2021

Experience of Parents Receiving In-Home Behavioral Treatment for Their Child With Autism

Gerald Lavarias
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Gerald B. Lavarias

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. Tony Hobson, Committee Chairperson, Psychology Faculty
Dr. Steven Little, Committee Member, Psychology Faculty
Dr. Bonnie Nastasi, University Reviewer, Psychology Faculty

Chief Academic Officer and Provost
Sue Subocz, Ph.D.

Walden University
2021

Abstract

Experience of Parents Receiving In-Home Behavioral Treatment

for Their Child With Autism

by

Gerald B. Lavarias

Dissertation Submitted in Partial Fulfillment

of the Requirements of the Degree of

Doctor of Philosophy

Psychology—Clinical Psychology

Walden University

February 2021

Abstract

In-home applied behavior analysis (ABA) treatment has well-documented results and is widely recommended for children with autism. Since 1987, parents have sought and implemented ABA treatment in their homes for their children with autism. However, research on parents' lived experiences with in-home ABA treatment is limited. As such, there is a need to study the impact and influence of ABA treatment on parents' quality of life (e.g., challenges, scheduling, parenting). This qualitative study explored parents' lived experiences while their children with autism received in-home ABA treatment. A phenomenological approach was used to explore the experiences of 5 parent participants who completed a 60-minute interview about in-home ABA treatment for their child with autism. After interview transcription, the data were input into NVivo 12 software and analyzed using structural and descriptive textures. Results revealed 5 themes: perceptions of the child's ABA clinicians, knowledge of in-home ABA services, satisfaction with child's progress, facing challenges, and commitment to child's in-home ABA treatment. The results of this study may help ABA professionals improve their understanding of parents' lived experiences involving their children's in-home ABA treatment. Additionally, the study may help parents understand the empirical implications of seeking and receiving in-home ABA treatment. Thus, the study may help to extend knowledge, support, and treatment integrity for positive social change in the effectiveness of in-home ABA treatment.

Experience of Parents Receiving In-Home Behavioral Treatment for Their Child With Autism

by

Gerald B. Lavarias

Dissertation Submitted in Partial Fulfillment

of the Requirements of the Degree of

Doctor of Philosophy

Psychology—Clinical Psychology

Walden University

February 2021

Dedication

I dedicate this study to my mentors, Amanda, Marci, Robin, Bill, Glenda, LeeAnne, Faye, and Doug, who taught me to be a compassionate clinical professional in the field of applied behavior analysis. In addition, I dedicate this study to my mother and father, Merlie and Carlos Lavarias, who continued to believe in my educational goals. I also dedicate this study to my brothers, Walter and Moishe G., who motivated, encouraged, and supported me throughout this journey. I also dedicate this study to Lola Juling, Lola Pacing, Lola Librada, mama Kathy, papa Clark, Renan, Dr. Mendoza, Anthony, Cris, Danny, Jeff, Jonny, Kenny, Manny G., Manny M., Mike, Sonny, Bicera family, Cachola family, Garde family, Herbst family, Lavarias family, Vasquez family, and Yoro family. Thanks for all the praise and support.

I also dedicate this study to my children, Lucas, Kaitlyn, and Kassidy, for being patient and understanding when I needed to work on my doctoral courses and dissertation writing. Lastly, I dedicate this study and educational accomplishments to my wife, Tara, who sacrificed her time and championed me from start to finish in my doctoral journey. Tara, you inspired me and filled my heart with love and motivation. You kept me driven during the toughest times and gave me hope to fulfil my dreams of becoming a doctor. I love you.

Acknowledgments

I thank God for giving me faith and strength to help me complete this journey. I also want to thank my internship supervisor, Dr. Laurie Koenig, who helped establish my dissertation path. I am grateful to my dissertation committee chair, Dr. Tony Hobson, for his support and guidance. Additionally, I am thankful to my dissertation committee member, Dr. Steven Little, for his insight on applied behavior analysis as well as his appreciation for my study. I acknowledge VAC, AST, BCSD, and MAPSS for providing me the opportunity to work in the field of applied behavior analysis. Lastly, I thank the families and people I worked for in the autism community. Your achievements and dedication motivated and influenced me to take on this study.

Table of Contents

List of Tables

Chapter 1: Introduction to the Study

The following study reports on the lived experiences of parents caring for a child with autism receiving in-home applied behavior analysis (ABA) treatment. The effects of ABA treatment on children with autism are widely known among parents and professionals. A large body of quantitative research illustrates that in-home ABA treatment is an effective approach for treating autism symptoms (American Psychological Association, 2016; Eldevik et al., 2010; Granpeesheh, Tarbox, Dixon, Carr, & Herbert, 2009; Healy, Connor, & Kenny, 2008; McEachin, Smith, & Lovaas, 1993). This treatment has positive effects on emerging vocalization (Barlow, Tiger, Slocum, & Miller, 2013; Battaglia & McDonald, 2015), social skills (Reichow & Volkmar, 2010), and coping and self-management skills (Dawson & Burner, 2011) while limiting negative behavior (Asmus et al., 2004; Beavers, Iwata, & Lerman, 2013).

Although in-home ABA treatment is accepted by parents, there is little to no evidence about the lived experiences of parents who choose in-home ABA treatment for their children. It remains unclear whether current research addresses the gap regarding this phenomenon. That is, there is a gap in the understanding of how parents live their lives throughout their children's in-home ABA treatment. Currently, there are few studies reporting on parents' perspectives regarding autistic children's ABA treatment, with none describing the parents' lived experiences. The study of this phenomenon has important social implications, given that in-home ABA treatment is widely accepted and recommended for autism throughout the United States (Romanczyk, Callahan, Tuner, & Cavalari, 2014). This study addressed parents' perceived lived experiences of in-home ABA treatment for their children with autism.

There are several social implications to address regarding parents whose children receive in-home ABA treatment. First, in-home ABA treatment is a widely accepted and recommended treatment for autism throughout the United States (Romanczyk et al., 2014). A parent's experience may provide testimony as to the benefits of in-home ABA treatment for a child. Second, in-home ABA treatment is dependent on funding sources. Funding sources for in-home ABA treatment range from federal and state funds to private insurance and private pay. It is recommended that in-home ABA treatment be implemented at least 30-40 hours per week per child. However, each state funds ABA treatment differently, which may limit the ability to provide children with autism 30-40 hours per week of in-home ABA treatment. This social implication is an additive concern for families who are seeking full-capacity in-home ABA treatment for their children but are unable to do so (because of their state) or need to privately pay for treatment. Although in-home ABA treatment is widely accepted, funding variables may benefit or harm a family's lifestyle as a child receives in-home ABA treatment.

Background

During the early 1960s and before, autism was considered a rare and incurable disorder (Gulati & Chakrabarty, 2013; Mello, Goldman, Urbano, & Hodapp, 2016). Currently, autism or autism spectrum disorder (ASD) occurs in 1 in 34 boys and 1 in 144 girls, with at least 1 in 54 children diagnosed (Centers for Disease Control and Prevention [CDC], 2016; DeVibiss & Lee, 2014). Since then, over a hundred types of autism treatments have been developed and used to respond to increased numbers of ASD diagnoses (Callahan, Methta, Magee, & Wie, 2010; Romanczyk et al., 2014). These have included aversive treatment for autistic symptoms, electroconvulsive therapy,

psychoanalysis, eclectic and single educational treatment, behavior modification, and a plethora of medical treatments (Agency for Healthcare Research and Quality, 2011; Golnik, Ryaboy, Scal, Wey, & Gaillard, 2012; Kuo, Bird, & Tilford, 2011).

Among all of the treatment options, ABA is considered the most appropriate and longstanding effective treatment for individuals with autism. In the United States, in-home ABA treatment has received increased approval over the last 2 decades (Romanczyk et al., 2014). Following a landmark study by Dr. Ivar Lovaas (1987), ABA became a new direction for autism treatment. However, ABA treatment for autism has been the subject of debate, especially with increased demand for in-home ABA treatment to be used as a sole intervention for autism. There is reason to believe that the lifestyle demands of in-home ABA treatment, which include the need for funding, the availability of hours for participation, and modifications to families' daily schedules, are unknown (Kirkham, 2017; Rivard, Terroux, Boursier, & Mercier, 2014; Silva & Schalock, 2011). Moreover, there is a need to understand parents' perceptions of stress (Tehee, Honan, & Hevey, 2009) and views and experiences of other non-ABA treatment, such as medical treatments (Levy, Merhar, & Pinto, 2003). Thus, there is a gap in existing literature concerning the lived experiences of parents raising children with autism as their children receive in-home ABA treatment.

Problem Statement

The CDC (2012) has indicated that ABA is an effective, evidence-based practice that is selected by most parents and professionals for the treatment of children with autism. The treatment of autism using ABA in the child's home has been well documented with experimental single-subject designs (Kazdin, 2010; Warren,

McPheeters, & Sathe, 2011; Welch & Polatajko, 2016). Many educational, social, and psychological peer-reviewed journals have published remarkable findings of researchers and expert views regarding in-home ABA treatment for ASD. Most programs for in-home ABA treatment involve 20-40 hours per week (Granpeesheh et al., 2009). Despite this significant time investment, there has been little to no documentation of how ABA affects lifestyle changes and lived experiences for parents. With the popularity of ABA treatment for children with autism, parents' perception and experiences are favorable for their child. Although parents' perceptions of raising a child with autism have been reported (Davis & Carter, 2008; Silva & Schalock, 2011), current studies capturing the meaning of these experiences are limited.

Since in-home ABA treatment has increased in use, a few studies have addressed parents' perceptions of their children's in-home ABA treatment. However, the primary focus of those studies consisted of parents' views on their children's progress, or whether ABA treatment had an impact on their child's life and their family life. Most of these studies of parental perceptions and experiences of ABA treatment focused on the child's perceived progress and the continuation of ABA treatment.

Dillenburger, Keenan, Gallagher, and McElhinney (2004) addressed parents' perceptions of outcomes regarding their child's ABA treatment and parallel experience during parent education training. Their study included an evaluation of the effectiveness of an in-home ABA treatment program and parent education training that involved 55 families. Their survey was restricted to a 5-point rating scale, ranging from *don't know* to *make a great difference*. The survey questions related to how ABA treatment made an impact on the parent's life and the child's life. Results indicated that ABA treatment

made a great difference and was considered effective. These results reflected parents' experiences of their child's progress toward goals and objectives targeted by their in-home ABA treatment clinical team. While positive experiences were evident, parents also stated that the financial burden and demands of the program made it difficult to manage. Some participants also reported that in-home ABA treatment improved their child's lifestyle but indicated the duration and energy needed to continue ABA treatment were stressful and tiresome. The burdens involved in the program included coping and managing ongoing daily schedules that needed constant monitoring.

Although Dillenburger et al. (2004) connected parents' views with their children's ABA program, their results were centered on the impact and influence that ABA intervention had on the children's progress and family. In my investigation, I did not intend to examine the impact of in-home ABA treatment on the family, nor did I seek to understand parents' views on their children's autistic symptoms. Instead, I wanted to explore how parents live through this experience and how it impacts their daily decisions. The Dillenburger et al. study did little to identify whether the parents' lived experiences were changed or stayed the same with in-home ABA treatment. In my research, I was interested in the meaning of parents' experience, rather than the effectiveness of the treatment for the parent or the child's progress.

Blacklock, Weiss, Perry, and Freeman (2012) investigated parents' perception regarding their children's progress during intensive behavioral interventions. Their results indicated that parental experiences may differ from the actual progress made by their child during treatment. These results led to questions about how the use of evidence-based practice via ABA treatment provides different parental experiences of their child.

For example, parents perceived their child's progress differently than the outcome reported by the clinical professionals involved in the program (Ambert, 2001; Giangreco & Broer, 2005; Perry, Prichard, & Penn, 2006). This research indicated that in-home ABA treatment provides value to the parents. However, the research did not offer information on how parents experienced ABA treatment delivered in the home environment. In other words, Blacklock et al. did not determine whether there was a deeper personal meaning that parents experienced or whether the experience shaped or changed the parents' view of life or parenting.

