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Fathers’ Perceptions of Stress and Resiliency in Raising Children with Down Syndrome: A Qualitative Study

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Walden University
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Abstract

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MPhil., Walden University, 2023

MA, Bowie State University, 2000

BS, Howard University, 1995

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
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Abstract

Little was known about how fathers perceived stress and resiliency when parenting children diagnosed with Down syndrome. Therefore, the purpose of this generic qualitative study was to explore perceptions involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand how stress and resiliency affected the parenting skills of those fathers who resided in Prince George's County, Charles County, or St. Mary's County in Maryland. This involved recruiting eight participants who completed semi-structured interviews where they were asked the same 10 open-ended questions. This study involved using a qualitative thematic analysis, was guided by the family resilience theory that supported a better understanding of how fathers of children who have been diagnosed with Down syndrome experienced stress and resiliency when raising their children. Participants in this study reported they experienced stress when raising their children who were diagnosed with Down syndrome. The main stressor that fathers experienced was uncertainty involving their children’s future. They reported that resilience assisted them with strength and the ability to persevere through challenging and difficult situations. The main barriers they experienced when raising their children with Down syndrome were their children’s behavior, communication, and health. They reported they overcame barriers by leaning on the support and love of their families. This study has the potential to lead to positive social change by providing fathers whose children have been diagnosed with Down syndrome with parenting classes and other community resources that focus on stressors that are mostly experienced when raising children.

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Dedication

I dedicate this body of research to my amazing son Amare, diagnosed with Down syndrome, whose life has inspired me to do this work. Also, my dedication is to my husband Ed who has been a constant pillar of strength and love throughout our son's journey.

Acknowledgments

I would like to acknowledge the fathers of the Parents of Down syndrome (PODS) association fully and greatly; as well as, the association's president, and the countless of other parents, advocates, nurses, teachers, specialists, local, regional, and national supports, as well as caregivers, that contribute the quality of life of people with Down syndrome.

I would also like to extend acknowledgements to Dr. Matthew Howren and Dr. Staci McPhaul, my dissertation committee who helped guide me along this scholarly pathway and extended their time and expertise to support this contribution to the literature for special needs children.

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Chapter 1: Introduction to the Study

Many studies have focused on children diagnosed with Down syndrome; however, the majority aimed to understand stress levels of mothers alone or both parents, without addressing experiences of fathers (see Cless et al., 2018; Phillips et al., 2017; Senses Dinc et al., 2019). Little is known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. Therefore, I addressed how fathers experienced stress when parenting children with Down syndrome for different community organizations to offer improved support and resources for these fathers potentially. The Centers for Disease Control and Prevention (CDC, 2019) revealed approximately 6,000 babies are born with Down syndrome each year. Studies have been completed on different parenting styles that are used by mothers who raise children with Down syndrome and coping mechanisms when managing children's adverse behaviors (see Phillips et al., 2017). However, little is known about how fathers experience and cope with stress when raising their children.

Amireh (2019) highlighted the importance of focusing on fathers' experiences with stress and coping mechanisms they use when raising children with Down syndrome. Amireh (2019) demonstrated parents of children with Down syndrome experience considerable stress and highlighted the importance of focusing on fathers and reported a lack of knowledge regarding this important group.

This chapter includes an introduction to the study. I begin by discussing the background of the problem and problem statement and identify the study's purpose and research questions. I then provide an overview of the conceptual framework that guided this study, nature of the study, assumptions, limitations, and delimitations. The chapter concludes with a discussion of the significance of this research of the field of health psychology.

Background

According to Ridding and Williams (2019), society in the United States has been unable to recognize the true importance of men's parenting roles and the extent of their duties, despite changes in socioeconomic conditions and cultural norms that have resulted in an increase in fathers' active engagement in their children's care. There is still a dearth of research regarding fathers as caregivers, as many studies depend on indirect accounts from mothers. Scant amount of extant research involved fathers of children without intellectual disabilities while emphasizing the critical role of parental participation in the development and satisfaction of both children and fathers (see Ridding & Williams, 2019). Ridding and Williams (2019) demonstrated a higher rate of maternal discomfort is frequently associated with confusion about their child's diagnosis and transition points. However, Experiences of both mothers and fathers of children with intellectual disabilities differ, notably in terms of stress (Ridding & Williams, 2019). Fathers have demonstrated higher levels of stress because of their children's social skills and acceptability delays (Ridding & Williams, 2019). Maternal-paternal disparities can be explained by variations in terms of coping techniques, such as suppressing feelings to protect their family and overcoming obstacles alone, owing to less available assistance (Ridding & Williams, 2019). There is a lack of literature about fathers' stress and resiliency in terms of raising children with Down syndrome.

According to Phillips et al. (2017), in comparison to mothers of typically developing children, mothers of children with Down syndrome usually use authoritative parenting styles to a lesser extent as they exhibit less restrictive parenting styles overall. Furthermore, mothers of Down syndrome children employ reasoning/induction and verbal aggression less and ignore misbehavior more than children who have typical development. These reasons were found to partially explain why mothers of children with Down syndrome experienced greater levels of parental stress.

Onyedibe et al. (2018) focused on parents whose children had Down syndrome and whether resilience and social support mattered to their experiences of stress and concluded those who demonstrated higher resilience and social support levels experienced lower forms of stress compared to other parents who had little social support and low resilience scores. There was a lack of information about the unique contributions of fathers. Caples et al. (2018) aimed to investigate adaptation and resilience of families of individuals who have been diagnosed with Down syndrome and showed factors that helped families become resilient included family hardiness and family communication. Families with strong communication patterns tended to experience higher rates of adaptability and resilience. However, fathers were underrepresented, further suggesting a need to study this group.

Sheldon et al. (2020) explored rewards and challenges of fathers raising children diagnosed with Down syndrome and found they perceived rewards associated with raising children with Down syndrome as establishing a strong and loving bond with their child. Additionally, they did not focus on negative aspects such as financial issues or negative behaviors. However, these fathers did indicate barriers, including speech or communication problems.

Kózka and Przybyła-Basista (2017) focused on parents' resiliency and satisfaction among those whose children had been diagnosed with Down syndrome and concluded there were no differences between mothers and fathers in terms of resiliency. However, there were differences in terms of measures of perceived stress, psychological wellbeing, and parental satisfaction, but only among those who had lower levels of resiliency. This suggested there were unexamined aspects of resiliency that may have impacted fathers and thus deserve further examination.

Problem Statement

The problem was that little was known about how fathers perceived stress and resiliency in parenting children diagnosed with Down syndrome. According to the CDC, 2020), approximately 6,000 babies are born with Down syndrome each year. Much of the existing research on parental stress focused on experience of mothers; for example, previous studies examined how characteristic parenting styles were used by mothers who raised children with Down syndrome in relation to their level of coping with their children's adverse behaviors (see Phillips et al., 2017). However, it was currently unknown how fathers experienced and coped with stress when raising children who had been diagnosed with Down syndrome, as much less research focused on this important half of the parenting dyad.

Pisula and Banasiak (2020) reported fathers who raised children who had been diagnosed with Down syndrome required support in terms of family empowerment.

Sheldon et al. (2019) reported fathers viewed challenges involved with raising their children as being more connected to their children's functional concerns (e.g., speech ability), but still little was known about how fathers in this context conceptualized and experienced stress and resiliency. Because there was a lack of research involving stressors and resilience of fathers, this study involved addressing how fathers of children who had Down syndrome described stress and resiliency.

Purpose of the Study

The purpose of this generic qualitative study was to explore perceptions involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. I collected data via semi-structured interviews. I recruited eight participants who completed semi-structured interviews where they were asked the same 10 open-ended questions, which they answered openly and candidly. To address the problem in this study, I used a qualitative thematic analysis. This allowed me to highlight common themes by identifying commonly used words, phrases, and ideas.

Research Questions

The following four research questions guided this study:

RQ1: How do fathers experience stress when raising children who have been diagnosed with Down syndrome?

RQ2: How do fathers perceive resilience as assisting them in raising children diagnosed with Down syndrome?

RQ3: What barriers do fathers experience when raising children who have been diagnosed with Down syndrome?

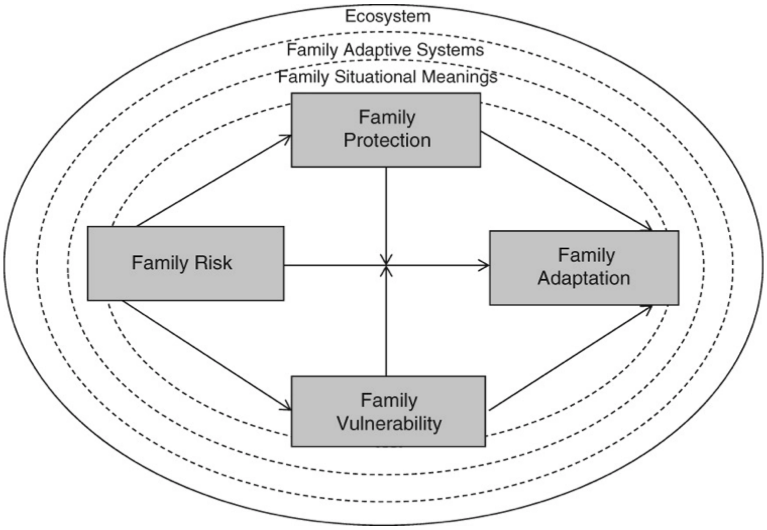
RQ4: How do fathers overcome barriers when raising children who have been diagnosed with Down syndrome?

Theoretical Framework

The family resiliency theory was used for this study. It is a strength-oriented framework involving positive outcomes for entire family systems (Masten, 2018). This framework assists in understanding how families develop successful coping strategies. Therefore, this theory was used to highlight the significance of resiliency among individuals within family systems, family members, and family ecosystems (see Figure 1).

Figure 1

Family Resilience Theory



(Henry & Harrist, 2022)

Different constructs must be acknowledged within systems of family resiliency. The four constructs are family protection, family adaptation, family vulnerability, and family risk (Masten, 2018). They occur among individual family members, core family units, and entire family ecosystems. Extremely stressful events and social situations have a cumulative effect on families, and family processes promote adaptability for all individuals, their relationships, and the family unit. Families of children with Down syndrome are more likely to adapt to their circumstances if they face fewer stressors, are more positive, and share strong beliefs that their bonds can help them overcome ongoing challenges. Families with better resources are more likely to adapt to raising children with Down syndrome better. It is not accurate to focus exclusively on perceptions and experiences of mothers raising children with Down syndrome and assume they represent experiences and perceptions of the entire family, particularly in terms of stresses and resiliency required in these circumstances (Masten, 2018).

Nature of the Study

The phenomenon being explored within this study was experiences involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and how stress and resiliency affected their parenting skills when raising Down syndrome children. I used a generic qualitative methodology with semi-structured interviews. This allowed me to collect data that was nonnumerical to explore this topic. I explored a complex phenomenon within a natural setting and context.

I collected data via semi-structured interviews with eight fathers whose children had been diagnosed with Down syndrome. I created 10 open-ended interviews questions where were the same for all participants. These open-ended questions allowed participants to answer questions however they chose. The final number of participants was determined after achieving data saturation. Data saturation occurred when I determined redundancy during the data collection process due to similar responses from which no new information was gleaned.

I completed a qualitative content analysis with coding that involved identifying and analyzing commonly used words, phrases, and ideas from the dataset. Codes were organized into thematic categories that were findings for this study. Coding was completed using NVivo Pro and a qualitative codebook.

Definitions

The following terms were used regularly throughout this research and are defined as follows:

Down syndrome: A chromosomal cause of mild to moderate intellectual disability (Bull, 2020). Down syndrome can cause distinct facial appearances and developmental delays, and results from extra genetic material in chromosome 21 (Asim et al., 2015).

Parenting skills: Skill sets parents used when raising their children (Dwivedi, 2017). Parenting skills include communication patterns, setting limits and consistency, and demonstrating love and affection (Dwivedi, 2017). Parenting skills influence children’s development (Sanders & Turner, 2018).

Resilience: How well individuals recover from or overcome difficulties or adverse situations in their lives (Hornor, 2017).

Stress: Source of both mental or emotional pressure during which individuals begin to feel overwhelmed and may find it challenging to cope (Crum et al., 2020).

Assumptions

Some assumptions were identified for this study. The first assumption was that participants answered semi-structured interview questions in open, honest, and straightforward manners. I assumed participants had enough life experiences involving parenting of Down syndrome children to answer semi-structured interview questions in full. I also assumed that because I selected a generic qualitative methodology, this study's nature could effectively collect the data using semi-structured interviews, which could answer the guiding research questions.

Scope and Delimitations

Because this study was focused on fathers' perceptions concerning how stress and resiliency affected their parenting skills when raising children with Down syndrome, I focused on this population. To take part in this study, all participants were fathers, had at least one child with Down syndrome, and resided in Prince George's County, Charles County, or St. Mary's County, MD. Individuals who were not fathers or did not have children who had been diagnosed with Down syndrome could not participate. Similarly, they could not participate if they did not live in Prince George's County, Charles County, or St. Mary's County, MD.

Limitations

This study had limitations, challenges, and barriers that must be identified. One limitation was that participants were studied within one identified geographical region, which may have existing support resources that are different from other regions. Future research would need to be conducted to understand how stress and resiliency affect parenting skills involving other populations, intellectual disabilities, or geographical regions outside this study. Another limitation or challenge that needed to be addressed was researcher bias. Researcher bias occurs when researchers interject their values, beliefs, and opinions into their study, affecting results (Baldwin et al., 2020). To limit any instances of research bias, I enlisted the assistance of a panel of experts who reviewed 10 open-ended questions to ensure they were in alignment with the study's problem, purpose, theoretical framework, research questions, and methodology. If the panel of experts determined any instances of misalignment, they were tasked to make recommendations to me, who could have amended open-ended questions. In this study, the panel of experts did not recommend changes to semi-structured interviews.

Another way that I addressed researcher bias was member checking. Member checking involves reviewing transcripts of interviews to ensure they reflect precisely what was said (Candela, 2019). If participants noticed inaccuracies within interview transcripts, they were asked to alert me, so I could amend transcripts to reflect precisely what the participant said. Participants in this study did not identify any inaccuracies within interview transcripts.

Significance

This study has the potential to lead to positive social change. Study results could aid in better understanding how fathers of children who have been diagnosed with Down syndrome experience stress and resiliency when raising their children. This study could also lead to understanding how stress and resiliency experiences affect parenting skills. Many studies that have been conducted on parents of children with Down syndrome have involved both parents (see Farkas et al., 2019; Onyedibe et al., 2018), or focused on Down syndrome with another form of disability (see Autism; Ilias et al., 2018; Mohan & Kulkarni, 2018). Therefore, I address a gap in literature by focusing specifically on fathers in this context.

Understanding fathers' perceptions of stress when raising their children who are diagnosed with Down syndrome could aid in better supportive measures for this population group, such as peer support or other structured support opportunities due to shared experiences. Results of this study could allow social workers and mental health agencies to understand better stressors for fathers and factors which lead to resiliency, which could ultimately be used to understand ways both fathers and their families could be better supported.

Summary

The problem was that little was known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. This qualitative study involved exploring perceptions of stress and resiliency among fathers whose children had been diagnosed with Down syndrome to understand better how stress and resiliency affected their parenting skills. This chapter included an introduction to the study, as well as the problem, purpose, and research questions that guided this research. I also discussed how the family resiliency theory guided this study. The theory was used to understand how families develop successful coping strategies. Therefore, this theory helped to highlight the significance of resiliency among individuals within family systems, members, and in ecosystems.

This chapter also included an overview of the nature of the study and an explanation of the generic qualitative design. I collected data via semi-structured interviews with eight fathers, with the final number being determined after reaching data saturation. This chapter also included discussions of study assumptions, limitations, delimitations, and significance. In Chapter 2, I provide a thorough overview of literature regarding the phenomenon being explored. I discuss in more depth the theoretical framework that guides this study, followed by relevant themes for this research, highlighting further the gap in literature this study is designed to address.

