

2016

A Phenomenological Study of Single Fathers of Children with Autism in Trinidad

Merisha Shirwell Margaret Seepersad
Walden University

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>

 Part of the [Educational Psychology Commons](#)

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact ScholarWorks@waldenu.edu.

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Merisha Seepersad

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee

Dr. Robin Friedman, Committee Chairperson, Psychology Faculty

Dr. Grant Rich, Committee Member, Psychology Faculty

Dr. Bonnie Nastasi, University Reviewer, Psychology Faculty

Chief Academic Officer

Eric Riedel, Ph.D.

Walden University

2016

Abstract

A Phenomenological Study of Single Fathers of Children with Autism in Trinidad

by

Merisha Seepersad

MSC, Walden University, 2012

BS, Andrews University, 2009

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

February 2016

Abstract

With an increase in diagnosis rates of autism in Trinidad, more parents of children with autism, especially single fathers, face numerous challenges on a daily basis. There is a lack of research on this topic and therefore an inadequate understanding of the experiences of Trinidadian single fathers as primary caregivers for children with autism. The purpose of this phenomenological study was to explore and depict the lived experiences of single fathers of children with autism. Social support theory was the guiding conceptual framework to explore and understand how single fathers effectively manage their daily challenges. Ten single fathers from Southern Trinidad were recruited through criterion sampling and they engaged in semi-structured interviews individually. Moustakas's steps to phenomenological analysis were used to analyze the data. There were seven major themes that emerged from describing the lived experience of single fathers of children with autism: (a) challenges, (b) social support systems, (c) day-to-day experiences, (d) the role of the father within the family, (e) effects on social life, (f) sibling reactions, and (g) adaptive coping mechanisms. This study may engender social change, as the findings may be used to support single fathers to continue to provide care for their children. This study could result in improved understanding and support for their children both at home, in school, and in the community. The findings will be available to other fathers who share similar experiences. Special education service providers may gain further information to improve their services to families of children with disabilities.

A Phenomenological Study of Single Fathers of Children with Autism in Trinidad

by

Merisha Seepersad

MSC, Walden University, 2012

BS, Andrews University, 2009

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Psychology

Walden University

February 2016

Table of Contents

List of Tables	v
Chapter 1: Introduction to the Study.....	1
Introduction.....	1
Background.....	3
Problem Statement.....	5
Purpose of Study.....	6
Research Questions.....	6
Conceptual Framework.....	7
Nature of Study.....	7
Definitions.....	8
Assumptions.....	9
Scope and Delimitations	10
Limitations	10
Significance.....	10
Summary	12
Chapter 2: Literature Review.....	14
Introduction.....	14
Literature Search Strategy.....	15
Conceptual Framework.....	16
Autism.....	20
Historical View of Autism.....	21

Characteristics of Autism.....	21
Diagnosis.....	25
Parental Reactions.....	26
Sibling Reactions	29
Men as Caregivers.....	31
Fathers as Caregivers	32
Meaning of Fatherhood.....	32
Meaning of Fatherhood for Single Fathers	34
Summary and Conclusions	43
Chapter 3: Research Method.....	45
Introduction.....	45
Research Design and Rationale	45
Research Questions.....	45
Role of Researcher.....	48
Methodology.....	49
Participant Selection Logic.....	49
Procedures for Data Collection.....	52
Data Analysis Plan.....	53
Issues of Trustworthiness.....	54
Ethical Procedures	57
Summary.....	58
Chapter 4: Results.....	59

Introduction.....	59
Setting.....	59
Demographics.....	59
Data Collection.....	62
Data Analysis.....	64
Theme 1: Challenges.....	65
Theme 2: Social Support Systems.....	66
Theme 3: Day-to-Day Experiences.....	67
Theme 4: Role of the Father Within the Family.....	67
Theme 5: Effects on Social Life.....	69
Theme 6: Sibling Reactions.....	69
Theme 7: Adaptive Coping Mechanisms.....	70
Discrepant Cases.....	71
Evidence of Trustworthiness.....	73
Results.....	73
Theme 1: Challenges.....	74
Theme 2: Social Support Systems.....	75
Theme 3: Day-to-Day Experiences.....	76
Theme 4: Role of the Father Within the Family.....	77
Theme 5: Effects on Social Life.....	78
Theme 6: Sibling Reactions.....	78
Theme 7: Adaptive Coping Mechanisms.....	79

Summary.....	80
Chapter 5: Discussion, Conclusions, and Recommendations.....	81
Introduction.....	81
Interpretation of Findings.....	81
Theme 1: Challenges.....	81
Theme 2: Social Support Systems.....	82
Theme 3: Day-to-Day Experiences.....	83
Theme 4: Role of the Father Within the Family.....	84
Theme 5: Effects on Social Life.....	86
Theme 6: Sibling Reactions.....	87
Theme 7: Adaptive Coping Mechanisms.....	88
Conceptual Framework and Finding Interpretation.....	89
Summary.....	90
Limitations of Study.....	91
Recommendations.....	92
Implications.....	92
Conclusion.....	94
References.....	96
Appendix A: Interview Questions	120

List of Tables

Table 1.....60

Chapter 1: Introduction to the Study

Introduction

Autism is a pervasive developmental disorder that has been on the rise over the last ten years in the U.S. (American Psychiatric Association, 2013). According to Johnson, Frenn, Feetham, and Simpson (2011), autism affects 1 in 10 children under the age of 5. According to the American Psychiatric Association ([American Psychiatric Association], 2013), autism spectrum disorder is a broad range of symptoms, skills, and a range of impairment or disability. It is characterized by a persistent deficit in group communication and social interaction, as well as limited behaviors such as walking, interests in interacting with others, and social events (APA, 2013).

Existing studies emphasized the challenges faced by mothers in parenting a child with autism but there is no information about single fathers and their experiences in parenting a child with autism, particularly in Trinidad (Barker et al., 2011; Beck et al., 2008; Ding et al., 2010). The U.S. fathers' perspectives are not given first preference in research, although the literature mentions the fathers (Smith & Elder, 2010). Single fathers have been under researched in studies and not given the opportunity to share their experiences. Parenting a child with a disability is considered a unique and challenging experience (Ding, et al. 2010), and the general public fail to realize that fathers do experience similar challenges compared to mothers (Larson, 2006).

There are studies that included both maternal and paternal views; however, the maternal perspectives are highlighted more (e.g., Beck, Hastings, & Daley, 2008; Ekas et al., 2010; Smith & Elder, 2010; West et al., 2009). Researchers highlighted the daily experiences of mothers and their challenges related to parenting a child with autism and the fathers' experiences were ignored.

Raising a child with autism has been considered as being more demanding than parenting a child with other developmental and intellectual disorders (Beck, Hastings, & Daley, 2008). Some of the challenges of raising a child with autism include physical burnout, financial burdens, and increase in stress levels. As autism is a pervasive developmental disorder, the stress of parenting such a child could continue throughout the child's lifespan, and the effects could be continuous. However, it is evident that lived paternal experiences were not sufficiently highlighted as a majority of the studies concentrated on maternal experiences (Berry & Jones, 2005; Duarte, Bordin, Yazigi, & Mooney, 2008).

There is a need for single fathers from Trinidad to be represented in the literature as it may give other fathers (married or single) knowledge that they are not alone in their experiences and challenges. For an outside perspective, single fathers of children with autism and fathers of typically developing children may have access to this literature available to them in the local libraries, various schools in the different districts in Trinidad, and in various special education organisations in the different areas in Trinidad. This study might contribute to the development of family systems affected by parenting a child with a disability and (West et al., 2009).

This study may encourage social change on a familial level, giving family members an opportunity to understand the challenges faced by single fathers. It may also engender social change on a community level, by bringing single fathers from various communities together to form social groups where they can discuss the ways in which they can eliminate the challenges they face. This study is beneficial to special education specialists as it may provide additional strategies for parenting a child with autism.

In this chapter, I will provide background information on autism, the problem statement, and the purpose of the study. There will also be an overview of the conceptual framework, definitions, assumptions, scope, and delimitations. The research questions will be stated as well as the nature and significance of the study.

Background

Autism and autism spectrum disorders became prevalent in the U.S. in the decade from 2000 to 2010 (CDC, 2012). In Trinidad, there has been an increase in clinically diagnosed rates of autism and autism spectrum disorders (Autistic Society of Trinidad and Tobago, 2012). In Trinidad, mothers have traditionally been seen as the primary caregiver (Allan & Shane, 2014; Crane & Winsler, 2008). In recent years in the U.S. and Trinidad, more men have become primary caregivers, especially of children with a developmental disability (Attwood, 2007; Autistic Society of Trinidad and Tobago, 2012; Towers, 2009). Even though there has been an increase in clinical diagnosis rates of autism, as well as a corresponding increase in male caregivers of children with developmental disabilities, there is limited research in Trinidad that explores single fathers' experiences in parenting a child with autism.

Research on the experiences of the primary caregivers in Trinidad and their stress levels mainly focused on mothers as opposed to fathers (Smith et al., 2010). According to Ogston, Mackintosh, and Myers (2011), mothers of children with autism showed emotions of anticipation, fear, anger, sadness, and helplessness. A significant amount of research on children with autism showed that mothers were the primary advocates for their children, with the goal of educating the general public about what the disorder entails (Rocque, 2010). Lyons et al. (2010) highlighted that maternal stress from caring for a child with autism is usually lowered once the mothers are given social support from other relatives and close friends. According to Rocque (2010), after being provided with social support systems, mothers knew that they were not alone, and they felt a small sense of relief.

In a study conducted by Ekas, Lickenbrock and Whitman (2010), mothers explained the daily challenges they faced in parenting and caring for their children with autism. These daily challenges included physical, emotional, and monetary stress. Although there is information on caregivers of children with autism, the information is only pertinent to maternal caregivers and not from a paternal perspective (Winter-Messiers, 2007).

Although there are studies on paternal perspectives on parenting a child with autism, these perspectives are very limited and highlighted married fathers and single fathers from the U.S, and not single fathers from Trinidad. The explored perspectives were very limited in terms of the number of single fathers who participated in the studies, as most of the participants are mothers (Higgins, Bailey, & Pearce, 2008; Olfman, 2008).

For instance, in a study conducted by Keenan, Dillenburg, Doherty, Byrne, and Gallagher (2010), out of the 105 parents, 90% were mothers, and 10% were fathers. In another study, Keok (2012) examined the lived experiences of parents parenting children with autism, and the participants consisted of 80 mothers and 8 fathers. As a result, it is evident that fathers have been under represented and under researched in existing literature, and there is a need for fathers, especially single fathers, to share their experiences and their challenges of parenting for a child with autism.

In Trinidad, research emphasis is also placed on single mothers as the single mothers are highlighted in the media, and there is no documented research that highlights single fathers and their experiences (Autism Society of Trinidad and Tobago, 2012). Single fathers in the society of Trinidad are viewed in a negative light (Single Fathers Association of Trinidad and Tobago, 2012). This study is necessary as it provides information on the experiences of single fathers who parent children with autism

Problem Statement

According to the CDC (2012), there was an increase in diagnosed cases of autism in the U.S. in the decade 2000 to 2010. In the school system, particularly in elementary schools, there are stressed parents of children with autism as these parents did not have efficient coping plans in parenting a child with autism (Siller, Reyes, Hote, Hutman, & Sigman, 2013).

In Trinidad, there was also an increase in the rates of children who were clinically diagnosed with autism (Autistic Society of Trinidad and Tobago, 2012). In Trinidad, 1 in every 10 children is clinically diagnosed with autism, and every 1 in 40 children with

autism live with a single father (Autism Society of Trinidad and Tobago, 2012). Single fathers from the first world countries have the advantage of various special education institutions and experts, therefore having the opportunity for support (Anderson, 2007). However, Trinidad being a third world country, there is not a vast amount of special education specialists as well as institutions (Autism Society of Trinidad and Tobago, 2012).

Purpose of Study

The purpose of this phenomenological study was to understand and depict the lived experiences of single fathers of children with autism in Trinidad.

It is important to explore the lived experiences of single fathers who have a child with autism or any other developmental disorder as it can provide much needed information about the effects a disability has on a father's capacity to parent, how fatherhood is modified with a child with autism, and finally offer the opportunity to extend social support theory concerning parenting a child with autism and other disabilities. The significance of their lived experiences gave the opportunity for single fathers to describe their joys and difficulties in parenting a child with autism, as well as give suggestions to other caregivers to children with autism.

Research Questions

The central question for this study was:

RQ1: What are the lived experiences of single fathers of children with autism?

The secondary question was:

RQ2: What are the challenges faced by single fathers of children with autism?

Conceptual Framework

The research of this study was based on social support theory. Social support theory states that the caregivers will need formal or informal support when parenting a child with a disability (Uchino, 2004). Formal support can be from professional services that provide single fathers educational tips and interventions that can be used when raising a child with autism (Renty & Roeyers, 2006). The informal support may be in the form of relatives, friends, and community members (Perry, 2008). Once single fathers know that they have support, it may alleviate the stress that comes from parenting a child with autism.

Social support theory was suitable for capturing the core of the lived experiences of these single fathers of children with autism as they summarized the study's purpose, meaning, and significance. Social support theory will be discussed fully in Chapter 2.

Nature of Study

In this study, I used a qualitative inquiry using a phenomenological approach. According to Creswell (2013a), the primary focus of phenomenology is to simplify the participants' viewpoints of their experiences as it is applied to the experiences of a broader phenomenon. A phenomenological approach was selected to understand the lived experiences of single fathers of children with autism. During the interviews, I heard the experiences of the single fathers as they described the challenges associated with parenting a child with autism. The responses that were given during the interview by the single fathers were expected to provide an understanding and awareness of their experiences. Data were gathered through the use of in-depth interviews with the single

father participants, field notes, and observations. Data were interpreted and coded for thematic significance as well as for textural descriptions to understand the expressed meaning of the participants' experiences.

A phenomenological approach gave the single fathers the opportunity to describe their experiences as caregivers to children with autism. Phenomenological method was suited to address the meanings and viewpoints of the single fathers as it allowed the researcher the opportunity to comprehend the participants' everyday challenges in parenting a child with autism (Mason, 2010). With this method of research, I was provided with rich descriptive information and perspectives of the single father participants.

The inquirer described personal experiences with the phenomenon of parenting a child with autism also known as the epoche, recognized significant reports in the database from the single father participants, and chunked these responses into meaning chunks and themes. Furthermore, the researcher combined the themes into a depiction of the experiences of the single fathers, and then created a combined representation of the meanings and the uniqueness of the experience. These steps will be explained in detail in Chapter 3. The data were collected during the interview process with the single father participants.

Definitions

The following terms are defined for clarity:

Autism: A mental condition that is characterized by great difficulty in communication, using language, abstract concepts, and forming social relationships with

other individuals, and is usually detected in the early childhood years (Berg, 2009; Levy, Mandell, & Schultz, 2009).

Autism Spectrum Disorder: A neurological developmental disorder that affects a child's capability to communicate and socialize with other individuals, and is characterized by restricted, repetitive behaviors and activities (Leekam, Prior, & Mirko, 2011). The difference between autism and Asperger's syndrome is children with autism tend to have a language delay and tend to have below average IQ, whereas individuals with Asperger's syndrome tend to have an average or above average IQ and do not have a language delay (APA, 2013).

Caregiver: A relative or friend of a disabled person who assists the disabled person with his or her daily activities (Mitnick, Leffler, & Hood, 2010). For this study, caregiver refers to single fathers of children with autism.

Fatherhood: A male's role in the family as the provider, protector, nurturer, role model, caregiver and disciplinarian (Kraemer, 2001).

Social Support Theory: The insight and certainty that an individual is cared for and has help available from family and friends in difficult, stressful times when parenting a child with autism (Taylor, 2011).

Assumptions

Within the context of this study, I assumed that the research participants answered the questions truthfully as well as conveyed their experiences efficiently and effectively. Another assumption for this study was that the single fathers' accurately reported their child's autism diagnosis.

Scope and Delimitations

The focus of this study included 10 single fathers from the southern region of Trinidad, who have a child with an accurate medical diagnosis of autism. The children were between the ages of 3 and sixteen years old. This age group was chosen because at age 3, the parent was aware that his child had a disability and at age 16, the single fathers provided information on the most critical developmental stages (infancy to adolescence) of their children.

I used the detailed description of the participants' responses as it relates to their lived experiences (Lincoln & Guba, 1985). The descriptions were supported by the participants' exact words as the data were based only on the experiences that were shared by the single fathers.

Limitations

This study only examined the parenting experiences of 10 single fathers of children with autism. This study was limited to Southern Trinidad. I have had previous contact with some parents; however, I ensured that my biases would not interfere with my analysis of data by using a reflective journal that bracketed my biases (Smith, Flowers, & Larkin, 2009).

Significance

Practitioners and researchers in Trinidad saw a rapid increase in the diagnosis of autism in the period of 2005-2010 (Autistic Society of Trinidad and Tobago, 2012; Palmer, Blanchard, Jean, & Mandell, 2005; Wilkinson, 2005; Yell, Katsiyannis, Drasgow, & Herbst, 2005). With this rapid increase in the diagnosis of autism, there was

also a need to understand the perspectives of caregivers, especially single fathers. It is important to portray the lived experiences of men who have a child or children diagnosed with a developmental disability. It is significant to understand what it means to be a father to a disabled child from the fathers' point of view. Also, it enables the single fathers to share, add, and contribute to the literature regarding the essence of family life.

Previous research focused solely on mothers and on married fathers, but did not include any studies that specifically examined single fathers' perspectives on parenting a child with autism in Trinidad (Autistic Society of Trinidad and Tobago, 2012; Flippin & Crais, 2011).

The findings of this study sought to fill the gap in the literature by understanding and depicting the roles of single fathers of children with autism. Special needs professionals may benefit from this study as they may learn about the lived experiences of single fathers with children of autism. With this information, the professionals may know how to provide the necessary and sufficient resources to such fathers. Similarly, fathers of children with autism and other disabilities may benefit from this study by gaining insights from the experiences of others and support from knowing that their experiences of parenting a child with a disability are shared by others. Additionally, special education organizations may gain rich descriptive information from this study which may aid as a stepping stone for these organizations to improve their services to parents and primary caregivers of children with autism and other disabilities.

In this study, I shed light on the experiences of Trinidadian single fathers that may lead to the development of appropriate support systems for single fathers of children with

autism. This positive social change for fathers impacts the care and support that they can provide to their children with autism.

This study may offer insight that helps society be supportive of single fathers who are parenting a child with autism alone. The findings of the study may address the stereotype in Trinidad that single fathers are delinquent.

Summary

In this chapter, I presented the major issues involved in parenting a child with autism and the lack of research on Trinidadian single fathers who have children clinically diagnosed with autism.