Another study may have illuminated parents' views of their children's progress much more. Grindle, Kovshoff, Hastings, and Remington (2008) investigated parents' experiences with an intensive in-home ABA program for their children with autism. They interpreted that a recent diagnosis of autism and receiving in-home ABA treatment may influence parent perception. Their study focused on the perceived benefits, advantages, and disadvantages of children's in-home ABA treatment by means of an early intensive behavioral intervention (EIBI) model. EIBI is founded on ABA principles and requires that a child with ASD, typically younger than 5 years old, receive the maximum duration and intensity of ABA treatment (Dawson & Burner, 2011). A sample of 53 parents who raised a child with autism between the ages of 54 to 77 months was selected.

Participants in the Grindle et al. (2008) study answered interview questions addressing topics such as the following: (a) difficulties or stress levels with observing or participating in EIBI sessions, (b) positive aspects of their child's program and progress that was being made, (c) their role and assignment during EIBI treatment, and (d) changes or views of parent management during their experiences. Results indicated that,

overall, parents responded positively to their children receiving EIBI or in-home ABA treatment. This positive response included a decrease in stress levels, improvement in parent–sibling relationships and child rearing, and increased patience with parental child management. A parent in the did report that stress levels increased every so often and described self-evaluating and reflecting on the demands presented in the program from time to time. Concerns that the parent reflected upon included the child's progress being slow or gradual, the program staff changing, and the possibility of problems in the ABA program or child's behavioral plan. Grindle et al. indicated that most parents learned to cope and tolerate the demands of the EIBI program.

The Grindle et al. (2009) study appeared to capture parents' perceptions as well as parents' experiences living with a child with autism while receiving intensive in-home ABA treatment. While this seemed to be the case, the researchers did not intend to study or focus on this. Grindle et al. indicated that although "the program or the success of the program may have affected parents' experiences … our descriptive study was not designed to answer these questions" (p. 54). In addition, parents did not report on aspects of their own living experiences such as their relationship with other family or friends, decisions regarding leisure time, parenting habits, toleration of schedule changes and having ABA staff in the home, participating in treatment routines, or paying for services. After searching for additional related studies, I concluded that the lived experiences of parents of children with autism receiving in-home ABA treatment are unexplored. In other words, parents' perceptions of their experiences of their children's in-home ABA treatment and its meaning had yet to be determined.

Purpose of the Study

The purpose of this study was to explore parents' perceived lived experiences of their child's in-home ABA treatment. Although a few previous studies have addressed parents' perceptions of their children's in-home ABA treatment, these past studies were focused on the quality of in-home ABA treatment and its influence on the family and the child's progress. Therefore, the current studies were interested in two areas of concern: (a) the effectiveness in-home ABA treatment for the child and (b) the parents' views of the child's progress and the ABA treatment that the child received. Despite past research on parents' perceptions of their children's in-home ABA treatment, the meaning of parent experiences of such treatment and how parents live as their children receive treatment have been unknown.

To address this gap, I used a phenomenological approach to capture lived experiences perceived by parents who raised a child with autism who received in-home ABA treatment. I used in-depth semi structured one-on-one interviews and recorded each response using an audio device. My interview questions focused on the meaning of the parent's perceived lived experience of the child's in-home ABA treatment. I explored the data collected from these interviews to ascertain the meaning of participants' experiences, develop themes, consider social implications, and develop recommendations for future studies.

Research Question

The following research question was used to address parents' experiences with their child's in-home ABA treatment: What are parents' lived experiences during the provision of in-home ABA treatment for their child with autism?

Conceptual Framework

Because parental experience was an important factor for filling the gap targeted by this research, it was essential that the conceptual lens was role theory. Role theory is defined as a person's role changes when they are the presented with different situations or contexts (Biddle, 1996). For example, a parent has a primary role as a mother or father, biologically, but change their role to an ABA therapist role when working alongside their child's therapist during their child's in-home ABA treatment. With this said, role theory was appropriate to this study because it can be assumed that a parent's role may change when other individuals aid in the child's development (Maccoby, 1992). In keeping with the phenomenological approach, parents' reporting of in-home ABA treatment was ideal for addressing the meaning of their experience. Furthermore, by applying role theory, I was able to be attentive to the circumstances that these parents experienced. This allowed awareness into the meaning of the parents' lived experiences and how they affected their life roles while raising a child with autism who was receiving in-home ABA treatment.

Nature of the Study

The nature of this study involved the use of a qualitative design. A qualitative approach was used to capture the experiences and interpretations of parents of children with autism via the phenomenological method. Data were collected using in-depth semi structured interviews. Parents' responses were analyzed as discussed in Chapters 3 and 4.

Recent studies revealed that parents perceived their child's in-home ABA treatment as effective and saw progress that their child made as a result of this intervention. Despite these findings, parents' perceived experiences of their child's ABA treatment remain unknown, along with how they live during ABA treatment. Michael

(2009) contended that translational science for children with autism and their families is needed to optimize the function and understanding of medical, behavioral, and educational interventions by clinicians. Michael noted that at least 2 and half decades of research in this area could inform clinical teams' efforts to collaborate more effectively with families on autism treatment. Given that ABA treatment is considered an evidence-based intervention, my research may provide additional assurance of its success, and, more importantly, how research may be translated at the practical level via a child's home.

Acceptability, fidelity, and sustainability are important considerations in the selection and use of ABA treatment. The selection of in-home ABA treatment should be determined by its acceptability. This means that the parent should view the clinician's implementation of the treatment as feasible and manageable, and the parent's beliefs and values should be consistent with the intended outcomes. The integrity of ABA treatment is also important, in that the implementation of ABA treatment by clinicians should be based on evidence-based approaches executed with treatment fidelity. Likewise, sustainability is a key consideration with ABA treatment, as it is important to understand the likelihood that families will be able to use or continue to use in-home ABA treatment on their own when their in-home ABA clinicians no longer provide services to them.

Definitions

To distinguish keywords within the study, the following definitions are specified:

Autism or autism spectrum disorder (ASD): Autism or ASD refers to a spectrum of specific neurodevelopmental disorder symptoms. Autistic symptoms are categorized in and affect three categories: (a) socialization and interactions, (b) repetitive or

uncontrollable behavior, and (c) communication of wants and needs (American Psychiatric Association, 2013; Bennett & Goodall, 2016). In the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V), autistic symptoms are described in terms of three levels of functioning and independence, with Level 3 being most severe, level two being moderately severe, and level one being least severe (American Psychiatric Association, 2015). Each functionling level also includes regression in motor skills, academic readiness skills, self-management of behaviors, functional and self-help skills, and executive functioning. In addition, autistic symptoms may progress over time, depending on the individual's level of participation in one or more forms of intervention. Recession or recovery is unique to each autistic individual during growth and development and dependent on the severity of ASD (Fogt, Miller, & Zirkel, 2003).

Applied behavior analysis (ABA): ABA involves engaging in the science and study of a living organism's "socially significant behaviors" while monitoring the effects of ABA applications (Agency for Healthcare Research and Quality, 2011; Baer, Wolf, & Risley, 1987). Theories and applications of ABA originate from behavioral psychology—specifically, B. F. Skinner's philosophy of radical behaviorism. ABA treatment is widely used to address various social problems and concerns. It should be noted that ABA was not designed specifically to treat autism; rather, its generalized implementation features have a positive effect in reducing ASD symptoms (Callahan et al., 2010; Cautilli, Rosenwasser, & Hantula, 2003).

In-home ABA treatment: In-home ABA treatment is typically provided by a public or privately funded organization whose services entail behavioral assessments and

interventions for a patient or client in their home (McEachin et al., 1993; Panagiota, 2015). In-home ABA treatment involves a clinical treatment team. Team members have different levels of experience and educational backgrounds in ABA as a specialty and working with individuals with autism. Many in-home ABA treatment staff are trained, certified, and/or licensed to practice and use ABA treatment in the home. The national governing Behavior Analyst Certification Board (BACB) provides standardization, monitoring, advocating, and ethical protection of professionals who practice ABA and the people they serve (BACB, 2012).

Assumptions

The following study was derived of participants with a robust description of their lived experiences with in-home ABA treatment for their child with autism. According to Creswell and Poth (2017), a phenomenological study may include 1 to 325 participants. However, Duke (1984) recommended 3 to 10 participants appeared to be a significant amount to study the phenomenon in question. The use of in-depth structured interviews provided an examination of the participant's experience. It was important that each participant is given an opportunity to express their feelings and interpret their experiences in a clear and meaningful way. The assumption was that participants provided an in-depth response about their experiences to fully capture their perspectives. Also, the researcher assumed that the interview provided a point of context and details regarding the meaning of their experience.

Scope of Delimitations

This study examined a sample size of 5 participants. A criterion-based selection was used to determine if participant's share similar experiences concerning this

phenomenon. Participants were described as parents who received an in-home ABA treatment for their child. This study was limited to participants who received a minimum of 1-year or more of in-home ABA treatment at least 2 or more times per week. Each participant was presented with a semi-structured interview lasting about 60-minutes.

Participants were described as parent of a child with autism. Furthermore, each parent used in-home ABA treatment as a part of their child's treatment. It was recommended that participants communicate with the ABA agency and/or professionals implementing and managing their child's in-home ABA treatment. Therefore, exclusion of participants included parents who's child received less than 1-year of in-home ABA treatment.

Limitations

There were some limitations included in this study. First, bias concerns included my professional work with implementing in-home ABA treatment and working with families who use in-home ABA treatment. To eliminate or reduce bias, the researcher (me) provided a description of professional beliefs, experiences, and values regarding parents of children with autism. Bracketing and reflexivity was used to limit bias as described in chapter 3. This included journaling my thoughts and reflections during the research and setting aside any biases. Secondly, data collection and managing the data was laborious, time consuming, and overwhelming. Each participant was asked to report their experience, which was extensive and rich in details. Therefore, it was important that the researcher understood and organized his time to collect data thoroughly and prepare for analyzing the data in the most effective way. There was also a lack of generalization for this phenomenological research because these findings would not generalize entirely

to other parents' experiences. In other words, parents in this research may have experienced a difference in perspective and views than other parents who were asked similar questions.

Significance

The goal of this research was to fill a gap in the understanding of parents' views of in-home ABA treatment from a phenomenological lens. This information may help in explaining parents' reasons for selecting in-home ABA treatment and determining common patterns among parents' perspectives. A significant amount of research on in-home ABA treatment has been reported quantitatively, presenting data indicating effects of the treatment in minimizing challenging behaviors, improving language, increasing social communication skills, and improving quality of life skills (Gulati & Chakrabarty, 2013; Shean, 2015). This research may help ABA professionals improve their understanding of parents' lived experiences of their children's in-home ABA treatment. Assumptions were made regarding ABA treatment and the child's progress being of primary importance to parents, rather than parent perceptions. However, there is little to no evidence from research regarding parents' lived experiences of their children's in-home ABA treatment.

This study has social significance in that it may be helpful to parents who are seeking in-home ABA treatment for the first time and are unaware of the lived experiences of parents whose children have received it. However, there is little to no evidence regarding how this experience may be perceived or viewed. This research may help parents to understand the meaning and implications of seeking and receiving in-home ABA treatment for the first time.

The results of past and current ABA studies can be assumed to be favorable. Rather than reporting the effects of ABA treatment on children with autism, this study attended to the parent's lived experience when ABA treatment was delivered in the home. Strunk, Pickler, McCain, Ameringer, and Myers (2014) indicated the importance of parents' perceptions and the experience of seeking health care to manage children with autism. Their results indicated that parents experience emotional and child-rearing challenges such as frustration, helplessness, confusion, and low self-esteem because autism requires unique, specialized assistance. Their results indicated that a parent was dependent on public assistance and a variety of other care such as respite and public resources. Their study did not document the parent's needs or referral for ABA treatment. By addressing the gap in this research, ABA clinicians may better understand how to address needs related to parents' lived experience and provide an in-depth description of this experience to parents who are unfamiliar with having in-home ABA treatment for their children with autism.