Chapter 2: Literature Review

The purpose of this generic qualitative study was to explore perceptions involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. I collected data via semi-structured interviews and recruited eight participants who completed semi-structured interviews where they were asked the same 10 open-ended questions, which they answered openly and candidly. To address the problem in this study, I used qualitative thematic analysis. This allowed me to highlight common themes by identifying commonly used words, phrases, and ideas.

In this chapter, I present findings from studies involving phenomena that is relevant to the topic, beginning with the family resilience theory, which guided this proposed study. I then provide a historical overview of parenting children with Down syndrome, stressors associated with parenting these children, and coping mechanisms parents use. I address the disproportionate focus on mothers' experiences, which are often mistaken as being representative of fathers and entire families in relation to stress, resilience, and coping when raising children with Down syndrome.

Literature Search Strategy

I conducted electronic searches using the following search engines: EBSCOHost, ERIC, PsycINFO, and Google Scholar. I used the following search terms: *coping with parenting stress, Down syndrome*, *parental stress, Down syndrome*, *fathers and children with Down syndrome*, *mothers and children with Down syndrome*, *resilience and parenting stressors, resilience,* and *parenting children with Down syndrome*. To be included, studies were published in Englishpeer-reviewed journals between 2000 and 2021.

Theoretical Framework

The family resilience theory has been used to explain processes of many distinct and interconnected systems within families that help them overcome crises or stressors. Walsh (2002) described family resilience as “the possibility for personal and relational development and progress that may be fashioned out of hardship” (p. 130) rather than the traditional definition of overcoming adversity. It includes three main family functioning domains and related subdomains: family belief systems (making sense of adversity, positive outlook, transcendence, and spirituality), organizational patterns (flexibility, connectedness, and social and economic resources), and communication processes (Walsh, 2002). Studies have involved using the family resilience theory to understand how families cope if children have mental and behavioral health issues such as autism and other related disabilities (see Cripe, 2013; Twigg, 2017; VanOrmer, 2020). However, there was a dearth of studies involving resiliency of parents, especially fathers caring for children with Down syndrome.

Families react differently to stressors based on their cultural and ethnic beliefs, experiences, social environment, and life stage and deploy both distinctive and more conventional reactions to overcome states of distress created due to stressors. This framework can be used to effectively identify similar reactions to crisis scenarios while also considering unique views of each family member (Walsh, 2003). Since stressors affect families differently, evolve over time, and can be exacerbated by a concurrent accumulation of demands, no single coping response can adequately explain family adaptation and resilience. Instead, resilience requires an adaptational pathway in which numerous resources or strengths are used and interact to facilitate adaptation over time (Walsh, 2003). Walsh (2003) identified critical processes across three domains of family functioning: (a) family belief systems, (b) organizational patterns, and (c) communication processes. These processes can help families reduce stress, foster growth, and empower themselves to overcome adversity and become resilient. Open family communications are a resource for family systems and critical component of appraising how well families can test situations such as raising children with Down syndrome. According to Walsh (2003), clarity and open emotional expression can make meaning easy to discern and conflicts easy to resolve. Moreover, changes to family patterns of functioning must be justified or validated according to the schema and dynamics of the family. These changes must always be acceptable to all family members. Walsh (2003) stated any course of action taken by families must be acceptable to both the family as a whole and individual family members. This theory was used to describe why fathers' roles and experiences with stress and resilience were as important as other members of families.

Review of the Literature

Historical Review

Parenting can also be stressful due to frustrations, problems, and daily obstacles. Unexpected responsibilities and obstacles for parents arise when their child is born with developmental problems. Being a parent of a child with special needs has far-reaching consequences for whole families (Martin & Colbert, 1997; Simmerman, 2001). Parents of children with developmental impairments are more stressed than parents of children with usual developmental processes (Roach et al., 1999; Sanders & Morgan, 1997). Children with impairments affect the rest of the family. Family members interactions are impacted in a variety of ways, which impacts the entire family system. Children with developmental difficulties may negatively impact their siblings' wellbeing, and stress may extend to siblings (Rossiter & Sharpe, 2001). Families with children with disabilities may suffer higher levels of stress and have more problems with their mental health overall compared to families with children who have typical development. Parents might also experience depression or anxiety (Beckman, 1991; Bristol & Schopher, 1984), have higher levels of hopelessness, failure, and guilt (Tommasone & Tommasone, 1989; Powers, 1989), and have fewer parenting skills and lower marital satisfaction (Rodrigue et al., 1990).

Parents' psychological wellbeing is critical. High levels of parental stress may negatively influence the functioning of children with disabilities; hence, intervention strategies to reduce parental stress are critical (Davis, 1985; Schilling & Schinke, 1984). Parents can also act in ways that harm their children with disabilities (Hastings, 2002). Parents who are under a lot of stress have different interactions with their children and react differently to their negative conduct compared to parents who are not under a lot of stress (Conger et al., 1995). Parents' self-reported despair was a powerful predictor of their attempts to control their children's problematic behaviors actively and successfully (Floyd & Phillipe, 1993). High levels of parental stress seem to hamper the success of intervention programs for children with Down syndrome (Brinker et al., 1994). Parents who are under large amounts of stress are less likely to see improvements in terms of their parenting skills after participating in these programs.

While people with Down syndrome have always existed and been raised by their parents, this section of the review begins with research from the 1960s on parents raising children with Down syndrome, as ideas from that era have had an insidious influence on medical professionals’ cultural narratives and attitudes today. In the mid-to-late 1960s, studies on parents of children with Down syndrome supported the notion that having a child with Down syndrome was a negative experience for parents and families (Farkas et al., 2009). To characterize the life of parents, researchers often used words like "pathological sadness" and "chronic anguish" (Barros et al., 2017; Rocha & Souza, 2018).

The defective child was viewed as a source of sadness and grieving (Solnit & Stark, 1961), causing family strife and jeopardizing parents' ego capabilities. This deficit-based concept of impairment was used to justify the removal of children from their homes and their placement in institutions in the 1960s (Harry & Ocasio-Stoutenburg, 2020). As more realistic understandings of developmental impairment and families living with disability evolved in the 1970s and 1980s, children with Down syndrome and their parents fared better. Early intervention programs, educational inclusion models, and family support systems improved significantly by the 1980s (Harry & Ocasio-Stoutenburg, 2020; Rose, 2021). The research evolved as parents' lives and experiences improved, reflecting greater services and results. The link was circular because research and development led to better outcomes, which led to alternative research orientations

(Harry & Ocasio-Stoutenburg, 2020; Rose, 2021). Research showing the formation of counter-narratives or alternative interpretations of the discourse of parenting children with disabilities was one-way critical disability studies challenged hegemonic power (Rose, 2021).

Historical Overview of Stressors of Parents with Children with Disabilities

Parents of children with Down syndrome often face high levels of stress. Stress connected to child traits, parental cognitive assessments of the circumstance, and family resources and support is characterized by Brinker et al. (1994). A child's primary diagnosis has a significant impact on the psychological well-being of their parents. Parents in these situations are likely to experience shock, denial, disbelief, and sadness (Martin & Colbert, 1997). Literature on the subject has demonstrated that the initial mental anguish experienced by expecting parents is because they are confronted with the reality that their perceptions of an ideal child are not coming to fruition. According to Martin and Colbert (1997), while this is true, some parents report feeling relieved after a diagnosis has been made since it ends any questions and uncertainties. Having a child with Down syndrome necessitates parents to rethink and readopt new roles and identities as parents of children with Down syndrome (Waisbren, 1980). This can lead to ambivalence or anxiety, which only serves to raise stress levels higher.

According to other research, parents may be under stress for reasons other than the diagnosis itself, such as their child's traits and behaviors associated with the disease. Minnes (1998) suggested that the amount of parental stress is closely linked to the child's disabilities and other features, such as their problematic behaviors. All these things take time away from the parents' normal lives (Simmerman et al., 2001). Parental stress can be exacerbated by maladaptive and difficult behaviors and self-mutilation of children with disabilities. Constant monitoring is essential for the well-being of children and their siblings as well (Cole, 1986). Many parents link their children's need for continual attention to their stress (Minnes, 1988; Beckman-Bell, 1981).

When it comes to self-care or performing activities required of children considering their age and developmental stage, many children with disabilities are unable to do so effectively. This requires parents to devote more time and attention to their children. Parents may have less anxiety because of this (Martin & Colbert, 1997). Parenting a child with disabilities affects the intensity and duration of caretaking. The impairment may cause a delay or limit the child's capacity to function independently.

Recent Literature on Down Syndrome

Down Syndrome is a group of genetic diseases that affect a child's physical as well as mental/psychological development, including Mild Retardation (MR), Intellectual Developmental Disability (IDD), and other relevant problems (Charlot et al., 2021; Farkas et al., 2019; Hahn et al., 2019; Krueger et al., 2019). This disease causes Down syndrome children to have more difficulty processing information, combining and using language, and emotional development. People's early emotions to learning information about a child's diagnosis of Down syndrome include significant emotional stress and unhappiness, restlessness, and pessimism about the child's future. In families, intimacy with their child takes place due to the process of acceptance.

Down syndrome, also known as Trisomy 21, is a chromosomal disorder named after John Langdon Down, an English physician who originally described it in 1866. The most prevalent type of the disease was eventually caused by an extra copy of chromosome 21 (Farkas et al., 2021). Down syndrome patients have a higher chance of congenital heart abnormalities (40-60%), as well as motor and cognitive impairments, gastrointestinal difficulties, epilepsy, orthopedic ailments, hastened age, and Alzheimer's disease (Korlimarla et al., 2021). In recent decades, the quality of life for people with Down syndrome has improved dramatically. In 1983, a person with Down syndrome had a 25-year life expectancy. Today, a person with Down syndrome has a 60-year life expectancy (Korlimarla et al., 2021). Other initiatives have disputed such deficit-based interpretations in favor of more socially created, dialogical definitions, whereas this definition explains Down syndrome in terms of its medical pathology (Korlimarla et al., 2021).

The gap between a medicalized concept of disability and a social model of disability is an essential distinction that sets the context for this research. Often, Down syndrome is perceived through the lens of a medical model, with its concentration on pathology. As a result, a medicalized paradigm of this disability begins with assumptions of lack, loss, abnormality, suffering, and humiliation, among other attitudes (Rose, 2021). It is a dehumanizing model that sees people as threats or risks to the dominant culture because of their disabilities (Rose, 2021). A social model of disability, on the other hand, maintains that disability is socially created and hence distinct from physical or mental damage. Disability is explored as a discourse of exclusion, obstacles, and oppression and a word reclaimed by disabled people for collective identification and activism (Rose, 2021).

However, as time passes, disability studies, including those that focused on Down syndrome, which sprang from the civil rights movement in the United States in the 1960s and drew inspiration from disability rights across the world, has become a major academic endeavor, particularly after the enactment of the Americans with Disabilities Act in 1990. (Rose, 2021). During the 2000s, disability studies extended their critical focus to confront power and reject dominant cultural narratives of disability, motivated by critical theory and seeking intersectionality among racism, socioeconomic position, and gender problems. Disability studies—most scholars have adopted the moniker critical disability studies to adhere to critical theory—can now be defined as an interdisciplinary critical tradition (Rose, 2021). This challenges hegemonic assumptions about the disability and considers the condition of Down syndrome as more humanized (Rose, 2021).

The idea that disability, in this example, Down syndrome, brings with it feelings of guilt and shame, difficulty, and the loss of an intended child labels children with Down syndrome as unwanted. The fact that 67% of prenatal diagnoses result in parents terminating their pregnancies in the United States provides evidence for children with Down syndrome (Rose, 2021). Medical workers such as doctors, nurses, genetic counselors, and bereavement counselors are not always educated to provide Down syndrome diagnoses or may not follow best practices in clinical settings (Orthmann Bless & Hofmann, 2020; Reilly, 2018). Consequently, medical practitioners frequently emphasize the medicalized model while doing little to debunk conceptions of sadness, misery, and loss and provide truthful representations of what life may be like for parents of children with Down syndrome. Most parents regard their child's diagnosis as a traumatic event (Reilly, 2018).

Down syndrome is a chromosomal disorder in which an embryo develops with three copies of chromosome 21 rather than the typical two and is described as the most prevalent of all the genetic disorders linked to and affecting people of all genders, socioeconomic levels, and races (Korlimarla et al., 2021). Approximately 7,000 newborns are born with Down syndrome every year, and there are presently over 400,000 persons with Down syndrome in the United States (Okpala & Okpala, 2021; Hahn et al., 2019). The physical, cognitive, and social/behavioral features of youth with Down syndrome are diverse. They are easily recognized within society due to physical characteristics such as a smaller midfacial area and flat facial profile; upturned, outward slanting eyes; a protruding tongue; small, low set ears; a broad neck with abundant neck skin; short, broad hands and fingers with a single transverse palmar crease; low muscle tone; and shorter stature (Okpala & Okpala, 2021; Hahn et al., 2019).

Visual processing and implicit memory are strengths for a child with Down syndrome, but verbal processing and explicit memory impairments, including speech and language production; auditory short-term memory; verbal short-term memory; and delayed recall, are typically weaknesses. The reading levels of students with Down syndrome tend to plateau around the 2nd-4th grade. Although development is delayed compared to atypical individuals and sensitive to mental age, the social-emotional domain is a relative area of ability for persons with Down syndrome (Mircher et al., 2017; Tungate & Conners, 2021). Despite this strength, persons with Down syndrome may struggle with social adaptation and selecting suitable social tactics when the demands and complexities of social circumstances rise in middle childhood and beyond. Many children with Down syndrome have a strong sense of self-worth, and being aware of their illness does not appear to influence their self-esteem negatively (Mircher et al., 2017; Tungate & Conners, 2021).

Individuals with Down syndrome typically have better receptive language abilities but poorer expressive language skills. They sometimes comprehend far more language than they can produce (Del Hoyo Soriano et al., 2020; Martzoukou et al., 2020). For persons with Down syndrome, cognitive functioning, and expressive language abilities are strongly connected to behavior. Oppositional, obstinate, or violent conduct might be a way of expressing displeasure at not communicating in an understood language. Alternatively, people with this condition are typically calm, even-tempered, and have a strong desire to imitate others (Del Hoyo Soriano et al., 2020; Martzoukou et al., 2020).

Parenting Children with Down Syndrome

Parents of children with Down syndrome have been the subject of several studies. Some approaches have challenged a medical model of disability and pushed a social model of disability. However, they have failed to adequately explore sociocultural elements that lead to stress and oppression (Naz & Sulman, 2019; Riser, 2021). Many psychosocial studies have contributed to developing a social model of the disability by investigating the conditions in and around parents. However, they have relied on survey tools with deficit-based assumptions about stress and hardship (Naz & Sulman, 2019; Riser, 2021).

Surveys that start with preconceptions may limit parents' perspectives, favoring a dominant discourse of Down syndrome as a problem or medical condition while rejecting parents' voices and knowledge. Some studies also asserted that parenting a child with Down syndrome is not as bad as many believe. As the first shock of the news wears off, most parents discover that parenting children with Down syndrome are a rewarding experience, contrary to their expectations (Clark et al., 2020; Huiracocha et al., 2017). According to Ferguson (2002), most parents do not experience a lifetime of misery and suffering due to raising their children. Instead, they fall into a cycle of stress, coping, and resilience (Ferguson, 2002). While stress is a frequent element in parents' lives, some research has shown beneficial consequences, such as personal growth, improved happiness or well-being, increased confidence in parenting abilities, and stronger family connections (Clark et al., 2020; Huiracocha et al., 2017).

Mothers

The mothers of children with Down syndrome exhibited reduced child-related demands as early as when the child reached three years of age (Cless et al., 2018; McLean & Halstead, 2021; Senses et al., 2019). Research studies have heavily documented how these demands grew with time or as these children age. Most et al. (2008) used the child-related aspects of the Parenting Stress Index (PSI) to compare the trajectories of child-related demands in mothers of a child with Down syndrome to mothers of a comparison group of children with intellectual disability mixed etiology. The children were between 12 and 15 months when the first wave of data was obtained, 30 months when the second wave was collected, and 45 months when the third wave was collected.