The purpose of this phenomenological study was to understand the lived experiences of single fathers of children with autism in Trinidad and be able to view this phenomenon from the perspective of a single father. In this study, I explored the emotions, experiences, and opinions of single fathers of children with autism in Trinidad. This research study added to the existing body of knowledge by studying the lived experiences of single fathers, and gave an insight of the emotional and physical aspects of paternal perspectives as it was related to parenting a child with autism. To explore the lived experience of the single fathers, the central research question identified for this study was: What are the lived experiences of single fathers of children with autism? A secondary research question was: What are the challenges faced by single fathers of children with autism?

The significance of this study was the possibility to contribute to available knowledge on primary caregivers and their experiences parenting a child with autism. An

implication for positive social change was an increase in awareness and understanding of single fathers from Trinidad as primary caregivers of children with autism.

In Chapter 2, I will explore the literature that is pertinent to autism and how it is related to paternal caregivers. The characteristics of autism and the parental and sibling reactions to the diagnosis of autism will be addressed. Furthermore, the concept of fatherhood will be discussed and the modification of fatherhood in relation to parenting a child with autism will be explored.

Chapter 2: Literature Review

Introduction

This literature review includes pertinent information related to the lack of information as it relates to single fathers of children with autism (Wilson & Prior, 2010). Single fathers are infrequently documented in existing literature (Rice, 2011) and single fathers from Trinidad are not documented in the literature at all (Single Fathers Association of Trinidad and Tobago, 2012). The purpose of this phenomenological study was to address this gap in the literature by exploring the lived experiences of single fathers parenting a child with autism in Trinidad.

There are numerous studies on autism, but these studies are limited to mothers and their lived experiences parenting a child with autism (Baker & Drapela, 2010; Blatt, 2008; Watson et al., 2011; Phetrasuwan & Miles, 2009). During the last 10 years, fathers have been given a place in research (Lyons & Fitzgerald, 2009; Ogston, Mackintosh, & Myers, 2011). However, studies on single fathers are limited, and no studies focused on single fathers from Trinidad (Single Fathers Association of Trinidad and Tobago, 2012; Watson, 2011).

Within the last three decades, there has been a significant growth in the interest of fathers as caregivers, and there is an emergent body of research on the importance of fathers and their effects on their children (Pleck & Masciadrelli, 2009). Fathers have opted to be stay at home dads so that they can provide care for their children.

Additional research is needed so there will be accurate strategies and guidelines for paternal caregivers of children with autism (Tucker, 2006). There are several potential

reasons for the lack of research on the experience of paternal caregivers of children with autism. Some fathers may be apprehensive about participating, or are ashamed of the stigma attached to parenting a child with autism (Attwood, 2006).

Being a single father of a child with autism is likely different than being a single father of a child or children with no disabilities. For this study, single fathers are being studied as they are considered the primary caregiver of the child with autism, rather than married fathers who share responsibility with the married mother. Single fathers from Trinidad have been targeted as there is a negative view of fatherhood for a single father, and single fathers are seen as the forgotten or delinquent parents. In the literature review I will present an overview of autism and themes that relate to the issues of single parenting with autism. A discussion of the conceptual framework for the study will also be presented.

Literature Search Strategy

I used the following databases to find various literature on paternal caregivers and their experiences parenting a child with autism: PsycARTICLES, PsycINFO, PsycBOOKS, PsycEXTRA, Google Scholar, ERIC-Educational Resource Information Centre, SciDIRECT, Academic Search Primer, Proquest, SAGE, and Human Services and Social Services Collection. Terms used in the searches include *father*, *single father*, *autism*, *fatherhood*, *child*, *parenting*, *social support theory*, *family life*, *children with autism*, *children with Asperger's*, *siblings of children with autism*, and *disability*. From 2006 to present, there were four hundred articles that were related to all of these search terms. When conducting the research, there was limited information pertaining to single

fathers with a child with autism. Some of the research included married fathers. For the purpose of this study, the contents of this literature review look at the meaning of fatherhood and what it means to be a single father of a child with autism. These keywords were used singularly and grouped.

Conceptual Framework

The conceptual framework for this study was formulated based on social support theory to capture the real essence of the lived experiences of single fathers of children who have autism. This theory centers on the well-being of the family and the significance of social support networks (Uchino, 2004; Wills, 1991). According to Uchino (2004), social support theory provides explanations for situations in which individuals find a balance in parenting a child with autism. Social support theory explains how individuals interpret and cope with stress in their lives (Uchino, 2004). Social support theory helps individuals understand the impact of stressful life events (Wills, 1991). A social support network is crucial to the overall health of individual members within the family unit (Armstrong, Birnie-Lefcovitch, & Ungar, 2008).

Social support theory can be used to understand the lived experiences of single fathers. Single fathers, as the primary caregivers of children with autism, experience some level of stress whether it is physical, emotional, psychological, spiritual, or financial. In a study conducted by Guranlnick, Harmond, Neville, and Connor (2009), findings indicated that once single fathers are given some level of support, their stress was reduced.

Whenever a diagnosis of autism is received, parents and caregivers ought to have sufficient support in raising and caring for a child with autism (Miller & Reynolds, 2009). The social support theory suggests that families of children with autism need to have social support from family, peers and the wider community to guarantee that the necessities of the child are met, in addition to, the necessities of the parents (Sencar, 2008). According to Unluer (2009), having social support resources is significant to reducing stress levels for the caregivers. These resources include other family members, neighbors, peers, colleagues, professionals, and the wider community (Kaner, 2009).

Social support is categorized as informal support or formal support. Formal social supports are considered to be support from professionals in special education, and informal support is that given by relatives or friends who are a part of a family's daily life (Tucker, 2009). Researchers reported that informal support is more effective than formal support for protection against negative stress (Boyd, 2012). Brown et al. (2009) suggested that support from relatives and friends is a good emotional support for caregivers and formal support from professionals is crucial, as it displayed exactly what the caregivers and parents needed to do to ensure the proper parenting and caring for a child with autism. As social support increased, parents tended to react more positively to their child with autism.

Wills (1991) postulated four types of social support. First, *emotional support* is defined by when other individuals offer empathy, concern, and affection to single fathers. This allows a single father to know that he is valued. Second, *tangible support* involves the provision of financial assistance, material goods, and services. Third, *informational*

support involves others providing advice, guidance, and suggestions. Lastly, *compassionate support* involves others making the distressed individual have a sense of belonging (Wills, 1991).

In a study completed by Tucker (2009), the findings indicated that when caregivers of children with autism were given the necessary support, they felt a sense of relief, knowing that someone was there for them. In another study conducted by Smith et al. (2012), researchers found that parenting, on the whole, was not an easy task, but parenting a child with autism caused more prominent challenges. Smith et al. (2012) stated that once difficulties arose, it was necessary for the primary caregivers to be given reassurance, affection and support from other family members, peers, and the wider community. Social support theory is therefore most suitable for capturing the core of the lived experiences of these single fathers of children with autism as this theory may show the different supports that can be available to single fathers and how single fathers interpret and cope with the challenges of parenting a child with autism.

Dardas and Ahmad (2015) showed the significance of social support in their study in the U.S. These researchers sought to determine the importance of coping strategies in parenting a child with autism. There were 74 parents who participated in this study, including 70 married fathers and 4 single fathers. All the participants noted that having an effective social support system helped to ease the tension and frustration that stemmed from parenting a child who has autism. One of the single fathers noted that he felt an improvement when he gained support from his relatives and church members in raising and caring for his two sons who have autism (Dardas & Ahmad, 2015).

Similarly, there is a comparison between mothers and fathers and their coping mechanisms in parenting a child with autism in the U.S. which indicated that both mothers and fathers share similar experiences parenting a child with autism (Woodman, 2014). Woodman (2014) interviewed 70 parents, including 50 single mothers, 10 married mothers, two single fathers and eight married fathers. The single parents were given a higher level of social support than that of the married parents. Woodman (2014) reported that the single fathers had a reduced stress and anxiety level when they received social support rather than not receiving social support. Two of the single fathers clarified that social support does not necessarily mean financial support, but simply having someone who will listen to them about the high and low points of parenting a child with autism (Wills, 1991).

Nelson (2015) also reported the importance of having social support in parenting a child who has autism. In the study, Nelson (2015) interviewed 60 parents who included 40 married mothers, 10 single mothers, five married fathers and five single fathers in the U.S. about the importance of helpfulness in raising a child with autism. The participants acknowledged that having support from family members helped in caring for a child who has autism. Two of the parents stated that having parents who shared the same experiences helped their coping strategies for parenting a child with autism (Nelson, 2015).

A study conducted by Factor, Perry, and Freeman (2009), concluded that social support was significant in caring for a child with autism in the U.S. These researchers interviewed 25 parents, two of whom were single fathers. The participants believed the

support they gained from other relatives helped ease the stress that came from parenting a child with autism (Factor, Perry, & Freeman 2009).

Hall and Graff (2011) interviewed 60 parents, six of whom were single fathers in the U.S., and examined the relationship between social support and reduced stress level. Findings showed that the participants who did not receive social support had a higher level of stress and anxiety levels as compared with the parents who received social support. Hall and Graff (2011) stated that social support was necessary for parenting but had significantly more advantages when given to a parent who raised a child with a disability.

Autism

According to the APA (2013), autism is a developmental disability that typically arises in the initial three years of an individual's existence and it affects a person's capability to communicate and interact with others. Autism can be defined as the specific set of behaviors and is deemed as a spectrum disorder that affects individuals differently and to varying degrees (Lerner, 2012).

Autism recently appeared to affect an average of 3.4 in every 1,000 children between the ages of 3-10 years (APA, 2013). Researchers who investigated this phenomenon decided that there were various factors that accounted for the increase in the number of children who were diagnosed with autism. Such factors include: altering conceptualization to a spectrum as opposed to a fundamental definite condition, modification in the diagnostic methods, and the inclusivity of children with other disorders such as attention deficit hyperactivity disorder (ADHD) and Tourette's

syndrome (Bauman, 2011). The occurrence of this spectrum of autism [ADHD and Tourette's syndrome] was said to be approximately five to six per 1000 in younger children between the ages of 4-5 years (Bauman, 2011).

Historical View of Autism

In 1943, Dr. Leo Kanner, who worked at John Hopkins hospital, studied a group of 11 children, and introduced the title of early infantile autism to the English language (Langan, 2011). Similarly, Dr. Hans Asperger, a German scientist, described a milder form of the disorder which was known as Asperger's syndrome (Bauman, 2011). Today, these two disorders are defined and recorded in the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association as two of the five prevalent developmental disorders (PDD), universally known as Autism Spectrum Disorders (ASD) (American Psychiatric Association, 2013). These disorders were classified by various degrees of impairment in communication skills, social interactions, limited, repetitive and stereotyped patterns of behavior. The following sections deal with the characteristics of and risk factors for autism.

Characteristics of Autism

According to APA (2013), there are usually three major developmental areas that are affected by autism: *social interaction*, *language*, and *behavior*. However, as the symptoms of autism varied, two children with autism may display strikingly different skills. For instance, some children may exhibit signs of autism in early infancy, whereas others normally developed for the first six months or years of life, but unexpectedly

became inhibited or belligerent, or in some cases lost language skills they already acquired (Dawson, Mottron, & Gernsbacher, 2008).

Social skills. Social skills varied across the spectrum of autism; however, the following reflected some of the common social issues. Children diagnosed with autism failed to react to their names. Some children tend to have poor eye contact and appear not to hear at times (Elliot, 2013). Another social skill impairment that some children with autism experience was the need to resist the urge to cuddle, hug, and be held. They tend to be withdrawn as they prefer to retreat to their world and play by themselves (Biever, 2012). Some of the children were unable to be empathetic, that is, they tended to be unaware of others' emotions and to understand the emotions of others (Elliot, 2013).

Language. Language difficulties differed across the spectrum of autism; however, the following reflected some of the common language issues. Language is usually impaired when children are diagnosed with autism. Some children were unable to speak efficiently, or they sometimes have delayed speech. Some children with autism lost formerly acquired ability to say words or speak in sentences (Bastiaansen et al., 2008). Children with autism speak using an uncharacteristic tone or rhythm, and some of the children used a sing-song voice or robot-like communication. When children with autism were engaged in conversation, some found difficulty in continuing the conversation or even initiating a conversation with someone. In communicating with a child with autism, the child may repeat words and does not fully comprehend how to use the words and phrases effectively (Elliot, 2013). Some of the children appear to understand simple questions or direction given.

Behavior. Children with autism are known for their repetitive behaviors. Some performed repetitive movements inclusive of rocking, spinning, flapping of the hands. Children with autism tend to develop particular routines or rituals and become very disturbed at the slightest change. In an article by Elliot (2013), the researcher observed seven autistic children and monitored their patterns. One boy in the study, who was named John Y, became very anxious as well as aggressive when John Y's routine was disturbed. For some, they tend to move steadily. Some of the children with autism were fascinated by the details of an object, but they cannot comprehend the bigger picture of the subject. According to Wong and Kwan (2010), some of the children with autism had an unusual interest in food preferences and cravings for chalk and dirt and an interest in unusual topics like the electric fans or the telephone directories. It was also evident that children with autism were remarkably sensitive to light, sound and touch, however, they tend to be unresponsive to pain (Rubin & Lennon, 2009). Accordingly, children with autism usually performed acts that were self-harming such as head bangs (Berney, 2009).

Some stereotypical traits for children with autism are they sometimes find difficulties in sharing with others whether it be time sharing or with toys or books. When someone reads to them, children with autism were unlikely to point at the pictures in the book as compared to normal developing children (Naseef, 2010). According to Berney (2009) some children with autism tend to become more interactive with family and peers and showed limited disturbances in behavior. Those children who had the least severe symptoms were able ultimately to lead an ordinary or near to ordinary life.

With regards to intelligence, most of the children with autism are slow to obtain fresh understanding and skills, and consequently have signs of lower levels of intelligence. Various children with autism can have to normal to high levels of intelligence and are capable of learning quickly (Kamp-Becker et al., 2011). However, they have difficulty in communicating and accommodating and adapting new information to social situations. A term for such children with autism was known as *savant*, that is, a small number of children who had extraordinary skills in art, arithmetic or music (Elliot, 2013).

Diagnosis

Research has shown that the diagnosis of autism could be reliably made at the age of 2 and 3 years. However, a determination of the broader autistic spectrum is less consistent at this age than in older children (CDC, 2007). Parents and caregivers wanted a diagnosis as early as possible, and there is evidence that indicated that suitable early intervention can improve outcomes (CDC, 2007). Additionally, hereditary guidance can be given at any time when parents were deciding on having a family.

There is limited literature that explored the sensitivity of overall developmental screens or precise screening tests for autism in the total populations (Wang & Brown, 2009). For instance, a study implemented the CHAT testing to monitor a total population of children 18 months of age with a sample size of 50 children. According to Wang and Brown (2009) only fifty parents were interested in being part of the study. In the study, the primary care staff asked the parents and other primary caregivers about behaviors displayed by their children (Wang & Brown, 2009). Two months after the study was

done, a follow-up was done, and the specificity of the test was high, which recorded at 97%; however, the sensitivity was too low at 35%, to permit commendation for use as a screening test for the whole population. The CHAT testing can be used by the general public to monitor a child with autism behaviors (Wang & Brown, 2009). The reason for the study according to Wang and Brown (2009) was once early detection was done, the child may have a chance to be treated efficiently and effectively.

In doing a diagnosis of autism, those children that were more severely affected have difficulties in social communication and have lower IQs and these symptoms usually presented as a language delay during the first five years [the preschool years] (Dawson, Mottron, & Gernsbacher, 2008). According to Dawson, Mottron, and Gernsbacher (2008), some children with higher IQs were antisocial whereas some children with lower IQs were very sociable. According to Kamp-Becker et al. (2011), experts should maintain contact with preschool and school age children to monitor their behaviors and give recommendations to the parents and educators. The reason is to ensure that the child is developing according to the expectations for autism. Literature indicated once parents recognized that their child may have delayed development, they should seek professional assistance and allow the child to be monitored to determine what the child had (Biever, 2012; Elliot, 2013).

Parental Reactions

A parent knows whether or not his or her child is normally developing. There are usually signs that indicate that there may be a disability or delayed development. In a study conducted by Jennings (2005), the parents in the U.S. stated that their babies

appeared to be different from birth, insensitive to others or just concentrating attentively on one particular object for long periods. When an engaging, babbling toddler abruptly became quiet, inhibited, self-abusive, or even uninterested in social advances, this indicated that there is a developmental abnormality. Research showed that parents were precise about observing developmental abnormalities, regardless of not knowing the origin of such abnormality (Saunders & Morgan, 2009).

An initial reaction to hearing your child is diagnosed with autism is denial. No parent wants to know that his or her child can be abnormal as society would see it (Davis & Carter, 2010). This initial denial is mixed with other emotions that instantaneously placed the entire family unit in a stressful state (Johnson, Frenn, Feetham, & Simpson, 2011; Kenny & Corkin, 2011). Knowing that your child is diagnosed with autism, there are challenges parents would have to face such as locating superior, sufficient services to ensure that the child has the best services to meet the child's needs, emotional problems, physical stress as well as financial problems (Altiere & Von Kluge, 2009).

In the U.S. parents and caregivers of children with autism experienced a higher level of stress and were more inclined to negative outcomes than parents and caregivers of children with other disabilities. In a study by Sanders and Morgan (2009), the researchers looked and examined both the mother and father and the results indicated that mothers had a higher level of stress than the fathers in the study. The fathers were better able to manage their stress levels efficiently and effectively (Sanders & Morgan, 2009).

Once parents moved from the stage of denial, there are still other emotions that they experienced such as anger, sadness, and loneliness (Rodrigue, Morgan, & Geffken,

2010) before they accepted that their child has autism (Gray, 2007). Parents are usually angry and asked themselves, “Why me?” According to Gray (2007), when these parents of children with autism observed parents of typically developing children the anger built up. Research indicated when parents expressed such anger it relieved the built-in tension (Jennings, 2005). A suggestion for releasing such anger was informing others how one feels upon hearing the diagnosis of one’s child (Sanders & Morgan, 2009).

At some point in time, parents would feel a sense of acceptance. It was crucial to differentiate between accepting that one’s child has autism and being able to accept autism. When the parent accepted the diagnosis, the parent was ready to be an advocate for the child. In a study, the researchers suggested that parents must not be harsh but be patient with themselves, to allow themselves sufficiently to accept the diagnosis of autism, so that they would be able better to assist their children better (Capps, Kasari, Yirmiya, & Sigman, 2009).

Once parents accepted that their child has autism, social supports may help alleviate the levels of stress (Gray, 2007). When parents knew that they had support whether it was through formal assistance such as community programs, religious programs or informal means from extended families and friends, the level of stress was lowered (Ekas, Whitman, & Shivers, 2009).