Summary

Chapter 1 addressed the importance of filling a gap in the literature regarding parental perspectives on children's in-home ABA treatment. Chapter 1 included the problem statement, the purposes and reasons for this study, my research question, a conceptual framework, the nature of the study, assumptions and limitations, and the significance of studying parent perspectives on children's in-home ABA treatment. My conceptual framework was role theory, and my research design involved a phenomenological approach. A qualitative design was used to investigate this topic to understand and determine how in-home ABA treatment is experienced by parents.

In Chapter 2, I provide a review of previous literature. I summarize previous research studies that investigated parental experiences during ABA programs and how they relate to the gap targeted by this study. In addition, Chapter 2 addresses concerns regarding the effectiveness of in-home ABA treatment and parents' views on ensuring that their children's needs are met during their experience.

The research methodology is described in Chapter 3. This chapter addresses the sample size, the research design, the role of the researcher, and data collection procedures. The analysis and findings are discussed in Chapter 4. Chapter 5 provides a final analysis summarizing and interpreting the results from Chapter 4 and providing recommendations for future research.

Chapter 2: Literature Review

Introduction

The purpose of this study was to examine parents' lived experience of their child's in-home ABA treatment. ASD affects 1 in 54 children diagnosed individuals. The CDC (2016) predicted a rise by 20% each year. As ASD diagnosis rates have increased, research has also increased in various areas related to autism, such as causes of autism, prevention of autism, improvement of detection at early ages, medical treatment, psychological treatment, and biological treatment (Gulati & Chakrabarty, 2013). Unfortunately, many autism treatments are still underdeveloped or regarded as experimental. With this said, the most significant research at the front line of evidence-based treatment is ABA.

There have been mixed reviews regarding the current state of in-home ABA treatment from media sources. The mixed reviews included the intensity and demands of in-home ABA treatment as it is recommended for a child with autism. Nevertheless, in-home ABA treatment is widely considered an effective approach and regarded by parents and professionals as an appropriate method for treating autistic symptoms (CDC, 2016). However, individuals against ABA treatment have presented their opinion on several public media sources found on the internet. They advocate and criticize in-home ABA treatment as a stressful experience for both children with autism and their families (Angell et al., 2016; Kirkham, 2017; Nelson & Huefner, 2003; Regehr & Feldman, 2009; Smith & Antolovich, 2000). A majority of the psychological and educational community favors ABA as a treatment option for children with autism because of rich scientific findings supporting ABA and the robust manner in which it is implemented.

Therefore, Chapter 2 provides information regarding the literature on in-home ABA treatment and research studies regarding parents' experiences of ABA treatment. These are discussed within Chapter 2 to provide evidence of the importance of this study.

Literature Search Strategy

Thousands of autism studies are conducted and published each year. The amount of research on ABA treatment for individuals with ASD has increased each year since the 1960s. In investigating this literature, I used search strategies to identify appropriate studies using web-based sources. I accessed large, robust databases from Walden University, Google Scholar, Fresno Pacific University Online Library, and Behavior Analyst Certification Board Gateway. I conducted literature searches using PsycINFO, ProQuest Central, PsycARTICLES, and Wiley Online Library. These databases afforded access to journals such as *Journal of Applied Behavior Analysis*, *Journal of Experimental Analysis of Behavior*, and *Behavioral Intervention*. Other sources that I accessed included books, manuals, case studies, textual presentations, media sources via video and audio recordings, and conference workshop and presentation materials related to ASD and in-home ABA treatment.

In order to identify appropriate studies related to this study, the following search terms were used, alone and in combination: *autism spectrum disorder* (*ASD*), *autism, applied behavior analysis* (*ABA*), *behavioral treatment on autism, parent experiences with autism, parent experiences with autism, caregiving an individual with autism, ASD treatment in-home, in-home ABA treatment, in-home ABA program, qualitative studies regarding ASD or autism, evidence-based treatment for ASD or autism, experiences of ABA as a treatment for ASD or autism, diagnostic criteria for ASD, DSM-V, public*

perception of ABA treatment for ASD or autism, stress levels of parents raising a child with autism, lifestyle of parents raising an individual with ASD or autism, and *role of family members caring for a child with ASD or autism*.

Based on the results of my searches, I identified appropriate studies based on peer-reviewed status, accessibility of the complete published study in Microsoft Word or PDF form, publication in the English language, acceptance, and acknowledgment of professional experts in ABA and autism, and publication from 2008 to the present. However, I also included significant literature published before 2008 due to its importance and relation to this study.

Conceptual Framework

The conceptual framework for this study was role theory. Role theory is applicable when discussing parents who care for a child with a neurodevelopmental disorder such as autism. Parent roles are described as "a very demanding admixture of childlike and adult perceptions" (Maccoby, 1992, p. 1015). That is, parents have a direct influence on their children's development. The assumption of role theory is that a person takes on a role based on interactions with other people and may conform to one role or transition into multiple ones (Kulik, Shilo-Levin, & Liberman, 2015).

Role theory indicates that an individual's role influences how that individual may behave or act in the presence of others. Role theory may be used to understand how parents perceive their role during their child's in-home ABA treatment. For instance, parents may choose to be involved in their child's ABA treatment or may limit interaction with their child's in-home ABA treatment clinician. Additionally, parents' behavior may change during their child's in-home ABA treatment; such change may be

influenced by the presence of ABA clinicians in the home. Role theory emphasizes the understanding and meaning of parents' lived experience during their child's in-home ABA treatment. Role theory has been applied in other studies involving parent experiences with autism, which have addressed topics such as perceptions of starting elementary school (Connolly & Gersch, 2016) and parent planning during autism diagnosis (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). A phenomenological approach was appropriate for this study because parent's may view their role differently in the presence and absence of their child's in-home ABA treatment.

Literature Review Related to Key Variables and/or Concepts

Applied Behavior Analysis Evolving Into an Autism Treatment

ABA is a science and study of behavior originating from the theoretical framework of B. F. Skinner's radical behaviorism (Baer et al., 1987; Cautilli et al., 2003). Radical behaviorism involves the use of both covert phenomena (i.e., private events or inner processes) and overt behaviors (i.e., observable or outer responses) to explain an organism's experience (Skinner, 1974). Skinner (1974) expressed his position regarding radical behaviorism as follows:

> Radical behaviorism restores some kind of balance. It does not insist upon truth by agreement and can therefore consider events taking place in the private world within the skin. It does not call these events unobservable, and it does not dismiss them as subjective. (p. 15)

This differs from traditional behaviorism (or Watson's behaviorism) because Skinner saw learned experiences as operations of environmental variables rather than conditional experiences.

Skinner later adopted the theory of operant learning or conditioning (Cautilli et al., 2003). He described operant conditioning as presentation of a stimulus eliciting a behavior followed by a consequence that strengthens or weakens an individual's response over time. If the history of these contingencies continues to be present, then it is likely to extinguish other unnecessary responses and reinforce future contingent responses. The theory of operant conditioning would later be adopted into the application of ABA implemented by Ivar Lovaas (1987).

Lovaas (1987) hypothesized that operant conditioning, if applied to children with autism, might strengthen positive development while decreasing autistic symptoms. Lovaas translated operant conditioning methods into an ABA method called *discrete trial training* (DTT). DTT is described as an short operant trial application involving the following steps:

1. An instructor presents one or more discriminative stimuli to a learner.
2. The instructor waits for a short time for the learner's response.
3. The instructor provides a reinforcing consequence or an extinguishing one, depending on the learner's response.
4. The instructor repeats this implementation 10 or more times. (Panagiota, 2015; Smith & Lovaas, 1998)

Due to the technological aspects of DTT, typical ABA programs may use DTT applied to receptive and expressive activities in academic and social subjects (Healy et al., 2008; Warren et al., 2011).

Applied Behavior Analysis for Autism Treatment

The popularity of in-home ABA as a treatment option for autism was primarily based on Lovaas's (1987) study. His study was significant to the popularity and standardized use of in-home ABA treatment. Lovaas examined the effects of an intensive ABA treatment for children with autism. Lovaas assigned 38 young children with autism to an experimental group and control group. At least 19 children with autism were provided with intensive ABA treatment, while others received less than 10 hours of one-to-one treatment per week. The study was conducted at the University of California Los Angeles (UCLA) psychology department, which was headed by Lovaas. Treatment conditions included home, school, and community settings.

Significant differences between the groups in Lovaas's (1987) study were the intensity of treatment, treatment duration per week, and teacher-to-student ratio. The independent variables included 40 hours of ABA treatment per week, along with (a) intensive discrete trial training (DTT), a type of ABA treatment application, and (b) one-to-one continuous implementation by an ABA trainer/instructor. The ABA trainer/instructor provided undivided attention to the child by means of implementing the study's ABA treatment. In addition, data were collected for 2 years to compare the progress and effects of ABA treatment for each group.

Results indicated that for at least nine of the 19 participants from the experimental group, autistic symptoms were significantly reduced, and intelligence levels increased to average. In addition, these participants were observed to attend school with reduction of special educational support compared to the control group. At least one participant from the control group had similar results. Lovaas's (1987) findings were later replicated in

studies by McEachin et al. (1993) and Cohen and Colleagues (2006), who reported similar results when comparing experimental and control groups. Since Lovaas's study, ABA has been recognized as a valued treatment option for young children with autism (Romanczyk et al., 2014; Smith & Eikeseth, 2011). These results provided a platform for other forms of ABA treatment for individuals with autism (Barbera, 2007; Battaglia & McDonald, 2015; Reichow & Volkmar, 2010).

Successful outcomes resulted in increased demand for ABA treatment in home, school, and community settings. In addition, studies outcome helped to popularize ABA as an evidence-based approach to treating autism and related disorders. However, experimental parameters such as the duration of hours per week and implementation by an ABA trainer/instructor were recommended to be explored in future research. It is hypothesized that these variables may contribute to family lifestyle modifications and changes to parenting habits for a child with autism (Angell et al., 2016; Davis & Carter, 2008; Lyons, Leon, Phelps, & Dunleavy, 2009) which may need to be determined in future studies. Fortunately, professional organizations recommend the use of ABA as an exceptional treatment for autism as recognized by the U.S. Surgeon General and Department of Health and Human Services (Smith, & Eikeseth, 2011).

Transitioning From Applied Behavior Analysis Research to In-Home Treatment

Lovaas popularized the implementation of in-home ABA treatment through his 1987 study as well as through the UCLA Young Autism Project (YAP; Smith & Lovaas, 1997, 1998). The YAP focused on implementing operant learning methods via DTT for young children with autism. This included intensive ABA implementation to address

specific and core skills after a child was diagnosed with autism at 4 years of age or younger. ABA treatment delivery involved 40 or more hours per week.

The YAP received attention from the scientific and educational community for its remarkable results, which included dramatic increases in social and academic readiness skills, as well as decreased challenging behaviors associated with autistic symptoms. At the time, YAP offered an option for autism treatment that was novel to parents, who had limited choices for treating a child with autism. Lovaas's (1987) contributions led to the beginning of autism treatment, research studies, and manuals on in-home ABA treatment used by professionals and parents. The YAP attracted national scientific interest, influencing and encouraging over 40 years of documented ABA research (Warren et al., 2011).

Description of In-Home Applied Behavior Analysis Treatment

Lovaas's (1987) study influenced other psychologists, mental health practitioners, and special education professionals to provide ABA treatment in the homes of children with autism. An in-home ABA treatment model became an extension of Lovaas's research (Granpeesheh et al., 2009; Lovaas, 1987; McEachin et al., 1993; Smith & Lovaas, 1997). In other words, in-home ABA treatment was developed through systematic replication of Lovaas's original methods. However, several differences were also considered. These included the intervention duration, clinical staff, and in-home ABA treatment focus.

Typically, it is recommended that a child with autism receive between 20 and 40 hours of ABA treatment in a variety of environments. One of the most popular ABA treatment options is in-home ABA treatment. General in-home ABA treatment requires a

team of behavioral specialists, ranging from a direct in-home therapist to a clinical supervisor. In addition, a general in-home ABA treatment program includes embedded curricular instruction and incorporates academic readiness skills, functional living skills, social skills, language and verbal training, community awareness training, and structured daily routines. In-home ABA treatment continues to be an acceptable and appropriate treatment option for young children with autism.