At 12 months, mothers of children with Down syndrome reported lower stress levels on the PSI than mothers in the comparison group, but there were no changes at 45 months. At the group level, mothers of children with Down syndrome demonstrated increased stress not seen in the other group. While the groups were initially equal on developmental levels, the children with Down syndrome performed at a lower cognitive level than the children in the comparison group by three times as great (Most et al., 2008). Lalvani (2013) spoke with 19 months of children with Down syndrome ranging from six months to six years. Thirteen young individuals were in formal education, four in inclusive classrooms, and nine in segregated classrooms or institutions. The mothers' responses revealed their firm conviction in inclusiveness as well as their dissatisfaction with segregated education.

High levels of depression and marital instability were investigated in mothers of disabled children and less frequently in fathers. It has been shown that a child with Down syndrome impacts mothers and fathers in different ways. Mothers of Down syndrome children reported poorer life satisfaction over time as they were shouldering the burden of day-to-day care (Cless et al.., 2018; Fatima & Suhail, 2019). Some mothers expressed depressive symptoms and poor mental health and complained about the reduction in the quality of their relationships. Depression and deteriorating marriages lead to challenges at work and in their careers (Cless et al.., 2018; Fatima & Suhail, 2019).

Fathers

Except for two doctoral studies on fathers specifically, most studies in this area have focused on women or families in general (Fleming, 2013; Ridge, 2013). More research is required to understand fathers' experiences of Down syndrome children better as they digest their diagnosis and adjust to life as parents. Fathers, like mothers, may be able to give counter-narratives to dominant societal narratives. A close examination of the literature accessible would show that most research on family functioning is still performed with women. Several factors influence this pattern. One is that mothers continue to be the primary caregivers in the case of children with Down syndrome. In a survey of fathers of children with Down syndrome who were asked about their parenting experiences, 46% said their spouses assumed all responsibility for the child with Down syndrome (Fleming, 2013) virtually. However, research on fathers of Down syndrome children shows that they contribute to family life in several ways (Ridge, 2013).

When days off work to care for a sick child were investigated, Hedov et al. (2002) discovered that fathers of children with Down syndrome who had a mean age of 4.7 years took a higher proportion of the childcare than fathers in households where all children were developing typically. Hodapp et al. (2003) discovered that fathers of children with Down syndrome perceived their child as having more positive personality characteristics and fewer behavior issues than fathers of children with other forms of intellectual impairments in one of the few studies concentrating on fathers' perceptions.

Alternatively, older Down syndrome children were less reinforcing and acceptable to fathers than younger Down syndrome children. A variety of factors have been identified as contributing to parental outcomes. It appears that mothers and fathers react differently to the demands of having a child with Down syndrome (Marshak et al., 2019). Although mothers and fathers of babies and toddlers with developmental impairments (including Down syndrome) had similar overall stress levels, their stress patterns differed. Due to physical and behavioral features associated with Down syndrome, fathers expressed fear that their children would be socially less acceptable.

Simmerman et al. (2001) investigated the marital happiness of parents of children who were 11 years old with significant intellectual impairments from middle to late childhood. Both mothers' and fathers' marital adjustment were predicted by mothers' satisfaction with fathers' support, not the quantity of help offered. Fathers' assistance was most reported in playing, nurturing, discipline, and service decision-making, with less frequently reported assistance in the areas of cleanliness, clothing, eating, teaching, therapy, and transporting a child to appointments. Although the dyadic connection between mothers and fathers has many characteristics, these studies show fathers generally have different manners of dealing with and reacting to a child with a disability (Boyd et al., 2019).

Parenting Stressors

Problems that emerge throughout the nurturing process in meeting the growth and development of children with Down syndrome include child development issues, health issues, educational issues, social issues, and financial issues to meet the high medical demands and therapy of Down syndrome children (Ashworth et al., 2019; Kozka & Przybyla-Basista, 2018; O'Toole et al., 2018; Phillips et al., 2017). Parental stress responses are triggered by the numerous challenges that parents confront; parents of Down syndrome children are more worried and protective of their children when it comes to parenting. Because parents are more concerned with excessive worries and protection, Down syndrome child development is also ignored (Ashworth et al., 2019; Kozka & Przybyla-Basista, 2018; O'Toole et al., 2018; Phillips et al., 2017). This condition makes their Down syndrome children's development more difficult. Children with Down syndrome must deal with their limitations while also adapting to their parents' excessive concern and protection. Parents' internal and societal issues have been linked to the presence of Down syndrome children (D'Souza et al., 2020; Swanepoel & Haw, 2018).

Many studies were also conducted to determine how parents responded to their children being diagnosed with Down syndrome. In addition to the emotions mentioned above, parents displayed some expressions after learning about their child's Down syndrome diagnosis findings. Stress, distrust, despair, rage, and uncertainty were some of these manifestations (Amireh, 2019; Piepmeier, 2021). Negative expressions such as wrath, tension, grief, and disbelief are examples of negative coping techniques used by parents to express their emotions after learning of their child's diagnosis. Parents' poor coping techniques exacerbate the problem and make it more difficult. As a result, parents must devise a coping strategy based on positive qualities to help them recover and instantly focus on their children with Down syndrome (Amireh, 2019; Piepmeier, 2021).

Witt et al. (2003) compared divorce rates in 5,089 couples with children with disabilities aged between 6 and 17 years, with more than 24,000 families without children in the most extensive research. Divorce was more common in the children with disabilities group (14.3%) than in the children without disabilities group (11.4%). Studying marriage quality and divorce rates over a more extended period provides further insight. The high degree of parental duties and stress of having a child with a disability and the consequent reduction in receptiveness to one's spouse's needs during these times might explain the vulnerability to divorce. The features of the child have an impact on marital misery. When comparing fathers and mothers, men's marital satisfaction was unrelated to their children's abilities or behaviors, but mothers' marital satisfaction was modestly connected to their children's conduct. The researchers also discovered that marital quality was linked to parental efficacy for mothers, but for fathers, their self-perception of parenting competence came from sources outside the marriage. Alternatively, both parents' social support was linked to marriage satisfaction, showing that variables outside the immediate family structure can impact marital quality.

Many parents may experience substantial stress because of parenting a child with a disability. Researchers have compared stress in parents of typically developing children to stress in parents of children with impairments in several studies. According to the overwhelming opinion of numerous scholars, many features connected with the child's disability were critical contributing factors to the parents' stress. Complex or disruptive behavioral difficulties are one aspect that contributes to parental stress. When children with disabilities struggle to meet expectations, their actions elicit various reactions from the wider population, including guilt, amusement, rage, and terror. When children's actions do not fit social norms, they are labeled as social issues and misfits (Green, 2007). As a result, some parents may think their children are unwelcome in various circumstances, limiting their connections with friends and other social groups. Furthermore, restricting such social connections prevents parents from receiving social support and engaging in activities other than parenting.

Mothers felt stigmatized in how people regarded them and their children because of their everyday looks and odd behavior. Individuals who are socially excluded may retreat and express scorn. Furthermore, the psychological anguish that comes with social isolation may be a harsh type of punishment. Parents who were stigmatized had emotions of isolation due to society's lack of understanding, and they felt as if they were in their universe. However, once parents had educated themselves about their child's illness, Woodgate et al. (2008) discovered that teaching others was a way to cope with the stigma. Individuals who are stigmatized are excluded from many parts of society and avoid specific settings as a result. Interactions with members of society may be uncomfortable for people who feel stigmatized by the community. Individuals who are stigmatized may feel as though they are being watched and are concerned about their messages to the community. When parents feel socially ostracized, they may seek out new social ties. When a vital urge is stifled, people look for other ways to satisfy the drive. As a result, those who feel socially alienated may have a strong desire to create positive social relationships. According to Maner et al. (2007), socially isolated persons reported a greater desire to make new acquaintances and complete tasks than other people.

Individuals who suffer social isolation respond to unpleasant interactions by retreating from persons who have triggered uncomfortable interactions and seeking out other social partners. Children with disabilities are less likely than children without impairments to participate in activities. According to Bedell et al. (2013), parents of disabled children between the ages of 5 and 17 saw environmental variables such as the availability or appropriateness of programs and services, information, and equipment as obstacles more frequently than parents of typically developing children. Furthermore, parents of disabled children between the ages of 5 and 17 wished for greater variety in their children's unstructured physical activities and opportunities to interact with other children in the neighborhood. According to Bedell et al., parents who sought a change in their children's activities were found to provide some shift in the duties connected with planning these activities. This adjustment in how these tasks is planned might provide parents some relief, allowing them to engage in other activities and reduce their stress and feelings of loneliness (Bedell et al., 2013).

Plant and Sanders (2007) discovered that caring duties linked to the variety of preschool children’s impairment, the distinctive profile of their talents, and the child's behavioral problems were associated with some variance in parental stress. Furthermore, the way parents cope with their caregiving duties, cognitive evaluations, coping methods, and coping resources may contribute to parental stress. The way parents understand, perceive, and evaluate their caregiving activities directly impacts their stress levels (Plant

& Sanders, 2007). Roles change and dissatisfaction can develop when parents find themselves in an unanticipated and undesired division of labor due to having a child with a disability, which can lead to feeling separated from others. In addition to dealing with changes in their sense of self, parents feel like they are giving up items connected with an everyday existence (Woodgate et al., 2008).

Another set of parental stress stems from how children with Down syndrome can receive their proper education. Naturally, school-aged children with Down syndrome placed in the school system can face various difficulties, and this causes great parental stress (van Bysterveldt et al., 2019). Public Law 94-142 of 1975, as well as the Individuals with Disabilities Education Act (IDEA) of 1990 and its amendment in 2004, declared that all children with disabilities should be educated in the Least Restrictive Environment (LRE) (Wagener, 2019).

Simply defined, LRE refers to an environment as near general education as possible while meeting the child's needs. The LRE requirement, on the other hand, contains wording that can be interpreted differently based on the resources available to a state, district, or school for a specific child with special needs. Because of the uncertainty, there is much confusion regarding applying the provision so that children with Down syndrome may get the help they need. Inclusive education has been a gradual and sometimes sluggish process (Wagener, 2019). For proponents of the initiative, overcoming resistance among educators and researchers to integrate children with more complicated and demanding Down syndrome in mainstream education remains a significant roadblock.

Compared to integrated or segregated classes, where little research is available, academic outcomes for children with Down syndrome in inclusive classrooms are primarily promising. It is unclear if the greater academic achievements of children in inclusive classes are attributable to higher cognitive ability (as opposed to students in other settings) or more developed social and behavioral tendencies (Kendall, 2019). When comparing inclusive, integrative, and segregated classes, the findings for non-academic outcomes were varied. Although children with Down syndrome improved socially in terms of maturity and expressive language, it was questioned whether these students and their typically developing peers developed real and enduring friendships in inclusive learning environments (Kendall, 2019).

Several studies have focused on parental views about inclusive educational environments for children with disabilities, particularly parents of Down syndrome. They often hold a variety of ideas about the best educational environment for their children. Several studies in the literature describe parental views and opinions about segregated, integrated, and inclusive educational environments for children with disabilities, particularly that with Down syndrome. (Kendall, 2019). This section describes and discusses these parents' hopes and worries for their children's educational results, both academic and non-academic (Kendall, 2019).

Lightfoot and Bond (2013) looked at the elements that influenced their transfer from primary to secondary school. Semi-structured interviews with each student's mother were part of their research. While the sample size was small, both mothers' replies indicated that their children with Down syndrome had been successfully integrated into primary school and that they "conveyed a common philosophy in terms of inclusion and believed in it as a concept" (Lightfoot & Bond, 2013, p. 172).

Parents' impressions of the impact of their child with Down syndrome on their lives are shaped by their belief systems regarding developmental disabilities (de Graaf et al., 2019). Spirituality or religiosity's involvement in the family is typically at the center of such perceptions. Some societies are more secular than others, and various religious traditions have varied perspectives on disability and its significance (Pandya, 2017). Cultures differ in their responses to and understandings of disability in a variety of ways, including religion. This study provides an example of probable cultural impacts on coping strategies (Pandya, 2017).

Parenting methods and aspects have been extensively examined among parents of typically developing children, while parents of children with intellectual disabilities have received less attention. An extra copy of chromosome 21 causes Down syndrome, the most prevalent genetic condition that leads to intellectual disabilities. Speech, language, and verbal short-term memory are all areas of obvious impairment in Down syndrome. However, people with Down syndrome do not have as many adaptive behavior difficulties as people with non-Down syndrome intellectual disabilities (Krueger et al., 2019). Because of this distinct phenotype, researching parenting in Down syndrome is critical since results may differ from other etiologies of intellectual disabilities or mixed etiology intellectual disability populations. There are differences between parenting children with Down syndrome and parenting children without Down syndrome intellectual disabilities (Krueger et al., 2019). Parents of children with Down syndrome report less stress, sadness, and pessimism than parents of children who do not have Down syndrome. The Down syndrome advantage has been coined to describe this. The favorable personality qualities of people with Down syndrome improved the parent's awareness of the nature and origin of Down syndrome, available support networks for parents, demonstrated higher maturity of women, and family socioeconomic statuses (Krueger et al., 2019).

Blacher et al. (2013) conducted a longitudinal study of 183 mothers of children with varying disabilities and discovered that mothers with Typically Developing (TD) children between the ages of 3, 4, and 5 had the lowest negative parenting evaluations. They hypothesized that mothers with Down syndrome children displayed more intrusive behaviors because of the intervention strategies they were instructed to employ with their children. Many programs advocate using directive words to refocus children and minimize behavior issues, but the study's classification methodology failed to distinguish between acceptable direction and actual intrusion. They also discovered that mothers of children with Down syndrome had the greatest levels of positive parenting, which they ascribed to the child's good personality traits and improved compliance and self-regulation compared to children with other forms of impairments (Blacher et al., 2013). As a result of these traits, parents may offer their children more positive respect, warmth, and affection. The first significant result was that mothers of Down syndrome children used authoritative parenting less frequently and permissive parenting more frequently than mothers of TD children. Another significant finding was that parental stress influenced variations in parenting styles between women in the two groups (Blacher et al., 2013). The disparities in authoritative and permissive parenting between mothers of children with Down syndrome and mothers of children with TD can thus be explained by parental stress. Mothers with Down syndrome children experience greater levels of parental stress than mothers of TD children. They may utilize authoritative parenting less and permissive parenting more due to this heightened stress (Blacher et al., 2013).

According to the second main finding, the mothers of children with Down syndrome used reasoning/induction and verbal aggression less and ignored misbehavior more than mothers of TD children. There were no significant differences between groups on any other parenting characteristics (Blacher et al., 2013). Parental stress or child executive function had no bearing on the variations in reasoning/induction. Due to the child's poorer cognitive functioning, it is conceivable that mothers of children with Down syndrome utilize reasoning/induction less. Mothers may think that their children lack the cognitive skills necessary to comprehend disciplinary reasons. Therefore, they do not offer them. However, the relationship between group and reasoning/induction was not mediated by the child's executive function.

It is also conceivable that mothers of children with Down syndrome have fewer restrictions and expectations than mothers of children with Down syndrome. The kind of rules, expectations, and disciplinary techniques employed by mothers of children with Down syndrome should be investigated in future studies. Because of their children's typically pleasant dispositions, parents with Down syndrome may not be verbally aggressive. This distinct phenotype of children with Down syndrome may lead to reduced levels of coercion among parents of children with Down syndrome compared to parents of children without Down syndrome intellectual disabilities. Because verbal aggression has been related to long-term poor child outcomes, mothers of children with Down syndrome who use it sparingly benefit their children.

Finally, mothers of Down syndrome children are more inclined than mothers of TD children to overlook misbehaving. To some extent, this might be a behavioral management approach that parents have picked up to help their children stop misbehaving (Lorang et al., 2018). However, the mediation studies revealed that parental stress mediated the group difference in ignoring misbehavior. Mothers of children with Down syndrome who are particularly burdened by increased caregiving obligations are more likely to ignore misbehavior than actively discipline their children. Stress levels among mothers of children with Down syndrome are high for various reasons (Lorang et al., 2018).