Previous research in Trinidad highlighted the stressful states and reactions of mothers of children with autism regardless of the mother being married or unmarried with the fathers’ reactions being pushed in the background (Single Fathers Association of Trinidad and Tobago, 2012). Only in recent times, the paternal perspectives in Trinidad

were given acknowledgment as the fathers stated their feelings upon knowing the diagnosis of their children (Single Fathers Association of Trinidad and Tobago, 2012). However, there remain no studies on the single fathers and their experiences in caring for a child with autism in Trinidad. In a study conducted by Bloch and Weinstein (2010), the fathers initially renounced displaying their emotions as the mothers instantly became flabbergasted and the fathers had to be labelled as the active parent for the family.

According to Gray's (2007) study in the U.S., single fathers like married fathers did not have much social support. Ekas, Whitman and Shivers (2009), in their study in the U.S., found that married fathers like single fathers did not have sufficient support as society perceived men as strong. Dumas, Wolf, Fisman and Culligan (2009) found that fathers especially single fathers in the U.S. did not have the same support that women had. In the U.S., fathers in the study by Bloch and Weinstein (2010) felt isolated and expressed that they sometimes distanced themselves from their family by working longer hours to cope with their feelings.

Sibling Reactions

Each family situation is unique and distinctive, and the relationships between siblings are just as exceptional. Previous research has looked at these relationships between a child diagnosed with autism and their typically developing siblings (Rodrigue, Morgan, & Geffken, 2010). Quintero and McIntyre (2010) have found that siblings to a child on the spectrum experience confusion and resentment in response to the stereotypical behaviors associated with autism such as the lack of social skills needed to form meaningful relationships when the diagnosis is not explained to them. Essentially, it

was a stressful time for the siblings of children with autism. According to Macks and Reeve (2008), siblings reported that there was a sense of mixed emotions of fear, anger, resentment, and confusion. One of the participants from the study said that he felt angry, confused and mad, but eventually he felt helpless as he could not assist his little brother.

Younger siblings are more concerned with the strange behaviors that were displayed by the children with autism. Some of the younger siblings become afraid of becoming the target of their sibling's annoyance and belligerence (Cornew, Dobkins, Akshoomoff, McCleery, & Carver, 2012). In a study by Pollard, McNamara-Barry, Freedman and Kotchick (2013), some siblings reported that they were envious of the attention and affection given to their siblings with autism by their parents and, as a result, felt frustrated and could not interact with their sibling. Consequently, some of the siblings stated because of envy, they would pinch their sibling with autism or hide their siblings' favorite toys (Macks & Reeve, 2008). When the parents became aware, the elder siblings were punished for their wrong acts against their siblings with autism (Cornew, Dobkins, Akshoomoff, McCleery, & Carver, 2012).

Teenagers of siblings with autism are preoccupied initially as to the future their sibling may have. They are concerned with the part of the responsibility they had to play in caring for their sibling (Macks & Reeve, 2008). Other teenagers are concerned and embarrassed by what their peers may think of their siblings' peculiar behaviors (O'Brien, 2009). Siblings of children with autism tend to be emotionally, psychologically, behaviorally and academically sound (Moyson & Roeyers, 2011). However, in research

conducted by Quintero and McIntyre (2010), the siblings' emotional states were dependent on the parents' general state of well-being.

Sibling reaction is included as single fathers of children with autism may have other children and this might be a factor in their ability to parent a child with autism. While this is not a specific focus of this study, the single fathers may discuss these siblings.

Men as Caregivers

Previous research on caregivers has focused on the roles of females in providing family care to the children and the household in Trinidad (Brereton, 2010). There is no research completed on the role of men as caregivers in the family structure in Trinidad. In recent times, there is emphasis concerning the role of men as caregivers to their families as men in some instances became the primary caregiver to their family in Trinidad (Single Fathers Association of Trinidad and Tobago, 2012). The primary reason for such a shift in roles is divorce that occurred in the 20th century in Trinidad (Autistic Society of Trinidad and Tobago, 2012). In Trinidad, fathers now have to take full responsibility for their child or children that are left in their care. Although there are fathers who do not take full responsibility, there are those who become primary caregivers and yet they are under-represented in research (Bishop, 2014).

In the U.S. men who are the primary caregivers appear to manage stress more effectively than women (Thompson, 2002; Bokker, Farley, & Denny, 2007). Similarly in Trinidad, men are seen as the primary caregiver (Bishop, 2014). Men are better able to complete a caregiving job and go to another job. In a study by Fromme, Drach and Tolle

(2005), women in the U.S. were generally socialized to be more nurturing than men, but women internalized their nurturing performance with constant worry and anxiety, thus increasing their stress levels and giving them persistent stress. Men tend to be more assertive when dealing and interacting with any professionals and were able to be better focused when faced with any problems that may arise. Thompson (2002) argued that men's assertive nature makes them the better caregiver in stressful situations.

Fathers as Caregivers

As limited information existed on single fathers, there is a need for researchers to explore and understand the paternal experiences (Honing, 2008; Radin, 2009). Research indicates that a father's interactions are very crucial and very different from that of a mother's interactions (Cabrera et al., 2009). Although, fathers are not widely studied; their role in their child's development is very crucial (Radin, 2009). Fromme, Drach, and Tolle (2005) found that when fathers were seen as the primary caregiver, the children had a positive and higher emotional well-being, as well as the fathers' level of happiness was increased in relation to the number of hours spent with their child. Even though, in Trinidad, mothers are traditionally known as the primary caregiver, Bishop (2014) found there were men who wanted to take an active role as the primary caregiver but were not given the opportunity to take such a role.

Meaning of Fatherhood

Traditionally, fathers in Trinidad play an essential part in the lives of their children, taking a broad range of duties that described and directed their children's development. Historically, in Trinidad and Tobago, domestic control was in the hands of

men, where the women were expected to defer to their husbands on issues of child rearing (Bishop, 2014). According to Rotundo (2009), a father's moral role continued throughout childhood into their child's adult life. The father's influence is prevalent and typically surpassed the mother's duties over the child (Shorter, 2009). However, in contemporary times, the meaning of fatherhood has changed (Jones, 2006). Research shows that fathers in Trinidad are slowly becoming more involved in their children's development, being more caring, nurturing and emotionally involved (Ivrendi & Isikoglu, 2010). The relationship between a father and child is very beneficial, not only to the child but the father as well. There is an increase in parent-child development research that indicated the positive effects such as cognitive and emotional gains of active fathers in their child's development (Jones, 2006). Mothers tend to adopt the role of the caregiver in the parent-child interaction; fathers tend to be the primary playmates with their children (Ivrendi & Isikoglu, 2010). Jones (2006) noted that men who had a strong sense of being a father and actually took the role and responsibility seriously were more inclined to be actively involved in their child's life whether the fathers were married or not.

Single fathers from Trinidad understand that it is their duty to provide care for their child whether or not the child lives with them. Jones (2006) noted that there are two categories of fatherhood that are a supportive father or an unsupportive father. Fathers who are nurturers, educators, disciplinarians, and spend time with their children were seen as supportive fathers. Similarly, Bronte-Tinkew, Carrano and Guzman (2009) found that fathers could be classified into two categories which are supportive and inactive. The

researchers found that the categories were related to the level of parent-child interaction in the U.S.

The meaning of fatherhood to normal developing children is seen as an exciting time for any father. In the U.S., fathers in general are seen as the ideal role model, breadwinner, educator, disciplinarian, caretaker and supporter (Bronte-Tinkew, Carrano and Guzman, 2009). In Trinidad, most of fathers are seen as having a sense of pride and admiration for their typically developing children. Most fathers of typically developing children in Trinidad look forward to the fishing or camping trips, teaching their children to drive or teaching their child a sport, and used this opportunity to develop strong father-child bonds (Bishop, 2014). However, a father with a child with autism in Trinidad the functions are there but these functions are represented differently.

Meaning of Fatherhood for Single Fathers

There is less research focused on single fathers of children with autism than with other fathers and no research on single fathers of children with autism in Trinidad. Parenting a child with autism was viewed as a stressful life experience and has been linked with poor motherly mental health and increased motherly emotional distress in Trinidad (Bishop, 2014). However, there is no literature on the experiences of fathers especially single fathers of children with autism in Trinidad (Autistic Society of Trinidad and Tobago, 2012). Paternal experiences associated with parenting a child with autism and any disability in Trinidad received no research consideration.

Parenting a typical developing child in Trinidad has its stressful periods but for a parent with a child with a disability, the entire parenting is strenuous and stressful (Gray,

2007). Caring for a child with a disability is very demanding especially for a single parent. According to Brereton (2010), in Trinidad, women are seen as playing an expressive role in the family as women are very nurturing, caring, warm, and affectionate. Agostini (2012) found that in recent times, Trinidad men want to be recognized but they are not given the opportunity to express their experiences. The meaning of fatherhood for a father of a typically developing child is remarkably different from a father of a child with autism (Single Fathers Association of Trinidad and Tobago, 2012). For this section, there is an explanation of the single father perspectives who either have children with autism and who have normal developing children from other study findings. The perspectives of single fathers with children with autism were fathers from the U.S. as there is no research on single fathers and their parental experiences in Trinidad. The perspectives of single fathers with normal developing children were from Trinidad and the U.S.

Children with autism are faced with various challenges. These challenges pose a trying time in their socioemotional, physical, psychological and cognitive development from birth and sometimes throughout their entire development (Elliot, 2013). Parenting a child with a disability is sometimes doubled or tripled when compared to parenting a normally developing child (Lee, 2009). Parents of children with autism reported having a higher level of doctor visits than parents of typical developing children (Liptak, Stuart, & Aninger, 2009). In the U.S. Lee (2009) found there is a higher financial strain for single fathers as opposed to married fathers, although the single fathers are given financial support by relatives and friends. The financial strain derives from the levels of medical

care and attention needed and the proper implementation of the medicine the child with autism needed (Koydemir & Tosun, 2009). In the U.S., parents of children with autism especially single fathers have extra accountability as they ought to certify that the child with autism is appropriately taken care of by getting an assortment of professional involvement as well as adjunct therapies (Myers, Mackintosh & Gon-Kochel, 2009). In Trinidad, the daily lives of a single father are very demanding as the fathers have to ensure the needs of the child with autism are met, then if there are other children made sure their needs were met, then the father's needs. In the U.S. researchers found that parents with autism especially fathers of children with autism found that it is very demanding to care for the disabled child, as well as other typically developing children (Meirschant et al., 2010). Parenting a child with autism presented single fathers with an elevated level of caregiver burnout (Tehee, Hoan & Hevey, 2008), reduced psychological wellbeing (Kuhn & Carter, 2006) and a heightened level of social isolation (Higgins, Bailey & Pierce, 2008).

Johnson, Frenn, Feetham and Simpson (2011) concluded that men and women reacted differently to any stressful event that they face especially in their respective roles in the family unit. Men are seen better to handle the situation better as women initially became emotionally overwhelmed. In a contrasting study, the findings indicated that mothers reported to have significantly more positive experiences than the fathers (Kayfitz, Gragg, & Orr, 2010). It is indicated that the level of maternal stress was positively linked to that of the paternal perception and management of stress.

The lives of single fathers of children with autism in Trinidad are very challenging (Bishop, 2014). According to Elder et al. (2011), training sessions were conducted to alleviate the stress levels of fathers who had children with autism as it was filled with continual hassles and struggles but love and admiration for their children. In this study conducted in the U.S., there were 60 fathers, of which 25 were single fathers. The general consensus of the single fathers was they were grateful as the sessions made the fathers feel better when parenting their children (Elder et al., 2011).

Researchers found that emotional talk was important in caregiving. In a study in the U.S. by Brinton and Fujiki (2011), the participants consisted of 50 married fathers and 10 single fathers. The single fathers reported having a lower level of engaging in emotional talk when compared to the married fathers. The fathers concluded that emotional talk was crucial as it aided in assisting the child with autism to regulate and understand the emotions (Brinton & Fujiki, 2011).

Like married fathers with children with autism, single fathers also experienced a level of depression. For example, in a study in the U.S. conducted by Hartley, Seltzer, Head, and Abbeduto (2012), single fathers who had a child with autism reported having higher depressive symptoms when compared to married fathers. A major theme in the study findings that was consistent in explaining this higher level was due to limited support from other relatives and peers (Hartley et al., 2012). In another study in the U.S. by Vacca (2013), single fathers displayed the same initial feelings of shock, doubt, guilt, and denial when they heard that their child was diagnosed with autism. According to the researcher, 20 of 50 of the participants were single fathers, and they shared the same

sentiments as the married fathers, that it was an overwhelming experience raising a child with autism.

Parenting a child with autism can be seen as a stressful task for parents, both married and single. Consequently, the stress levels tend to be higher for single parents with children with autism. In a study done in the U.S. by Silva and Schalock (2010), the parents reported high stress levels. The participants consisting of 60 parents, of which 5 were single fathers. There was a common response among the five single fathers who stated that there were times when they felt helpless, confused, frustrated and overwhelmed when parenting a child with autism and this led to an increase to their stress levels. When compared to the married fathers in the study, the single fathers reported having higher stress levels. An explanation given was the fact that the married fathers had more support (Silva & Schalock, 2010).

In a study by Donaldson, Elder, Self, and Christie (2011), with 100 participants consisting of 78 married fathers and 22 single fathers in the U.S., the participants noted the importance of communication. The single fathers reported to have a higher communication with their children compared to the married fathers. One single father stated that verbal communication was crucial as one was able to build a rapport with the children (Donaldson et al., 2011). Depending on the severity of the autism, the fathers of children with autism from the U.S. suggested other means of communication which included spending quality time with the child as well as engaging in play (Donaldson et al., 2011). Woodgate, Ateah and Secco (2008) conducted a study in the U.S. of 98 fathers of which 20 were single fathers. The single fathers in this study reported a higher stress

level than married fathers, stating that this resulted from not knowing at times what to do best for their children (Woodgate et al., 2008).

Hock, Timm and Ramisch (2012) found in their study the participants did not have intimate relationships. The participants consisted of 70 parents, 40 were married, 25 were single mothers and 5 were single fathers in the U.S. The single fathers claimed that it was difficult to have a social life when parenting a child with autism. With the limited social life, there was not any time for pursuing intimate relationships (Hock et al., 2012). According to Schieve et al. (2007), some areas that were affected by single fathers are (a) quality of life, (b) financial hardship, (c) stigma and (d) respite care.

Quality of life. According to Schieve et.al (2007), parents or caregivers for children with autism reported about their high levels of life sacrifices that are made to care their child, their difficulty for caring for the child, their frustration with the child's unusual behaviors and occasionally their anger toward their child. When compared to single fathers of children with autism to fathers of children with other developmental difficulties, fathers with autism scored statistically higher with high levels of aggravation.

Single fathers with children with autism in the U.S. reported being provoked, harassed, and irritated at times of being the parent of a child with autism (Elliot, 2013). A study in the U.S. by Mc Stay, Dissanayake, Scheeren, Koot, and Begeer (2014) suggested that parents of children with autism had a diminished lifestyle. The research participants consisted of 30 parents, 20 were married mothers, five married fathers, and five single fathers. The single fathers were more disgusted about their lifestyle as there was not the opportunity for them to do activities that they wanted to do. When compared to the

married fathers, the single fathers were more concerned with being fulltime caregivers to their children with autism (Mc Stay et al., 2014).

Financial hardship. Economic concerns of parenting a child with autism are very harsh. The cost of caring for a child with autism in Trinidad throughout their lifetime is estimated to be \$3.2 million compared to an estimated \$1.9 million in caring for a normal developing child in Trinidad (Single Fathers Association of Trinidad and Tobago, 2012). The cost is inclusive for medical fees, therapies, special care education, and child care. For a single father in Trinidad, this is very demanding. With this financial burden, it led to more parental stress and burnout. These expenses are extreme compared to the general income and cost of living in Trinidad (Single Fathers Association of Trinidad and Tobago, 2012).

In the U.S. with an estimated cost for caring for a child with autism, sometimes some of the fathers are not able to provide the specialist care for their child and in some cases the fathers had to quit their job in order to be a full-time service provider for their children (Fletcher, Markoulaakis, & Bryden, 2012). This is a tough situation, but arrangements had to be made. The absence of outside work and low levels of employment are correlated with greater degrees of psychological distress, higher rates of despair, apprehension, and resentment (Gray, 2007). Possible indicators for such heightened level of stress consisted of spending great amount of time caring for a child with autism, limited adult interaction, and lowered levels of income which are linked to increased economic hardships (Datz, 2008).

Stigma. Having a child with a disability at times is embarrassing and traumatizing for parents in Trinidad. In a study in the U.S., the effect of social stigma and social isolation and rejection has caused some parents especially fathers to become withdrawn (Gray, 2007). However, as time progressed, fathers reported becoming braver and becoming more comfortable in speaking publicly and confidently about autism regardless of the criticisms that they received (Konstantareas & Stewart, 2008). Gray (2007) found that fathers reported that they gained strength and motivation from the establishment of supportive networking from other parents and caregivers with children with autism. Some of the fathers claimed that it made them realize that they were not alone and there is nothing wrong with having a child with a disability (Gray, 2007). This aids in reducing the extent of the impact of stigmatization through joint experiences and the awareness that the fathers are not alone in their struggles.

Respite care. In a study conducted in the U.S. by Cramer and Carlin (2008), the participants all agreed that short breaks are necessary when caring for a child with autism. Of the 70 fathers, 40 were single fathers. The researchers were amazed to know the married fathers wanted respite care more than the single fathers. The single fathers claimed that when they could not deal with the pressures they asked for assistance (Cramer & Carlin, 2008). Respite care is considered important for minimizing the levels of parental stress. According to Preece (2010), respite care is seen as a method of allowing single fathers to reunite with their personal and social lives, as well as the time needed to rebuild the fathers' physical health.

Abelson (2009) believed that single fathers who received respite care are better able to function effectively and efficiently in parenting their children with autism. When Abelson (2009) conducted a study, he noticed that parents who engaged in respite care compared to those who did not reported lower stress levels. Caregivers need that time off to rejuvenate themselves to continue providing efficient care and support to their children (Cramer & Carlin, 2008).

However, in a study done in the U.S. by Openden, Symon, Koegel and Koegel (2006), the participants noted that there are challenges in allocating suitable individuals to fill the position as caregiver. The study comprised of 100 parents, with 10 single fathers. The single fathers agreed that respite care is necessary but only two of the 10 single fathers are able to find a suitable person to care for their children with autism (Openden et al., 2006). One of the responses given by the single fathers was there were not sufficient available services at a reasonable cost in caring for a child with autism (Openden et al., 2006).

Furthermore, although the respite care is beneficial for the single fathers, research has shown that this caused mixed emotions for some children diagnosed with autism (Preece, 2010). In a study in the U.S. conducted by Preece (2010), the findings indicated that some of the children appreciated the strange faces and interacted with the substitute caregiver but some did not appreciate a change in face and the noises and rules the substitute caregiver brought.