In-home ABA treatment may be delivered in specific or various locations of the child's home setting, such as the living room, the kitchen table, a designated office or workspace, the child's room, or a play or game room. These settings may include a variety of visual supports, ranging from a schedule to colorful or appealing prompts to help the child with attending to direct instructions from the in-home therapist. Other setting arrangements include (a) modifying or manipulating the environment, such as by minimizing or removing access to toys or switching the location of furniture; (b) providing additional instructional material related to the child's goals and objectives; (c) implementing ongoing data collection systems through a program book or media device that is specific to ABA treatment data; and (d) providing family or parent support, which may be optional or highly recommended (Dawson & Burner, 2011). Each week, in-home ABA treatment may be implemented for 20-40 hours over 2 to 7 days.

The role of the parent depends on the recommendations of the in-home ABA treatment clinician. For example, many in-home ABA treatment clinicians will not require a parent to participate at the beginning of treatment, whereas others may require the parent to participate for a limited or short amount of time. In general, most in-home ABA treatment clinicians do not require a parent to participate in treatment sessions

because of the increased potential for distraction with the presence of both the in-home therapist and the parent, increases in the parent's emotional stress level, overwhelming or overstimulating effects of the parent's presence on the child, and/or inconsistency in the implementation of the child's treatment. Typically, a child will be provided with at least one in-home ABA therapist to implement the ABA program plan and work one-on-one with the child.

In-home ABA treatment sessions vary in duration, which depends on the number of recommended hours per week. For example, clients may be recommended 15 to 30 hours per week based on the number of recommended goals and objectives and ABA curricular intervention methods used. A clinical supervisor will provide home supervisions at least once per week or once every 2 weeks to ensure treatment fidelity and observe the child's progress. This treatment modality may last 2 or more years, depending on the child's needs and the success of the in-home ABA treatment program.

A social concern involving in-home ABA treatment is funding. In the United States, federal, local, and private insurance organizations recognize the importance of ABA treatment and allocate funding for families who seek ABA treatment for their children within home, school, or community settings (American Academy of Child and Adolescent Psychiatry, 2014; CDC, 2012). In-home ABA treatment is expensive and may be costly if parents privately pay for their children's services when federal or state funding is not available or declined (DeVibiss & Lee, 2014; Romanczyk et al., 2014). Financial stress is correlated to in-home ABA treatment (Dillenburger et al., 2004; Blacklock et al., 2012; Up To Date, 2017) and should be considered as an important variable when examining parents' experiences with the treatment. Although a few studies

in this area have included parent experiences involving financial concerns, those studies have not highlighted the impact of these concerns on parents' experiences of their children's in-home ABA treatment.

Parent Perceptions

While YAPs study set the groundwork for autism treatment options, a qualitative account of a parent's experience in an ABA program originates from Catherine Maurice's novel *Let Me Hear Your Voice*. Maurice documents and reports her experience and perspectives with using Lovaas's YAP methods on her child within her home. The concept of providing early intensive ABA treatment in a child's home was considered unique or unorthodox during a period where autism treatment was rare or treated in clinical institutions. Therefore, Maurice's experience of ABA treatment for her child at home provided a novel approach and a positive alternative to treating young children with autism. *Let Me Hear Your Voice* (Maurice, 1993) was widely published and inspired other families to seek ABA treatment and replicate Maurice's child's experience with ABA within a home environment.

Maurice's (1993) book provided an assurance that ASD is treatable under an ABA treatment model. Additionally, the use of in-home ABA treatment and the incorporation of parent training models could be assumed that the parent experience of their child's treatment may increase to positive levels while reducing parental stress levels (Zaidman-Zait et al., 2010). In-home ABA treatment models included parent participation led by a clinical manager to help extend ABA procedures during the child's non-treatment time periods. This is called the workshop model or parent education model (Kuo et al., 2011; Tellegen & Sanders, 2014).

The use of in-home ABA treatment may involve parent participation during sessions and workshop training with a clinical supervisor (Tellegen & Sanders, 2014; Yanqing, 2006). While important, ABA treatment could also influence some parents to pursuing a career in ABA. Barbera (2009) examined the experiences of mother's who cared for a child with autism and later became Board Certified Behavior Analysts (BCBAs). A BCBA is a professionally nationally credentialed or state-specific licensed clinician whose professional and educational experience is based on meeting the BACB requirements. Currently, many BCBAs work in special education, especially with individuals with autism. A unique characteristic of Barbera's investigation is that the participants, or "Autism Parents" (p. 58), did not become BCBAs until after their child showed success while receiving in-home ABA treatment.

According to Barbera (2009), each parent had different professional backgrounds ranging from education to business and professional and educational ABA experiences were based solely on their interaction in their child's ABA program. Barbera provided 6 parents with a 3-item questionnaire. Data collection was analyzed using a pattern analysis, organized into a several themes. Results indicated several factors regarding the participants' pursuit for a profession in ABA, experiences of working as a BCBA-parent, and aspects and perspectives of training other parents when it comes to ABA treatment. Overall, each parent indicated that their experience with ABA treatment with their own child led to their interest and pursuit for an ABA profession. Furthermore, they related to other families receiving ABA treatment and established rapport easily due to similar personal concerns regarding their child's autistic symptoms. Overall, Barbera's research provided speculation that a parent could be influenced to seek a profession in ABA. The

importance of Barbera's study indicated that a parent's lived experience with ABA treatment for their child may influence their decision from being a parent to becoming an ABA treatment professional.

Robertson (2016) studied parent's acceptability of behavior interventions for 3 African American families with a child with autism. Before Robertson's study, there were no known studies regarding the integrity and acceptability of intervention effectiveness and acceptability with African American families. According to their results, parents rated behavioral interventions as highly effective and accepted as a treatment choice for their child. However, they also indicated that results should be taken with caution because each family had variations of their child's ABA treatment being applied. For example, one family had a variety of behavioral interventions implemented, but another family had limited amounts of ABA treatment used during certain parts of their child's treatment. They also indicated that certain ABA treatment components may have provided more acceptance than others such as differential reinforcement procedures or visual supports. In addition, some parent's participated in parts of their child's ABA treatment, while other's observed or did not participate at all. Their results indicated that in-home ABA treatment acceptability and integrity of in-home ABA treatment may be based on differential uses of ABA rather than a specific ABA treatment modality.

Summary and Conclusions

In-home ABA treatment is an effective model for treating ASD, which are evident within the research and widely accepted by a variety of private and public sources. Furthermore, in-home ABA treatment is recommended as standard form of ASD treatment. Th increase of ABA trained professionals assists with these services.

Therefore, a child's in-home ABA treatment provides value to our understanding of the parent's lived experience.

Chapter 2 reviewed literature associated to this study and addressed the importance of gathering additional insight as to parent experiences during their child's in-home ABA treatment. The following investigation examined parent's interpretations and insights based on their subjective experiences during their child's in-home ABA treatment. Chapter 3 provided a description of the methodology, the role of the researcher, the qualitative research design and rationale, and population recruitment and selection of participants.

Chapter 3: Research Method

Introduction

The importance of parents' lived experiences involving such treatment for their children led to the need for this qualitative study. Chapter 3 reviews the research design and rationale, my role as the researcher, and the methods used within this study. A central theme within this study was the parent's lived experience during a child's in-home ABA treatment. The main goal was to interview each participant and analyze results, as discussed in this chapter.

This research has several social implications. First, this study may help ABA professionals understand parents' lived experience during their children's in-home ABA treatment. Second, it may help other parents understand the meaning and living implications of seeking and receiving in-home ABA treatment.

Research Design and Rationale

The following research question was developed to address the gap targeted by this study: What are parents' lived experiences during the provision of in-home ABA treatment for their child with autism? To address this research question, I chose a phenomenological approach to capture the lived experience of parents who were raising a child with autism while their child received in-home ABA treatment. The following research may help in understanding a parent's perspective with their child's in-home ABA treatment. The limited research on a parent's lived experiences with their child's in-home ABA treatment should raise social concerns on the impact on a family, but more so, whether it shapes or informs parents' views of their experiences. This is the reason that a phenomenological approach was selected for this qualitative study.

In past research on ABA treatment, quantitative approaches have been most common. Quantitative data collection may occur through survey questionnaires and with the use of rating scales, which help to control specific variables and address specific categories for large samples (Levitt, Moutulsky, Wertz, Morrow, & Ponterotto, 2017). A majority of studies on ABA treatments for ASD have been based on experimental, single-subject designs, in which data have been quantitatively analyzed by each participant's response (i.e., "raw" data; Granpeesheh et al., 2009; Heyvaert, Maes, Van Den Noortgate, Kuppens, & Onghena, 2012; Romanczyk et al., 2014). Whereas most quantitative research designs involve relatively large participant pools, single-subject designs (like qualitative designs) are better examined with smaller participant samples.

Participants' expressions of their perspective may be limited by surveys with response options that involve Likert scales or other rating scales. Such limitations are not appropriate for in-depth exploration of parents' perceptions of their lived experience. A quantitative research design may limit a participant's full reported expression, perspective, or view. The purpose of quantitative research designs is to investigate participants' responses to manipulating (or independent) variables and use statistical calculations to analyze the independent and dependent variables' relationship. In contrast, qualitative research is appropriate for reporting on lived experiences as perceived by parents who are raising a child with autism while their child receives in-home ABA treatment. The purpose to select a qualitative research includes implementing criteria for adequacy and appropriateness of data (Creswell, 2013; Morse, 1998) to address the trustworthiness of data collection.

The phenomenological approach was chosen because it clarified the meaning of lived experiences as identified by several participants who shared common experiences. In choosing a phenomenological approach for this research, I also considered other qualitative research designs. Narrative research may be used to explore the lived experiences of participants, but this type of research focuses on the analysis and nature of a story, rather than its meaning. The purpose of this study was to analyze the participants' statements and look for their essence or significance; therefore, narrative analysis was not the most appropriate choice. Ethnography does not usually involve a phenomenon that individuals experience; instead, it involves the exploration of a group whose members share a culture. I assumed that participants in this study might have different cultural backgrounds but would encounter a similar phenomenon: in-home ABA treatment.

Another qualitative design, grounded theory, is based on the development of a theory that is grounded in the data collected. The process of grounded theory involves many individuals' interpretations and interactions (Burden & Roodt, 2007). This study did not focus on developing a theory based on the phenomenon. Instead, the focus was on exploring the lived experiences of parents.

A qualitative research design allows for the researcher to discover participants' vivid descriptions of their experiences with a phenomenon (Creswell, 2013). This means that the participants' accounts and reports provide their experiences and perspectives with the phenomenon. An important dynamic of this study involved collecting participants' broad textual or verbal reports or accounts regarding their perspectives, views, and experiences. A phenomenological approach is the most appropriate choice for a study of

lived experiences. For this study, I collected broad details on participants' perspectives on and experiences with their children's in-home ABA treatment.

Role of the Researcher

I currently practice as a BCBA. I have a history of working in special education and have specialized in ABA treatment for individuals with ASD since 1997. My professional and educational history is extensive, with responsibilities including one-on-one direct ABA treatment in clients' homes, schools, institutions, and various community settings (e.g., parks, afterschool sports). I have worked with individuals with ASD between 2 years of age and adulthood, in addition to directing families and teams of professionals who manage and care for individuals with ASD. I have been a guest speaker, workshop trainer, graduate university professor, independent consultant, and presenter at local and state ABA and ASD awareness conferences and other events. My work has included mentoring and supervising graduate students who attained supervisory hours to meet BCBA examination qualifications. In addition, I am a member of local, state, and national professional organizations such as the Association of Professional Behavior Analysts, Autism Speaks, and California Association for Behavior Analysis.