Barriers to Parenting Children with Down Syndrome

Children with Down syndrome have more behavioral issues and are at higher risk for a variety of health issues. Parenting demands are higher, financial burdens are higher, advocacy difficulties are more prevalent, formal and informal support is restricted, and perceptions of maternal competency are lower (Barros, 2017). Because higher stress was linked to decreased use of parenting strategies associated with favorable child outcomes and increased use of parenting techniques associated with poor outcomes in mothers of children with Down syndrome, reducing stress might focus on parenting intervention efforts. Parents of children with Down syndrome could start utilizing positive parenting strategies more, and hostile parenting approaches less if this intervention could reduce parental stress (Barros, 2017). As a result, children with Down syndrome are likely to progress in behavioral, social, and intellectual areas throughout time. Another option is to use parenting treatments to deal with stress-related parenting. In addition to decreasing stress, parents should be taught how to manage stress or parent when under stress (Barros, 2017).

The success of a coping strategy in decreasing stress levels is dependent on the methods selected by parents, the family's resources, and the social environment's capacity to give support. In this case, what must be investigated further is if the coping techniques discovered in future studies also apply to circumstances, such as when parents are confronted with the reality of having a child with Down syndrome. Furthermore, components of religion that are connected to coping mechanisms are currently being investigated and evaluated.

Eisenhower et al. (2005) also found an increase in stress as preschool children with Down syndrome grow older. These researchers first spoke with families when the child was 36 months old, then gathered data at 48 and 60 months, and discovered that children with Down syndrome had more problem behavior linked to increased maternal stress. Consideration of family functioning might provide a different perspective on parental adaptation. Parental stress may be mitigated or exacerbated depending on how the family functions. Cohesive families (i.e., families in which members feel linked to and supported by one another) have been reported to have lower trajectories in mothers' parenting stress of children with developmental disabilities (Halstead et al., 2018; Van Riper, 2007). Another component of family functioning that has lately been examined is the perceived quality of family life. Quality of life research covers a wide range of topics in family life, including health, financial security, family relationships, spiritual and cultural views, social support, leisure enjoyment, and community participation (Halstead et al.,2018; Van Riper, 2007).

Coping Techniques: Overcoming Barriers to Parenting Children with Down Syndrome

Various descriptions of the issues parents face with Down syndrome children, particularly those relating to psychological disorders, necessitate a solution so that parents may adjust to their Down syndrome child's condition. These are the so-called coping techniques. A coping technique is one way for parents of Down syndrome children to deal with their stress and other care issues (Krueger et al., 2019). Coping techniques are cognitive or behavioral efforts to overcome feelings of disappointment or hopelessness resulting from the inability to satisfy internal or external demands due to constraints.

When parents receive a diagnosis concerning their children with Down syndrome, coping methods are unquestionably required. When parents learn of their child's diagnosis with Down syndrome, their immediate reaction is one of shock, despair, and denial of the realities. Not only that, but parents frequently experience anxiety, anger, and guilt. Most mothers from Europe, America, and Mexico adopted the same coping method to deal with their Down syndrome children's issues (Krueger et al., 2019). Similarly, the data reveal the same phenomenon for mothers from various social and economic backgrounds. There are some notable coping strategies uncovered in the available literature.

Religion and Spirituality. As it relates to coping with Down syndrome-related child issues, the solution selected is to become more religious. Some women have claimed that becoming closer to God, participating in a religious program, embracing their child's condition, and accepting that all circumstances felt to be favored by God might help them become better mothers and people (Gotay et al., 2019; Mohammed et al., 2021). According to Cless et al. (2018), the description of the process of identifying and using an effective coping strategy is a protracted process. The protracted process begins with trying to accept the child's condition when first learning the results of the diagnosis. The next step is adapting to the conditions of different children. Afterward, the process transitions to managing household affairs more thoroughly. Especially with an increasing number of challenges, which include learning how to manage emotions when faced with the fact that not everyone in their environment can accept the condition (Cless et al., 2018). However, most coping methods chosen by parents were coping strategies with a positive attitude. Parents who regarded their children’s Down syndrome condition to be a gift from God had a positive attitude and were more active in childcare and activities. They are likely to have joined a community with other parents with Down syndrome children (Gotay, 2019). Parents who used positive coping methods were more likely to be positive parents and assisted their children in having hope for a brighter future. They were also less likely to endure extended stress, making things harder (Gotay, 2019).

Being Positive. The efforts of parents when their children with Down syndrome are diagnosed in an upbeat and optimistic manner constitute a coping strategy with a positive attitude (Amireh, 2019). Using a coping technique and maintaining a positive attitude can assist parents in dealing with their children's less-than-ideal situations. Families that use coping methods and have a positive attitude when caring for and loving their children with Down syndrome adjust better to the pressures they may face when treating children with Down syndrome (Amireh, 2019).

The relational life of families is the fundamental ecological setting in which children are fostered from a family systems perspective (Clark et al., 2020). Each individual's qualities contribute to family interactions, and family members' views of those attributes impact the family system. From the micro-level of dyadic interaction to the macro-level of cultural beliefs influencing parent perceptions of developmental impairment, the birth of a child with Down syndrome is likely to influence the family system in various ways. Several studies have shown that a child with Down syndrome harms the family (Clark et al., 2020). Some of the impacts are related to a child's chance of displaying the cognitive and behavioral traits considered characteristic of children with Down syndrome. Specific patterns of strengths and limitations in information processing, social interaction, expressive language, receptive skills, motor abilities, and motivation are among them (Clark et al., 2020).

Parental or Caregiver Adaptation. Such patterns and expectations may influence the behavior of caregivers in a dyadic connection with the child. Other consequences might include high dissatisfaction with the parenting role, as well as having limited job success. Alternatively, positive impacts may result from the parents' determination of a specific purpose in life or the development of certain skills that may not have been utilized in other circumstances (Korkow-Moradi et al., 2017).

Parental adaptation to a child with Down syndrome has also been widely researched related to parental well-being, particularly parents' psychological emotions. Much research on how parents adjust to having a child with Down syndrome has primarily focused on stress (Phillips et al., 2017). The definition of stress is frequently ambiguous in the literature. Parental adaptation research has been interpreted in at least three ways. Stoneman claimed that the findings of a new study exploring *the Down syndrome* advantage generally mirrored the Down syndrome advantage discovered by previous researchers (Phillips et al., 2017). On the other hand, the Down syndrome advantage vanished after eliminating the income variance.

Resilience and Parenting Children with Down Syndrome

In the context of being a parent of a child with a disability such as Down syndrome, resilience may be viewed from various angles. Emotional resilience is one of them since it guards against apathy, depression, anxiety, and an excessive type of egocentrism (Kózka & Przybyła-Basista, 2017). Resilience is a psychological process that governs one's resistance resources. It allows one to bounce back from adverse life events despite unfavorable conditions, not a feature that defines one's success or failure as an outcome of a challenging scenario (Kózka & Przybyła-Basista, 2017).

Parents who cope with their child's Down syndrome can become more conscious of life priorities, modify their goals, and adapt family patterns (Kózka & Przybyła-Basista, 2017). In addition, ego-resiliency is one of these variables, and it influences how people adjust to traumatic and ordinary life situations (Kózka & Przybyła-Basista, 2017). The capacity to manage impulses and modify one's degree of self-control in the face of diverse stresses is characterized as ego-resiliency (Kózka & Przybyła-Basista, 2017). Resilience is a character trait. Individuals with psychological resilience can survive challenges in their lives and grow stronger due to them (Kózka & Przybyła-Basista, 2017). Resilience and ego-resiliency are critical factors in coping with high-stress levels because they help people "get away" from bad experiences and arouse good feelings (Kózka & Przybyła-Basista, 2017). Through the years, even though studies have not focused on resilience, some factors can lead to a stronger adjustment to traumatic and ordinary life conditions, including raising children with disabilities.

When given a chance, parents recognize various positive contributions that the child with Down syndrome provides to the family. As examples of the positive changes, they ascribed their experience of parenting a child around eight years old with a disability. Parents reported enhanced emotions of empowerment, personal growth, and a reorganization of priorities (Pastor-Cerezuela et al., 2021). Researchers discovered that mothers viewed their Down syndrome children as possessing various highly favorable personal traits that functioned to preserve and create relationships between family members and others (Pastor-Cerezuela et al., 2021). The perception of Down syndrome children possessing highly favorable personal traits can add to mothers' resilience. Unfortunately, that chance is rarely offered since research has tended to focus on the adverse effects on family members. Most partnerships have positive and negative features, and the prevailing characteristic may shift (Pastor-Cerezuela et al., 2021).

Families with children with Down syndrome are likely to experience a combination of difficulties and joys, disappointments, and tremendous satisfaction. It is critical to consider the joys and satisfaction if an authentic picture of family life is acquired. These outstanding features of family life are also likely to contribute to a family's ability to cope with challenges (Pastor-Cerezuela et al., 2021).

Disability is often seen as a burden, and many people have unfavorable feelings about raising a child with Down syndrome (Caples et al., 2019). Naturally, many people who become parents of children with Down syndrome share these beliefs before their child is born. While many parents' perspectives change following the birth of a child with Down syndrome (Caples et al., 2019), they remain part of a community that sees having a child with a disability as a tragedy. Viewing a child that has Down syndrome as a tragedy is undoubtedly an exaggeration. However, people share this viewpoint, and families with a child with Down syndrome will encounter others who hold a variety of viewpoints (Caples et al., 2019). When parents first hear that their child has a disability, they experience a range of emotions that significantly impact their relationships. Raising a child with a disability without seeing the positive can ruin marriage quality and lead to parental stress (Caples et al., 2019).

Communication and basic expectations were also important factors in resilience. Parents who talked honestly about their children, other thoughts and worries, and their readiness for child responsibility were shown to help keep their marriages together (Ramisch et al., 2014). Fathers who participated in parent-child interventions early in life improved family relationships. This paternal assistance aided in maintaining marital ties by alleviating the all-consuming mother-child contact (Mount & Dillon, 2014). Furthermore, mothers' attitudes toward their children who were younger than 18 years of age with disabilities were linked to marital adjustment (Lickenbrock et al., 2011). Mothers who had more favorable feelings about their children also had more positive feelings about their marriage. Furthermore, the mothers' well-being was shown to be linked to their marital connection. Parents with disabled children have been found to have higher divorce rates than parents who do not have disabled children.

Solomon and Chung (2012) recommended taking action, such as holding couple meetings, which can help parents set aside time to report on their spheres, reconnect with their children, and decrease the danger of separation and blame. Stay-at-home mothers who deal with their child's disability all day may become irritated and withdraw, effectively isolating themselves. They are burdened by ongoing caring obligations, which impact their employment, social life, and emotional well-being. Furthermore, because mothers in households with disabled children are more likely to be responsible for childcare, their involvement in social activities is reduced (Sen & Yurtsever, 2007).

Families are challenged by the views of others in the social arena and the problems of integrating their children into peer activities. Even when parents successfully enable peer acceptance of their disabled children, this requires substantial effort from the parents, who are already overburdened by many responsibilities. As a result, receiving social support from family members, friends, support groups, and other parents of children with disabilities is valuable and essential. Informal, nonprofessional social assistance can be provided by family and friends in the form of information, guidance, or more concrete kinds of help, such as childcare. Information and emotional assistance can be obtained via support groups. Other parents of disabled children can offer support by sharing their experiences, which can help to alleviate parental stress and feelings of loneliness.

Armstrong et al. (2005) looked at how social support affected family well-being and parental capacity. This research yielded two models. According to the primary effect model, social support enhances well-being by integrating individuals into a more comprehensive social network. According to the buffering concept, social support shielded people from stressful situations' potentially adverse effects. When they were given their child's diagnosis, parents commonly said that they were generally offered little hope and advice about parenting a disabled child (Bedell et al., 2013).

Only 40% of 146 caregivers in a study conducted by Rhoades et al. (2007) stated that the diagnosing physician offered information and resources concerning the diagnosis of a disability, and 15% to 34% provided recommendations on educational or medical programs. A small percentage of experts (6%) made referrals to specialists, while 18% did not give any more information regarding the disability. Furthermore, just 15% to 20% of parents said they sought support from other health care or educational professionals. In contrast, 71% to 73% said they relied on social media for information about their child's diagnosis.

According to Solomon and Chung (2012), parents of children with disabilities may benefit from receiving psychotherapy to help them cope with the numerous chronic and severe stressors of raising a child with a disability. Harper et al. (2013) discovered in a study of 101 mother-father dyads parenting at least one child with a disability discovered the demand for respite programs. Respite care is an example of an outside resource meant to provide parents with rest from substantial caregiving responsibilities. Respite care allows a family to unwind, refocus, and recharge by shifting the attention away from the child's demands and onto the needs of the family members. Respite can allow family members to go out to dine, shop, and engage in other everyday activities without having to always focus on the child who requires constant care (Doig et al., 2009).

Strunk (2010) conducted a comprehensive assessment of the literature on respite care for families with special needs children who were under the age of 18. A study found that respite care was linked to lower parental stress and more possibilities for family time with typically developing siblings. Strunk has noticed that respite care might be a proactive intervention for children with challenging behaviors who are being abused. The requirement for respite care cut across numerous differences among families, including the degree of impairment, family income, and whether they lived in the city or the country. When the children are not in school during the summer months, respite care is higher. As a result, respite care for families with special needs children can help to relieve some of the stress that comes with raising a child with special needs. Parental support is essential. Social support from groups and other parents might be significant for parents of children with developmental impairments. Family members and friends may be a great source of emotional support. However, they often lack the understanding, firsthand knowledge, and experiences of raising a child with special needs. As a result, seeking assistance from groups and forming relationships with other parents in a similar situation might help reduce the social isolation that parents of disabled children feel. As family members struggle to live with and comprehend their children's disabilities, societal assistance is usually mobilized. As an active method to deal with, parents seek knowledge of the illness.

A family with a child with Down syndrome can impact it on many levels, from micro-level interpersonal interactions to macro-level societal and cultural attitudes influencing parental perceptions of the child's impairment. Parents experience specific, unpleasant daily pressures connected with their child's disability. Down syndrome is a chromosomal mutation that affects both physical and mental skills. It affects one out of every 800 babies born. Around 25% to 33% of families with a Down syndrome child have problems, resulting in greater levels of assessed distress and lower levels of life satisfaction (Lee et al., 2021). Depression symptoms were shown to be more prevalent among parents of children with chronic medical problems. Stress may undoubtedly be viewed as a risk factor for parental adaptability and family functioning. There are several reasons for anxiety for parents of children with Down syndrome (Lee et al., 2021). This type of stress may be linked to various non-specific conditions and challenges that arise when parents care for a mentally disabled child with many limitations and little hope for improvement. It can become a burden and negatively impact both the mother and father's physical and psychological health (Vadakedom et al., 2017). Apart from concerns for their children's daily medical and social situations, parents are also concerned about their uncertain future. Parents' relationships with family, friends, and neighbors can be affected by parental stress. Families with special-needs children, for example, are more prone to have marital problems and are unable to benefit from social support and assistance from family and friends (Young et al., 2021). As a result, many studies on parents' adaptation to a child with Down syndrome emphasize stress.

A valid concern about the impact of having a child with Down syndrome on a family develops. Some researchers agree that there is a detrimental impact on the family, whereas others disagree. There is yet to be a consistent response to this question. For almost three decades, there has been a persistent belief that having a child with an intellectual or developmental disability causes issues for the family, including increased stress and parental depression. As a result, it was implicitly expected that having a child with Down syndrome would result in misery. As a result, research has concentrated mainly on the child's negative consequences on the family. Most families with children with impairments function similarly to other families.

Individual variations in cognitive, social, and physical ability, health conditions, and personality traits are common among children with Down syndrome (De Clercq et al., 2019). To begin with, there are variances amongst children; second, the parents' positive attitude toward the disabled child might be crucial. The current study's authors conducted qualitative research on parental duties, which revealed that mothers and fathers of children with Down syndrome view their parenthood differently. Some view it as a burden, while others view it as a challenge. Some view it as a gift, while others look at it with ordinariness or nothing special. Some rely on being parents for happiness, while others derive their satisfaction in life outside of their children (De Clercq et al., 2019).