Summary and Conclusions

Chapter 2 explored the characteristics of autism, the diagnosis of autism, parental and sibling reactions, caregivers, and the meaning of fatherhood for single fathers as it was associated with having a child with autism. Each category educated the reader on this neurological disorder and all of its components.

The purpose of this review is to provide research related evidence focused on single fathers as the primary caregivers of their children with autism. The review also draws attention to some of the distinct elements that male caregivers undergo in parenting a child with autism (Wallace & Rogers, 2010). Fathers especially single fathers were seldom focused on in the current literature as the primary caregiver of a child with a disability especially autism. Although mention was given to the paternal experiences, the emphasis was on maternal experiences (Huws & Jones, 2010).

Although there are studies in the U.S. on paternal experiences, there are no studies on single fathers and their lived experiences in caring for a child with autism in Trinidad. The study serves as an opportunity for single fathers to explain their experiences in parenting a child with autism. Researchers in the U.S. found that fathers both married and single did not participate in their study because of ego issues and they were afraid of being stigmatized (Huws & Jones, 2010; Watson et al., 2009). There are numerous studies in the U.S. on caregivers of children with autism but a majority focused on the mother's experiences (Baron-Cohen et al., 2011; Cassel et al., 2007; Mandel, 2010; Phelps et al., 2009; Watson et al., 2011). A reason for the lack or under-representation of

single fathers is that men are seen as the inactive and forgotten parent (Baker, Seltzer, & Greenberg, 2011).

Single fathers in Trinidad are not given the opportunity to engage the wider community and professional services on their feelings, thoughts, as well as daily challenges with being a caregiver to a child with autism. The purpose of the phenomenological study was to help fill the gap in studies of single fathers with children with autism and to understand the lived experiences of single fathers of children with autism in Trinidad.

In Chapter 3, I will explore the research methodology, research inquiry and approach, participants, as well as the data collection and analysis processes and credibility and trustworthiness of the study.

Chapter 3: Research Method

Introduction

The purpose of this phenomenological study was to understand and depict the lived experiences of single fathers of children with autism in Trinidad. The researcher attempted to understand the lived experiences of single fathers and the challenges they faced in raising a child with autism.

In this chapter, the methodology and design used in this research will be presented. First, the research design and rationale will be presented, followed by the research questions that directed the study. The role of the researcher in this study will be analysed, followed by procedures adopted for participant selection. In this chapter, I will provide clarification on the procedures for data collection and data analysis. Finally, ethical issues such as researcher objectivity and confidentiality will be discussed. The chapter ends with a summary of the major issues which emerged from the research.

Research Design and Rationale

Research Questions

The central question for this study was:

RQ1: What are the lived experiences of single fathers of children with autism?

The secondary question was:

RQ2: What are the challenges faced by single fathers of children with autism?

A qualitative research methodology is used in order to gain a better understanding of the lived experiences of single fathers of children with autism. According to Creswell

(2013a), qualitative research is a systematic approach that strives to discover reactions to a stated phenomenon. Qualitative research uses comprehensive studies of a small target audience, which in this case will be single fathers, to guide and support the given responses.

Qualitative methods are used when there is an opportunity to inquire on a given phenomenon (Sirota, 2010). The advantage of qualitative inquiry is the ability to supply complex textual descriptions of how individuals experience a given phenomenon (Stirling, 2007). Through this approach, I formed insights on the human perspective of parenting a child with autism (Creswell & Miller, 2000).

As mentioned earlier, this research method is the means of understanding and exploring human and social issues (Hood, 2000). According to Hatch (2006), qualitative research is used to develop a holistic view of a given phenomenon in the participants' natural setting. It is also implemented to gain a better understanding of a social or human problem from the viewpoints of the individuals who are experiencing the human and social issue. This research requires a level of commitment to study the specific issues in-depth.

For this study, a phenomenological approach was used in order to gain rich, in-depth information from the single fathers. The researcher must begin the study with an open mind and rid himself of preconceived notions. A phenomenologist relies heavily on interviewing rather than observing the participants (McCaslin & Wilson Scott, 2003). Most interviews are long and in-depth, and because they are often detailed and descriptive, the use of video or audio recording devices is very common because they

permit the capturing all the details. The aim is to gain an understanding of the phenomenon through the consciousness of the participants.

Phenomenological theory is a perspective that looks at gaining knowledge about how individuals experience things (Creswell, 2013a). From a phenomenological perspective, childhood disability can be examined through the eyes of their caregivers, in this instance, single fathers of children diagnosed with autism.

With phenomenology, the goal is to comprehend and explore how individuals construct meanings to a given phenomenon. Phenomenology is “bringing to light the lived experience through the interpretation of meaning acquired in text created from the narratives of those being studied” (Newman, Cashin, & Waters, 2010, p. 267).

Phenomenology also involves assuming that the problem or situation being explored is itself part of the data (Gibson, 2012). Huang, Kellett, and St. John (2010) described a hermeneutic circle as “analysis moved between the focused experiences of learning the diagnosis to the whole experience of having a child with a developmental disability” (p. 1216). In a previous study by Keller, Ramisch, and Carolan (2014), the researchers used phenomenological theory and from the findings of the study, the researchers suggested that clinicians may help fathers to develop appropriate relationships with their children that involve shared activities. Clinicians assisted fathers in coping with isolation and expectations regarding fatherhood, developing desired fatherhood roles, and finding appropriate shared activities with their children. As a result, the objective of phenomenology is the direct investigation and description of a given phenomenon as consciously experienced by a group of individuals. A phenomenological study was

conducted to understand and describe the meanings of the lived experiences of single fathers with children with autism. The single fathers in Trinidad were interviewed using open-ended questions that were based on their experiences as primary caregivers to children with autism.

Role of Researcher

The role of a qualitative researcher is different from the role of a quantitative researcher (Creswell & Miller, 2000; Page, 1997). Qualitative researchers are seen as the main instrument of the collection and analysis of data (Greenbank, 2003; Page, 1997). My intention was to understand the meanings of the experiences of the single fathers in order to understand the participants' words. As a result, I directly engaged and immersed in the phenomenon to be able to understand the single fathers' experiences. I gained a full understanding of the phenomenon, and provided rich descriptions from the narratives given by the participants. Also, it allowed the researcher to understand and illustrate the participants' experiences and generate empathetic understanding (Greenbank, 2003).

The role of a phenomenological research is to ask probing questions, then listen and then ask more probing questions to gain deeper levels of understanding from the single fathers. The researcher had no previous relationship with any of the participants with regard to professional, personal, or social concerns. I sought to develop a trusting rapport and relationship with the participants to ensure that the participants are comfortable in the setting. I assumed that the participants honestly answered the interview questions revealing a valid social reality of their experiences (Hood, 2000). My role in this study was to gain insight on single fathers and their experiences through

in-depth interviews. I probed the participants for specific details so to gather as much information needed to describe and portray their experiences as primary caregivers to children with autism in Trinidad.

All researchers have varying degrees of bias when conducting a study; as a result, there may be bias in the data collection and data analysis processes (Englander, 2012). To reduce my biases, I kept a journal with the intent to bracket my personal reactions and prejudices from my interpretation of the participant's experiences (Sanchez, 2007).

Methodology

Participant Selection Logic

The majority of research in the area of parental behaviors associated with autism explored maternal perspectives on raising a child with autism (Bayat, 2007; Rivers & Stoneman, 2003; Yamada et al. 2007). The participants of this study were single fathers parenting a child with autism. A criterion sampling was used to select the research participants who have a child with autism. A criterion sampling involves the identification of specific criteria of significance, articulation of the specific criteria, and a logical analysis and review of cases that meet the specific criteria (Hood, 2000). The participant criteria for this study were that the father (1) must be a single parent, (2) must be the child's biological father, (3) must be the primary caregiver of the child; (4) the child must have a diagnosis of autism based on the information provided by the single father; (5) the father must be between the ages of 25 and 40 years; (6) the child must be between the ages of 3-16 years; and (7) participant must be from a region in Trinidad. Mason (2010) believed that criterion sampling is the most suitable sampling for a

phenomenological study. In this study, the participants all have experienced the exact phenomenon of engaging in single parenting of a child with autism. If there are not sufficient participants, a snowball sampling would be used to ensure that I recruit participants who are experiencing the same phenomenon.

I recruited participants through the local Strategic Learning and Special Education Institute which serves all the areas in Trinidad that provides services for children with various disabilities including autism. I contacted the Special Education organization to give them an overview of the study. The organization posted the Invitation Flyer (Appendix A) on their bulletin board. Participants came from the Southern region of Trinidad. The participants came from the Strategic Learning and Special Education Institute. The Strategic Learning and Special Education Institute provides special needs services for disabled children from ages 2 to 18. Children attend this institute from 8:30 am to 4 pm, from Mondays through to Fridays, and the educators are trained in teaching and dealing with children with autism, communication disorders, giftedness, ADHD, and Down Syndrome. In general about eighty percent (80%) of the students in this institute are diagnosed with autism (De Freitas, 2010).

I gained approval from Walden's Institutional Review Board (IRB) before I invited the fathers to participate in this study. When approval was granted, I contacted Strategic Learning and Special Education Institute to distribute the Invitation Flyer (Appendix A). Fathers who responded to the flyer received the Invitation to Participate letter (Appendix B) and a copy of the Informed Consent to review (Appendix D).

I gave the fathers one month to make contact with me. Once there was feedback from the parents, I contacted the potential fathers and then screened each father to ensure they met the criteria. This included asking the potential participants if their children have a diagnosis of autism and accept their answers because of medical records privacy issues. The screening process took place through email and telephone. Single fathers who met the participant criteria were given a consent form (Appendix D) to review. The form was reviewed, questions were answered and the consent was signed on the day of the interview. The consent form (Appendix D) outlined the goals and methods of this study. It stated that there were no incentives and that they can withdraw at any time from the study. The interviews were held face-to-face at a mutually agreed upon location that can ensure privacy.

In qualitative research, saturation is imperative (Mason, 2010). Saturation occurred when adequate data were collected. If there are too few participants, the researcher will not capture the true social reality of a given phenomenon (Hood, 2000). According to Mason (2010), saturation occurs when no new information is provided by the participants; therefore saturation is significant. According to Hood (2000), a minimum of six participants are needed for a phenomenological study. For this study, the number of participants was expected to range between 10 and 15. This number of participants was considered sufficient to provide adequate data to interpret the phenomenon thoroughly and assure saturation. The single fathers engaged in an in-depth interview pertaining to their lived experiences in parenting a child with autism. The

single fathers who were the participants reflected on their experiences in caring for a child with autism.

Procedures for Data Collection

When approval was gained from Walden University's IRB, the data collection process began. I screened the potential research participants based on the above mentioned criteria and then I provided an overview of the study and invited the potential participants to participate in the study (Seidman, 2006). I acted as the main data collector by conducting the interviews.

In-depth questions were used to gain an understanding on the lived experiences of the single fathers. The interview consisted of open-ended questions (Appendix E), which allowed for prompts. The questions attempted to capture the lived experiences and their expressed meaning of what it is to care for a child with autism.

Trust and rapport were significant during the interviewing process. Maintaining a positive relationship between the interviewees and myself allowed the participants to convey their experiences honestly (Thomas & Magilvy, 2011). Trust and rapport were initiated at the first interview prior to the interviewing process. The interviews were conducted at a location that was comfortable for the participants, had limited distractions, and high levels of privacy. The location was at a mutually agreed location. The interview lasted between one and two hours. Each interview was recorded with the permission of each participant and transcribed. I used a journal for field notes during the interviews to record any personal observations or nonverbal cues.

The responses given by the single fathers were kept confidential. Each participant was identified with a code such as D1 and D2. The data were organized by creating files for the transcription. The files were saved on a password protected computer, on flash drives, and on an external hard drive. After five years, the raw data will be destroyed (Creswell & Miller, 2000). Password protection was used to maintain data integrity and confidentiality.

When the interviews were completed, I informed the participants that I would contact them with a summary of their responses to verify my interpretations of their experiences (Berscheid, Abrahams, & Aronson, 1967). To verify the interpretations, I provided a written description of my analysis in a text document and emailed the document to the research participants. In the case of any inconsistent cases or discrepant cases, I did member checking to ensure that the findings and my interpretation of the findings were accurate by emailing the respondents a word document of my interpretations of their answers.

Data Analysis Plan

Once data collection was completed, the analysis was conducted. The interview transcripts were transcribed verbatim and each participant was assigned a code, such as D1, and D2. I used Moustakas (1994) steps for data analysis. For the purpose of this study, the interview recording was transcribed verbatim. According to Moustakas (1994), each transcript is read to gain a general knowledge of the information provided by the participants on their experiences. The purpose of the first step of data analysis is to comprehend the information that is being conveyed.

According to Moustakas (1994), the second step is to highlight words that have pertinent relevance to the phenomenon being explored. This proposed study is attempting to extract statements to understand how single fathers experience parenting a child with autism. These extracted statements are known as horizons (Moustakas, 1994). According to Moustakas (1994), each horizon ought to contain a component of the experience that is pertinent to the interview question. Once there is pertinence, each horizon has the prospective to be labelled. If there are components that are not necessary for each horizon, it cannot be labelled and will therefore be eliminated (Moustakas, 1994).

Moustakas (1994) stated that clustering the horizons into themes is the third step of the data analysis plan. The emerged themes represented the feelings, thoughts, emotions, and actions on how the single fathers experienced the phenomenon.

Moustakas (1994) stated that individual and group descriptions of the experience are the final steps in the analyzing of data. Meaningful depictions of each father's experiences were developed from the themes. Using verbatim data from the transcripts, the meanings and essences of the phenomenon were developed to represent the participant group as a whole (Moustakas, 1994).

Issues of Trustworthiness

Trustworthiness is significant in qualitative research. In qualitative inquiry, trustworthiness encompassed four aspects including credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). According to Patton (2002) credibility is an assessment to detect that the results were credible by representing the information given by the participants. Transferability is the process by which the research

results can be applied beyond the limits of the study. Lincoln and Guba (1985) believed that dependability is a valuation of the quality of the integrated processes of the collection and analysis of data. Confirmability is the degree to which the research results were supported by the data collected (Hood, 2000).

The first aspect of trustworthiness is credibility. Ensuring that there is a high level of credibility, I used triangulation. Triangulation is a method used by qualitative researchers to check and establish validity in their studies by analyzing a research question from multiple perspectives (Patton, 2002). To accomplish triangulation, I ensured that there is a level of consistency of data provided (Angen, 2000). Also, I used multiple participants as described by Smith, Flowers, and Larkin (2009). Smith et al. (2009) described this procedure as completing an analysis of each participant's interview separately and then using these multiple analyses combined to establish credibility of the overall analysis. Data triangulation was used to check the interviewees' responses. I sent the participants a summary of my interpretation of their responses to ensure consistency of the data (Hood, 2000).

According to Casey and Murphy (2009), triangulation assists in establishing overall trustworthiness of the study in addition to adding a level of rigor. Triangulation of data allows the researcher to uncover more imminent information and may generate richer, truer reflections (Casey & Murphy, 2009). In addition to triangulation, member checking was used to ensure credibility (Thomas & Magilvy, 2011). A summary of each participant's interview was sent in an email in a text document to ensure that the findings represented their expressed feelings on parenting a child with autism.

I also maintained a reflexive journal throughout the research process. First, this enhanced my ability to bracket my experiences so I could be conscious of my own biases and remove them from my analysis (Thomas & Magilvy, 2011). Secondly, I used the journal to document my thought processes throughout the study to further support the credibility of my interpretations.

Transferability is another aspect of ensuring trustworthiness. I included rich, detailed descriptions of each participant's responses and their lived experiences. The participants' exact words were included to support the emergence of main themes from their responses (Smith, Flowers, & Larkin, 2009).

To ensure dependability, I developed an audit trail (Morrow, 2005; Smith, Flowers, & Larkin, 2009; Thomas & Magilvy, 2011). The audit trail maintained all word document files of the interviews, the reflective journals, and other field notes to ensure that someone else, unconnected to this research procedure, can review the raw data as well as the data analysis (Smith, Flowers, & Larkin, 2009). Thematic analysis was used to ensure dependability. Thematic analysis is a method for identifying, analyzing and reporting patterns within the data (Morrow, 2005). The six steps of thematic analysis which are familiarizing myself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report was used (Morrow, 2005).

Confirmability is also known as the neutrality of the researcher. Bias is evident; however, being objective is paramount. The researcher must self-reflect with the use of a journal to ensure the biases are separated in the data collection and data analysis

processes (Smith, Flowers, & Larkin, 2009). When the researcher reflects it is known as reflexivity (Morrow, 2005).

Ethical Procedures

Before I conducted the interviews, I gained approval from the Institutional Review Board (07-06-15-0239751). When I received approval, I held a meeting with each potential participant who was willing to a participant in the study. I discussed the details and purpose of the study and the procedures for the protection of the participants. The participants were single fathers who were free to decide whether they want to participate in the study. The participants were selected through criterion sampling. When the participants were selected they were given further details of the study, and given consent forms to give their consent. The single fathers were debriefed on the study informing them that they can withdraw from the study at any time, the limits to confidentiality, and that no incentives were provided. There were no known risks or harm associated in participating in the study. Although not anticipated, if any information provided by the fathers indicates potential harm to either themselves or a child, an immediate report will be made to the appropriate agency in Trinidad.

I addressed confidentiality by assuring the participants that a code name was used in place of their real name. The participants were informed that I was the only person who had access to the responses. Field notes, audiotapes, and transcripts, were stored in a locked cabinet in my home office and external hard drive. All files stored in an external hard drive have and will continue to have a password. All data will be stored for a period

of five years and then it will be destroyed as per university and established research guidelines.

Summary

The purpose of this study was to understand the lived experiences of single fathers of children with autism. Chapter three discussed the phenomenological inquiry and the appropriateness for this study. Phenomenology was used as I captured the expressed meaning of the experiences of the single fathers. I explored and described the meanings for each participant as accurately as possible. I discussed how the participants were selected through criterion sampling, how data were collected and analyzed as well as the ethical issues. Data were collected through in-depth interviews and field notes. These interviews were audiotaped, transcribed, and analyzed for emerging themes that captured the true meanings for each single father. Validity of the findings is crucial; therefore, the issues of trustworthiness were discussed.

In chapter four, I will discuss the findings of the study. I will describe the setting of the study and demographics. Lastly, I will describe the results of the study.

Chapter 4: Results

Introduction

The goal of this study was to describe the lived experiences of single fathers of children with autism in Trinidad. The study involved 10 single fathers from Southern Trinidad, who identified themselves as having a child with autism between the ages of three and 16. The central research question was the following: What are the lived experiences of single fathers of children with autism? The secondary question was the following: What are the challenges faced by single fathers of children with autism? In this chapter, I discuss participant demographics and characteristics, describe data collection methods, provide a thorough account of the data analysis process, present evidence of trustworthiness, and address the results of the study.