For this study, I was the investigator and researcher. I developed and used appropriate materials for this study while maintaining and limiting my biases based on my history with this population through bracketing or epoche. Bracketing, a type of data analysis, involves setting aside "all preconceived experiences to best understand the experiences of participants in the study" (Creswell & Poth, 2017, p. 78). Reflexivity was used to limit bias along with an audit trail through journaling. For example, I journaled my reflections during the research and self-checked my thoughts and reflections

throughout the study. I conducted the interviews, recorded data, analyzed findings, and recorded my findings during this study. It was my intention that this study represent a clear example of a qualitative research while addressing each participant's account as it related to this study. Additionally, intuiting was to hold myself accountable and recognize that participants views are individualized and unique. Their parenting experiences were observed as their own experiences not to be compared to my experience with parents I have provided in-home ABA treatment to.

Methodology

The following study had a qualitative research design, whereby participants were selected into a small sample based on select criteria. Participants were sought and contacted through social media platforms, with a focus on participants in parent autism groups associated with in-home ABA services. Parents' who responded to topics in the autism parent social media platforms shared their experiences with a variety of autism advocacy and parent support groups such as California's Regional Center, Kern Autism Network, Autism Society of America, Autism Speaks, Autism Mother's Group, local ABA agencies and schools, and Families for Effective Autism Treatment.

I planned to gather data from a sample of three to 10 participants, adding participants until saturation was met. However, 5 participants completed the research and saturation was met. A criterion-based selection for participants was used to recruit through the parent autism social media platforms. To be eligible to participate in the study, an individual needed to be the biological parent or legal guardian of a child who had received a DSM-V (APA, 2015) diagnosis of ASD. Additionally, the child needed to currently receive at least 1 year of in-home ABA treatment during this study. The child in

question needed to be under 18 years of age and under the direct care of the biological parent(s) or legal guardian(s). The in-home ABA treatment needed to be implemented from a minimum of 2 times per week to a maximum of 7 times per week. Additionally, the parent needed to be the primary or co- decision maker regarding the child's in-home ABA treatment. Finally, I could not be the provider for the participant's in-home ABA treatment services. In other words, all current clients associated with my current employment as an ABA provider were excluded from participating in this research.

Participants were provided with a consent form indicating their agreement to participate. Additionally, they were provided with a summary of the research, a description of their role and responsibilities, a description of limitations to confidentiality, and volunteering instructions. I conducted in-depth interviews remotely by phone to accommodate the participants in terms of comfort, location, and privacy. The interviews were 60 minutes; however, longer time periods were allowed so long as each question met the needs of the research. Participants agreed to have their interview audio recorded for purposes of data collection. Audio recordings were collected on a digital recording device and were securely coded so that the identity of the participants would remain protected, but the data could be easily referenced.

The interview questions in this study explored the participants' experiences (see Appendix C). First, the parents were asked to describe the child's current in-home ABA treatment and the parent's role during the sessions. Second, the parents were asked to describe their emotions or feelings before, during, and after in-home ABA treatment sessions. Third, parents were asked to describe experiences important to themselves, their family, and their child's experience. Fourth, parents were asked to describe their

perceptions of parenting a child with autism. Last, parents were asked about their role during their child's in-home ABA treatment.

All participants were provided with a copy of their transcript to review for accuracy. This process involved contacting participants by telephone and e-mail so that they could confirm the transcriptions, make necessary corrections, address any concerns, and question the transcripts as desired. After all participants had agreed to the accuracy of the transcripts, safeguards were used to protect the clients' information, including a protected password and playback review in private, secure locations. These same features were applied to anecdotal documentations, whereby written documents were secured in a protective sealed binder that was retrievable to a limited private location, organized, managed under a file, assigned a participant identification code, and limited to the researcher's and dissertation committee's views.

Data analysis was achieved by bracketing and using clusters of meaning. Bracketing involves setting aside one's experiences to address or review a phenomenon in a new way (Creswell & Poth, 2017). For bracketing, I set aside my own experiences that suggested my own biases. I did this by reminding myself to keep my personal and professional experiences aside to ensure that my analysis was based on the data being collected. Additionally, reflexivity was used to document and reflect my experience as part of an audit trail. This helped me to understand the participants' experiences and my experience throughout the research. Second, I used a cluster of meaning as the last step in data analysis. This process involves the researcher clustering the participants' statements and responses into themes and eliminating repetition or overlapping of participant statements (Creswell & Poth, 2017).

After gathering and reviewing the participants' statements and responses, I prepared the data for entry into NVivo 12 (n.d.), computer software designed for qualitative and mixed method studies. Once participant data had been collected, I organized and stored the data in NVivo 12. Using NVivo 12, I managed and analyzed the data. In doing this, I was able to analyze similarities and dissimilarities in participants' responses and statements. By determining the variables, I determined the elements of the data that overlapped or repeated. In the final stage, I analyzed the data and identified common themes.

Trustworthiness of the Study

The study met needs for reliability and validity by means of adequacy and appropriateness or criteria of adequacy and appropriateness of data (Morse, 1998). Data collection or documentation was made decisively through criterion-based sampling. An important factor for all research is the dependability, confirmability, and transferability of data. It is imperative that dependability, credibility, confirmability, and transferability are sustained during a study. I used ethical procedures to ensure safeguards and protection for participants during the study.

The study met needs for reliability and validity by means of adequacy and appropriateness or criteria of adequacy and appropriateness of data (Morse, 1998). Data collection or documentation was made decisively through criterion-based sampling. An important factor for all research is the dependability, confirmability, and transferability of data. It is imperative that dependability, credibility, confirmability, and transferability are sustained during a study. I used ethical procedures to ensure safeguards and protection for participants during the study.

The method that I used to meet credibility criteria in this research was member checking. Member checking involved the interviewees reviewing and confirming their responses to the interview questions (Creswell, 2013). This allowed parent participants to provide feedback on the data recorded. To demonstrate member checking, I followed up with participants to clarify their responses to the interview questions. I provided an opportunity for parents to review their responses and allowed them to correct or approve the responses and interpretations that I made of their original responses.

Dependability establishes a study's findings to be consistent and repeatable (Creswell, 2013). An audit trail was used to meet dependability criteria. I sought to ensure that other researchers could review the data and reach similar interpretations and conclusions regarding the data collected. I kept a detailed record of my procedures, which included the sampling methods, data collection methods, data analysis methods, interpretation of the data, and description of the trustworthiness of the study. The coding-recoding procedures were repeated several times to identify, categorize, determine several themes. Additionally, coding-recoding helped organize themes and units that were kept, deleted, or transferred to meet the criteria of dependability of this research.

The criteria for transferability were met by reporting elements of the study's methodology such as sampling methods and procedures for collecting and analyzing data, as well as describing the context to readers. The goal for transferability is to provide the potential for readers to relate their own experiences to a study. For example, special education teachers who read this study may relate it to their lived experiences of working with children with autism who receive ABA treatment in their classroom.

Confirmability is established by ensuring that the results reflect the participants' responses and not the researcher's bias. The criteria for confirmability were met through reflexivity and audit trail using a journal. The process I used for confirmability included self-checking my thoughts and reflections throughout the study as a process of reflexivity. Additionally, I recorded my reflections in a journal as part of an audit trail.

There were several ethical considerations in research, especially when human participants are used. Participants were provided with information regarding the purpose and methods of this study. This included providing information on informed consent and the limits of confidentiality, as well as disclosing any risks and benefits of participating in the study.

In addition, I reviewed and ensured adherence to the American Psychological Association's (2016) ethical code of conduct and the guidelines of Walden University regarding ethical issues in qualitative research (Sanjari, Bahramnezhad, Fomani, Sho-ghi, & Cheraghi, 2014) throughout the study. I ensured that I had approval from my Walden dissertation committee and Institutional Review Board (IRB) before implementing the research methods.

Summary

Chapter 3 described the qualitative research methods used to address this study's research questions. These included descriptions of the study population, participant recruitment, criteria for participation, participant consent, sample size, data collection instruments, data reliability, and validation of the results. I also presented a description of safeguards and the security of data. Chapter 4 illustrates the results of data collection.

Chapter 4: Results

Introduction

The purpose of this qualitative phenomenological study was to capture the lived experiences of parents whose children received in-home ABA treatment. For this study, the research question was the following: What are parents' lived experiences during the provision of in-home ABA treatment for their child with autism? Chapter 4 describes the procedures for data collection and data analysis. I outline the participant selection process and describe the participants interviewed for this study. This chapter consists of the results and analysis of participants' interview responses. To demonstrate reliability and validity, I also address issues of trustworthiness: credibility, transferability, dependability, and confirmability.

Setting

Interviews were conducted over the telephone in California. Parents who were interested in the study and responded to a digital flyer contacted me directly by e-mail. Parents who met the research participation criteria were provided with a consent form and several dates and time periods for the interviews. Participants were asked to either provide their phone number or call a phone number on the day and time of the interview. I sent each participant an email that included an appointment time for the interview, my phone number for the interview, and instructions to reply to confirm the information.

Each participant was scheduled for an interview by e-mail. All interviews were scheduled between 9:00 a.m. and 1:00 p.m. Pacific Standard Time. With these interviews being completed by telephone, I asked questions from my location while the participants responded by telephone from their residence. To record my questions and the

participants' responses, I placed an audio device approximately 24 inches away from the telephone to eliminate static or distortion when playing and analyzing the interview recording. Each interview was completed on the day and at the time confirmed.

Demographics

5 parents of children with autism participated in the study. Originally, 6 parents completed an interview, but one parent decided to leave the research. The participants who completed the research ranged between the ages of 29 and 58 years. Participants shared several similarities. Participant demographics are displayed in Table 1. For instance, each participant was the biological mother of a child who received in-home ABA treatment. All participants lived in California suburban neighborhoods.

Table 1

Demographics

	Participant				
	Parent 1	Parent 2	Parent 3	Parent 4	Parent 5
Gender	F	F	F	F	F
Level of education	Bachelor's	Bachelor's	Bachelor's	Bachelor's	Bachelor's
Region	Suburban	Suburban	Suburban	Suburban	Suburban
Years in-home ABA	6	3	9	2	3
Child's age starting in-home ABA	4	2	3	3	8

Note. F = Female.

Another similarity among the participants was that all reported their level of education as earning a bachelor's degree. All parents were the biological parent or legal guardian who made decisions regarding their child's in-home ABA treatment. All participants had attended workshops or presentations regarding parent training in ABA and autism. However, their current employment status varied, with one working full time, two working part time, and two not working.

Data Collection

Six parents agreed and consented to participate in an interview for this research. However, 5 participants completed the interview and confirmed the final transcription via member checking. Participants were recruited on social media platform groups related to autism and ABA services. A digital recruitment flyer was posted on these platforms with the permission of group moderators where available. The digital recruitment flyer remained open for 5 months. For confidentiality, the digital recruitment flyer instructed potential participants to contact my email or send a private direct message to me.

Participants were selected based on meeting the following criteria: (a) each was the biological parent or legal guardian, (b) their child had received a DSM-V (APA, 2015) diagnosis of ASD, (c) their child received at least 1 year of in-home ABA treatment, (d) their child was under the age of 18 years and was under the direct care of a biological parent, (e) in-home ABA treatment was implemented for a minimum of 2 times per week to a maximum of 7 times per week, and (f) the parent was the primary or co- decision maker regarding the child's in-home ABA treatment. Most participants who met the criteria were contacted by email to schedule an initial interview with their written consent.

Interviews were conducted by phone and recorded with a digital audio device. Participants were able to respond via telephone to interview questions from their location. The 12 interview questions were semi structured. I started each interview by reviewing information from the consent form, determining the participant's current comfort level, and providing information regarding the interview structure.

The average length of the interviews was approximately 60 minutes. All interview questions were provided in the same order. I asked each interview question, paused for a response, and allowed for the participant to respond. As the participant responded, I took notes regarding the responses as well as my impressions of the participant responses via bracketing. All participants provided detailed responses to each question. Participants required little to no clarification of questions. There were little to no variations to data collection, meaning that procedures and questions followed the same order and path for each interview. All participants understood the interview questions, which helped in addressing the primary interview questions.

