013) stated that parents experience phases of grieving after learning that their kid has a congenital disability. Moreover, Medeiros (2021) emphasized that the mother goes through an emotional process that exhibits the typical symptoms of psychological when she finds out that her child has a congenital deformity. The mother experiences feelings of shame, despair, anger, and doubts about her ability to be a mother. They are denying the facts and the necessity of verifying the accuracy of such a diagnosis.

This theme belongs to the lived body since the lived body itself does not necessarily mean the physical body only; rather, it also covers the feelings, emotions, and experiences of a primiparous mother in dealing with her child with congenital anomalies. Thus, navigating the emotionally challenging realities of having a child with congenital anomalies, particularly in moments of knowing the truth, profoundly affects the psychological and emotional state of primiparous women. The intense feelings of worry, denial, and uncertainty upon learning about their child's condition may hurt their mental state.

Handling a delicate butterfly

This depicts the experiences of a primiparous woman of advanced maternal age in handling a child with congenital anomalies. This helps in determining the challenges encountered by the primiparous mothers in raising a child with congenital anomalies.

Primiparous mothers eventually realize that they need to put forth the effort to provide the best care possible for their children after they can accept the circumstances surrounding them (Mokhtari & Abootorabi, 2019). According to Sukmak and Sangsuk (2018), mothers must balance their roles as parents, mediators, and navigators because they are the center of their children's universe (Vukkadala et al., 2019). In addition, mothers need to learn how to cope with stigma and make every effort to keep their kids safe (Heer, Larkin, et al., 2015). They must also attempt to approach impairment from a different angle and make the wise decision to seek assistance (Heer, Rose, et al., 2015).

“I realized that my child needed me to be strong. I had to learn everything—how to feed, bathe, and lift him carefully. It wasn’t just about physical care; it was about understanding his needs when he couldn’t express them. There were days when he would cry, frustrated, and I had to be patient, even when I was exhausted. People stare, and some make insensitive comments, but I’ve learned to block it out.

My child is my priority, and I will do whatever it takes to give him the best care. It's a daily challenge, but I've grown stronger because of him."

In this theme, it belongs to the lived body because handling a child with congenital anomalies involves the physical aspect of the mother. Depending on the child's condition, it requires various bodily activities, such as bathing, feeding, and lifting. Thus, handling a child with special needs comes with challenges. Children with special needs may struggle to express what they need and want, which can cause them to become frustrated and have tantrums. It is tough and exhausting to control their emotions and behaviors. A mother requires a long patience and resilience to provide a suitable need and wants of her child.

Lived Time

This aims to explore and describe human experiences as they lived. His methodology focuses on the temporal dimensions of experience, capturing how individuals perceive and interact with time, from moments of significant impact to ongoing adaptation and coping mechanisms over the years.

Strength, Adaptability, and Challenges

The core of the human experience is found not just over time but also in the depth of these participants' lived experiences, where obstacles, strength, and adaptation all come together to create the complex tapestry that is my life. Research such as that done by Bowlby (1988) on attachment theory and Bandura (1977) on social learning theory helps to clarify the intricate relationship that shapes mother experiences between an individual's resilience and environmental influences. As a result, this participant's knowledge of becoming a mother is a tribute to the human spirit's persistent capacity to overcome hardship. It is a tale intertwined with resilience. Upon contemplating her path, a participant realized that her son's presence had a significant impact on their family. She learned from his condition the importance of advocacy for children with special needs and the value of unconditional love. Obstacles, fortitude, and adaptability are skillfully woven together in this story to create a complex tapestry of life. Motherhood is a monument to the resilient spirit's capacity to overcome hardship. Reflection reveals the significant influence of a child's presence in the family dynamic in this resilient story. Through this journey, a deep appreciation for the need to support kids with special needs and accepting the transformational power of unconditional love has been developed. These realizations reinforce the idea that social and institutional support networks are essential.