Setting

I interviewed the participants at a mutually agreed upon location: a private room in a public library in Central Trinidad. The room was air conditioned and comfortable for the participants. There were no external factors such as noise to distract the participants. During the semi-structured interviews, I gained insight about their lived experiences as single fathers to children with autism from the participants' nonverbal communication cues.

Demographics

The participants' ages ranged from 25 to 40 years old. Four of the participants were Indo-Trinidadian, four were Afro-Trinidadian, and two were of mixed race. Table 1 provides further demographic information on each single father. The demographic

information includes the age of the father, race of the father, age of the child diagnosed with autism, and gender of the child diagnosed with autism.

Table 1

Participant Information

Participant	Age	Race	Age of child	Gender of child
Dad 1	39	Indo-Trinidadian	12	Male
Dad 2	28	Indo-Trinidadian	4	Female
Dad 3	40	Indo-Trinidadian	10	Female
Dad 4	30	Indo-Trinidadian	12	Male
Dad 5	35	Afro-Trinidadian	9	Male
Dad 6	37	Afro-Trinidadian	11	Female
Dad 7	29	Afro-Trinidadian	8	Female
Dad 8	39	Afro-Trinidadian	10	Male
Dad 9	35	Mixed	6	Female
Dad 10	33	Mixed	5	Male

I refer to participants by assigned pseudonyms throughout the study, which take the form of *Dad* followed by the participant number. Participant 1, for instance, is referred to as *Dad 1*. Dad 1 is an Indo-Trinidadian 39-year-old man with a 12-year-old son who has autism and a 7-year-old daughter. His son was clinically diagnosed with

autism at the age of 6. He and his wife are divorced, and he has full custody of his two children.

Dad 2 is an Indo-Trinidadian man who is 28 years old. He was the youngest single father in the study. He has a daughter who has autism, and she is 4 years old. His girlfriend left when their daughter was clinically diagnosed with autism. Dad 2 only has one child.

Dad 3, at 40 years of age, was the oldest father in the study. He has one child, a 10-year-old daughter who has autism. After his wife died, he decided to focus on his child. His daughter was clinically diagnosed with autism at the age of 8. Dad 3 has only one child.

Dad 4 had his son when he was 18 years old. He is now 30 years old, and his son who has autism is 12 years of age. He has sole custody of his two children. His second child, a daughter, is 8 years old. His wife filed for divorce when she could not manage the stress of parenting a child with autism. His son was clinically diagnosed with autism at the age of 6.

Dad 5 is a 35-year-old Afro-Trinidadian single father with a 9-year-old son who has autism. His son was clinically diagnosed with autism at the age of 3. Dad 5 has a daughter who is 11. His wife left him to take care of the children. She does not provide any care or support for the children.

Dad 6 is a 37-year-old Afro-Trinidadian. He has two children, a daughter with autism who is 11 years old and a son who is 8 years old. His daughter was clinically diagnosed with autism when she was 7 years old. His wife is an engineer who got a job in

Canada. The duration of the job was 3 months, but it has been 4 years since the wife left. The wife does not provide any support to her children.

Dad 7 is an Afro-Trinidadian man who has an 8-year-old daughter who was clinically diagnosed with autism at the age of 4. He has sole custody of his daughter. He has only one child.

Dad 8 is an Afro-Trinidadian man who is 39 years old. He has a son who is 10 years old and is clinically diagnosed with autism. He has no other children. His girlfriend left when she learned of his son's diagnosis of autism.

Dad 9 is of mixed descent and is 35 years old. He has a daughter who is 6 years old and is clinically diagnosed with autism. He has an older daughter who is 10 years old. He has sole custody of the two children.

Dad 10 is of mixed descent and is 33 years old. He has a son who is 5 years old and was diagnosed with autism at the age of 4. Dad 10 has no other children and has custody of his son.

Data Collection

I collected data for this study from 10 single fathers who volunteered to be part of the study. The single fathers who volunteered met the study criteria outlined in the invitation flyer, invitation to participate, and informed consent. I posted the invitation flyer on the Strategic Learning and Special Education Institute bulletin board. The participants contacted me by telephone and email. I debriefed them on the study, and we agreed on a location and time to conduct the interviews. It took a week to agree on a time and location for the interviews.

To provide data for the study, each single father participated in a face-to-face interview that lasted between 60 and 75 minutes. I conducted the interviews over a period of 2 weeks. As per IRB approval (07-06-15-0239751), interviews occurred at a mutually agreed upon location that ensured privacy and confidentiality. The single fathers were asked 14 interview questions (see Appendix A). During the interviews, there were follow-up questions that allowed for the development of rich, in-depth meanings from the information given by the single fathers.

Each interview was digitally recorded and then transcribed. During the data collection process and subsequent dissertation development process, I was the only person who had access to the data. All audiotapes, informed consents, and transcripts were kept in a locked cabinet in my home office. Transcribed interviews were kept on a password-protected computer kept in a locked drawer in my home office. Upon transcription, electronic forms of data were transferred to a password-protected external hard drive and stored in a locked cabinet within my home office.

Each interview was subsequently summarized and provided to the participant by email for member checking. One week after the interview, each single father received a summary of his responses by email and was asked to make any necessary corrections. None of the single fathers provided further information. There were no variations or unusual circumstances in the data collection that led me to deviate from the proposed plan I presented in Chapter 3.

Data Analysis

To organize and analyze the data collected, I used Moustakas's (1994) process and steps for phenomenological research. I kept journals, reviewed transcripts, and repetitively listened to interviews as soon as possible after they occurred to assist in the self-reflection process and in an effort to be aware of the identified phenomenon from the single fathers' perspectives.

I reviewed the transcripts and listened to the audiotapes of each interview. I listened to each participant's interview with a focus on his views on parenting a child with autism, and I weighed each interview equally. During this process, I repeatedly reviewed each interview with the intent to immerse myself fully in the data in order to identify relevant horizons without any biases.

I listed participants' expressions of their experiences as single fathers of children with autism and identified overlapping, repetitive, or irrelevant statements. The irrelevant statements were discarded, leaving the essential horizons of the phenomenon. Once relevant statements were identified, they were considered the units of meanings described by Moustakas (1994). I reread and reconsidered the possible meanings and viewpoints developed through phenomenological reduction.

I color coded and clustered the essential qualities of the experience of the participants into themes based upon commonalities in the data. As the number of participants was 10, themes were identified when six or more participants identified a common unit of meaning within their interviews.

When the core themes of shared experiences regarding the lived experiences of single fathers had been identified, I created titles to capture the essence of the themes. I then reviewed the data and identified quotations from the single fathers that correlated to or supported the themes. During the data analysis process, the seven primary themes that I identified were (a) challenges, (b) having social support systems, (c) day-to-day experiences, (d) the role of the father within the family, (e) effects on social life, (f) sibling reactions, and (g) adaptive coping mechanisms.

Theme 1: Challenges

Having a child with autism presented significant challenges for each participant in the study. Challenges included financial, physical, and emotional burdens for the fathers. Economic challenges were dominant for eight of the single fathers. Money was spent for services for their children that were not covered by insurance. Dad 8 claimed that he went into bankruptcy previously, and Dad 7 stated, “The way things are going, I may be bankrupt soon.” Although Dad 9 and Dad 10 did not have many financial stressors, they claimed that they spent a great deal of money on specialized diets, therapists, and school supplies. Dad 4 stated, “Having a child with autism financially weighed my pockets down, as I want what is best for my child.”

Emotionally and physically, the single fathers of this study were burned out. Dad 1 stated, “I have emotional stressors, as I am always worried about son [sic]. I am frustrated, anxious, and upset sometimes.” Dad 10 claimed, “I never suffered from high blood pressure, but with parenting an autistic child, I do now.” Dad 6 stated, “I am more physically tired. My muscles and joints hurt from the stress.” Dad 5 stated that he became

exhausted very quickly. Dad 5 exclaimed, “When I am on work, it is difficult for me to function efficiently, as my body feels tired.”

Theme 2: Social Support Systems

Having an efficient support system is crucial in parenting a child with autism. All of the participants similarly expressed the idea that a functioning social support network is significant for a primary caregiver to a child with autism. The single fathers identified that their social support system included parents, siblings, other relatives, friends, religious leaders, members of the community, and professional agencies. With a support system, they claimed, parenting was a somewhat easier process.

Dad 5 expressed, “My son has a shadow teacher who works with him individually in the classroom. The teacher ensures that he is taught what the main classroom teacher teaches.” Dad 7 revealed that the special education instructors are valuable. Dad 1 stated,

Well, my son has a special education instructor who works with him in the classroom. This is part of the inclusion that the education system has implemented. The teachers are very helping [helpful] in ensuring he is taken care of at school. The students are very protective of him. My parents assist financially at times, or they will babysit when I do go out and hang with friends. The Autistic Society of Trinidad and Tobago has sessions for the kids twice a month, so they help out. The church members help out as well.

Dad 2 stated, “My daughter has a special education instructor who works with her in the classroom. She also has a speech therapist. So that is good.” Dad 7 expressed, “It is

important that special needs children have someone to work with them. I am happy my daughter has a special educator and a speech therapist.”

Theme 3: Day-to-Day Experiences

Parenting a child with autism was very challenging for the participants in this study. All of the single fathers expressed this challenge and indicated that it affects their day-to-day life, as everything has to be on a schedule and routine. Dad 10 stated, “I was so stressed that I did not follow the schedule. That caused more stress, as my child could not function, as I didn’t follow the schedule.” Dad 6 described his parenting experience as “always challenging and it impacted my life, as I look at life differently. I love see the joy [sic] on my child’s face, so I know the rearrangements to my life are worth it.” Of the fathers who felt that the diagnosis of autism affected their day-to-day experiences, Dad 5 stated, “Completely. Everything I do from the moment I wake up to the moment I put my child to bed—Is L. safe? Is L. contained? It’s like having an infant. Every time you leave the house, you have to have a diaper bag.” Dad 1 conveyed that his life is

Tedious, hectic but organized. He requires most of my time. A normal child may take 10-15 minutes to get dressed; he will take 25-30 minutes. From the time he is awake to the time it is his bedtime, he is the main focus, as I hope that he is safe and well taken care of. It comes with having an infant, as I always have a diaper bag when we leave the house. When I leave the house with my son, I have to prepare mentally myself for the looks we often receive from other members of society.

Theme 4: Role of the Father Within the Family

All ten single fathers reported that being the primary caregiver for a child with autism was very challenging. Dad 3 expressed that being the primary caregiver was “very tedious, very emotional.” Dad 10 described caregiving as “very overwhelming, as I am Mummy and Daddy in one, I have to dress, feed, and take him to school and other events.” Dad 4 stated, “It is very challenging, as I have to figure out what day he will have as it depended on my child’s tantrums.” Dad 2 stated that “it was chaotic and challenging.” Dad 5 expressed joy in the fact that providing care for his son allowed him to spend quality time with him and helped him to become more informed on autism. Dad 9 acknowledged that he was initially “careful with my child, as I thought my child was fragile” but “learning more on autism, I pushed my child to be a normal functioning child.” Dad 8 also expressed that he was “careful with his child but ensured he was treated as a normal kid.”

The fathers indicated that in being the primary caregiver, they had also grown in their roles as fathers in the household. Dad 2 reflected,

I have grown more spiritually. I believe that God is in charge. Initially, I was in denial, but I have accepted my child has autism through counseling and support of family and friends, I have accepted, and it is not the end of the world with the help of counseling. Yes, I have grown. I believe I have grown more spiritually. I believe that God is with me each day and ensuring that my children’s needs and my needs are met. We may not have a fancy house or drive a fancy car, but we are living comfortably.

Dad 4 explained, “I have found God. Without knowing God, I would not have been here having this interview with you. I would have given up.” Dad 7 stated, “Jesus, Jesus, is my realest friend. I have grown more in my faith.” Dad 10 claimed that he had become “more confident” in himself. He had become educated about autism and therefore was a better advocate for his child.

Theme 5: Effects on Social Life

Eight of the ten single fathers reported that they had little to no social lives. The other two fathers will be discussed below as discrepant cases. Dad 8 expressed his social life was “non-existent.” He continued saying, “I feel guilty to leave my child, so I rather stay home and be with him.” Dad 1 also claimed that his social life is non-existent, and he probably goes out every three months. Dad 2 stated, “Ha! I do not have a social life since I have my daughter.” He further stated, “When I see my friends posting pics on social media having a time of their lives, and I am home it is difficult and depressing at times. However, when I hear my daughter say “Daddy” I would rather be at home than get stoned drunk or laid.” Dad 6 stated, “I do not have a social life. I am too tired to hang with friends. So I will stay home and sleep.” Dad 7 exclaimed, “Social life? What is that?” He continued saying, “All my time is ensuring that my kid is good.” Dad 4 said, “I have a social life, but I would rather stay home with children than burdening someone else. My children are my responsibility.”

Theme 6: Sibling Reactions

All ten (10) fathers reported that having a child with autism affected the other siblings in their household. The fathers indicated that some of the siblings had a change

in career interest, one single father's other offspring was stressed, and others were well adjusted. Dad 1 expressed that his other child is very supportive of her brother. He stated that "My daughter although she is younger wants to be an advocate for her brother and study Special Education." Dad 5 stated that "His child also wants to be an advocate and help other children with autism." Dad 6 stated "My other child wants to increase advocacy in Trinidad and open a Special education preschool and elementary school. My other child is well-adjusted and took a positive approach to having a sibling who is autistic. Dad 4 stated that "My other offspring is a defender to my child who is autistic and has well-adjusted to a sibling who is autistic."

Theme 7: Adaptive Coping Mechanisms

Parenting is not an easy process at times, especially parenting a child with autism. The single fathers developed coping strategies that they implemented to deal with the daily challenges that derived from parenting a child with autism. All the parents claimed that they exercised to cope with their physical stress, take loans from their family members, and seek therapy and they socialize with their peers to control their emotional stressors. Dad 10 stated, "I do not like to borrow money from my family, but to survive and ensure that my child has everything, I will borrow to ease the financial burdens." Dad 5 stated, "The government has grants for special needs individuals, so that helps a little, but I still borrow from my family." Dad 8 stated, "Family, family, and family. I am thankful for my parents; they are a major and great financial help. I don't like to ask, but you have to do what you have to do to live comfortably." From the responses from the single fathers, it was evident that family has helped them financially.

To combat the physical stressors, all the single fathers expressed that exercise was very important. Dad 9 stated, “I have gained 40 pounds in the last year. It is so shamefully.” He continued saying, “I do not have the time to exercise, and I have become very sluggish and lazy. I do try to exercise at least once a month by jogging for an hour and do some sit-ups and push-ups.” He chuckled and said, “I am saving to buy a treadmill, so this will also aid in alleviating my physical stressor.” Dad 6 stated, “My child calls me fatty boy. I have gained so much weight as I do not have time to do my usual work-out.” He continued saying, “When I get tired, I will tell my child let’s do some sit-ups so we will work out together.” I try to involve her in most things I do.” It was evident that the single fathers exercised to eliminate the physical stressors.

To deal with the emotional stressor, all of the 10 single fathers echoed that therapy was crucial. Dad 10 claimed, “Initially, I was in denial that my child is autistic. When I experience the pains of parenting a child with autism, I felt like a failure. However, the therapy assisted me in managing my emotional states.” Dad 8 expressed, “It is emotional providing care to a child who autistic. Some days you are good, and some days you are not.” Dad 8 elaborated by saying, “My child will have tantrums that will last forever, and I will not know what to do. Then there will be days, where my child is tantrum free. I went to therapy, and it helped me manage my emotions and that of my child’s.”

Discrepant Cases

There were two discrepant cases regarding the impact of having a child with autism on other family members and the impact on the single fathers’ social lives.

Regarding the impact of having a child with autism on other family members in the household, Dad 9 had a negative experience compared to the other 9 participants. Dad 9 was the only single father who had a negative experience as his other daughter was stressed. He indicated that, "My daughter wishes she was not related to her younger sister as her friends think that my younger daughter is a freak." Dad 9 expressed that he tried explaining to his older daughter about autism by doing fun activities. However, that did not work, so they are in therapy.

Regarding the single fathers and their social lives, Dads 9 and 10, were the only two single fathers who had active social lives. Dad 9 stated that he has a great social life. He stated, "Parenting a child who is autistic is demanding and causes physical and emotional stress. My parents and I came to an agreement, which is the last Friday of each month for two hours; I will meet with my friends." I asked Dad 9 if he feels guilty about leaving his child. He stated, "Initially, I did, but if I do not de-stress, I will drop dead and who will see about my children. Respite care is good and needed when seeing about kids whether they normal or need special attention."

Dad 10 also had an active and existent social life. He stated, "Not because I have a child who has autism means life ends. As parents, you must find that balance. I have a great support system, so my brother and his wife would supervise my child every Saturday night, so that I can relax and do what I like such as playing cricket or going to the bar with friends."

Evidence of Trustworthiness

To establish credibility, triangulation, member checks, and journaling were used. I analyzed each of the participant's interviews as separate data sets. This process allowed triangulation of the data to establish the credibility of the findings. Member checks were used to verify my understanding of each single father's experience. Journaling was also used to record my biases and opinions throughout the analysis process.

To ensure transferability, I used thick description throughout the chapter. I described as close as possible in-depth description of each single father. From these detailed descriptions, other researchers can determine the transferability of the findings.

To maintain dependability, I used an audit trail as well as thematic analysis. I kept a record of the transcript of all the interviews as well as the journal recording my processes and thoughts throughout the data analysis process. I identified, analyzed and reported the common patterns or themes that emerged from the data to allow for thematic analysis.

To ensure confirmability, I used a journal. My journal notes ensured that my personal beliefs and values did not interfere with the data analysis process.

Results

In a qualitative phenomenological study, the researcher gains the true understanding of the participants' experiences by bringing awareness to the context of their existence (Allan & Dixson, 2009). Seven themes emerged from the interviews, allowing me to gain a deep understanding of the single fathers' experiences parenting a child with autism in Trinidad and the challenges faced by the single fathers in parenting a

child with autism. Through this study I sought to describe the lived experiences of single fathers of children with autism in Trinidad, and explore the challenges they faced as primary caregivers to children with autism. In essence, the study captured a meaningful understanding of each single father and his lived experiences, as well as challenges.

Theme 1: Challenges

Single fathers faced different challenges as primary caregivers to their children. A child with autism presents a set of unique challenges that can either weaken or strengthen a single father's spirit. For the research participants, they all faced challenges. They were left to be both mother and father to their child with autism. All the respondents in this study indicated that having a child with autism affected their relationships with their other children. According to Swanpoel (2003), caregivers to children with autism spent less time with their normally developing children and had to make the effort to spend time with their typically developing children. In this present study, two of the respondents indicated their guilt and regrets for not spending time with their other children. The major challenges faced by the research participants were financial, physical, and emotional stressors.

Most of the single fathers had financial challenges as their earnings were spent on speech therapists, and extracurricular activities. There was a single father who went bankrupt before and one dad expressed that he is on the verge of bankruptcy. As the fathers are the primary caregivers, there is only one income coming to the household, and the single fathers have to manage their finances efficiently.