During data collection, I implemented bracketing and reflexivity to assure that I set aside my biases to understand the research topic and journaling my experience as an interviewer. Additionally, I monitored how I interpreted my experiences against the data collected, ridding myself of any preconceived notions. This effort included writing notes about my views and interpretations of the data collected. For intuiting, I also held myself accountable for recognizing how parents view their experiences uniquely from one another and refraining from comparing my experiences or past readings to their responses. I used the pseudonym *Parent* with a number in place of the name of each participant being interviewed. For instance, the first participant's name was changed to *Parent 1*.

A digital audio device was used to record the participants' interview responses. In addition, I wrote down notes on participants' responses to the interview questions. Participants were debriefed on the scope of the interview questions. At the end of the

interview, participants were provided with information regarding the next steps of this study.

Data Analysis

Data analysis was completed by transcribing the audio interviews and transferring the text to a Microsoft Word 2016 document. Next, the transcriptions were imported into NVivo 12 software. Data analysis was conducted once all transcriptions had been imported into NVivo 12. Using Moustakas's (1994) methods as described by Creswell and Poth (2018), I captured descriptive textures of the participants' experience by listing significant statements as examples of the phenomenon. *Textual descriptions* refer to "what" participants experienced with a phenomenon, via participants' verbatim responses. "How" participants experienced the presence of the phenomenon is also called the *structural description* (Saldana, 2016). From here, the essence of the experience incorporates a textural and structural description of the participants' experience.

The process included reviewing data repeatedly, documenting data entries, identifying trends, and clarifying the transcriptions and audio recordings. Because themes had not yet been developed, I started descriptive coding by placing significant statements into meaning units. This was done by grouping "the significant statements into broader units of information" (Creswell & Poth, 2018, p. 201) to provide a basis for interpreting data and "create clusters and remove repetition" (Creswell & Poth, 2018, p. 201).

I also used two strategies in NVivo 12 to examine and minimize units into meaning units and finally into themes. This included a matrix coding query (determining macro, meso, and micro levels within the units) and code weaving (integrating key code words and phrases taken from the narration). I used matrix coding query to color code

primary meaning units. Next, I used code weaving to examine close interrelations to broader themes. I then examined meaning units to determine the significance of these meanings to the study's research question. 5 major themes emerged from this process. These 5 themes are illustrated in Table 2.

Table 2

Meaning Units and Themes

Theme	Meaning units
Perceptions of their child's ABA clinicians	Importance of clinician qualifications
	Trusting clinician's suggestions
Knowledge of in-home ABA services	Training in ABA
	Addressing various situations
Satisfaction of child's progress	Child's relationship with clinician
	Family relationships
Facing challenges	Importance of communication
	Setting rules during treatment
Commitment to child's in-home ABA treatment	Importance of participating or learning
	Control of personal schedule

Evidence of Trustworthiness

Credibility

Credibility was established through member checking. Member checking involves interviewees reviewing their responses to interview questions and approving them or omitting responses that they do not feel comfortable with (Creswell, 2013). Once the interview responses were transcribed into a text document, I sent participants their own transcriptions for review and approval. They were offered the opportunity to decline participation after reviewing their interview transcripts. All participants approved their interview responses.

In addition, I improved credibility through member checking by allowing the participants' individualized responses to the interview and ability to review their responses in textual form supported common themes, serving to verify data. Common themes were developed from the participants' descriptions associated to the lived experiences of parents whose children received in-home ABA treatment.

Transferability

Transferability was met by the study's methodology with sampling and this studies data collection method. Transferability was evident because participants provided rich, detailed responses to the interview questions, which were filled with essential accounts of their lived experiences with in-home ABA treatment for their child. By doing so, their rich descriptions provided readers with an opportunity to differentiate between the participants' experiences and the readers' own experience.

Dependability

Dependability is based on being consistent and repeatable (Creswell, 2013). Dependability was established though an auditing trail whereby I recorded notes and documented my experienced throughout this research such as recordkeeping of my procedures, my experience during the interview, and self-analysis of the interviews. Through coding-recoding procedures, I repeated this process by identifying important themes, categorizing possible themes, determining potential themes to keep or delete, and organizing themes into units. Throughout the data analysis, I documented changes made during the coding process. The process included three cycles of coding-recoding which is analyzed repeatedly. The repetition during data analysis strengthened this study's

dependability and will allow for future researchers to assess and determine the repeatability of my work.

Confirmability

Confirmability was established by an audit trail and by self-checking through a reflexive journal. First, I stored all audio recordings, digital files, field notes, and journal entries to maintain an audit trail. This process included describing and reviewing the data and my interpretations and conclusions. Second, I documented self-checking using a journal to review my thoughts, biases, interpretations of each interview as whole, and reflections on each interview. By doing so, I strengthened the criteria for confirmability.

Results

The research question for this study was the following: What are parents' lived experiences during the provision of in-home ABA treatment for their child with autism? This question was explored through interviews with parents regarding this experience. 5 themes emerged describing their experiences: (a) perceptions of their child's ABA clinicians, (b) knowledge of in-home ABA services, (c) satisfaction with child's progress, (d) facing challenges, and (e) commitment to child's in-home ABA treatment.

Each theme was operationally defined to determine and describe parent's experiences clearly. To highlight the parents' responses to these themes, a summary of their experiences are presented for each theme, followed by excerpts representing the parents. Each participant's response is presented verbatim for each theme.

Theme 1: Perceptions of Their Child's Applied Behavior Analysis Clinicians

The theme *perceptions of their child's ABA clinicians* involved the parents' views of the clinicians' style of teaching, the parent's flexibility with the clinicians'

suggestions, the parents' trust in the clinicians' suggestions, and the importance of the clinicians' qualifications. The parents' perceptions of their child's ABA clinicians described their views of the ABA clinicians' overall implementation of in-home ABA treatment. The parents considered the importance of training and experience as well as their child's response to the ABA clinicians' implementation. While each parent provided detailed and unique encounters, they expressed similar views on what in-home ABA treatment should be like for their child and the impact it could have. The following excerpts provide detailed examples of parents' perceptions of their child's ABA clinicians.

Importance of clinician qualifications.

Parent 1:

- "Ideally really the verbiage on how a therapist [ABA clinician] approaches each task is so important … sometimes they just, sometimes we get a therapist that doesn't see it that way."
- "It's important that the therapist [ABA clinician] know or know and understand how to work with him … teaching him to do something like tying shoes or coloring is important, but it has to fit with what we do at home too."

Parent 2:

- "I mean, there's no doubt that whatever they've [ABA clinicians] done all this time just in a tiny thing. I mean we have accomplished so much. And I think just even just a little timeframe and just even being educated on our approach towards."

Parent 3:

- “Have been very fortunate with the company [ABA company] as I've worked with. It's had good rapport with them … as long as he's with a trained individual, which is very different than what you get with the school district aid, he [their child] can thrive.”
- “a lot of people have a lot of experience working younger kids, but when you're getting into this older age range, like what are you bringing to the table?”

Parent 4:

- “There is a high turnover rate with Bis [ABA clinician] and staff in general for all the agencies [other ABA agencies] and, and we've been very fortunate to have really good people on our team and I can, I can tell from their behaviors that they're really focused on my son.”

Parent 5:

- “I want the therapist [ABA clinician] to be more natural. With the, you know, like natural. Like when I say natural like, you know, they are like very playful with the kids. Like you can see like the affections to the kids, unlike others they are just like, you know, you can feel that they're just working just for the sake of money.”

Trusting clinicians' suggestions.

Parent 1:

- "Playing back to the first visit I was talking about like she [ABA clinician], she gave my husband and I that glimpse of hope that like she can get there, like that ABA will work for her with the right therapist."
- "You know, we had such great teammates [ABA clinicians]. I mean they did all the parent training for me and has been predominantly been me."

Parent 2:

- "So, they're [ABA clinicians] a main representative and I kind of counted on them to help me to kind of just be that extra voice or maybe to point out something that I didn't notice or have questions that I wouldn't have thought of or kind of try to also be that you know that person to connect the dots. "

Parent 3:

- "How are you [ABA clinician] helping us prepare to transition out of it though, you know, we do not, our son does not model us forever. So, I need somebody who has a little more insight of what it is going to take to possibly be living on your own. "

Parent 4:

- "So, I've, I've also experienced a BI [ABA clinician] where a, we're focusing a lot on tablet time, which I was against. Even though the tablet was a big reinforcer, it was also a cause of huge meltdown."

- “I think just having I'm a very indecisive person, so just having that support and, and help from Bis [ABA clinician] is a huge blessing.”

Parent 5:

- “The supervisors and the case manager [ABA clinician] like I can tell that. And even the therapists [ABA clinician], they are so nice friendly.”
- “I can treat them [ABA clinician] like as a friend, as a part of a family member, and I can tell them like, I'm not, like I can tell them what's happening in school.”

Theme 2: Knowledge of In-Home Applied Behavior Analysis Services

Knowledge of in-home ABA services is defined as parents’ suggestions with in-home ABA treatment, perceptions of their child’s progress without ABA services, and addressing the process and implementation involved with having an in-home ABA treatment program. The parent’s knowledge of child’s in-home ABA services described their experience learning and understanding the process and involvement of in-home ABA treatment. An important factor to each parent was the parent training and the ability to understand the ABA clinician’s implementation. Details of their unique encounters provided a rich account of parent’s experience with learning about in-home ABA. The following exerts provide a detailed example of each parent’s knowledge of in-home ABA treatment.

Training in ABA.

Parent 1:

- “You go through in the beginning and then in the very beginning you go through, you know, your actual parent training, learning that the

assumptions of behavior and learning, you know, all the antecedents and everything like that."

- "And to me the whole point of ABA as a parent is you watch, you observe, you, you observe, you take notes, you learn techniques, you do your parent training and gain all these tools."

Parent 2:

- "My husband and I, without that parent training, we are clueless. You know, I mean, you could hear from one autistic parent moment from all of them and we all have some similar story, but not everything works for every child. And when you have a trained therapist coming to your home, they, if they are good, will quickly learn what's going to work for your child."

Parent 3:

- "To have somebody [ABA clinician] else come in and, teaching a task analysis, to teach you how to ignore a behavior. I'm like stealing your parental toolbox with tools that would actually be effective."
- "Like those are things he [Parent 3's child] could not do before we had ABA even washing his hands or being toilet trained. Like I just do not know that if we did not have ABA, that that would have been achievable."

Parent 4:

- "I honestly wouldn't know what to do or how, how things would be right now if I didn't have any [in-home ABA treatment] of that. Just having that community support and help. Just wonderful to have."

- “the biggest thing I've learned is just to be very vocal and, and what's being done in his [Parent 4’s child] sessions [in-home ABA treatment] … it is just being consistent with what we have learned. Using the skills that we've learned every day.”

Parent 5:

- “They [ABA clinicians] check first with our weakness and strengths are like, and before they decided what to do and focus on what our best things are before we started the ABA therapy at home.”
- “I think ABA is like a, it's a good program for you to know these things.”

Addressing various situations.

Parent 1:

- “But I know without the ABA, my daughter wouldn't have gotten any kind of guidance on how to deal or how to replace behaviors.”
- “We [ABA clinician and Parent 1] also have, I created body checks is what we call it. And that is for stop and think if, for instance, how is her head doing? Does she have a headache? Does she have her glasses on? Is she thirsty? Uh, is she hungry? Does she have to use the restroom? What does she have on her toes? That is her [Parent 1’s child] favorite one.”

Parent 2:

- “I definitely thought it was interesting and wanted to learn more about it and it just kind of the things that they were doing pretty much started making more sense and kind of helped me understand my own child on like what his wants and needs.”

- “Learning ABA, kind of look at the whole picture of what happened before that. How did he [Parent 2’s child] react? Why did he react that way? Or, you know, it was not an avoidance, was it, you know, seeking attention or one of those.”

Parent 3:

- “I truly believe without ABA; we would be home bound…I guess that I do not think he [Parent 3’s child] would be in general education. I don't think that we would be accessing the public freely.”