Apart from the apparent hardship, parents of disabled children may also have good outcomes such as increased receptivity to challenges, the ability to overcome their psychological obstacles, and personal growth. Those parents express significant levels of happiness and pleasure in their roles. They are frequently willing to rethink their ambitions and objectives, change family priorities, and become more conscious of their ideals (De Clercq et al., 2019).

Children with Down syndrome frequently exhibit positive personality qualities, which encourage their parents' positive adaption to their circumstances. According to Bower et al. (1998), a family member's disability triggers resilience mechanisms while making the family emotionally stronger and more resilient. Despite various challenges, mothers of Down syndrome children still highlight good elements of their circumstances. They claim that having a child with Down syndrome improves their mental and physical well-being.

According to Pisula (2007), aside from financial resources, parents of children with Down syndrome who are younger than 18 years of age value the most assistance from family members, professionals, and other parents of children with impairments. This support can also lead to resilience. Mothers of children with Down syndrome usually seek social support as a coping technique. Contrarily, fathers are less likely than mothers to engage in group social support; they prefer assistance tailored to both them and their spouses. However, mothers are more likely than fathers to express a need for social and family assistance, particularly in areas such as childcare. When parents have resources like social support, stress has a reduced impact on their well-being. A robust social network allows parents to share duties and anxieties with others, such as friends, family members, and neighbors, while also receiving emotional support. The tension in the marriage connection can be alleviated in this way. In addition, programs created for families with children with disabilities can provide information and beneficial improvements in establishing family plans and participating in various organizations. Individual, family, and society viewpoints can all be used to examine how parents' function. A solid emotional bond between the mother and father might help prevent the child from stress related to developmental problems. The happiness of spouses parenting children with Down syndrome is linked to the quality of their marriage.

Literature Gap

Many researchers focused on children with Down syndrome; nevertheless, the vast majority had sought to understand mothers' stress levels alone or both parents without distinguishing fathers' experiences (Cless et al., 2018; Phillips et al., 2017; Senses Dinc et al., 2019). According to Phillips et al. (2017), mothers with Down syndrome children used authoritative parenting methods less frequently than mothers of typically developing children and had a less restricted parenting style overall. In addition, mothers of Down syndrome children used reasoning/induction and verbal aggressiveness less and ignored misbehavior more than mothers of children with average development. These factors were discovered to account for some of the increased parental stress reported by mothers of children with Down syndrome. In addition, Onyedibe et al. (2018) investigated whether resilience and social support mattered to the stress experiences of parents whose children had Down syndrome. The authors conducted quantitative research with 193 people, using a survey to collect data. According to the findings, parents who exhibited higher resilience and social support levels had less stress than those with limited social support and poor resilience scores. The distinctive contributions of fathers, on the other hand, were not examined in this study. Caples et al. (2018) performed a study to look at the adaptation and resilience of families who have a member identified with Down syndrome. The authors conducted quantitative research in which 95 parents provided data (75 mothers and 16 fathers). The authors discovered that families might adjust and exhibit resilience after collecting data using surveys as their data collection instrument. Family hardiness and family communication, according to the authors, were two characteristics that helped a family become robust. The findings also showed that families with good communication patterns had greater rates of adaptation and resilience.

Fathers were underrepresented in this study once again, further underscoring the need for more research on this group. So far, only a few studies have focused primarily on fathers. For example, Sheldon et al. (2020) did qualitative research to examine the benefits and challenges of fathers raising a child with Down syndrome. The authors discovered that the rewards of parenting a child with Down syndrome were creating a deep, loving relationship with their child, based on data collected from 175 days. Furthermore, the fathers did not dwell on the harmful elements of financial problems or their children's bad habits. However, many fathers did mention obstacles, such as speech and communication issues. Kózka and Przybya-Basista (2017) researched the resiliency and contentment of parents whose children were diagnosed with Down syndrome. The authors used a quantitative technique to collect data from 126 parents, 51 of whom were fathers. When it came to resiliency, the study revealed that there was no difference between mothers and fathers. However, there was a link between perceived stress, psychological well-being, and parental satisfaction, although it was only noticeable among mothers and fathers with lesser resilience. This implied that there were unexplored areas of resilience that may have influenced fathers and should be investigated further. The statement of the issue under investigation was that little was known about how fathers perceived stress and resiliency when raising children with Down syndrome. Each year, approximately 6,000 newborns are born with Down syndrome (CDC, 2020).

Summary

Much of the existing research on parental stress focused on women's experiences; for example, how mothers who raised children with Down syndrome adopted specific parenting techniques in connection with their ability to cope with their children's negative behaviors. However, because less research has been done, it was presently unknown how fathers experienced and managed stress when raising children with Down syndrome. Pisula and Banasiak (2020) reported fathers who raised children with Down syndrome required family empowerment support. Sheldon et al. (2019) reported fathers viewed challenges involved with raising their children as being more connected to their children's functional concerns such as speech ability. However, little was known about how fathers in these situations coped. Because there was a paucity of research on fathers' stressors and areas of resilience, this study involved supporting and emphasizing how men expressed stress and resiliency as parents of Down syndrome children.

This research has the potential to make a positive impact on society. Study findings might help researchers better understand how fathers of children with Down syndrome deal with stress and resiliency while parenting their children. This research might also help researchers better understand how stress and resilience experiences impact parenting abilities. Much research on children with Down syndrome has included both parents, and studies have focused on Down syndrome combined with other disabilities. The present research could fill a gap by concentrating on fathers in this setting and their perceptions of stress when parenting children with Down syndrome to increase supportive resources by providing them with much-needed peer support or other organized support options. Findings of this study may help social workers, mental health organizations, and society better understand pressures fathers face and how to help them cope, resulting in more robust knowledge of how fathers and their families may be better supported. Chapter 3 includes a discussion of the chosen research method.

Chapter 3: Research Method

The problem being studied was that little was known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. Therefore, the purpose of this qualitative study was to explore perceptions involved with stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. This chapter includes an overview of the study methodology. I begin by restating the research question and providing a discussion of my role as the researcher. I then highlight the study's methodology, including participant selection logic, recruitment, and data collection methods. The chapter then concludes with a discussion of the study data analysis plan, how trustworthiness was maintained, and ethical considerations that I followed.

Research Questions

The following four research questions guided this study:

RQ1: How do fathers experience stress when raising their children who have been diagnosed with Down syndrome?

RQ2: How do fathers perceive resilience as assisting them in raising their children diagnosed with Down syndrome?

RQ3: What barriers do fathers experience when raising their children who have been diagnosed with Down syndrome?

RQ4: How do fathers overcome barriers when raising their children who have been diagnosed with Down syndrome?

Role of the Researcher

I was committed to contributing to society by informing readers about significant aspects of fatherhood who had children with special needs, specifically Down syndrome. I have personal experiences raising a child with Down syndrome and observing stress factors linked to this unique parenting. Fathers have unique challenges and disappointments that can foster resilience and help children reach their fullest potential. I watched my own husband actively participate in our child's life and overcome stressors through resiliency that led to some great successes.

To ensure objectivity during the semi-structured interview process, I had limited knowledge about participants' prior personal history and no personal relationships with participants. I maintained a reflexive approach before and during the research process by not ignoring my own biases. However, I carefully reflected upon limitations due to my own subjectivity in terms of worldview and positions, and thoroughly expounded upon this in a clear and coherent way so readers could gain insights regarding how information was gathered, analyzed, and reported.

I sought to access participants' thoughts and feelings that influence their behaviors involving resilience and stress factors related to parenting children with Down syndrome. This was at times difficult for participants as it elicited feelings associated with initial knowledge of their children's diagnoses. My role as the researcher was to protect the data obtained from participants of the study in an ethical manner that was approved by Walden University's Institutional Review Board (IRB).

Methodology

This section includes a discussion of the study methodology. I discuss the study research design while providing a rationale for the design. I then provide an overview of participant selection logic, data collection procedures, participant recruitment, and data collection methods for semi-structured interviews.

Research Design and Rationale

I used a generic qualitative design. This method was selected because it allowed me to collect data that was nonnumerical to explore perceptions of fathers regarding experiences with stress and resilience when it came to raising children who had been diagnosed with Down syndrome. I explored a complex phenomenon within a natural setting and context. The quantitative method was considered but rejected for this current study, as the aim of quantitative studies is to determine predictions or relationships among variables using a variety of statistical, mathematical, and computational techniques (Fryer et al., 2018). This would not allow me to explore perceptions of fathers because participants would not be able to respond to questions using their own words.

Additionally, I did not use grounded theory or ethnography. A grounded theory approach involves researchers testing or grounding a theory through collection of data (Chun Tie et al., 2019). However, since the family resilience theory guided this current study, a grounded theory approach was not appropriate. Similarly, an ethnographic study design was considered but rejected, as this type of research involves exploring a social phenomenon via observational data collection (Gobo & Marciniak, 2011). Collecting observational data did not aid in answering research questions or exploring rich textural answers that participants required. Thus, a generic qualitative method was selected because it allowed me to have additional flexibility.

Participant Selection Logic

The population was fathers whose children had been diagnosed with Down syndrome and resided in Prince George's County, Charles County, or St. Mary's County in Maryland. I recruited eight individuals for this study, with the final number of participants determined after reaching data saturation. Data saturation occurred when I experienced redundancy in the data collection process due to similar participant perceptions, experiences, and patterns (Fusch & Ness, 2015).

When recruiting participants, I used the purposive sampling method. Purposive sampling is a form of non-probability sampling where participants are selected for the study based on a researcher’s judgments and specific criteria that have been set. Therefore, to participate in this study, participants were fathers, had children between the ages of 4 and 18 who had been diagnosed with Down syndrome, and resided in Prince George’s, Charles, or St. Mary’s County, MD.

Data Collection Procedures

I followed specific procedures when collecting data via the semi-structured interviews for this study. Before beginning the study, I obtained approval from the university’s IRB. I did not begin the study or start recruitment until such approval had been granted (see Appendix A). I also gained site approval from the Parents of Down Syndrome Support groups (PODS) (see Appendix A). PODS is a non-profit national parent support and resource group for parents whose children have been diagnosed with

Down Syndrome. Although PODS is a national organization, they have chapters located in most states. Therefore, for this study, I contacted the president of local chapters of PODS in Prince George's County, Charles County, and St. Mary’s County, Maryland, to receive permission to contact potential participants.

Participant Recruitment

After receiving IRB and site approval and beginning to recruit participants, I had the president of PODS send out a recruitment flyer to their members. The president of PODS provided members with information about the purpose of the study, what was expected of the participants, and the criteria needed to participate (see Appendix B). Interested individuals responded to the flyer and contacted me directly. As individuals contacted me, I checked to ensure that they met all the study’s recruitment criteria. I recruited individuals on a first-come-first-serve basis. After the individuals had met the study’s criteria, they were accepted and emailed an informed consent form. The informed consent included information that the participants must agree to and sign. The consent highlighted the purpose of the study, what was expected of the participants, how the study was completely voluntary, how the participants could remove themselves at any time and without any repercussions, how confidentiality was maintained, and the level of risk associated in participating in the study. The participants signed the informed consent, scanned the document, and returned it to me before completing their semi-structured interviews.

Semi-Structured Interviews

I collected data via semi-structured interviews where I asked the eight participants the same semi-structured interview questions. I developed a list of 10 semi-structured questions to ask the participants during the interview. After developing the initial list of open-ended questions, I employed the assistance of a panel of experts who reviewed the questions to ensure that they were in alignment with the study's problem, purpose, research questions, theoretical framework, and methodology. The panel of experts consisted of three individuals who had similar professional and educational experiences as myself. When reviewing the open-ended questions for alignment, the panel members would have recommended for me to make any changes to the questions to bring them into stronger alignment. I would have discussed any recommended changes with the university's chair and second committee member and would have adjusted the open-ended questions accordingly. It is important to note that within this study, the panel of experts did not recommend any changes to be made to the semi-structured interview questions.

Although I offered face-to-face interviews with each of the participants, I also allowed them to meet via Zoom to remain in alignment with the Center for Disease Control and Prevention's (CDC) recommendations for social distancing guidelines in response to the COVID-19 pandemic. I sent the Zoom meeting room weblink and password to each participant prior to the interview. During each semi-structured interview, I asked each participant the same open-ended questions; however, I was also able to ask any follow-up questions to clarify information or encourage participants to expand on their answers. Each semi-structured interview was electronically recorded and transcribed in preparation for data analysis. Each of the semi-structured interviews lasted approximately 45 minutes.

Follow-Up Interviews

After each participant had completed a semi-structured interview and the transcriptions had been completed, I conducted a follow-up interview via member checking. Member checking was a process where I had the participants review their transcripts to ensure they reflected precisely what they said (Candela, 2019). Similarly, if the participants noticed any inaccuracies within the interview transcripts, they would have alerted me, who would have amended the transcripts to reflect precisely what the participant said. In this study, none of the participants reported any inaccuracies within their semi-structured interview transcripts.

Data Analysis

When analyzing the data, I followed a qualitative thematic analysis. Qualitative thematic analysis was defined as a method of analyzing non-numerical data. I identified the participants' commonly used words, phrases, and ideas to interpret patterns of meaning within the dataset (Sundler et al., 2019). Before beginning the data analysis, I studied each of the participants' transcripts to ensure that they were complete and accurate, per the participants and ensured that no identifying information was included in the data.

I utilized NVivo Pro and a qualitative codebook when completing the data analysis. NVivo was a software program that coded and managed qualitative data

(Phillips & Lu, 2018). Additionally, a qualitative codebook assisted me in labeling the thematic categories that emerged from the dataset while highlighting the participant's exact quotations that contributed to each theme (Roberts et al., 2019).

When conducting coding, I reviewed each of the interview transcripts multiple times, highlighting commonly used words, phrases, and ideas of the participants (Williams & Moser, 2019). After identifying the different codes, I continued breaking down the codes and arranging them into categories that assisted in identifying themes. The themes identified in this study acted as the research findings and are reported in full in Chapter 4.

Trustworthiness

Trustworthiness is defined as the degree of confidence that I had in the data and the quality of the study (McSweeney, 2021). When discussing trustworthiness in qualitative research, there were four constructs that were identified: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

Credibility

Credibility is defined as the level of confidence that I had in the study’s findings (McSweeney, 2021). In this study, I established credibility as I utilized the assistance of a panel of experts to ensure that the interview questions aligned with the study’s problem, purpose, research questions, theoretical framework, and methodology. This process, along with ensuring that the participants of the study met strict criteria to participate, decreased instances of researcher bias, as the results were not based upon my own personal thoughts, values, and opinions.

Transferability

Transferability is defined as how I applied the study’s findings to other contexts (Kyngäs et al., 2020). One limitation of this study was the lack of generalizability of the research findings, as this study concentrated on a specific population and geographical area. Therefore, future research will have to be completed because the results cannot be generalized to other populations and geographical regions. Therefore, I provided a detailed description of how I conducted my study so that it could be replicated in other geographical areas and populations.

Dependability

Dependability is defined as the extent to which the study could be repeated by future researchers (Kyngäs et al., 2020). Although future studies would have to be completed when researching this phenomenon on other populations and geographical regions, this study still upheld dependability. This occurred when I created an interview protocol that demonstrated how to ask each participant the same question, which increased the ability to experience consistent and repeatable findings. Therefore, future researchers could use similar interview protocols that have been adjusted based on the population and geographical region being studied.

Confirmability

Confirmability is defined as the study's findings being based on the participants’ responses and not my biases (Kyngäs et al., 2020). This study upheld confirmability as I completed member checking. Member checking allowed me to have the participants review their interview transcripts so that they could be assured that their information was being represented in the data analysis. If the participants had reported any instances of inaccuracies, I would have adjusted exactly what the participants said.

Ethical Procedures

Specific ethical procedures were followed in this study. First, before beginning the study or contacting the participants, I ensured that she I received approval from both her university's IRB and site approval from PODS. Second, I ensured that each participant reviewed and signed informed consent. The informed consent included information that the participants must have agreed to and signed. The consent highlighted the purpose of the study, what was expected of the participants, how the study was completely voluntary, how the participants could remove themselves at any time and without any repercussions, how confidentiality was maintained, and the level of risk associated with participating in the study.