Physical stressor was another challenge. The physical stress derived from carpools, preparing meals, bathing, homework, and shopping to name a few. A child with autism may not express their basic needs or wants in the manner the parents would expect. Therefore, the fathers are left guessing what the child needs. Is the child crying because he/she is thirsty, hungry, or sick? When the single fathers cannot determine their child's needs, the fathers are left feeling frustrated.

Emotional stressors were another challenge. The emotional stressors derived when they took their children out in the community. Some people stared, made comments and failed to understand any mishaps or behaviors that were displayed by the child with autism. As a result, the fathers often felt uncomfortable taking their children to the play parks, malls, or movie theatres. Some of their research participants indicated that they experienced a sense of isolation from the community, and sometimes from their friends.

Theme 2: Social Support Systems

It was evident that having effective and efficient social support systems were crucial and vital to the research participants in this study. Having strong support systems, specifically family and friends were identified by 100% of research participants as significant to their experiences as the primary caregiver for a child with autism. Families, friends, church community, parental support groups, and professional agencies were stated to be key factors in motivating the single fathers in parenting children with autism. Without these social support systems, parenting would have been harder for the research participants. All the participants highlighted the importance of having parental social groups who can provide critical strategic support for coping with the challenges faced as

the primary caregiver for a child with autism. The participants all noted that their families and friends were very supportive especially when the fathers had emotional breakdowns.

Support groups gave the fathers an opportunity to share with other fathers and interact with people who understand the challenges they face. Support groups also give the fathers information about new treatment methods, seminars for parents, discounted services that can benefit their children and many more. In support groups, fathers encourage each other, which help them become stronger and better caregivers.

Theme 3: Day-to-Day Experiences

There is little doubt that parenting a child with autism is extremely demanding. Due to the socially inappropriate and aggressive nature of much autistic behaviour, caregivers of children with autism often report high levels of anxiety, depression, and everyday stress from parenting. Participants found that daily family activities (that typically foster family cohesion) became cumbersome chores, rather than opportunities to enjoy socially as a family. Shopping and family meals, either at home or restaurants were mentioned as specific challenging activities. According to research participants, it is easy for their children with autism to become over-stimulated in shops, which usually results in temper tantrums and defiant behavior.

The daily lives for all the research participants were challenging. The daily schedules for the single fathers were getting their children dressed for school, taking them to school, going to work, picking up their children from school, and taking them to their various extracurricular activities. The fathers reported that their daily routines were very routine and scheduled. One participant highlighted if he did not follow the schedule, his

child could not function, as his child had to follow a schedule (Dad 10). Although, the day-to-day experiences were challenging, the participants became more involved in their children's lives and appreciated their roles as primary caregivers. Dad 5 expressed, "I am joyful for the fact that I am providing care for my son, and I can spend quality time with him."

Theme 4: Role of the Father within the Family

Parenting as a single father is a tedious job. Raising children with autism adds additional pressure on the single fathers. All the research participants highlighted that they were both mother and father to their child with autism. They all accepted their role as a single father and primary caregiver to a child with autism. The fathers expressed in a nuclear family, the concerns, and pressures were divided; however, as a single father, it is not divided. Participants felt that extra planning and preparation are necessary for a family member with autism, since activities such as outdoor camping that lack structure or boundaries are not necessarily suitable for children with autism. All participants felt that the presence of a family member with autism makes it very difficult and challenging to do things as a family, but they nonetheless agreed on the importance of building pleasant family memories.

The participants noted although it was challenging being the primary caregiver, they appreciated their role as they are more involved in their children's lives. Dad 10 stated that "I have learnt not to take things for granted and appreciate the small progress my child makes and this makes caring for a child with autism a joyous experience."

Theme 5: Effects on Social Life

Single fathers often find it difficult to attend social events as they spend most of their time taking care of and providing for their children with autism. Attending events such as family gatherings, parties and all-adult events is a challenge. However, it is important that their friends and family understand that their child is their priority. Some of the participants had a nonexistent social life, some had limited social life, and two single fathers had consistent and existent social lives. In parenting a child with autism, there are various stressors, and it is very crucial that parents of children with autism have some time to socialize with their peers. Single fathers who had a nonexistent social life should take the advantage of the Internet and catch up with family and friends through Skype. Also, the single fathers can invite their friends and families to their house to reduce the hustle associated with commuting with a child with autism.

Theme 6: Sibling Reactions

Raising a child with autism places some extraordinary demands on parents as individuals and the family as a whole. Prime among these demands is the lack of enough hours in the day to do all one wishes. Specifically, the time involved in meeting the needs of a family member with autism may leave parents with little time for their other children. Sibling reactions are crucial as some siblings may be empathetic, and some siblings may be upset about having a sibling with autism.

For the research participants who had other children, a majority of the participants had positive experiences. The siblings were very welcoming and understood to their sibling with autism. The fathers indicated that some of the siblings had a change in career

interest and were well adjusted. Dad 1 expressed that his other child is very supportive of her brother. He stated that “My daughter although she is younger wants to be an advocate for her brother and study Special Education.” Dad 5 stated, “My child also wants to be an advocate and help others like her brother.” Although most of the research participants had positive experiences, one father had a negative experience. Dad 9 expressed, “My other daughter did not appreciate the fact her younger sister was clinically diagnosed with autism.”

Theme 7: Adaptive Coping Mechanisms

It is paramount to have coping strategies to eliminate any challenges associated with parenting a child with autism. Parenting a typically developing child has its challenges and so does parenting a child with autism. In coping with the stressors associated with parenting a child with autism, the single fathers developed adaptive coping mechanisms. All the single fathers stated that therapy was crucial for them to manage their emotions efficiently. Dad 6 stated, “I go for counseling in the church. It has helped me a lot in dealing with my emotional stressor.” Dad 1 stated, “Emotionally, I am seeking counseling to help me better deal with my emotional management skills and emotional well-being.”

The fathers stated family and professional agencies were necessary for managing their economic challenges. Dad 1 exclaimed, “Financially, there is financial aid now being provided at the Autistic support group, the professional agency.” To manage their physical stressors, exercise was the key strategy. Dad 4 stated, “I will go hiking, and run

in the park to eliminate my physical stress.” Dad 1 said, “Physically, I will go jogging or workout on the treadmill.”

Summary

In Chapter 4, I presented the findings of the research study. I explored the lived experiences of 10 single fathers with children with autism in Trinidad through a phenomenological research design. The identified goal of the study was to understand the lived experiences of single fathers with children with autism in Trinidad. Also, I sought to address an identified gap in the literature regarding the lack of information on single fathers and their experiences from Trinidad.

Following Moustakas’ (1994) phenomenological process, data from each single father was analyzed to identify the essence of their experiences through the process of the identification of the major themes that were derived from the interview questions of the research study. The major themes were day-to-day experiences, social support systems, challenges, effects on social life, sibling reactions, adaptive coping mechanisms, and the role of the father within the family.

In Chapter 5, I will present information regarding the interpretation of the findings as they relate to the social support theoretical framework. Also, in Chapter 5, I will address social change implications, recommendations for action, recommendation for further study, limitations of the study, and conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this study, I used phenomenological methods to examine the lived experiences of single fathers of children with autism. The intent of this phenomenological study was to depict the lived experiences of single fathers of children with autism in Trinidad, in order to enhance understanding of the challenges they face.

Significant findings of the study indicated seven crucial themes in the lived experiences of single fathers of children with autism in Trinidad: (a) day-to-day experiences, (b) support systems, (c) challenges, (d) role of the father within the family, (e) effects on social life, (f) sibling reactions, and (g) adaptive coping mechanisms.

Interpretation of the Findings

Fourteen open-ended questions were developed to capture the lived experiences of single fathers of children with autism in Trinidad. The following is a review of the research literature as it compared to the study findings.

Themes 1: Challenges

All of the single fathers indicated that there were significant challenges in being the primary caregiver for a child with autism. Financial challenges were shared by all the single fathers. One father claimed that he had been declared bankrupt in the past; another stated that he would soon be filing for bankruptcy. The financial hardship expressed by the single fathers in the study was similar to that found in a study conducted by Saunders et al. (2015). They argued that families of children with ASD had a significant level of financial hardships because of their children's special needs care.

The single fathers also expressed physical challenges. They described feeling physically drained by the experience of parenting a child with autism. One single father reported an increase in his blood pressure since he had become the primary caregiver for a child with autism. This finding is consistent with a study conducted by Esdaile and Greenwood (2009) who reported that both mothers and fathers experienced physical stress because they were preoccupied with worry about their children. In the study, the fathers consisted of two single fathers and they expressed they had a great deal of stress as they were the primary caregivers to their children.

Emotional stress was also a factor indicated by the single fathers. There are many emotions involved in parenting a child with autism. When dealing with their child's tantrums or strangers' stares, for instance, the single fathers sometimes became emotionally overwhelmed. One single father noted that when one is a child's primary caregiver, one does not have a companion in the household to share the pains and joys of parenting. As presented in the literature review, the quality of life was different in relation to parenting for caregivers of children with autism (Schieve et al., 2007). For all of the single fathers in this study, the entire diagnosis process was stressful filled with uncertainty, and frustration. Some fathers felt as though they had experienced discrimination during this process.

Theme 2: Social Support Systems

All of the single fathers indicated the importance of having a great support system. Their support systems consisted of other family members, relatives, friends, coworkers, church community members, and professional agencies. Social support theory

focuses on family well-being and the importance of a support network to the overall health of individual members of a family unit (Armstrong et al., 2008). Single fathers who serve as caregivers to children with autism experience stress due to the lifelong duties associated with this developmental disorder, and the participants in this study therefore welcomed support from others.

Researchers have found that receiving support helps alleviate stress for the single fathers (Guranlnick et al., 2009). In a study conducted by Unluer (2009), it was reported that once there is social support, primary caregivers experienced a decline in their stress levels. According to Kaner (2009), other family members, neighbors, peers, colleagues, professionals, and the wider community as sources of social support necessary for primary caregivers.

Theme 3: Day-to-Day Experiences

All of the single fathers in the study experienced negative impacts of having a child clinically diagnosed with autism. They all claimed that although their child's condition had negative impacts, they had adapted their daily activities accordingly. Eight out of 10 single fathers indicated an intense focus on their children's behaviors, needs and wants. All of their attention was directed toward their children. Two of the single fathers indicated that although they were worried about their children, they tried to ensure that this concern did not affect their daily work schedule.

All of the single fathers highlighted the amount of time spent attending to their child's needs, whether this involved helping the child with getting dressed, feeding the child, or planning events, indicating that this amount of time was much greater than what

would be required in parenting a typically developing child. Some of the single fathers also expressed a significant level of stress; these fathers were worried about not only daily experiences, but also what would happen to their children in the future, especially after their own death. Stress increased when the single fathers had to balance work life and family life, as well as their relationships with their children with autism and their relationships with their normally functioning child. The findings of a study by Twombly et al. (2011) support the idea that a life-long burden and ongoing stress are associated with taking care of a child with special needs such as autism. The findings from Twombly et al. (2011) indicated that caregivers of children with special needs had a heightened increase in their stress levels which were similar to what the single fathers expressed in this phenomenological study.

The effects of stigma were also part of the single fathers' day-to-day experiences. The single fathers described the stares they received when in public with their children. Initially, they felt ashamed, but they realized that they had to be strong for their children and needed to serve as advocates for them. This finding is similar to what was presented in the literature review. Gray (2007) argued that the effects of social stigma lead to fathers becoming withdrawn. However, as time progressed, the fathers became stronger. This was evident for Gray's (2007) study and for this phenomenological study.

Theme 4: Role of Father Within the Family

All of the single fathers from this study were affected by having a child with autism. Their sense of self, self-esteem, and roles as primary caregivers were impacted in various ways. The challenges and demands of providing care for a child with autism were

evident, and all of the single fathers indicated that their children's needs and wants took priority in their lives. All of the participants expressed a sense of urgency and recognized the need to be attentive to their child's well-being. Some indicated that they had developed greater creativity and patience in meeting the challenges of parenting a child with autism.

Overall, each single father acknowledged the challenges he faced but highlighted the positive aspects of being the primary caregiver for a child with autism. The single fathers had become more informed and educated on autism, had become advocates for their children, and expressed no regrets about being primary caregivers. All participants expressed the pride and joy they felt toward their children indicating that they would not change their children for anything. They further stated that they looked at life differently since becoming parents to children with autism, and they all claimed that different was good. All of the participants had accepted the challenge of being a father to a child diagnosed with autism, in stark contrast to the findings of DeGrace (2004), who reported that parents of children with autism had the feeling of being robbed of a normal family life.

The single fathers in this study spoke of the significance of assisting their children to solve many of the critical problems of growing up. The crucial problems included what occupation to have, what college to attend, or, daily activities as homework, or riding a bike (Fogarty & Evans, 2009). According to Fogarty and Evans (2009), fathers are seen as problem solvers. The single fathers were given the chance to support their children in any decision making process, and the positive and negative results for a decision.

The single fathers were also seen as the disciplinarians in their families. According to Fogarty and Evans (2009), fathers serve as guides to their children. Assistance is a combined effort between parent and child that included an ongoing process of father-child interaction (Fogarty & Evans, 2009). The single fathers in this study had to serve as guides to their children as the single fathers are the primary caregivers.

Theme 5: Effects on Social Life

Most of the participants identified that their social lives were limited or nonexistent because they served as primary caregivers. Most felt guilt when leaving their children at home, and for burdening someone else with supervising their children. At times, the single fathers wished that they could go out, socializing with their friends more often. However, they perceived their children as more important than socializing. Some of the single fathers, nevertheless, had active social lives as they made arrangements with their families, and relatives to supervise their children. Respite care is often necessary for caregivers; two of the single fathers found that respite care was important and helpful. As stated in the literature review, respite care was seen as a tool of reducing parental stress, in addition to providing the single fathers with the chance to sustain a social life and good physical health (Preece, 2010).

Hock et al. (2012) found that many single fathers did not have intimate relationships or social lives. The single fathers in their study conveyed that they did not have the time, strength, or energy to socialize with their peers (Hock et al., 2012). This

was similar to the findings of the current study in which some of the single fathers reported that they had little to no social lives.

Theme 6: Sibling Reactions

Family members with children with autism experience a host of feelings that can be difficult to process. Siblings, for instance, may deal with anger, resentment, guilt, and loss. They may not know how to cope, or they may not want to talk to their parents about their feelings for fear of being a burden or sounding negative about their sibling with autism. In this study, the majority of the participants' other children had a positive experience with their sibling with autism. Some of the fathers expressed that their other children wanted to be advocates for their siblings, and had even made a change in career interest to pursue this goal. One single father reported a negative experience, in that his other child was angry about having a sibling with autism. However, there was no literature that stated that nearly all the siblings with autism had positive experiences. This finding is similar to information reported in the literature review. O'Brien (2009), for instance, found that teenagers were embarrassed and angry about having a sibling with autism.

Siblings of a child with autism may express resentment and confusion when the child with autism displays stereotypical behaviors (Quintero & McIntyre, 2010).

Essentially, it is a stressful time for the siblings of children with autism. In research by Macks and Reeve (2008), siblings of children with autism reported mixed emotions of fear, anger, resentment, and confusion. According to Cornew et al. (2012), younger siblings expressed concern and anger when their siblings with autism displayed strange

behaviors. However, in this study, eight of the single fathers indicated that their normal developing children had positive experiences.

Theme 7: Adaptive Coping Mechanisms

Most participants in this study identified the importance of developing coping strategies to manage financial, physical, and emotional stressors. To manage financial stressors, the participants sought assistance from family members, peers, and the Government of Trinidad and Tobago. Lee (2009) found that single fathers experience greater financial strain than do married fathers, though single fathers may receive financial support from relatives and friends. According to Koydemir and Tosun (2009), such financial strain derives from the levels of medical care and attention needed, and the cost of medicine for the child with autism.

To control their physical stressors, the single fathers engaged in exercise and sports. Emotional talk with peers and counseling were the tools the participants used to manage emotional stress. In a study by Brinton and Fujiki (2011), single fathers considered emotional talk to be significant when caring for a child with autism. Socializing with peers was also seen in this phenomenological study, as a tool that could be used to address emotional stress associated with parenting a child with autism. According to Preece (2010), single fathers experienced a decline in stress level when they interacted with their peers and discussed challenges associated with parenting a child with autism.

Conceptual Framework and Finding Interpretations

Social support theory was the conceptual framework used for this study. The theory focuses on the well-being of the family and the significance of social support networks (Uchino, 2004; Wills, 1991). Social support theory was applied to explain how individuals in this study interpreted and cope with parenting a child with autism.

As presented in the literature review, social support can be categorized as informal or formal support (Tucker, 2009). The responses given by the single fathers concerning support systems indicated that they received support from family, relatives, friends, colleagues, church members, and professional agencies. Informal support came from family, friends, relatives, colleagues, and church members. Aligned with a study finding by Boyd (2012), informal support was most effective form of support for these caregivers of children with special needs. Informal support provided the single fathers with empathy, concern, and affection. According to Brown et al. (2009), relatives and friends provide meaningful emotional support to caregivers.

The single fathers also indicated that formal support came from professional organizations. For instance, Autistic Society of Trinidad and Tobago offered a support group for parents of children with autism. Other services they received from the Autistic Society were free sessions for their children with speech therapists and financial aid. Some of the single fathers stated that the help they received from professional agencies was beneficial, particularly what they needed to ensure proper caregiving for a child with autism. Although, they described this formal support as effective, the research participants believed that more could be given by professional agencies, and they

expressed a preference for informal support. The result is aligned with Brown et al. (2009) who argued that informal support from relatives and friends is more effective than formal support.

Wills (1991) postulated four types of support: (a) emotional support, (b) tangible support, (c) informational support, and (d) compassionate support. All 10 single fathers received all four types of support. Emotional support came from their family members, church members, and friends. Tangible support came from professional agencies and family members. Informational support came from professional agencies, and support groups, and, compassionate support came from support groups, friends, family, and church members.

Summary

In summary, the findings of this phenomenological study align with the importance of social support systems identified by Uchino (1994) and Wills (1991). All participants agreed that having effective social support systems made parenthood of a child with autism easier. The participants identified family, relatives, professional agencies, religious leaders, and peers as elements of their support system. There were two participants who had negative experiences as primary caregivers for children with autism. Additionally, there were seven themes that emerged from the findings: challenges, day-to-day experiences, support systems, adaptive coping mechanisms, role of the father within the family, sibling reactions, and effects on social life.

Limitations of Study

There were limitations to this study. First, the study was limited by the sample size, as 10 participants volunteered. All participants were required to be single fathers between the ages of 25 and 40 who served as primary caregivers to a child clinically diagnosed with autism. The child's age was required to be between 3 and 16 years. Further, the individual thoughts shared by the single fathers represent their experiences and perspectives into the phenomenon and may not be representative of the population of persons with a child with autism. As a result, the study was limited by the characteristics of sample.