"My son has changed our family in ways I never expected. He taught me the true meaning of resilience and unconditional love. I've learned to speak up, to advocate for his needs, and to fight for his place in this world. It hasn't been easy. There are moments of frustration, exhaustion, and even isolation, but there are also moments of pure joy—when he smiles, when he achieves something, no matter how small"

The theme captures the resilience, strength, and difficulties people face as they navigate their lived time. As time passes, one's accomplishments and personal development are revealed,

along with the wounds and lessons one has learned from hardship. This journey through lived time emphasizes the dynamic interaction between celebrating victories and persevering through adversity.

Embracing resilience and growth

The psychological effects of having a child with a congenital disability, for example, highlight the psychological toll that these conditions take on families and emphasize the importance of strong social and medical support networks. Research on mother experiences highlights the psychological burden and necessity of strong support networks for moms of children born with congenital disabilities. Bernier et al. (2016). Demonstrate how these women often cope with elevated stress and disrupted routines, similar to their experience of learning to value every small victory amid chaos.

“I realized something: I was growing. I was learning. Every small milestone my child achieved, no matter how minor it seemed to others, became a huge victory for us. I started seeing progress where I used to see the struggle. I found strength in the little moments—his laughter, his determination, and his trust in me”.

The theme of embracing resilience and growth. As people learn from and adjust to their past experiences, they experience growth through the prism of their lived time. Every experience weaves itself into the complex fabric of their existence, molding their resilience and comprehension. Future decisions and personal growth are based on this experience, which is full of memories and lessons.

Lived Space

Thinking beyond the physical aspects of locations and proximities necessitated considering the various uses of space, including emotional space, dividing lines between private and public domains, and overstepping personal bounds. As stated by Zhang (2006), it is because another space in itself may not change, but the perception of a person that comes from the experience can make the space finer, subtler, more profound, or more differentiated.

Environment

Life is filled with wonders, yet unexpected challenges can arise, making it even more complex and fascinating. One significant challenge faced by families of children with congenital anomalies is the **lack of empathy**, which contributes to stigma and negative attitudes. This societal judgment often makes it difficult for parents to feel comfortable leaving their homes or interacting with others. According to Lavery (2003), individuals experience the **lifeworld**—the world of lived experience—before they begin to categorize or analyze it. Similarly, Fuchs & Psychother (2007) describe **lived space** as a person's unique ecological niche, constantly shaped by their interactions with the outside world. Norlyk et al. (2013) emphasize that home is often seen as a place of security and self-expression. However, illness or disability can disrupt this sense of belonging, making home feel burdensome and uncontrollable. Patients may experience loneliness and abandonment,

even by those who are meant to support them. As Norlyk, Martinsen, and Dahlberg (2013) highlight, healthcare workers must recognize the impact of spatial factors on well-being, both at home and in hospital settings. Enhancing home environments and fostering a "sense of home" in hospitals could improve patient outcomes and emotional well-being.

"I know my child needs a stable, predictable environment to feel secure. Routines are important, and any small change can be overwhelming for them. Because of this, I do everything I can to create a space where my child feels comfortable, supported, and safe"

For children with congenital anomalies, a stable and supportive environment is essential. Sensory challenges or difficulty processing information can make routine and familiarity crucial to their well-being. A structured environment helps them develop confidence, allowing them to explore and interact with their surroundings despite their disabilities. Lived space, in this context, extends beyond physical surroundings—it includes social and emotional support, accessibility to resources, and environmental adaptations that promote inclusion. By creating experienced surroundings tailored to their needs, caregivers, and society can help improve the overall development and quality of life for these children

Societal Expectations

Depending on society, people have different information and opinions regarding congenital abnormalities and their causes. The community's perceptions of parents' knowledge and views on congenital abnormalities and the factors that increase their likelihood are lacking (Taye, 2021). Furthermore, primiparous mothers are often expected by society to be emotionally strong and resilient, to handle the demands and hardships of raising a child with special needs gracefully and without displaying outward signs of struggle.

"One of the hardest things isn't just the medical side of things—it's how people see and treat us. The lack of understanding and empathy from others makes it difficult to go out and feel truly accepted. Sometimes, I feel isolated, as if the world doesn't quite understand what my family is going through".