Third, I protected the participants' confidentiality. I did not use any identifying information to protect the participants' confidentiality. Therefore, when referring to the participants, I did so in a numerical fashion (e.g., Participant 1, Participant 2, etc.). When referring to the local chapter of PODS, I also did so in alphabetical order (e.g., PODS A, PODS B, etc.). Additionally, I also protected the participants' information by storing all paper documents in a locked filing cabinet inside my home office and storing all electronic data on a password-protected removable flash drive that was locked inside the same filing cabinet. Only I had immediate access to the data. I will destroy or delete all data after a period of five years which coincides with my university's IRB policies and procedures. When destroying all data, I will personally shred all paper documents and delete all electronic files from both her removable flash drive and the computer’s hard drive.

Summary

The problem being studied was that little was known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. Therefore, the purpose of this qualitative study was to explore perceptions involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. This chapter includes an overview of the study research methods. The chapter began by restating the study research questions and discussion of the research design and its appropriateness. I then discussed my role as the researcher, setting and sample, and data collection procedures. The chapter then concluded with a discussion of the data analysis plan, how trustworthiness was maintained, and ethical procedures that I followed. The next chapter is Chapter 4, which includes a comprehensive overview of study findings.

Chapter 4: Results

The problem being studied was that little was known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. Therefore, the purpose of this generic qualitative study was to explore perceptions involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. The following four research questions guided this study:

RQ1: How do fathers experience stress when raising their children who have been diagnosed with Down syndrome?

RQ2: How do fathers perceive resilience as assisting them in raising their children diagnosed with Down syndrome?

RQ3: What barriers do fathers experience when raising their children who have been diagnosed with Down syndrome?

RQ4: How do fathers overcome barriers when raising their children who have been diagnosed with Down syndrome?

This chapter includes study findings. I begin this chapter by discussing the setting, participant demographics, data collection procedures, and how analysis was conducted. I then highlight evidence of trustworthiness and results and conclude by identifying any discrepant cases.

Setting

I only began this study after receiving approval from the university's IRB. Due to the CDC, I conducted semi-structured interviews via Zoom. When conducting interviews, I ensured confidentiality by sending each participant a private link to a secure Zoom meeting room to which only they had access. In addition, I also encouraged each participant to meet in a private room with the door closed, as well as wear headphones. During each semi-structured interview, I did not note any major distractions that would have affected data being collected; each participant was able to answer questions comprehensively, as they appeared fully engaged in the research process.

Demographics

Eight participants were included in this study. I had initially aimed to recruit between 10 to 15 participants; however, the final number of participants was determined after reaching data saturation. Data saturation occurs when redundancies in answers that participants provide during the data collection process led to no new information (Braun & Clarke, 2021).

Eight participants had various demographic characteristics (see Table 1) .

Table 1

Participant Demographic Characteristics

	Age	Race/Ethnicity	Marital Status	Age of Child
Participant 1	46	African American	Single	13
Participant 2	52	African American	Married	16
Participant 3	57	African American	Married	16
Participant 4	55	African American	Married	17
Participant 5	47	African American	Married	8

Participant 6	45	African American	Married	14
Participant 7	50	African American	Single	10
Participant 8	34	African American	Divorced	13

Participants had a variety of ages. All reported they were currently fathers who had children who had been diagnosed with Down syndrome, and were currently residing in Prince George's, Charles, or St. Mary's County, MD Ages ranged from 34 to 57 years, with a mean age of 49.2 years. All participants identified as African American; five participants reported they were married, while two stated they were single and another reported being divorced. Participants reported their children who had been diagnosed with Down syndrome ranged from eight to 17. The mean age of children was 13.6 years.

Data Collection

After receiving Walden University IRB approval (#07-14-22-0112041), I followed specific procedures when collecting data for this study. I gained site approval from PODS groups (see Appendix A). PODS is a national organization and has chapters located in most states. For this study, I contacted the president of local chapters of PODS in Prince George's, Charles, and St. Mary's County, MD to receive permission to contact potential participants. I had the president of PODS send out recruitment flyers to their members. Interested individuals responded to flyers and contacted me directly. I checked to ensure they met all study recruitment criteria.

I recruited individuals on a first-come first-serve basis. I included eight participants. Each participant was assigned a numeric code as they were accepted into the study (e.g., Participant 1, Participant 2, etc.). On average, I conducted one semi-structured interview per week until I confirmed data saturation after the eighth interview. Each semi-structured interview was electronically recorded and transcribed in preparation for data analysis. Each interview transcript had over 6 pages of text, with each session lasting between 45 minutes to one hour. There were no unusual circumstances encountered during data collection.

Data Analysis

When conducting data analysis, I used qualitative thematic analysis. Qualitative thematic analysis is a method of analyzing nonnumerical data. During this process, I identified commonly used words, phrases, and ideas to interpret patterns of meaning within the dataset. When conducting coding, I reviewed interview transcripts multiple times, highlighting commonly used words, phrases, and ideas. After identifying different codes, I continued breaking down codes and arranging them into categories that assisted in identifying themes. I used NVivo Pro and a qualitative codebook when completing data analysis. The qualitative codebook assisted me in labeling thematic categories that emerged from the dataset while highlighting participants' exact quotations that contributed to each theme. After completing the analysis, six themes emerged from the dataset: (a) uncertainty regarding the future, (b) resilience promoting strength and perseverance, (c) fathers experiencing guilt, (d) behavior, communication, and health as main barriers, (e) focusing as provider and protectors, and (f) family as the biggest support in overcoming obstacles. There were no unusual circumstances or discrepant cases identified within the dataset.

Evidence of Trustworthiness

When discussing trustworthiness in qualitative research, there were four constructs that I ensured: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability.

Credibility

Credibility was defined as the level of confidence that I had in the study's findings (McSweeney, 2021). In this study, I established credibility as I utilized the assistance of a panel of experts to ensure that the interview questions aligned with the study's problem, purpose, research questions, theoretical framework, and methodology. This process, along with ensuring that the participants of the study met strict criteria to participate, decreased instances of researcher bias, as the results were not based on my own personal thoughts, values, and opinions.

Transferability

Transferability was defined as how I applied the study's findings to other contexts (Kyngäs et al., 2020). One limitation of this study was the lack of generalizability of the research findings, as this study concentrated on a specific population and geographical area. Therefore, future research will have to be completed because the results cannot be generalized to other populations and geographical regions. Therefore, I provided a detailed description of how I conducted my study so that it could be replicated in other geographical areas and populations.

Dependability

Dependability was defined as the extent to which the study could be repeated by future researchers (Kyngäs et al., 2020). Although future studies would have to be completed when researching this phenomenon on other populations and geographical regions, this study still upheld dependability. This occurred when I created an interview protocol that demonstrated how to ask each participant the same question, which increased the ability to experience consistent and repeatable findings. Therefore, future researchers could use similar interview protocols that have been adjusted based upon the population and geographical region being studied.

Confirmability

Confirmability was defined as the study's findings being based on the participants’ responses and not my biases (Kyngäs et al., 2020). This study upheld confirmability as I completed member checking. Member checking allowed me to have the participants review their interview transcripts so that they could be assured that their information was being represented within the data analysis. If the participants reported any instances of inaccuracies, I would have adjusted the information to reflect exactly what the participant said. It is important to note that in this study, the participants did not report any inaccuracies when reviewing their interview transcripts.

Results

After analyzing the data and identifying the codes and themes that acted as the results and findings of this study, I reported them in alignment with each of the research questions. In this section, I will report the results under each of the research questions after identifying the codes, the theme that emerged, and the participants that contributed to each theme. Each theme will be represented by direct participant quotations that support each theme. There were six themes that emerged from the dataset: (a) uncertainty of the future, (b) resilience promotes strength and perseverance, (c) fathers experience guilt, (d) behavior, communication, and health are the main barriers, (e) focusing as a provider and protector, and (f) family is the biggest support in overcoming obstacles.

RQ1

RQ1 involved understanding how fathers experienced stress when raising their children who have been diagnosed with Down syndrome. Within this research question, one theme emerged from the dataset: uncertainty of the future.

Theme 1: Uncertainty Regarding the Future

The first theme that emerged under RQ1 had the participants perceive that their major source of stress was uncertainty of the future (see Table 2).

Table 2

Theme 1: Participant Contribution

	P1	P2	P3	P4	P5	P6	P7	P8	Total
Theme 1: Uncertainty about the future	X	X	X	X			X	X	6

Table 3

Theme 1: Identified Codes

	Codes
Theme 1: Uncertainty about the future	Hope The element of hope Making sure he’s going to be okay Hopefully can live an independent life Future What the future is going to look like Not knowing what the future holds Not knowing

As depicted in Table 2, six of the eight participants contributed to this theme. Participants 5 and 6 did not participate in this theme, as their responses to the semi-structured interview questions did not elicit any discussions about uncertainty for the future. The identified codes highlighted how the participants identified uncertainty of the future as being one of their major sources of stress. For example, Participant 1 (P1) reported that his major source of stress was the element of hope. He was able to state that his stress comes from hoping that his son can have as much of a normal life as possible. P1 stated:

> Today my main stressor would probably deal with the element of hope, or the perspective of hope for [my son] and his future. I still want him to have, as a father, the most normal life possible. That normal comes from my perspective of normal, not his. My perspective of normal would be that he would be able to act, and respond, and interact as the other kids are, and I want him to experience all the joys of life that "normalcy" would bring.

P2 was also able to discuss how his major source of stress was related to not knowing whether his child would have as normal a life as possible due to his Down syndrome diagnosis:

> I think, for me, I have a child with Down Syndrome, but my goal for him is hopefully that he can live an independent life, either separate from me and his mother, or with minimal supports from me and his mother. That's the goal, so I worry about that, especially as we begin to look at our age. With us being 30-plus years ahead of him, in terms of age, 36 or more actually, of us growing old and him still kind of going through life, and how that all fits in the long-term prospects.

P3 also discussed the stress of uncertainty of the future; however, it was in relation to his child’s medical history. P3 reported:

> My main stressor is just because he had such a medical history, just making sure that he's going to be okay medically. He was born with two holes in his heart, so it was just a lot. It was just a lot. And as a father, just trying to make sure everything is taken care of so that there's no issues later down the road.

P4 was able to discuss their stress with not knowing what the future holds for their child diagnosed with Down syndrome. P4 reported that he is doing his best to make sure that his child is being educated and learning skills necessary for the future:

> Just not knowing what his future is going to look like. Not knowing maybe who's going to provide for him once we're no... you know, my wife and I may not be here. Just trying to make sure everything is in place for him once that time comes.

> Trying to make sure that he is learning all that he can learn in school. Trying to see if he can be on the right track to try to learn some skills that will help him along the way.

P7 discussed that although schooling and education is a major stressor for him, he worried about the future on how his child would be treated in a school system and whether he would be treated respectfully by his peers and learn the necessary social skills:

> The main stressor at 10 years old would be his schooling. How would he fair in school? Will he get this? What he needs out of school? Or would the kids be nice to him? Or would people try to take advantage of him?

P8 also reported that his main stressor is not knowing what the future brings. P8 discussed:

> I think that is... The main stressor is just not knowing what the future holds, not knowing how, what services to look for, how is life is going to be. Just not knowing what the future holds and trying to make sure they get what... That she gets what she needs educationally.

Many participants reported that their main stressor when raising a child who has been diagnosed with Down syndrome was uncertainty for the future. The participants reported that they are doing all they can to provide their children with proper education and skill building practices; however, they still do not know whether it is enough so that they can live as normal of a life as possible. Although the fathers reported that they are also concerned about other issues, such as education or the health status of their children, they perceived that it increases their stressors about the uncertainty of what the future will bring.

RQ2

RQ2 involved understanding how fathers perceived resilience as assisting them in raising their children diagnosed with Down syndrome. One theme emerged under this research question: Resilience promotes strength and perseverance.

Theme 2: Resilience Promotes Strength and Perseverance

The second theme that emerged from the dataset under RQ2 was that the fathers perceived that resilience helped them increase their strength and perseverance. Table 4 and Table 5 highlight the participants that contributed to this theme, as well as the codes that were identified within the dataset.

Table 4

Theme 2: Participant Contribution

	P1	P2	P3	P4	P5	P6	P7	P8	Total
Theme 2: Resilience promoting strength and perseverance	X	X	X	X	X	X	X	X	8

Table 5

Theme 2: Identified Codes

	Codes
Theme 2: Resilience promoting strength and perseverance	Resilience Strength Perseverance Trying to understand Stronger person Not giving up Keep pushing forward. Constantly learning I’ve learned to be strong and understand. Fight I have to fight for everything. Keep doing whatever I need. Having that desire Keep wanting to fight

Fathers were constantly learning, fighting, understanding, and kept pushing forward so that they could ensure that they were not only successful as a father but also that their children received everything they could. by P1 stated:

> Not to take away anyone else's experience, but for us, we developed a more consistent faith and hope and development and wanted the best for him in every area. I'm sure every parent would have a very similar testimony for their child. So, we wanted to be able to do that for [my son] throughout days. He turned 16 now, so he's 16 years old. I'd hate to say that we missed anything, but he's done amazing up until now, so we're grateful for that.

Additionally, P2 reported:

> But I would say as you go through a difficult situation, in his case, right now he's going through puberty, and it's becoming a lot more challenging because he's kind of, so he does things that can get him in a decent amount of trouble, even though he knows the difference between right wrong. Resilient is trying to understand, how effectively am I communicating that to him, as well as how much of it he understands.

P3 was able to discuss how resilience has helped him evolve into a stronger person. P3 reported:

> It helped me become a stronger person because you just have to be strong. You just don't know what to expect. So much go on and no matter what, you just have to continue and continue to keep pushing because it's for the best interest of your child.

P4 discussed how they continue to persevere even when experiencing obstacles and reported it is essential to keep pushing forward:

> It helped me by just not giving up, always trying to do what's best for my child. Because, I guess, we are his biggest advocates. So, we have to be able to press forward, even when things seem like it's hard, or we may not seem to have any answers right then and there. So, we have to keep pushing forward.

P5 discussed how resilience has made him stronger and has provided him with the perseverance to continue to be a strong role model for his child and reported:

> So, your resilience and your ability to bounce back from anything that is wearing you down is important, because the larger issue is their development in the way

> of, you're the person that they trust the most. The larger issue is them being able to be secure, is them being able to be solid in the fact, "Okay, I'm getting messed up. That's not who Daddy decided I am. He didn't decide that I'm a bad person." Instead, you bounce back. So, if I have to spank my children from time to time, I will. I come back and I have to look, and say, "You know, I love you. This is not for the purpose of hurting you. You have to be able..." So, the resilience lends itself to me being able to teach them a lesson and being able to establish some discipline without creating distance.

P6 was able to provide a discussion that focused on how gaining strength and perseverance had to do with being in a constant state of learning and reported:

> I'm constantly learning. I think I've learned a lot from my wife on how to deal with certain things. She's very good. She'll help me out. She's helped me a lot on the correct way to do things. What did she say one day? If I tell her, she doesn't understand. If she does something wrong and I try to, we don't believe in hitting, but she must understand what she's doing is wrong and there's consequences to what she's doing. My wife really has helped me out to overcome those things and to tell her to do things, "Okay, if you don't do this, you won't be able to, for example, have your iPad or watch any TV," or something like that. She understands that. She still, "Oh." There's a lot of that. There's more of that, "Oh, oh." A lot of talking back now. It can be a little overwhelming sometimes, but I've learned to be strong and understand. I'm very understanding now in how it should be, but it can be difficult.

P7 reported that he always fights for his child and provided an example of having to continue to fight for him during his educational journey:

> It has helped me as far as making sure his teachers do what they supposed to do. I'm always going up to the school, always talking with his counselor, always trying to make sure all his services are met, and his goals match the services that he's supposed to get. So, I'm just always trying to fight for him.