Another limitation of the study was that all of the single fathers were from the Southern region of Trinidad and therefore, did not represent the general population of the Western, Eastern, Northern, and Central regions of Trinidad. The single fathers' children all attended the same school and did not represent the general population: this was another limiting factor. Another geographical limitation was that no single father was included from the sister isle of Tobago. Trinidad and Tobago is a 'twin island' country, and the participants came from Trinidad only.

All researchers have biases, and researcher bias was acknowledged as a potential limitation of the study. To reduce this potential bias, I worked to engage in bracketing my preconceived biases and judgments. I also listened to each single father with an open mind, attentively engaging to understand his descriptions of the lived experiences as a single father to a child with autism (Smith, Flowers, & Larkin, 2009).

Recommendations

Through this phenomenological study, I sought to address the identified gap in the literature regarding the lived experiences of single fathers of children with autism in Trinidad. The 10 single fathers who participated in the study were from the Southern region of Trinidad, and had a child clinically diagnosed with autism. While this study required participants between the ages of 25 and 40, further research addressing the lived experiences of single fathers from any age group is recommended. Further study would be improved if the sample included single fathers from Trinidad as well as Tobago so that the findings would be more representative of the country's population.

Most participants identified lack of support from professional agencies in parenting a child with autism. The single fathers indicated that support groups included married parents, and that there was no support group specifically for single fathers with children with autism. Thus, a potential area for future research is social networking from professional agencies. Ultimately, any additional research into the area of single fathers parenting a child with autism in Trinidad and Tobago would contribute knowledge to the discipline and could inform practices leading to improved functioning for this population.

Another recommendation is to conduct a quantitative study to compare and contrast the stress levels involved with parenting a male child with autism to a female child with autism.

Implications

Clinical diagnosis of children with autism in Trinidad is rapidly increasing (Autistic Society of Trinidad and Tobago, 2012). The goal of this study was to promote

social change regarding the lived experiences of single fathers of children with autism in Trinidad and to highlight the day-to-day challenges faced by these single fathers. The single fathers identified an area of concern in that there was no support group dedicated to single fathers of children with autism only. One single father indicated that he perceived a lack of interest by professional agencies. He left as he was not taken seriously by the necessary authorities, which led to him feeling frustrated.

The research participants provided valuable insight, from an emic perspective, into lived experiences, daily challenges, and the role of support systems in parenting a child with autism. Understanding their lived experiences, contribute toward understanding how to support this population best in raising a child with autism. The insights the single fathers shared, should provide family members, educators, other professionals, and the general population valuable information on providing support and other resources to single fathers of children with special needs.

Therefore, this phenomenological study has implications for positive social change in that it may increase awareness of challenges and supports to single fathers of a children with autism. In this study, single fathers were given the opportunity to voice their experiences of being a primary caregiver of a child with autism. With this availability of findings, there is a possibility that single fathers will not be portrayed in a negative light by members of society. Just like single mothers, single fathers also are preoccupied with their children's well-being.

Research participants indicated the need for more support for single fathers specifically and better communication from professional agencies. In this study, I have

shed light on the experiences of Trinidad single fathers of children with autism presenting information that may lead to the development of appropriate supports for this population. With increased support from professional agencies, single fathers would be able to provide better support and care for their children with autism, leading to positive change.

Conclusion

The goal of this phenomenological study was to offer a meaningful understanding of the lived experience of single fathers of children with autism in Trinidad. Most of the research findings reflected previous empirical data from the literature on caregiving and autism. At the end of all of the interviews, I had a great sense of appreciation and respect for these single fathers, who are dedicated to providing the best love, care, and support to their children with autism. Their level of commitment that they demonstrate on a daily basis is admirable.

The findings revealed what previous studies reported concerning the increased stress level borne by caregivers in the family unit when a child has special needs. Most of the single fathers indicated that following the clinical diagnosis of autism their children's mothers had left as the mothers could not manage the stress effectively. For those single fathers who had other children, the siblings initially were upset by the diagnosis but took responsibility for their siblings and wanted to be advocates for their needs. Although the single fathers expressed struggles in dealing with a child with autism on a daily basis, they all indicated that they had no regrets. Each single father had a glow when he expressed the joy and pride of being a father. All of these men were dedicated to their children. Each single father spoke highly of his children and shared incredible stories

with excitement. Overall, all of the participants embraced the challenges of being a single father of a child with autism. They accepted the responsibility and did not complain. Each was committed to being the best father possible, regardless of physical, emotional, and financial challenges. Each of the single fathers is to be commended for his high level of devotion.

This phenomenological study efficaciously accomplished its purpose, as it gave the single fathers a chance to express their day-to-day experiences and provided them a much-needed voice. Through this study, I have offered the public a glimpse into the life of a single father of a child with autism. The study has revealed the outstanding sacrifice made by each single father who is genuinely devoted to his child with autism. It also offered an authentic depiction of pure love between father and child.

References

- Agar, M. (1996). *The professional stranger: An informal introduction to ethnography*. New York, NY: Academic Press.
- Agostini, L.A. (2012). *Man and woman thing*. Retrieved from <http://www.guardian.com>
- Allan, J., & Dixon, A. (2009). Older women's experiences of depression. A hermeneutic phenomenological study. *Journal of Psychiatric and Mental Health Nursing*, 16(10), 865-873. doi:10.1111/j.1365-2850.2009.01465.x
- Altieri, M. J., & von Kluge, S. (2009). Family functioning and coping behaviors on parents of children with autism. *Journal of Child and Family Studies*, 8(1), 83-92. doi:10.1007/s10826-008-9209-y
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. Arlington, VA: American Psychiatric Publishing.
- Anderson, C. (2007). Relieving parental stress and depression: How helping parents helps children. *The IAN Community*, 1, 80-89. Retrieved from <http://www.iancommunity.org>
- Armstrong, M. I., Birnie-Lefcovitch, S., & Ungar, M. T. (2008). Pathways between social support, family well-being, quality of parenting, and child resilience: What we know. *Journal of Child and Family Studies*, 14(2), 269-281. Retrieved from <http://www.psycnet.apa.org>
- Angen, M. J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening dialogue. *Qualitative Health Research*, 10(3), 378-395. Retrieved from <http://www.psycnet.apa.org>

- Attwood, T. (2006). Asperger's syndrome. *Learning Disability Review*, 11(4), 3-11.
Retrieved from <http://www.psycnet.apa.org>
- Attwood, T. (2007). *The complete guide to Asperger Syndrome*. London: Kingsley Publication.
- Autistic Society of Trinidad and Tobago. (2012). *Autistic Services*. Retrieved from <http://ww.autismtt.org>
- Baker, D. L., & Drapela, L. A. (2010). Mostly the mother: Concentration of adverse employment effects on mothers of children with autism. *The Social Science Journal*, 47(3), 578-592. Retrieved from <http://www.psycnet.apa.org>
- Barbour, R. (2008). *Introducing qualitative research: A student's guide to the craft of doing qualitative research*. London, UK: Sage Publishers.
- Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, 47(2), 551-561.
doi:10.1037/a0021268
- Baron-Cohen, S., Lombardo, M. V., Auyeung, B., Ashwin, E., Chakrabarti, B., & Knickmeyer, R. (2011). Why are autism spectrum conditions more prevalent in males? *PLoS Biology*, 9(6), 1-10. doi:10.1371/journal.pbio.1001081
- Barton, H. (2012). Maximizing individuals' control over their lives. *Learning Disability Practice*, 15(3), 12-16. Retrieved from <http://www.psycnet.apa.org>
- Bastiaansen, D et al. (2008). Quality of life in children with psychiatric disorders: Self, parent and clinician report. *Journal of the American Academy of Child and*

- Adolescent Psychiatry*, 43(2), 221-230. Retrieved from
<http://www.psycnet.apa.org>
- Bauman, M. (2010). Autism spectrum disorders: Clinical and medical perspectives. *The Neurochemical Basis of Autism*, 8, 1-11. Retrieved from
<http://www.psycnet.apa.org>
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 5(19), 702-714. doi:10.1111/j.1365-2785.2007.00960.x
- Beck, A., Daley, D., Hastings, R. P., & Stevenson, J. (2008). Mothers' expressed emotions towards children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 48(7), 628-638. doi:10.1111/j.1365-2788.2003.00564.x
- Berg, R. (2009). Autism- An environmental health issue after all? *Journal of Environmental Health*, 71(10), 14-18. Retrieved from <http://www.psycnet.apa.org>
- Berscheid, E., Abrahams, D., & Aronson, V. (1967). Effectiveness of debriefing following deception experiments. *Journal of Personality and Social Psychology*, 6, 371-380. Retrieved from <http://www.psycnet.apa.org>
- Biever, C. (2012). Web removes social barriers for those with autism. *New Science*, 26(10), 26-47. Retrieved from <http://www.psycnet.apa.org>
- Bishop, V. (2014). *Multiple challenges for single fathers*. Retrieved from
<http://trinidadexpress.com>
- Blatt, J. (2008). A father's role in supporting his son's developing awareness of self.

- Infant Observation*, 10(2), 173-182. Retrieved from <http://www.psycnet.apa.org>
- Bloch, J. S., & Weinstein, J. D., (2010). Families of young children with autism. *Social Work in Mental Health*, 8(1), 23-40. doi:10.1080/15332980902932342
- Bokker, L. P., Farley, R. C., & Denny, G. (2006). The relationship between father/child contact and emotional well-being among recently divorced fathers. *Journal of Divorce & Remarriage*, 45(1/2), 63-77. doi:10.1300/J08v45n01-04
- Boyd, B. A., Odom, S.L., Humphreys, B. P., Sam, A.M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention*, 32(2), 75-98. doi:10.1177/1053815110362690
- Brereton, B. (2010). The historical background to the culture of mothers in Trinidad and Tobago: Caribbean review of gender studies. *A Journal of Caribbean Perspective on Gender and Feminism*, 4, 1-16. Retrieved from <http://www.psycnet.org>
- Brinton, B., Fujiki, M. (2011). Emotional talk: Helping caregivers facilitate emotional understanding and emotional regulation. *Topics in Language Disorders*, 31(3), 262-272. doi:10.1097/TLD.0b013e18227bccc
- Bronte-Tinkew, J., Carrano, J., & Guzman, L. (2009). Resident fathers' perceptions of their roles and links to involvement with infants. *Fathering: A Journal of Theory, Research, & Practice about Men as Fathers*, 4(3), 254-285. doi:1537-6680.04-254
- Brown, R.I., MacAdam-Crisp, J., Wang, M., Iarocci, G. (2009). Family quality of life when there is a child with a developmental disorder. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 238-245. Retrieved from <http://www.psycnet.apa.org>

- Cabrera, N. J., Tamis-LeMonda, C. S., Bradley, R. H., Hofferth, S., & Lamb, M. E. (2009). Fatherhood in the twenty-first century. *Child Development, 71*(1), 127-136. Retrieved from <http://www.psycnet.apa.org>
- Capps, L., Kassari, C., Yirmiya, N., Sigman, M. (2009). Parental perceptions of emotional expressiveness in children with autism. *Journal of Counseling and Clinical Psychology, 6*(3), 475-484. doi:10.1037/0022-006x.61.3.475
- Casey, D., & Murphy, K. (2009). Issues in using methodological triangulation in research. *Nurse Researcher, 16*(4), 40-55. Retrieved from <http://www.psycnet.apa.org>
- Cassel, T. D., Messinger, D. S., Ibanez, L.V., Haltigan, J. D., Acosta, S. I., & Buchman, A.C. (2007). Early social and emotional communication in the infant siblings of children of autism spectrum disorders: An examination of the broad phenotype. *Journal of Autism and Developmental Disorders, 37*(1), 122-132. doi:10.1007/s10803-006-0337-1
- Centers for Disease Control and Prevention. (2007). *Prevalence of autism spectrum disorders: Surveillance summaries*. Retrieved from <http://www.cdc.gov/mmwr/pdf/ss/ss5601.pdf>
- Centers for Disease Control and Prevention. (2012). *Developmental disabilities increasing in US*. Retrieved from <http://www/cdc.gov/features/dsdevdisabilities/>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publishers.
- Clandinin, D. J., & Connelly, F. M. (2004). *Narrative inquiry: Experience and story in*

qualitative research. Brooklyn, New York, NY: John Wiley & Sons, Inc.

Connelly, F. M., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry.

Educational Researcher, 19(5), 2-14. Retrieved from <http://www.psycnet.apa.org>

Cooper, J., Brandon, P., & Lindberg, M. (1998). Evaluators' use of peer debriefing:

Three impressionist tales. *Qualitative Inquiry*, 4(2), 265-279.

doi:10.1117/107780049800400207

Cornew, L., Dobkins, K. R., Akshoomoff, N., McCleery, J. P., & Carver, C. J. (2012).

Atypical social referencing in infant siblings of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(2), 2611-2621.

Retrieved from <http://www.psycnet.apa.org>

Cramer, H., Carlin, J. (2008). Family-based short breaks (respite) for disabled children:

Results from the fourth national survey. *British Journal of Social Work*, 38(6), 1060-1075. doi:10.1093/bjsw/bc1393

Crane, J. L., & Winsler, A. (2008). Early autism detection: Implications for paediatric

practice and public policy. *Journal of Disability Policy Studies*, 18(4), 245-253.

Retrieved from <http://www.psycnet.apa.org>

Creswell, J. W. (2013a). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage Publishers.

Creswell, J.W. (2013b). *Research design: Qualitative, quantitative, and mixed method approaches*. Thousand Oaks, CA: Sage Publishers.

Creswell, J.W., & Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130. Retrieved from <http://www.psycnet.apa.org>

- Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3), 266-280. doi:10.1111/j.1365-2788.2010.01258.x
- Dardas, L.A., & Ahmad, M.M. (2015). For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and quality of life. *Research in Developmental Disability*, 36, 620-629. doi:10.1016/j.ridd.2014.10.047
- Datz, T. (2008). Autism has high costs to U.S. society. *Harvard School of Public Health*, 1, 67-80. Retrieved from <http://www.psycnet.apa.org>
- Davis, N.O., & Carter, A.S. (2010). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278-1291. doi:10.1007/s10803-007-0512-z
- Dawson, M., Mottron, L., & Gernsbacher, M.A. (2008). Learning in autism. *Learning and Memory*, 2, 759-772. doi:10.1016/8978-012370509-9.00152
- De Freitas, S. (2010). *Help for special children with special gifts on Trinidad and Tobago*. Retrieved from <http://www.newsday.com>
- DeGarmo, D.S. (2010). A time varying evaluation of identity theory and father involvement for full custody, and no custody divorced fathers. *Fathering: A Journal of Theory, Research, & Practice about Men as Fathers*, 8(2), 181-202. doi:10.3149/ft.1802.181

- Denzin, N.K., & Lincoln, Y.S. (2008). *Handbook of qualitative research*. London: Sage Publications.
- Ding, Y., Yang, L.Y., & Salyers, K., Harper, H., Guo, J.P., Liu, H., & Feng, Y. H. (2010). Assessing needs and challenges reported by caregivers and teachers of children with autism spectrum disorders in China. *Journal of the International Association of Special Education*, 11(1), 4-14. Retrieved from <http://www.psycnet.apa.org>
- Donaldson, S.O., Elder, J.H., Self, E., & Christie, M. (2011). Fathers' perceptions of their roles during in-home training for children with autism. *Adolescent Psychiatric Nursing*, 24(4), 200-207. doi:10.1111/j.1744-6171.2011.00300.x
- Duarte, C.S., Bordin, I.A., & Mooney, J. (2008). Factors associated with stress in mothers of children with autism. *Autism*, 9(4), 416-427. doi:10.1177/13261305056081
- Dumas, J.E., Wolf, L.C., Fisman, S.N., & Gulligan, A. (2009). Parenting stress, child behavior problems, and dysphonia in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality: A Special Education*, 2(2), 97-110. doi:110.1080/09362839109424770
- Eisner, E.W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. Old Tappan, NJ: Macmillan.
- Ekas, N.V., Lickenbrock, D.M., & Whitman, T.L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(10), 1274-1284. doi:10.1007/s10803-010-0986-y

- Ekas, N.V., Whitman, T.L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39*(5), 706-719. doi:10.1007/s10803-008-073-4
- Elder, J., Donaldson, S. Kairalla, J., Valcante, G., Bendixen, R., Ferdig, R., Self, E., & Walker, J. (2011). In-home training for fathers of children with autism. A follow up study and evaluation of four individual training components. *Journal of Child & Family Studies, 20*(3), 263-271. doi:10.1007/s10826-010-9387-2
- Elliot, D. (2013). In autism, the importance of the gut. *The Atlantic June, 1*, 67-74. Retrieved from <http://www.psycnet.apa.org>
- Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology, 43*(1), 13-35. doi:10.1163/15691621X632943
- Esdaile, S.A., & Greenwood, K.M. (2009). A comparison of mothers' and fathers' experience of parenting stress and attributions for parent-child interaction outcomes. *Occupational Theory, 10*(2), 115-126. doi:10.1002/oti.274
- Factor, D.C., Perry, A., & Freeman, N. (2009). Brief report: Stress, social support, and respite care use in families with autistic children. *Journal of Autism and Developmental Disorders, 20*(1). doi:10.1007/BF02206863
- Fletcher, P.C., Markoulakis, R., & Bryden, P.J. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues Compr Pediatr Nursing, 35*(1), 45-69. doi:10.3109/01460862.2012.645407

- Flippin, M., & Crais, E.R. (2011). The need for more effective father involvement in early autism intervention: A Systematic review and recommendations. *Journal of Early Intervention, 33*(1), 24-50. doi:10.1177/1053815111400415
- Flyvberg, B. (2006). Five misunderstandings about case study research. *Qualitative inquiry, 12*(2), 219-245. Retrieved from <http://www.psycnet.apa.org>
- Fromme, E.K., Drach, L.L., & Tolle, S.W. (2005). Men as caregivers in the end of life. *Journal of Palliative Medicine, 8*(6), 1167-1175. doi:10.1089/jpm.2005.8.1167
- Gibson, M. F. (2012). Stressing reduction: Reading into parents of disabled children. *Disability Studies Quarterly, 32*(1), 7-7. Retrieved from <http://www.psycnet.apa.org>
- Giorgi, A.P., & Giorgi, B.M. (2003). The descriptive phenomenological psychological method. In P.M. Camic, J.E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design*. Washington, DC: American Psychological Association.
- Gray, D.E. (2007). Everybody just freezes. Everybody is just embarrassed: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Wellness, 24*(6), 734-749. Retrieved from <http://www.psycnet.apa.org>
- Greenbank, P. (2003). The role of values in educational research: The case for reflexivity. *British Educational Research Journal, 29*(6), 78-86. Retrieved from <http://www.psycnet.apa.org>
- Guralnick, M. J., Hammond, M. A., Neville, B., & Connor, R. T. (2008). The relationship

between sources and functions of social support and dimensions of child and parent-related stress. *Journal of Intellectual Disability Research*, 52(12), 1138-1154. doi:10.1111/j.1365-2788.2008.01073.x

Hall, H.R., & Graff, C. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing*, 34(1), 4-25. doi:10.3109/01460862.2011.555270

Hartley, S.L., Seltzer, M., Head, L., & Abbeduto, L. (2012). Psychological well-being in fathers of adolescents and young adults with Down syndrome, Fragile X syndrome and autism. *Family Relations*, 61(2), 327-342. doi: 10.1111/j.1741-3729.2011.00693.x

Hatch, J. A. (2006). *Doing qualitative research in educational settings*. Albany, NY: State University of New York.