Societal expectations greatly influence families' and communities' responses to children with congenital anomalies. These expectations have the power to influence attitudes, actions, and available networks of support. It may be expected in societies that place a high value on self-sufficiency that home modifications will support the child's access and mobility.

Lived Human Relations

In the lived human relation, it reveals the complex and profound multifaceted nature of a primipara in advanced maternal age dealing with a child with congenital anomalies. Through Van Manen's analysis, it allows the researchers to investigate the depth and richness of human connection.

Relational Nexus

Mothers often face the challenges of raising a child with congenital anomalies, which makes them rely on their spouses for both practical and emotional help. Mothers have better emotional well-being when they feel supported. Having someone to rely on and offering support and love helps alleviate some of the emotional burdens. According to Reid S. (2023), healthy relationships with friends and family can lift your moods, broaden your perspective, and protect your mental health.

In the social aspects of motherhood, mothers also deal with expectations and responses from the outside world that might vary from judgmental to encouraging. Her sense of self and belonging is impacted by how her child's illness filters social encounters. It is possible to weave a social fabric that is both supportive and isolating, depending on how friends, family, and strangers respond to you. The reactions of family, friends, and strangers create a social tapestry that is sometimes supportive and isolating. Knowing that her child was being oppressed by lot of people has caused the mother pain. They are aware of the widespread prejudice and criticism, as well as the fact that not everyone can understand their child's condition. However, it is acceptable to them as long as it does not concern their child. Despite all of the love and support, mothers still face obstacles like insensitive remarks or a lack of understanding from others, which increases their emotional burden.

“Even with all the love I receive, there are still moments when I feel emotionally exhausted. Some people just don’t understand what it’s like to raise a child with special needs. I hear insensitive remarks, or I notice the way people avoid us, and it adds to the emotional burden I carry. But through it all, I remind myself that my child deserves love and respect, no matter how others perceive us. I focus on the relationships that uplift us, knowing that the support of my loved ones helps me navigate this journey”

These circumstances highlight the complexity of her social environment, which affects her experience. The relational nexus belongs to lived human relations as it pertains to the connection and interactions of mothers within their social networks. These social networks may greatly influence their behaviors, thoughts, and emotions when dealing with a child with congenital anomalies.

Unbreakable Bond

According to Bjelica et al. (n.d), infants form bonds with their moms even before they are born. Each challenge was met with a mixture of determination and exhaustion. Their bond even grew stronger as they overcame all the challenges they faced. When a mother forms a bond with her child, the child's chances of receiving comfort and protection and surviving to adulthood increase (Cherry K., 2023).

"Even before my child was born, I felt a deep connection with them. It's something I can't fully explain, but I knew we were bonded from the start. No matter how difficult things became, that bond only grew stronger. Every challenge—every sleepless night, every hospital visit, every moment of uncertainty—was met with both exhaustion and determination

The emotional bond that grew between them was intense, a mix of nurturing care and empowering strength. Their bond was a living testament to the power of unconditional love. This dynamic relationship demonstrates the acceptance and resiliency that come with parental love. According to Wise R. (2023), this kind of love accepts your child just as they are, regardless of their behaviors, accomplishments, or circumstances. Van Manen's method allows us to see and understand how these lived experiences lead to a deep and dynamic maternal identity.

The unbreakable bond belongs to the theme of lived human relationships, highlighting the strong bonds and unconditional love a mother establishes with her child. The theme depicts that despite any challenges, they always manage to deal with them because of their unbreakable bond, which allows them to find resilience with each other.

Conclusion

Raising a child with congenital anomalies is both physically and emotionally demanding, especially for first-time mothers of advanced maternal age. This study highlights their journey—one filled with challenges, resilience, and growth. While the weight of caregiving can be overwhelming, acceptance and adaptation help them find strength over time.

Beyond personal struggles, societal judgment and stigma add to their burden. However, a strong support system—family, friends, and healthcare providers—offers comfort and encouragement, helping them navigate this difficult path. Most importantly, the deep bond between mother and child becomes a powerful source of resilience, proving that love and perseverance can overcome even the toughest obstacles. These insights call for greater awareness, better healthcare support, and stronger policies to ensure that these mothers and their children receive the care and understanding they deserve.

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