P8 reported that he must fight for his child in all aspects of their life:

> Well, I'm her biggest advocate, so I can't give up. I have to fight for everything. I have to make sure all her IEP goals are met. I have to make sure her doctors' appointments are scheduled and met. So, I just can't give up. I have to just keep on doing whatever I need to do to make sure she has what she needs (P8).

Participants reported that resilience helped them gain strength and persevere when experiencing challenges of raising their child who has been diagnosed with Down syndrome. They were able to provide examples in many different life areas where they had to continue fighting for their children to ensure that they are provided with appropriate education, services, and attention required for them to be successful. It was the perception of all participants that they will do whatever they need to do so that their children can thrive.

RQ3

RQ3 involved understanding barriers that fathers experienced when raising their children who had been diagnosed with Down syndrome. Within this research question, two themes emerged from the dataset: (a) fathers experiencing guilt and (b) behavior, communication, and health as main barriers.

Theme 3: Fathers Experiencing Guilt

The third theme that emerged from the dataset under RQ3 was that the fathers reported that they experienced guilt. Table 6 and Table 7 highlight the participants that contributed to this theme, as well as the codes that were identified within the dataset.

Table 6

Theme 3: Participant Contribution

	P1	P2	P3	P4	P5	P6	P7	P8	Total
Theme 3: Fathers experience guilt	X	X						X	3

Table 7

Theme 3: Identified Codes

	Codes
Theme 3: Fathers experience guilt	Guilt Guilty I felt guilty Overcome that guilt Understanding what it’s like Different from other children

Three participants mentioned this theme. Participants 3, 4, 5, 6, and 7 did not mention this theme, as they did not report any feelings of guilt as fathers. Codes that were identified highlighted how fathers perceived they experienced guilt as a major barrier. P1 stated:

> I felt early that pride was hidden because I was reserved, and I didn't want to tell nobody, and I didn't want to show him off, and I didn't want to beat my chest, so to speak, like I did with the first one, because I felt in some kind of way, it was hidden in a sense, where I felt guilty in a way.

P1 continued to discuss how he has managed that guilt and how it has changed over the years:

> I am having to overcome that guilt. I think the younger years were easier because we took him to places, and we sought out folk that had patience and experience with dealing with babies or infants with Down syndrome. So, those years were easy because we maintained environments where it was limited access and exposure. Even with family members, you were holding back something without being consciously aware at first what you were really doing.

P2 was able to discuss feelings of guilt when not being able to have family members and friends understand the experiences that he is going through when raising a child that has been diagnosed with Down syndrome. P2 reported:

> I think one of probably the first barriers that I did run into is sometimes having your friends, and to some extent your family members, understanding what it's like to have a child with Down Syndrome or special needs for that matter. They may not really understand some of the issues that the child may have at birth that you're going to go through.

Finally, P8 reported that they experienced feelings of guilt through having to focus on ensuring that their child’s friends are strong and that their child does not feel different than any other child:

> Some of the roadblocks are making sure or... You know, with my other child, they have a good friend group and a barrier for me has been to make sure that she has friends that she can hang out with and friends that can come over so that she doesn't feel like she's any different from my other child.

Some participants reported feeling guilt as a major barrier when it came to raising a child that had been diagnosed with Down syndrome. The participants who contributed to this theme discussed how there was guilt when it came to the diagnosis of Down syndrome and not wanting to be proud of their child, as well as fathers feeling guilty that they had to worry about their children having social and educational experiences that were like other children within their age group.

Theme 4: Behavior, Communication, and Health as Main Barriers

The fourth theme that emerged from the dataset was that fathers perceived that their child’s behavior, communication, and healthcare needs were the main barriers (see Table 8).

Table 8

Theme 4: Participant Contribution

	P1	P2	P3	P4	P5	P6	P7	P8	Total
Theme 4: Behavior, communication, and health as main barriers		X	X	X	X	X	X		6

Table 9

Theme 4: Identified Codes

	Codes
Theme 4: Behavior, communication, and health as main barriers	Behavior Behavioral challenges Medical Medically Health Healthcare Well-being Therapy Speech therapy Communication

Six of the eight participants mentioned this theme. P1 and P8 did not mention this theme, as they did not discuss barriers that they experienced when raising a child that had been diagnosed with Down syndrome. The participants reported that there are a variety of barriers that are experienced when raising a child diagnosed with Down syndrome. The identified codes highlighted the three main barriers experienced in the child's behavior, communication patterns, and health. For example, P2 was able to discuss behavioral barriers that his child displayed:

> Some of the behavioral challenges. They may act out in a certain way. Even though they look like as if they're older, their capacity of understanding may still be ... For example, my son sometimes, even though he's gone into 11th grade, he's at times socially probably closer to a third or fourth grader in certain situations,

> where you just do things that are like, "Wow, I can't believe you did that." But again, with your age, that creates a problem.

P3 was able to discuss how they experienced barriers that focused on health and communication:

> A lot of the barriers that were faced was medically. He had to have round the clock nursing. So, we had to go through different nurses, just the speech, just sometimes he doesn’t use his thumbs. He can't use his thumbs correctly. So, trying to make sure he knows how to tie his shoe, that he's writing correctly, just a lot of the physical side and trying to make sure that he has not only physically, but emotionally, that he has friends that he can communicate with and spend time with trying to make sure he has a connection outside of just at home.

P4 discussed how his child’s health and well-being were major barriers and stated:

> Making sure that his well-being is always maintained. Even with his health, he had a lot of issues as a child, and we didn't necessarily know how to maneuver everything at that point in time. So, just medically there was a lot of things, and educationally there are some things as well.

P5 reported that he experienced communication as a major barrier by stating:

> I guess the primary barrier is going to be communication, right? Because he is nonverbal for the most part. When he was younger, we got him into... Well, not we got him into. We all, myself, my wife, and he were in sign language classes, and he began to use some sign language, but he prefers... It's interesting. He's not

> very verbal, but he is very vocal, right? He prefers to speak rather than... You know, to say he does use some signs.

P6 appeared to agree with P5 as they reported how communication was a main barrier and the steps that they followed to address the difficulties:

> She's been in all kinds of therapy, speech therapy and everything. She speaks really well. She speaks really well now. But it was one time a few years back, she was trying to tell us something and we couldn't get it. We couldn't get it and she just kept saying it and saying it. She just got so frustrated.

P7 discussed how the health of his child was a main barrier:

> I guess some of the barriers... It just, it's his health. I know it once, it was hard for him to walk or trying to just be patient and just trying to understand and get information or figure out how to manage, and how to deal with a child with Down Syndrome (P7).

In summary, this theme highlighted three main areas that the fathers perceived as being major barriers: (a) behavior, (b) communication, and (c) health. The fathers reported how there were many challenges in these three areas that have to be overcome and addressed to work towards providing their children with a normal life as possible.

RQ4

RQ4 involved understanding how fathers overcame barriers when raising their children who had been diagnosed with Down syndrome. Two themes emerged from the dataset: (a) family as the biggest support in overcoming barriers and (b) focusing as providers and protectors.

Theme 5: Family as the Biggest Support in Overcoming Barriers

The fifth theme that emerged from the dataset was that fathers perceived that family is the biggest support in overcoming barriers (see Table 10).

Table 10

Theme 5: Participant Contribution

	P1	P2	P3	P4	P5	P6	P7	P8	Total
Theme 5: Family is the biggest support in overcoming barriers		X	X	X	X	X			5

Table 11

Theme 5: Identified Codes

	Codes
Theme 5: Family is the biggest support in overcoming barriers	Family Leaning on immediate family Different family members Support of my wife My family Cousin

Five of the eight participants mentioned this theme. Participants 1, 7, and 8 did not mention this theme because they did not identify the family as being the biggest support in overcoming barriers. As identified in Table 11, many of the participants reported that different family members assisted them in overcoming the barriers that they experienced when raising their children diagnosed with Down syndrome. For example, P2 discussed how their immediate family is their biggest support:

> I think the first one is leaning on my immediate family, those that live in this household who are dealing with it day in, and day out. Then it extends to our friends, his god parents, and those that have gotten to know him through social media, or him being part of different things.

P3 was able to report that his other children are very helpful and supportive when raising his child diagnosed with Down syndrome. P3 stated:

> There are different family members who are great support. His siblings are really good and my spouse she's pretty good. So together we try to manage everything pretty well.

P4 was able to discuss how his wife, coupled with prayer, is the biggest support system:

> The main one, again, is the support of my wife, and prayer. We pretty much manage most of it ourselves, and we've been able to manage most things. Whenever I'm weak, she's strong, whenever she's weak, I'm strong. So together, we've been able to manage. Along with a lot of prayer.

P5 reported that his family is the biggest support because his other siblings and family members do not treat his child diagnosed with Down syndrome as different:

> We do have family. My family, thank God, they actually love treating my son like they don't act like he's a special needs kid. They treat my son like he's just my son, their nephew, their cousin, that type of thing. So, my family, I love the fact that they don't shy away from anything concerning him and they inquire as far as when he can't understand what they're saying, but it's all a positive situation.

P6 reported that their biggest support comes from extended family, such as his wife's cousin:

> Some of the resources that I've utilized, my wife has a cousin who has a daughter with Down syndrome as well who's a little older than mine. At one of the family picnics, I spent quite a good amount talking to them and I reached out to them because this is, I don't say not new to me, but it's a different experience. It's different, it's very different.

Participants perceived that family was the biggest support system when raising their child diagnosed with Down syndrome. They reported that it could include immediate family members, who tended to treat everyone equally, to other extended family members such as cousins who have had similar experiences.

Theme 6: Focusing as Providers and Protectors

The sixth theme that emerged from the dataset under the fourth research question was that the fathers perceived that they overcame barriers by focusing on their role in the family as a provider and protectors (see Table 12).

Table 12

Theme 6: Participant Contribution

	P1	P2	P3	P4	P5	P6	P7	P8	Total
Theme 6: Focusing as a provider and protector	X	X	X	X	X		X	X	7

Table 13

Theme 6: Identified Codes

	Codes
Theme 6: Focusing as a provider and protector	Provider Protector Protection My role is very important Support Role model To provide and to protect My responsibility

Seven of eight participants mentioned this theme. P6 did not participate in this theme because they did not report that they viewed their role as a provider and protector. The identified codes highlighted how the fathers perceived that their role as a provider and protectors was their responsibility and helped them overcome barriers that they experienced. For example, P1 discussed how they experienced protection as a barrier:

> Over time I realized, "You are not being honest with yourself about how you are feeling about this child with Down Syndrome." I felt that. That was real. So, I developed this early protection thing, where you didn't want him to be thought less of, or ridiculed, or talked about, or misused or abused. You wanted to protect him from that.

P2 discussed how he would have to focus on being the protector of his child as they would learn to do new things as they get older. P2 reported:

> That's a kind of back and forth thought process. I would say I'm excited for him to learn how to drive and be able to operate a vehicle. Whether that's just moving it

> in the driveway for us, or pulling it out of the driveway, or moving it in a non-heavy traffic area. I'm nervous to put him, even as he gets older, in a situation where he's driving, say, in heavy traffic, or long distances, or high speeds, because I'm nervous his reaction may not be there.

P3 reported that as a provider and protector, he needs to be a strong role model for his son, especially since he has been diagnosed with Down syndrome:

> I feel my role is very important, not just because he has down syndrome, but because he's also a male and a male is a male no matter what their diagnosis is. And so, I think that my role is very important. I need to be a role model. I need to set great examples and I need to be his support. So, I feel like my role is very, very important.

P4 reported that to be a provider and protector, he needs to be heavily involved in all aspects of his child’s life:

> I think my role as a father is very important. To me, it's no different from raising any other child. I have to show love, I have to show discipline, I have to be supportive. I have to be very active in my child's life. I have to participate in schooling. Everything that I would do with any of my other children, I also need to do with my son. Even if he... Kids with Down Syndrome, they're just like anybody else. They have a little girlfriend, boyfriend, so I need to be able to have an open line of communication when it comes to hygiene. He's a guy, so I have to teach him, just like I would have to teach any other teenage kid.

P5 highlighted how his role was to be a provider and protector to ensure that his child has a strong sense of security:

> My role as a father, period, is to provide and to protect, nurture my children, and their path, an example of a path for them to walk many different areas, financially, spiritually, socially, mentally, physically. In all those areas, it's my responsibility to give them that example. And as well, it's to give them security pretty much from every angle.

P7 appeared to agree with P5 as they reported that their role is to simply provide and protect their child:

> I view my role as the ultimate provider. The protector. That's, that's pretty much it. I'm his provider. I'm his protector. I'm the one that has to make sure what he needs, he has.

Finally, P8 reported that being a provider is essential with the relationship that he has with his child. P8 stated:

> I mean, I don't view my role any different from raising my other child. I'm the father. I'm responsible. It is my job to make sure she has everything that she has and just to make sure she's provided for. So, that's it. My role is to make sure that she's taken care for, that she's taken care of and that she has whatever she needs to be successful.

Participants used their roles as providers and protectors to overcome barriers with their children. The participants reported that it was essential to ensure that their children have everything that they need to be successful, feel protected and secure, and have a strong involvement with their children in all areas of their lives.

Discrepant Cases

Discrepant cases involve identifying alternative perceptions that differ from what has been found in the analysis (Creswell & Poth, 2016). Within this study's findings, there were no participants that had alternative views to what was being discussed. There was no evidence of any outliers or abnormalities within the data or the analysis.

Summary

The problem being studied was that little was known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. Therefore, the purpose of this generic qualitative study was to explore perceptions involving stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. Four research questions guided this study and subsequent analysis.

Participants in this study reported they experienced stress when raising their children who had been diagnosed with Down syndrome. The main stressor that fathers experienced was uncertainty involving the future. When it came to how they perceived resilience assisted them in terms of raising their children, they reported it provided them with strength and the ability to persevere through challenging and difficult situations. The main barriers they experienced when raising their children with Down syndrome were their children's behavior, communication, and health. Finally, participants reported they overcame barriers by leaning on the support and love of their families.

This chapter included study findings. I began this chapter by discussing the setting, participant demographics, data collection procedures, and analysis. There were eight participants in the study, all of whom completed semi-structured interviews via Zoom with me. I then highlighted evidence of trustworthiness, results, and identification of any discrepant cases. Via a qualitative thematic analysis, six themes emerged from the dataset: (a) uncertainty regarding the future, (b) resilience promoting strength and perseverance, (c) fathers experiencing guilt, (d) behavior, communication, and health as main barriers, (e) focusing as providers and protectors, and (f) family as the biggest support in overcoming obstacles. Chapter 5 includes results related to previous literature, implications of results, recommendations, limitations, and recommendations for future research.

Chapter 5: Discussion, Conclusions, and Recommendations

The problem was that little was known about how fathers perceived stress and resiliency in terms of parenting children diagnosed with Down syndrome. Therefore, this generic qualitative study involved exploring perceptions of stress and resiliency among fathers whose children had been diagnosed with Down syndrome and understand better how stress and resiliency affected their parenting skills. I collected data from eight fathers currently raising children diagnosed with Down syndrome who resided in Prince George’s, Charles, or St. Mary’s County, MD. Data were collected via semi-structured interviews, and after completing qualitative thematic analysis, six themes emerged from the dataset: (a) uncertainty regarding the future, (b) resilience promoting strength and perseverance, (c) fathers experiencing guilt, (d) behavior, communication, and health as main barriers, (e) focusing as provider and protectors, and (f) family as the biggest support in overcoming obstacles.

Participants in this study reported they experienced stress when raising their children who had been diagnosed with Down syndrome. The primary stressor that participants experienced was uncertainty regarding the future. When it came to fathers perceiving how resilience assisted them in raising their children, they reported it provided them with strength and the ability to persevere through challenging and difficult situations. Main barriers they experienced when raising their children with Down syndrome were their children’s behavior, communication, and health. They that they overcame barriers by leaning on support and love of their families.

In Chapter 5, I interpret findings concerning previous literature and the family resiliency theory. I then identify limitations while providing recommendations for future studies. This chapter concludes with a discussion of implications that can be derived from results.

Interpretation of Findings

The following four research questions guided this study:

RQ1: How do fathers experience stress when raising their children who have been diagnosed with Down syndrome?