Parent 4:

- “I understand that part of the sessions [in-home ABA treatment] and trying to kind of provoke him [Parent 4’s child] in a sense until he kind of gets it and uses his words immediately versus whining immediately.”

Parent 5:

- “Like they [ABA clinicians] are telling us and said, oh we can help my son [Parent 5’s child] improve by also changing their programs [in-home ABA treatment] that we are doing here at home. So, it is, they, they're also like they are professionals.”
- “I think ABA is like a, it's a good program for you to know these things.”

Theme 3: Satisfaction With Child’s Progress

Satisfaction of Child’s Progress is based on their observation of their child’s relationship with the clinician and positive interactions the child receives during in-home ABA sessions. This also included the effects it had on improving the family’s relationship and interaction with each other. Parent’s perception of their child’s progress

is an important factor for their child's in-home ABA treatment. Their satisfaction of their child's progress was paired with reports of their family household relationship with one another. This presented a unique factor of how the parent's views of hope and progress was worth the time and investment of their child's in-home ABA services. Their encounters are documented in this theme. Their satisfaction of their child's progress is presented in the following exert examples.

Child's relationship with clinician.

Parent 1:

- "She [ABA clinician] empowered my daughter [Parent 1's child] to move forward. And it was in a time where we really were not sure if she was going to and that hope it still stays with us."

Parent 2:

- "I think that it [in-home ABA treatment] also helped him [Parent 2's child] to understand what we need to do to help him. Or that we need him to request and answer us. "

Parent 3:

- "ABA has meant that my son is fully included in school despite his multiple disabilities, not just autism."

Parent 4:

- "I know that as soon as he's [Parent 4's child] done fake crying, he will be up and out and doing his own thing in his room or playing again. I think that part has been the biggest change from the start of ABA [in-home ABA treatment]."

Parent 5:

- “He [Parent 5’s child] tried to socialize, but still, there's still like some things for him to work on but I feel like I can see the improvement.”
- “My son has less meltdowns. He can help me with something. Like if I have, like if I need something, I can ask him, can you get this for me, like he's helping me right now.”

Family relationships.

Parent 1:

- “Being able to learn categories of emotion and being able to recognize that like just, it's not like a super happy, happy moment a, but it's like our tremendous moment for our family and for our daughter to recognize it.”
- “Learning to deal with that rejection that some of the peers give her. That was huge because then she started looking for her friends. She started looking for people to play and approaching them herself without a prompt. That was big.”

Parent 2:

- “But I mean that's one thing definitely that he's [Parent 2’s child] gotten better at, is that he does his requesting instead of guessing it or just grabbing our hand and taking us to wherever he wants to go or telling us to sit and giving eye contact is better.”

Parent 3:

- “We can all sit and have dinner together in a conversation and can, take him [Parent 3’s child] into public with us all the time to sporting events for siblings, for grocery shopping or running into the store for clothing.”

Parent 4:

- “And usually if he whines, I just kind of reiterate it and make sure he understands, and he cooperates. And if I get an okay mommy, then we're good to go.”
- “If you are kind of stressed out already, kind of tag team with your partner [Father of Parent 4’s child] and say, Hey, you know, you got this, and you take a break. So that, that is the commitment with, with myself and my son's dad.”

Parent 5:

- “Because of some little coping skills that he is learning from the ABA therapy [in-home ABA treatment], he learns how to ignore that boy. So even the boys are bothering him, he would just walk away, or he would just tell the teacher, but before he does not know how to do that, he would just cry, scream, or throw his things.”

Theme 4: Facing Challenges

Facing Challenges is defined as challenges that occur during in-home ABA sessions, how concerns are addressed, and communication with their ABA clinicians. Parents describe the challenges they face with having in-home ABA treatment for their child. Their experiences range from scheduling concerns to preparing for in-home ABA treatment. The limits and willingness to confront these challenges and seek solutions

were evident in their responses. Some of these factors may correlate to their perceptions of other themes. However, their rich account of facing challenges and deciding how to handle them are documented clearly here. The following exert examples are presented in this theme.

Importance of communication.

Parent 1:

- "As a parent, you know, having that extra help, that extra guidance of someone [ABA clinician] implementing very targeted skills that I am not doing and that I just cannot stop and do it because life, no lie. I was losing it. You learn all that, which is great, but then you get to a point where they [ABA clinicians] are such a support system how you are as parents."

Parent 2:

- "This last supervisor [ABA clinician manager] had really liked her. Super nice, but I don't know what happened, but we've [in-home ABA treatment team and Parent 2] seem to always have scheduling issues and mix ups and confusion where they're [ABA clinician] at the house and I wasn't expecting them, or I didn't know that it [in-home ABA treatment] was canceled or rescheduled or different time or whatever the case may be."

Parent 3:

- "When I had to say this person [ABA clinician] is no longer welcome to come back to our home I was told by the clinical director [ABA clinician manager] that my standards were just too high. And then I said, well, I beg

to differ, and my standards are high for all my children. So, if you cannot meet my high standards, then I guess we should go somewhere else."

Parent 4:

- "I mean I'm open, I'm open to, to talk to our Bis [ABA clinicians], but then it comes to a point where, okay, what is the focus here? It is supposed to be my son that needs to work. If they care for his wellbeing, make sure that he's focused on those goals."

Parent 5:

- "The challenges sometimes you know, sometimes when my son is so tired from school, sometimes he doesn't want, or doesn't want the therapy [in-home ABA treatment], but like he just wants to stay in his room and will tell us, I'm so tired, I'm so tired."

Setting rules during treatment.

Parent 1:

- "And we made a lot of progress in that timeframe and then when she [ABA clinician] left that was just a little more challenging then and she [Parent 1's child] had big regressions after that…I have really good, supervisors and BCBAs that I could talk to about it and they, you know, they understood where we [Parent 1's family] were coming from and they, they fixed it."

Parent 2:

- "But to be honest at this point, I think we should have left it [in-home ABA treatment schedule] alone because he worked really well with all

those girls [ABA clinicians] and now we're down to three days with the one girl that is his [Parent 2's child] least favorite."

Parent 3:

- "I mean, they [ABA clinicians] sit at our dinner table every night with us [Parent 3's family], but they do not get to eat. That is like, I think you just end up accepting it. But in the beginning, that is very weird and odd, and you are not allowed to give them presents or get some gratitude. That is a, a part of that that I don't like."

Parent 4:

- "I was really upset about the first ABA agency because as a worried mom, I wanted the best for my son, so I would have preferred rather than losing out on sessions [in-home ABA treatment] for them [ABA clinicians] to be available to reschedule sessions for us."

Parent 5:

- "You see we have ABA therapy at home, and I need to drop her [Parent 5's other child] to her work. So, it is like I must tell the therapist [ABA clinician] that, Oh I need to drop my daughter [Parent 5's other child] or something like that. So, I need to bring my son with me to drop my daughter to work and the therapist stays outside because she [ABA clinician] told me she cannot stay inside the house [referring to ABA clinician's rules] if I, like they [ABA company] told me that I could also cancel the therapy."

Theme 5: Commitment to Child's Applied Behavior Analysis Program

Commitment to Child's ABA program is defined as parent's scheduling and preparation of child's in-home ABA treatment, importance of participating and learning from the ABA clinicians. Parents shared their perceptions and suggestions for committing to their child's in-home ABA treatment. This includes their participation and tolerance to continuing in-home ABA treatment. Their exclusive responses are presented in the following quotes.

Importance of participating or learning.

Parent 1:

- "I am a very involved parent in ABA. I will help make the schedule; I will participate in that activity…I will be in the kitchen doing something or the dining table working on the computer or whatever. But the main thing I am doing is I am observing [in-home ABA treatment]."

Parent 2:

- "We're highly committed. I mean, I am surprised, you know, people [other Parents with in-home ABA treatment] do not utilize all their hours [in-home ABA treatment hours]. I mean, I try to get everything I can."

Parent 3:

- "I think we [Parent 3's child] have 18 hours a week [in-home ABA treatment hours] right now at home and sometimes I do feel like we [Parent 3's family] are trapped at home. I do not know any better way, like when they are [Parent 3's children] at school, I'm usually out running errands constantly."

Parent 4:

- “My son has a pretty good memory and he's, he's aware of what therapy [in-home ABA treatment] is going to happen during the day or later after school. I just give him a reminder; we're going to see so-and-so [ABA clinician] today.”

Parent 5:

- “I have to explain to him [Parent 5’s child] that we paid to do the therapy [in-home ABA treatment] and asking me why, why do I have to have therapy and I told him that because we need to improve your behavior and he will ask me, but up to when? I told him unless you do not have any meltdowns or any bad behavior, I'm going to stop the therapy.”

Control of personal schedule.

Parent 1:

- “It's a completely different ball game. You know, we have our rules, we have these things, but we deal with a lot more. These, these therapists [ABA clinicians], and supervisors [ABA clinician managers] come into your home, into your personal space and you get very in depth with them about your household and your life and what's going on with your child.”

Parent 2:

- “He [Parent 2’s child] really should not have to be in a diaper at all. And so, we are, we are highly committed as parents, but I also get it too. I get lazy.”

- “We [Parent 2’s family] think it [in-home ABA treatment] is working. But as far as our commitment to do the thing that they [ABA clinicians] are doing or is doing full time, a hundred percent probably not, or probably more of or at 80%.”

Parent 3:

- “I have, you know, if it's a day that is a social skills day [during in-home ABA treatment], I have to find a peer to come over to be available to make that a more meaningful experience during therapy.”
- “You're [Parent 3] dependent on other people [Parent 3’s relatives] to get them [Parent 3’s children] there because we have an ABA session [in-home ABA treatment] to go to.”

Parent 4:

- “It definitely takes a lot. Because even though we are having three-hour sessions [in-home ABA treatment] with our team [ABA clinicians], I, you know, as a parent, we must continue those things every day without, without their [ABA clinician] supervision. So that is, that's pretty much the commitment right there.”

Parent 5:

- “Even if I must go somewhere, I have to cancel my appointment [Parent 5’s personal appointment]. And usually, I think it is more of a mindset. I am always thinking that it is [in-home ABA treatment] for my son. Like it's for my son improvement and part for me that like in the future he can be independent.”

Summary

In chapter 4, I provided results of the parents' lived experiences of their child's in-home ABA treatment. This study's data analysis emerged with five themes: (a) Perceptions of their child's ABA clinicians, (b) Knowledge of in-home ABA services, (c) Satisfaction of Child's Progress, (d) Facing Challenges, and (e) Commitment to Child's in-home ABA treatment. The results revealed that parents' deal with a meaningful experience while organizing their day around their child's in-home ABA treatment.

The parents' in this study overcame their challenges by learning ABA treatment from their child's ABA clinician and participating during in-home ABA treatment. This was often referred to as parent training. While positive outcomes were evident in their experiences, parents addressed obstacles and conflicts when it was related to their child's progress.

In chapter 5 of this study, I provide interpretations of these results as it relates to the literature review in Chapter 2 and the results presented in this chapter. Furthermore, I will provide a summary of the limitations, recommendations for future studies, and social change implications.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this qualitative phenomenological study was to explore the lived experiences of parents whose children with autism received in-home ABA treatment. This study focused on parents' descriptions of their experiences and views of in-home ABA treatment for their children. I identified a gap in the literature focusing mainly on the effects of ABA treatment on children with autism (Romanczyk et al., 2014; Smith & Eikeseth, 2011;) and quantitative studies regarding parents' views of their children's progress (Robertson, 2016) and participation in ABA parent training (Kuo et al., 2011; Tellegen & Sanders, 2014). Although it is known that ABA treatment is effective with children with autism, there has been little to no qualitative phenomenological research investigating the lived experiences of parents who care for a child receiving in-home ABA treatment. Therefore, my goal with this study was to increase understanding of how parents report their experiences with their children's in-home ABA treatment.