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2008). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9, 125-137. Retrieved from <http://www.psycnet.apa.org>

Hock, R.M., Timm, T.M., & Ramisch, J.L. (2012). Parenting children with autism spectrum disorders: A crucible for couple relationships. *Child and Family Social Work*, 17(4), 406-415. doi:10.1111/j.1365-2206.2012.00794.x

Honig, A. S. (2008). Supporting men as fathers, caregivers, and educators. *Early Child Development and Care*, 178(7 & 8), 665-687. Retrieved from <http://www.psycnet.apa.org>

- Hood, Jr., R. W. (2000). A phenomenological analysis of the anointing among religious serpent handlers. *International Journal for the Psychology of Religion, 10*(4), 221–240. Retrieved from <http://www.psycnet.apa.org>
- Huang, Y. P., Kellett, U. M., & St John, W. (2010). Cerebral palsy: Experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing, 66*(6), 1213-1221. doi:10.1111/j.1365-2648.2010.05270.x
- Huws, J. C., & Jones, R. S. P. (2010). They just seem to live their lives in their own little world: Lay perceptions of autism. *Disability & Society, 25*(3), 331-344. doi:10.1080/09687591003701231
- Ivrendi, A. & Isikoglu, N. (2010). A Turkish view on fathers' involvement in children's play. *Early Childhood Education Journal, 37*(6), 519-526. doi:10.1007/s10643-010-0376-2
- Jennings, S. (2005). Autism in children and parents: Unique considerations for family court professionals. *Family Court Review, 43*(4), 582-595.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems, & Health, 29*(3), 232-252. doi:10.1037/a0025341
- Jones, K. (2006). The role of father in psychoanalytic theory: Historical and contemporary trends. *Smith College Studies in Social Work, 75*(1), 7-28. doi:10.1300/J497v75n01_02
- Kaner, S. (2009). A study about perceived stress, social support and life satisfaction of parents of disabled children. *Final Report of Scientific Research Project, 1*, 24-35.

Retrieved from <http://www.psycnet.apa.org>

- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 390-397. doi:10.1111/j.1468-3148.2010.00555.x
- Keller, T., Ramisch, J., & Carolan, M. (2014). Relationships of children with Autism Spectrum Disorders and their fathers. *The Qualitative Report, 19*(33), 1-15. Retrieved from <http://nsuworks.nova.edu/tqr/vol19/iss33/2>
- Keok, C.A. (2012). Parental experience of having a child diagnosed with Autism: An integrative literature review. *Singapore Nursing Journal, 39*(1), 8-18. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles>
- Kraemer, S. (2001). The origins of fatherhood: An ancient family process. *Family Process, 30*(4), 377-392. doi:10.1111/j.1545-5300.2001.00377.x
- Larson, E. (2006). Caregiving and autism: How does children's propensity for routinization influence participation in family activities? *OTJR: Occupation, Participation and Health, 26*(2), 69-79. Retrieved from <http://www.psycnet.apa.org>
- Leedy, P. D., & Ormrod, J. E. (2010). *Practical research: Planning and design* (9th ed.). Upper Saddle River, NJ: Pearson.
- Leekam, S. R., Prior, M. R., & Mirko, U. (2011). Restricted and repetitive behaviors in autism spectrum disorders: A review of research in the last decade. *Psychological Bulletin, 137*(4), 562-593. doi:10.1037/a0023341

- Lemay, C. A., Cashman, S. B., Elfenbein, D. S., & Felice, M. E. (2010). A qualitative study of the meaning of fatherhood among young urban fathers. *Public Health Nursing, 27*(3), 221-231. Retrieved from <http://www.psycnet.apa.org>
- Levy, S. E., Mandell, D. S., & Schultz, R. T. (2009). Autism. *Lancet, 347*(9701), 1627-38. doi:10.1016/S0140-6736(09)61376-3
- Liebman, S. J., & Abell, S. C. (2000). The forgotten parent no more: A Psychoanalytic reconsideration of fatherhood. *Psychoanalytic Psychology, 17*(1), 88-105. doi:10.1037//0736-9735.17.1.88
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lyons, A. M., Leon, S. C., Roecker Phelps, C. E., & Dunleavy, A. M. (2010). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child & Family Studies, 19*(4), 516-524. doi:10.1007/s10826-009-9323-5
- Mason, M. (2010). Sample size and saturation in Ph.D. studies using qualitative interviews. *Forum: Qualitative Social Research, 11*(3), 1-19. doi: 10.1177/14687941112446106
- Mandel, D. (2010). The lived experience of pregnancy complications in single older women. *Journal of Maternal Child Nursing, 35*(6), 336-340. Retrieved from <http://www.psycnet.apa.org>
- Mays, G. D., & Lund, C. H. (1999). Male caregivers of mentally ill relatives. *Perspectives in Psychiatric Care, 35*(2), 19-28. Retrieved from <http://www.psycnet.apa.org>

- McCaslin, M., & Wilson Scott, K. (2003). The five questions method for framing a qualitative research study. *The Qualitative Reports*, 8(3), 447-461. Retrieved from <http://www.nova.edu/ssss/QR/QR8-3/mccaslin.pdf>
- Mc Stay, R.L., Dissanayake, C., Scheeren, A., Koot, H., & Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behavior of children and adolescents with autism. *The International Journal of Research and Practice*, 18(5), 502-510. doi:10.1177/1362361313485163
- Miller, L., & Reynolds, J. (2009). Autism and vaccination – The current evidence. *Journal for Specialists in Pediatric Nursing*, 14(3), 167-172. Retrieved from <http://www.pscynet.apa.org>
- Mitnick, S., Leffler, C., Hood, V. (2010). Family caregivers, patients and physicians: Ethical guidance to optimize relationships. *Journal of General Internal Medicine*, 25(3), 255-260. doi:10.1007/s11606-009-1206-38
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52(2), 250-260. Retrieved from <http://www.pscynet.apa.org>
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Naseef, R. (2010). When the bough breaks: A father's story. *Journal of Religion, Disability, & Health*, 6(1), 75-87. Retrieved from <http://www.pscynet.apa.org>
- Nelson, N. (2015). Helpfulness of parent to parent support among parents of children with autism. *Society for Social Work and Research*, 1, 1-20. Retrieved from <http://sswr.confex.com>

- Newman, C., Cashin, A., & Waters, C. D. (2010). A modified hermeneutic phenomenological approach toward individuals who have autism. *Research in Nursing & Health, 33*(3), 265-271. doi:10.1002/nur.20382
- O'Brien, M. (2009). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations, 56*(2), 135-146. Retrieved from <http://www.psycnet.apa.org>
- Ogston, P., Mackintosh, V. H., & Myers, B. J. (2011). Hope and worry in mothers of children with an autism spectrum disorder or Down syndrome. *Research in Autism Spectrum Disorders, 5*(4), 1378-1384. Retrieved from <http://www.psycnet.apa.org>
- Olfman, S. (2008). Asperger's disorder in a cultural context. *Encounter, 15*(1), 50-58. Retrieved from <http://www.psycnet.apa.org>
- Openden, D., Symon, J. B., Koegel, L.K., & Koegel, R. L. (2006). Developing a student respite provider system for children with autism. *Journal of Positive Behavior Interventions, 8*(2), 119-123. Retrieved from <http://www.psycnet.apa.org>
- Page, R.N. (1997). A thought about curriculum in qualitative methods. *Qualitative Studies in Education, 10*(2), 171-173. Retrieved from <http://www.psycnet.apa.org>
- Palmer, R., Blanchard, S., Jean, C. & Mandell, D. (2005). School district resources and identification of children with autistic disorder. *American Journal of Public Health, 95*(1), 125-130. Retrieved from <http://www.psycnet.apa.org>
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

- Pelto, P., & Pelto G. (2007). Studying knowledge, culture and behavior in applied medical anthropology. *Med Anthropol Q*, *11*(2), 147-63. Retrieved from <http://www.psycnet.apa.org>
- Perry, A. (2008). A model of stress in families of children with developmental disabilities: Clinical and research applications. *Journal on Developmental Disabilities*, *2*(1), 1-16. Retrieved from <http://www.psycnet.apa.org>
- Phelps, K. W., Hodgson, J. L., McCammon, S. L., & Lamson, A.L. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability*, *34*(1), 27-35. doi:10.1080/13668250802690930
- Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Paediatrics Nursing*, *14*(3), 157-165. Retrieved from <http://www.psycnet.apa.org>
- Pleck, J., & Masciadrelli, B. (2009). Paternal involvement in U.S. residential fathers: Levels, sources, and consequences. In M. Lamb (Ed.), *The role of the father in child development* (4th ed., pp. 222-271). New York, NY: John Wiley.
- Preece, D. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. *British Journal of Learning Disabilities*, *38*(1), 10-20. doi:10.1111/j.1468-3156.2009.00548.x
- Radin, N. (2009). Primary caregivers: Fathers in intact families. *Redefining Families*, 11-54. doi:10.1007/1978-1-4899-0961_9_2
- Renty, J., & Roeyers, H. (2006). Satisfaction with formal support and education for

- children with autism spectrum disorder: The voices of the parents. *Child: Care, Health, & Development*, 32(3), 371-385. Retrieved from <http://www.psycnet.apa.org>
- Rice, C. E. (2011). The changing prevalence of the autism spectrum disorders. *American Family Physician*, 83(5), 515-520. Retrieved from <http://www.psycnet.apa.org>
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism & Developmental Disorders*, 33(4), 383-394. Retrieved from <http://www.psycnet.apa.org>
- Rocco, T. S. (2003). Shaping the future: Writing up the method on qualitative studies. *Human*, (3), 343-349. Retrieved from <http://www.psycnet.apa.org>
- Rocque, B. (2010). Mediating self-hood: Exploring the construction and maintenance of identity by mothers of children labelled with autism spectrum disorder. *Disability & Society*, 25(4), 485-497. doi:10.1080/09687591003755864
- Rotundo, E. A. (2009). American fatherhood: A historical perspective. *American Behavioral Scientist*, 29(1), 7-25. Retrieved from <http://www.psycnet.apa.org>
- Ryan, G.W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, 15(1), 85-109. Retrieved from <http://www.psycnet.apa.org>
- Ryan, S., & Runswick Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22(1), 43-53. doi:10.1111/j.1468-3148.2008.00438.x
- Sanchez, C. (2007). Husserl's way to authentic being. *Human Studies*, 30(4), 377-393.

doi:10.1007/s10746-007-9061-x

- Saunders, B., Tilford, J., Mick, F., Fussell, J.J., Schulz, E., Eldon, G., Casey, P., Patrick, H., & Dennis, Z. (2015). Financial and employment impact of intellectual disability on families of children with autism. *Families, Systems, & Health, 33*(1), 36-45. doi:10.1037/fsh0000102
- Schieve, L.A., et al. (2007). The relationship between autism and parenting stress. *Pediatrics 119*, 114-121. Retrieved from <http://www.psycnet.apa.org>
- Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences*. New York: Teachers College Press.
- Sencar, B. (2008). A study on relation between perceived social support level and stress level of parents who have children with autism. *Journal of Palliative Medicine, 8*(4), 110-120. Retrieved from <http://www.psycnet.apa.org>
- Shorter, E. (2009). *The making of the modern family*. New York: Basic Books.
- Siller, M., Reyes, N., Hote, E., Hutman, T., & Sigman, M. (2013). Longitudinal change in the use of services in autism spectrum disorder: Understanding the role of child characteristics, family demographics and parent cognition. *Autism, 18*(3), 160-178. doi:1177/13623616/3476766
- Silva, L., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorder, 42*(4), 566-574. doi:10.1007/s10803-01-1274-1
- Single Fathers Association of Trinidad and Tobago. (2012). *Single fathers and their concerns*. Retrieved from <http://www.sfatt.org>

- Sirota, K. G. (2010). Narratives of distinction: Personal life narratives as a technology of the self in the everyday lives and relational worlds of children with autism. *Ethos*, 38(1), 93-115. doi:10.1111/j.1548-1352.2009.01083.x
- Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child & Adolescent Psychiatric Nursing*, 23(3), 189-195. doi:10.1111/j.1744-6171.2010.00240.x
- Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child & Adolescent Psychiatric Nursing*, 23(3), 189-195. doi:10.1111/j.1744-6171.2010.00240.x
- Smith, L. E., Hong, J., Mailick Seltzer, M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40(2), 167-178. doi:10.1007/s10803-009-0844-y
- Smith, H. L., & Morgan, S. P. (2010). Children's closeness to father as reported by mothers, sons, and daughters: Evaluating subjective assessments with the Rasch Model. *Journal of Family Issues*, 15(1), 3-29. Retrieved from <http://www.pscynet.apa.org>
- Stirling, J.A. (2007). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, 1(3), 385-405. doi: 10.1177/146879410100100307
- Taylor, S. E. (2011). Social support: A review. *Remedial and Special Education*, 28(1),

- 189-214. Retrieved from <http://www.psycnet.apa.org>
- Taylor, B., Jick, H., & Maclaughlin, D. (2013). Prevalence and incidence rates of autism in the world: Time trend from 2004-2010 in children aged 8 years. *BMJ Open*, 3(2), 56-66. doi:10.1136/bmjopen-2013-003219
- Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing*, 16(2), 151-155. Retrieved from <http://www.psycnet.apa.org>
- Towers, C. (2009). Recognising fathers: A national survey of fathers who have children with learning disabilities. *Foundation for People with Learning Disabilities*, 1(2), 3-11. Retrieved from <http://www.psycnet.apa.org>
- Tucker, P. (2006). Stay-at-home dads. *Futurist*, 39(5), 12-13. Retrieved from <http://www.psycnet.apa.org>
- Twombly, E. C., Holtz, K. D., & Daub-Sychra, A. (2011). Exploring the use of the internet by caregivers of people with autism spectrum disorders to obtain caregiving information. *Journal of Consumer Health on the Internet*, 15(1), 3242. doi:10.1080/15398285.2011.54707
- Uchino, B. (2004). *Social support and physical health: Understanding the health consequences of relationships*. New Haven, CT: Yale University Press.
- Unluer, E. (2009). A relation between self-despair level and perceived social support of parents who have children with autism aged between 2-6 years. *Final Report of Scientific Research Project*, 2, 67-80. Retrieved from <http://www.psycnet.apa.org>
- Vacca, J.J. (2013). The parenting process from the father's perspective: Analysis of

perceptions of fathers about raising their children with autism spectrum disorder.

Best Practice in Mental Health, 9(2), 79-93. Retrieved from

<http://www.psycnet.apa.org>

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London: Althouse.

Wallace, K. S., & Rogers, S. J. (2010). Intervening in infancy: Implications for autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 51(12), 1300-1320. doi:10.1111/j.1469-7610.2010.02308.x

Walsh, C.E., & O'Leary, D.K. (2013). A comparative study of the marital relationship between parents with children with autism and those with children without autism. *Good Autism Practice*, 10(1), 28-36. Retrieved from <http://psycnet.apa.org/psycinfo>

Wang, M., & Brown, R. (2009). Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work*, 12(2), 144-167. Retrieved from <http://www.psycnet.apa.org>

Watson, L. R., Patten, E., Baranek, G. T., Poe, M., Boyd, B. A., Freuler, A., & Lorenzi, J. (2011). Differential associations between sensory response patterns and language, social, and communication measures in children with autism or other developmental disabilities. *Journal of Speech, Language, and Hearing Research*, 54(6), 1562-1576. Retrieved from <http://www.psycnet.apa.org>

West, A. F., Lewis, S., Ram, B., Barnes, J., Leach, P., Sylva, K., & Stein, A. (2009). Why do some fathers become primary caregivers for their infants? A qualitative study.

Child: Care, Health & Development, 35(2), 208-216. doi:10.1111/j.1365-2214.2008.00926.x

Wilkinson, L. (2005). Supporting the inclusion of a student with Asperger syndrome: A case study using conjoint behavioural consultation and self-management.

Educational Psychology in Practice, 21(4), 307-326. Retrieved from <http://www.psycnet.apa.org>

Wills, T.A. (1991). Social support and interpersonal relationship. *Prosocial Behavior*,

Review of Personality and Social Psychology, 12, 265-285. Retrieved from <http://www.psycnet.apa.org>

Winter-Messiers, M. (2007). From tarantulas to toilet brushes: understanding the special

interest areas of children and youth with Asperger Syndrome. *Remedial and Special Education*, 28(3), 140-152. Retrieved from <http://www.psycnet.apa.org>

Woodgate, R.L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The

experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075-1083. Retrieved from <http://www.psycnet.apa.org>

Woodman, A.C. (2014). Trajectories of stress among parents of children with disabilities:

A dyadic analysis. *Family Relations*, 63(1), 39-54. doi:10.1111/fare.12049

Yamada, A., Suzuki, M., Kato, M., Suzuki, M., Tanaka, S., Shindo, T., Taketani, K.,

Akechi, T., & Furukawa, T. A. (2007). Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry and Clinical Neurosciences*,

61(6), 651-657. doi:10.1111/j.1440-

1819.2007.01736.x

Yell, M., Katsiyannis, A., Drasgow, E. & Herbst, M. (2003). Developing legally correct and educationally appropriate programs for students with autism spectrum disorders. *Focus on Autism & Other Developmental Disabilities*, 18(3), 182-191.
Retrieved from <http://www.psycnet.apa.org>

Appendix A: Interview Questions

1. Describe your role as primary caregiver to a child with autism.
2. What impact does having a child with autism have on your family?
3. What impact does having a child with autism have on your social life?
4. How does having a child with autism impact your sense of self and self-esteem?
5. What is day-to-day life like for you with a child with autism?
6. What kinds of support are available to you as a primary caregiver of a child with autism?
7. What kind of stressors do you experience related to parenting a child with autism?
8. How do you cope with these stressors?
9. Tell me more about the services and support that are available for supporting your child?
10. What kind of support do you have for yourself?
11. Explain whether the support services available to you and your child were beneficial.
12. What are your hopes and dreams for your child?
13. How have you grown from raising a child with autism?
14. Do you have any regrets in being the primary caregiver to a child with autism?