RQ2: How do fathers perceive resilience as assisting them in raising their children diagnosed with Down syndrome?

RQ3: What barriers do fathers experience when raising their children who have been diagnosed with Down syndrome?

RQ4: How do fathers overcome barriers when raising their children who have been diagnosed with Down syndrome?

RQ1

RQ1 involved understanding how fathers experienced stress when raising children diagnosed with Down syndrome. One theme emerged from the dataset: uncertainty regarding the future.

Theme 1: Uncertainty Regarding the Future

Participants perceived their most significant stressor was uncertainty regarding the future. Some of the stressors they experienced when it came to being uncertain regarding the future included their children having as normal a life as possible, being independent, medical issues, and educational endeavors. In essence, participants reported doing all they could to provide their children with proper education and skill-building practices. However, they did not know whether it was enough so that they could live as much of a typical life as possible. They reported they are also concerned about other issues, such as education and health status of their children.

Bujnowska et al. (2019) reported impacts parents can experience when raising children with a developmental disorder led to uncertainty regarding the future. Stress due to uncertainty regarding the future is rooted in fear (Bujnowska et al., 2019). Lack of uncertainty about the future can be influenced by individual expectations, hope, and unpredictability of events, which many participants reported in this current study. Hope for independence and unpredictability of medical events were reported.

Cless et al. (2018) reported mothers with children diagnosed with Down syndrome experience stressors involving uncertainty regarding the future; however, they appear to cope with this stressor via hope. Many participants in this current study reported they were hopeful about the future, which demonstrated a coping strategy. Cless et al. (2018) reported through hope, individuals can experience a kind of internal coping strategy, which increases quality of their relationships with their children.

RQ2

RQ2 involved exploring how fathers viewed resilience as assisting them when raising their children diagnosed with Down syndrome. One theme emerged under this research question: resilience promoting strength and perseverance.

Theme 2: Resilience Promoting Strength and Perseverance

Participants perceived resilience as promoting strength and perseverance. They reported resilience helped them gain strength and persevere when experiencing challenges of raising their children diagnosed with Down syndrome. Participants were able to provide examples where they had to continue fighting for their children to ensure they were provided with appropriate education, services, and attention required for them to be successful. Participants said they would do whatever they needed to so their children could thrive.

According to Pastor-Cerezuela et al. (2021), parents recognize various positive contributions that their children with Down syndrome provide to families when given a chance. Pastor-Cerezuela et al. (2021) found parents reported enhanced emotions involving empowerment, personal growth, and reorganization of priorities. In addition, mothers viewed their Down syndrome children as possessing highly favorable personal traits that functioned to preserve and create relationships between family members and others (Pastor-Cerezuela et al., 2021). Perceptions of Down syndrome children possessing highly favorable personal traits can add to mothers’ resilience.

Ramisch et al. (2014) reported communication and basic expectations were also important factors in terms of resilience. Parents who talked honestly about their children’s other thoughts and worries and readiness in terms of child responsibility were shown to help keep their marriages together (Ramisch et al., 2014). In this study, participants demonstrated this level of resilience through their emotions and communication, as they could openly discuss their experiences honestly and candidly.

This level of openness and transparency can lead to reorganized priorities, give them strength, and allow them to flourish and persevere amidst adversity.

RQ3

RQ3 involved understanding barriers participants experienced when raising their children diagnosed with Down syndrome. Two themes emerged from the dataset: fathers experiencing guilt and behavior, communication, and health as main barriers.

Theme 3: Fathers Experiencing Guilt

The third theme that emerged from the dataset under the third research question was that the fathers reported that they experienced guilt. Some participants in this current study reported feeling guilty as a significant barrier when it came to raising a child that had been diagnosed with Down syndrome. The participants who contributed to this theme discussed how there was guilt when it came to the diagnosis of Down syndrome and not wanting to be proud of their child, as well as fathers feeling guilty that they had to worry about their children having social and educational experiences that were like other children within their age group.

This theme appears in alignment with previous literature. For example, Rose (2021) reported that a diagnosis of Down syndrome could bring about feelings of guilt and shame, difficulty, and the loss of an intended child, which labels children with Down syndrome as unwanted. To understand how guilty feelings are promoted by parents of children diagnosed with Down syndrome, Green (2007) reported that when children with disabilities struggle to meet expectations, their actions elicit various reactions from the wider population, including guilt, amusement, rage, and terror. When children's actions do not fit social norms, they are labeled as social issues and misfits (Green, 2007). As a result, some parents may think their children are unwelcome in various circumstances and limit their connections with friends and other social groups. This lack of connections and perceived labeling can prevent parents from receiving social support and engaging in activities other than parenting. In addition, Krueger et al. (2019) also discussed that when parents learn of their child's diagnosis with Down syndrome, their immediate reaction is shock, despair, and denial of the realities. Not only that, but parents frequently experience anxiety, anger, and guilt. These studies highlight how guilt is a common experience for all parents when raising a child diagnosed with Down syndrome.

Theme 4: Behavior, Communication, and Health as Main Barriers

The fourth theme from the dataset under the third research question was that the fathers perceived that their child's behavior, communication, and healthcare needs were the main barriers. The fathers reported how many challenges in these three areas must be overcome and addressed to work towards providing their children with as much of everyday life as possible. This theme appears in alignment with previous literature. For example, Eisenhower et al. (2005) also found that stress increases as preschool children with Down syndrome grow older. These researchers first spoke with families when the child was 36 months old, then gathered data at 48 and 60 months, and discovered that children with Down syndrome had more problem behavior linked to increased maternal stress.

Additionally, previous researchers have concluded that a barrier to parenting children diagnosed with Down syndrome can include the quality of life. Quality of life research covers a wide range of topics in family life, including health, financial security, family relationships, spiritual and cultural views, social support, leisure enjoyment, and community participation (Halstead et al., 2018; Van Riper, 2007). Barros (2017) also reported that children with Down syndrome have more behavioral issues and are at higher risk for various health issues. Therefore, parenting demands are higher, financial burdens are higher, advocacy difficulties are more prevalent, formal and informal support is restricted, and perceptions of maternal competency are lower (Barros, 2017).

RQ4

RQ4 involved understanding how fathers overcame barriers when raising children diagnosed with Down syndrome. Two themes emerged from the dataset: Family as the biggest support in terms of overcoming barriers and (b) focusing as a provider and protector.

Theme 5: Family as the Biggest Support in Terms of Overcoming Barriers

The fifth theme from the dataset under the fourth research question was that the fathers perceived that family is the biggest support in overcoming barriers. The participants reported that it could include immediate family members, who tended to treat everyone equally, to other extended family members, such as cousins who have had similar experiences. This theme appears in alignment with previous literature. For example, Strunk (2010) reported that although family members may be a great source of emotional support, they often lack the understanding, firsthand knowledge, and experiences of raising a child with special needs. However, research has shown that family support includes immediate family members. Victor et al. (2021) discussed that immediate family members, such as spouses and siblings, are the key to a robust support system. The author reported that the entire immediate family being supportive can strengthen family dynamics. If immediate family members support parents raising a child diagnosed with Down syndrome, acceptance, love, and independence can be created throughout the family system.

Theme 6: Focusing as Provider and Protectors

The sixth theme from the dataset under the fourth research question was that the fathers perceived that they overcame barriers by focusing on their role as providers and protectors in the family. The participants reported that it was essential to ensure that their children have everything they need to be successful, feel protected and secure, and have a strong involvement with their children in all areas of their lives. This theme also appears in alignment with previous literature. For example, Ridding and Williams (2019) studied how fathers overcome the adjustment of becoming a parent to a child diagnosed with Down syndrome. The authors concluded that the idea of a father being the provider and protector could be seen as outdated.

Nevertheless, many fathers see themselves in this position within the family unit. Additionally, Ridding and Williams (2019) argued that because of being perceived or identified as the provider and protector of the family, fathers often experience a limitation in support and services. This is a critical study to highlight amidst the results because many of the fathers in this study perceived themselves to be in the role of a provider and protector.

Family Resiliency Theory

These results also appear in alignment with the family resiliency theory. This framework assists in understanding how families develop successful coping strategies outside of individual levels. There are four constructs in the theoretical framework that include: (a) family protection, (b) family adaptation, (c) family vulnerability, and (d) family risk (Masten, 2018). These constructs occur within different levels, including individual family members, the core family unit, and the entire family ecosystem.

The results of this current study are aligned with the family resiliency theory, as fathers reported that they see themselves as the provider and protector of the family (e.g., family protection), they experience resilience through strength and perseverance (e.g., family adaptation), they experience stress that includes uncertainty for the future (e.g., family vulnerability), and experience different barriers in the areas of behavior, communication, and health (e.g., family risk). Identifying and discussing these different areas and developing coping strategies can strengthen the family unit, even by understanding fathers' perceptions and experiences of raising a child diagnosed with Down syndrome.

Limitations of the Study

Some limitations must be identified within this current study. The first limitation experienced included the sample size. Because I conducted a qualitative study, I only was required to collect data from eight participants as I experienced data saturation. Larger sample sizes can provide increased reliability and validity regarding research findings (Fryer et al., 2018). A secondary limitation was the lack of generalizability. Because I recruited participants that were fathers, had children between the ages of 4 and 18 years and lived in one of three counties in Maryland, the results may not be generalizable to other populations and geographical regions. Therefore, future research would need to be conducted to understand this phenomenon better in other contexts outside of what was represented in this study.

Researcher bias could have been experienced within this study, as I have personal experiences of raising a child that has been diagnosed with Down syndrome. To limit researcher bias in this study, I utilized a panel of experts to ensure that the semi-structured interview questions were aligned with the study's problem and purpose and completed member checking with the participants. The participants were able to review their interview transcripts, which ensured that I was working with a true and accurate representation of the participant's perceptions and experiences. A final limitation of this study could include the COVID-19 pandemic. Because the COVID-19 pandemic has brought about many challenges to families, especially in the education and social areas of life, the results could have been affected by social distancing, quarantining, and healthcare issues that individuals had to follow. Therefore, future research could focus on how the COVID-19 pandemic has influenced fathers' stress levels and other experiences when raising children diagnosed with Down syndrome.

Recommendations

Some recommendations for future research must be identified due to the limitations experienced in this current study. The first recommendation is that future research should focus on studies that explore fathers' stress levels and their experiences of raising a child diagnosed with Down syndrome. However, future research should focus on larger sample sizes to increase the reliability and validity of the results (Fryer et al., 2018). This could be conducted by future researchers following a quantitative design, where a large sample size of participants can provide data via a survey or questionnaire. A second recommendation for future research is to replicate this study in other geographical areas to understand better how fathers experience stress outside of the three counties of Maryland, which this study focused on.

It would also behoove future researchers to complete research on how the COVID-19 pandemic has influenced their stress levels, the barriers they experience, and how they overcome those barriers. This could be completed via qualitative research where future researchers can understand fathers' perceptions and lived experiences when raising their children amidst the COVID-19 pandemic.

Implications

Some implications must be identified due to the results of this current study. The first implication is that resources and support groups should be set up that cater to fathers with children diagnosed with Down syndrome. This is an important implication because it will allow fathers to experience support that underscores their perceptions of being the provider and protector of families. Previous research has depicted that it is a traditional perspective that fathers are seen as the provider and protectors of families. Because of this, they often miss out on vital services and resources for their children with developmental disabilities (Rose, 2021). Therefore, building a support group that caters to fathers specifically will be beneficial to address issues that are perceived and experienced when raising children diagnosed with Down syndrome.

A second implication is to create local and national programs to help fathers build resiliency in their parenting skills. Because the fathers in this current study reported that there are primary barriers to health, communication, and education, and they are often overcome through strength and perseverance, providing them with the opportunity to learn new parenting skill sets that increase strength and perseverance can assist them in their parenting processes and give them greater access to community resources to support their children. Building resilience of fathers with children diagnosed with Down syndrome is paramount in ensuring that they have the tools to be successful fathers and appropriate coping strategies to overcome obstacles and adversity.

These implications can directly affect positive social change in families and communities of fathers who experience stress and other comorbidities related to rearing children with Down syndrome. Additionally, these implications can support pathways to create positive education and training environments where new ideas, strategies, and advocacy can help promote resiliency and a greater sense of self-worth when parenting a child with Down syndrome, which is also in alignment with a vision for social change.

Conclusion

The problem being studied was that little was known about how fathers perceived stress and resiliency in parenting children diagnosed with Down syndrome. Therefore, this generic qualitative study explored the perceptions of stress and resiliency in fathers whose children had been diagnosed with Down syndrome and to understand better how stress and resiliency affected their parenting skills. I collected data from eight fathers currently raising a child diagnosed with Down syndrome; all participants resided in Prince George's County, Charles County, or St. Mary's County in Maryland. Data were collected via semi-structured interviews, and after completing a qualitative thematic analysis, six themes emerged from the dataset: (a) uncertainty of the future, (b) resilience promotes strength and perseverance, (c) fathers experience guilt, (d) behavior, communication, and health are the main barriers, (e) focusing as a provider and protector, and (f) family is the biggest support in overcoming obstacles.

The participants in this study reported that they experienced stress when raising their children who had been diagnosed with Down syndrome. The primary stressor that the fathers experienced was the uncertainty of the future. When it came to the fathers perceiving how resilience assisted them in raising their children, they reported that it provided them with strength and the ability to persevere through challenging and difficult situations. The main barriers that the fathers experienced when raising their children with Down syndrome were their child's behavior, communication, and health. Finally, the fathers reported that they overcame barriers by leaning on the support and love of their families.

This chapter concluded this dissertation. I interpreted the findings in the chapter concerning previous literature and the family resiliency theory. I then identified limitations experienced within the research while providing recommendations for future studies. By providing support systems for fathers specifically, they will be able to cope more effectively with the stressors they experience when raising a child with Down syndrome while also learning to build resilience through strength and perseverance; fathers can fully experience and enjoy the love that their children give them.

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Appendix A: IRB Approval

Dear Latanya Randolph,

This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, "Fathers' Perceptions of Stress and Resiliency in Raising Children with Down Syndrome: A Qualitative Study." Your approval # is 07-14-22-0112041. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail is the IRB approved consent form. Please note, if this is already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date.

Your IRB approval expires on July 13, 2023 (or when your student status ends, whichever occurs first). One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date.

Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application document that has been submitted as of this date. This includes maintaining your current status with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 10 business days of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you made a commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

Sincerely,
Libby Munson
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Template updated November 2020

Appendix B: Recruitment Flyer

My name is LaTanya Randolph, and I am a doctoral candidate at Walden University. I am conducting a study that is exploring the stress that fathers experience whose children have Down Syndrome, and how they overcome stress when raising their children.

I would love for you to volunteer to participate in this study if you meet the following criteria:

- You must currently be a father.
- You must currently have a child who has been diagnosed with Down Syndrome who is between the ages of 4 and 18.
- You must reside in the Prince George's County, Charles County, St. Mary's County or in a surrounding county or jurisdiction.

When participating in this study, you will be required to complete the following:

- Complete a private interview on Zoom video conferencing that is audio recorded (approximately 45 minutes to 1 hour)
- Complete a follow-up interview on Zoom video conferencing to review a typed transcript of the interview (approximately 15 minutes).

Appendix C: Interview Protocol

Demographic Questions

Age?
Ethnicity?
Number of Children?
Age of Child with Down Syndrome?
Marital Status?

Interview Questions

1. Tell me about the stressors you experience when raising your child with Down syndrome.

2. Out of the stressors you have mentioned, what is your main stressor?

3. Resilience is defined as how well an individual recovers or overcomes difficulties or adverse situations within their lives (Hornor, 2017). Tell me how resilience has helped you in raising your children with Down syndrome.

4. Discuss barriers you have experienced when raising your child that has Down syndrome.
5. How have you overcome these barriers?

6. Tell me different support structures you have in your life to help you cope with stressors.

7. Tell me any resources you utilize when raising your child with Down syndrome.

8. How do you view your role as a father when it comes to raising your child with Down syndrome?

9. Tell me your favorite memory that you have so far when it comes to your child with Down syndrome.

10. Is there anything else you would like to tell me about this topic?