Parents who participated in this study resided in California. I recruited 5 parents to participate in a semi structured 60-minute interview. All interviews were scheduled by email and conducted by phone; therefore, participants were able to participate in an interview at their residence or location. Data analysis was completed using NVivo 12 software. I implemented Moustakas's (1994) methods using descriptive textures. My key findings resulted in five major themes: (a) perceptions of their child's ABA clinicians, (b) knowledge of in-home ABA services, (c) satisfaction with child's progress, (d) facing challenges, and (e) commitment to child's in-home ABA treatment. The research question for this study was the following: What are parents' lived experiences during the

provision of in-home ABA treatment for their child with autism? In Chapter 5, I examine the findings of this study, offer interpretations of the findings, address limitations of the study, provide recommendations for future studies, and present the study's implications for positive social change.

Interpretation of the Findings

An interpretation of the findings confirms and extends the knowledge I reviewed compared to the literature review in Chapter 2. Participants' experiences in this study were consistent with the literature in relation to their perceptions of their child's ABA program, satisfaction with their child's progress, and knowledge of in-home ABA services. This study extended knowledge gained from the literature reviewed in Chapter 2 in relation to participants' descriptions of their experiences facing challenges and their commitment to their child's in-home ABA treatment. In addition, this study's findings extend to the importance of parent experiences as a catalyst to their lived experiences with in-home ABA treatment for their child with autism.

Theme 1: Perceptions of Their Child's Applied Behavior Analysis Clinicians

The parents' perceptions of their child's ABA clinicians described their views of the ABA clinicians' overall implementation of in-home ABA treatment. This included the importance of clinician qualifications and trusting the clinicians' suggestions. Participants discussed the impact an ABA clinician has on building their child's rapport with their ABA clinician and earning the parent's trust working with their child.

Strunk et al. (2014) indicated the importance of parents' experiences with health care management for their children with autism. Strunk et al.'s results indicated that parents were frustrated with physicians' knowledge of autism or had minimal trust in the

health care community. While their study focused on parents' experience with managing their children's health care, they highlighted the importance of a parent's perception toward behavioral care (in-home ABA treatment).

Angell et al. (2016) found that parents felt that trust and collaboration were important to address their child's in-home ABA treatment approach. Furthermore, these factors appeared to confirm a parent's flexibility and trust in ABA treatment suggestions by the ABA clinician. The participants considered the importance of training and experience as a factor in their child's response to the ABA clinician's implementation.

Theme 2: Knowledge of In-Home Applied Behavior Analysis Services

Most participants were knowledgeable about in-home ABA services. The parent's experiences suggested that ABA treatment requires training, learning, and understanding the process to address situations regarding their child's needs. Gale, Eikeseth, and Rudrud's (2011) study on using parents and ABA tutors as therapists was consistent with this study's results. Gale et al. trained parents and ABA tutors to work with children struggling with eating difficulties using in-home ABA treatment. Their findings indicated that parent training in ABA methods specific to feeding difficulties was effective and could assist in maintaining implementation during and after in-home ABA treatment including addressing various situations regarding a parent's concerns with ABA treatment.

Parents' knowledge of ABA is also important to addressing various situations, such as stress related to parenting skills and difficult implementations (Rivard et al., 2014). Participants in this study described a variety of parenting solutions based on their knowledge of in-home ABA treatment, including a parent's implementation of learned

ABA treatment implementations without the guidance or assistance of the child's in-home ABA therapists or clinician. These results were consistent with previous research regarding parents' knowledge of in-home ABA services by describing learning to address various situations with a child with autism (Barbera, 2009; Gale et al., 2011; Rivard et al., 2014).

Theme 3: Satisfaction With Child's Progress

Most participants in this study identified the primary reason for using in-home ABA treatment as their satisfaction with their child's progress. Blacklock et al.'s (2012) findings on parents' perceptions of their children's progress helped determine the continuation of intensive behavioral interventions. The results of this study confirm parents' perceptions of their children's progress and their child's growth with family relationships.

Participants in this study also described their experiences based on their child's relationship with the clinician and the quality of interactions that their child received during in-home ABA sessions. Angell et al. (2016) indicated the importance of a child's relationship with their clinician regarding the effects it has on family's relationship with each other. Most participants reported that their child's progress assisted with positive experiences in the family members' relationships with one another. Their child's progress appeared to result in less parental stress and improvement in parenting skills and family interactions.

Theme 4: Facing Challenges

While participants in this study described their support for in-home ABA treatment, most indicated the importance of communication and negotiating in-home

ABA treatment guidelines (i.e., setting rules) when facing various challenges. The literature review in Chapter 2 confirmed parents' experiences with facing challenges leading to family stress and doubts for continuing in-home ABA treatment for their child with autism (Angell et al., 2016). Additionally, Chapter 2 included responding to the parent participants' rules for in-home ABA treatment with their child's ABA company. In other words, parents felt comfortable when the ABA therapists and BCBA's were willing to listen and follow through with parent requests or instructions as well as provide problems solving suggestions for their child.

Participants in this study indicated that efforts to address challenges that occurred during their autistic children's in-home ABA treatment were based on how the ABA treatment clinicians responded to their concerns. Within the literature, evidence suggests that consistent communication with ABA therapists determines a parent's trust and ease with continued in-home ABA treatment (Perry et al., 2006). The results of this study extend to the importance of ABA therapists communicating with parents to address the challenges that they face before, during, and after in-home ABA treatment for their child. Although parents in this study described their occasional frustrations with communication or poor follow through with their child's in-home ABA therapists, no participant felt that it was necessary to terminate or discontinue in-home ABA treatment. In fact, all participants in this study fully supported their child's in-home ABA treatment and were confident with the overall experience of the ABA company's communication and compliance with parent rules during in-home ABA treatment.

Theme 5: Commitment to Child's Applied Behavior Analysis Program

Most participants reported that the commitment to their child's in-home ABA treatment provided a chance to participate and learn about using ABA with their child. More importantly, participants expressed that their commitment meant organizing and sacrificing control over their personal schedule. The results of this study confirm and extend knowledge on parents' commitment to their child's ABA program by reporting their experiences with ABA parent training and committing to their child's in-home ABA treatment schedule over their personal schedule.

Barbera (2009) found that "autism mothers" who became behavior analysts understood the importance of learning a variety of ABA treatments to improve their parenting skills. In turn, these skills may have influenced parents to work in the field of ABA. Barbera indicated that "autism mothers" who became behavior analysts were able to relate to the experiences of other parents whose autistic children received in-home ABA treatment, such as navigating conflicts with personal schedules and shuffling family activities such as afterschool events, doctor's appointments, and so forth. While parent participants in this study expressed their concerns with commitment, they expressed praise and recommendations for committing to their child's in-home ABA treatment and described the value it had for their child's progress and their family's well-being.

Conceptual Framework

The conceptual framework for this study was guided by Biddle's (1996) role theory. According to Biddle, role theory is based on a person's behaviors and actions, as characterized by their defined social role, aspects, and responsibilities. Role theory was relevant to this study because it described the parent participants' experience in the parent

role in their child's in-home ABA treatment. In other words, based on role theory, I assumed in this study that parents' roles may change when their children's in-home ABA therapists provide treatment.

The aim of this study was to capture the lived experience of parents whose children with autism received in-home ABA treatment. Role theory provided attention to the circumstances that parents experience in adapting to role changes as parents and as parent learners (Maccoby, 1992). Furthermore, the participants in this study reported their experiences with participating in their children's in-home ABA treatment by means of in vivo participation and parent skills training. The aspects of role theory were evident in the description of the participants' experience of raising a child with autism who was receiving in-home ABA treatment. As they gain more experience and knowledge of in-home ABA treatment, parent participants may share their views and experiences with other parents who are undecided about using in-home ABA treatment and may describe the impact that ABA treatment has had on their role as a parent. In turn, a parent raising a child with autism who receives in-home ABA treatment may influence other parents who are skeptical about the advantages of in-home ABA treatment compared to school-based or clinical ABA treatment.

Limitations of the Study

While this study provided a rich understanding of the parents' lived experiences, it had several limitations. First, the sample size was small at 5 participants. Second, all participants lived in California, where their children received in-home ABA treatment. Third, all participants were mothers of a child with autism. No father participated in the research.

The first limitation of this study was the sample size. 5 parents whose children with autism received in-home ABA treatment provided a rich account of their lived experiences, including their feelings, past accounts, decision making, and the impact of ABA treatment on their children's progress. While saturation was met with this study, additional participants might have provided extensive details and shift perspectives of more participants' responses (Creswell & Poth, 2018). Creswell and Poth (2018) noted that "Dukes (1984) recommends studying 3 to 10 participants" (p. 159), which was appropriate for the scope of this research. However, it is recommended that future researchers increase the sample size of parent participants to collect broad data about parents' lived experiences with in-home ABA treatment for their children with autism.

The second limitation of this study related to the participants' residence in California. Parents in California who are seeking ABA treatment for their children have a variety of resources to select from, ranging from the Department of Developmental Services to public schools to nonpublic ABA agencies (State of California, 2020). The plethora of ABA services in California are not saturated, but the parent support and resources that are available to secure in-home ABA treatment services are reasonable compared to other states (Agency for Healthcare Research and Quality, 2011; Romanczyk et al., 2014). Sampling participants from various regions (in the United States or internationally) might benefit the understanding of the similarities and differences in parents' lived experiences with in-home ABA treatment for their children with autism.

The third limitation of this study was that all data were based on mothers' lived experiences. Although the recruitment flyer did not specify a gender for the parents whose perspectives were sought, no fathers responded to or were interested in

participating in this study. Although it is common for a mother who raises a child with autism to be a primary caretaker and decision maker regarding the child's in-home ABA treatment, a father's perspective, and account are equally important in addressing the gap in this research (Rivard at al., 2014). Furthermore, fathers' perspectives might extend knowledge of parents' lived experiences of in-home ABA treatment concerning commitment to in-home ABA treatment, communication, and rapport with the child's ABA clinicians, understanding of in-home ABA services, the impact of ABA treatment on the child's progress, and managing challenges associated with in-home ABA treatment.

Recommendations

In this study, I explored the phenomenon of the lived experiences of parents who care for a child with autism receiving in-home ABA treatment. Because participants in this study were all located in California, it is recommended that research on this topic be extended across the United States and/or internationally. Future studies should include both parents' perspectives and interviews with fathers. Other recommendations include increasing the sample size of the study to extend understanding of parents' lived experience of caring for a child with autism who receives in-home ABA treatment. Overall, the parents' perspectives and lived experiences in this study may contribute to the understanding of how parents are influenced and impacted by their child's in-home ABA treatment.

Implications

Individual, Family, and Organizational Implications

The implications for positive social change in this study include our understanding about the parent participants will and dedication to provide their child with in-home ABA treatment. Since the autism community rely on the behavioral healthcare resources, this study extends our understanding about the impact in-home ABA treatment may have on family outcomes and parenting success given the lived experience of the participants in this study. This study identifies the importance of evidence-based treatment such as in-home ABA treatment (Granpeesheh et al., 2009; Healy et al., 2008). Encourage families with user-friendly information about the advantages and disadvantages without limiting the foundations and principles associated to in-home ABA treatment.

In addition, the participants in this study shared accounts of their personal growth and motivation to continue using in-home ABA treatment for their child with autism. This included the opportunities each parent participant reported with invested time, effort, and sacrifice to increase their child's progress. At the family and individual level, this study promoted positive social change for the community so other families have an opportunity to support their child with an early diagnosis of autism. Furthermore, this study helps address the beginning essentials for preparing families for an in-home ABA treatment, which can enable and influence ABA agencies to be sensitive to family concerns, encourage collaboration in the treatment model, and extend the effectiveness of ABA treatment to the family.

Empirical Implications

The empirical implications of this study focused on the importance and practical implementations that are necessary to know, use, evaluate, and advocate for their child in an in-home ABA program. The findings of this study added to the limited phenomenological studies and understanding regarding in-home ABA treatment from a parent's lived experience. Since the role of the parent during in-home ABA treatment services is a factor to this study, it is important that their perspectives contribute to our current understanding of the experiences of parents raising a child with autism and their child's progress when receiving in-home ABA treatment.

An increase understanding of the lived experiences of parents with in-home ABA treatment for their child is significant to other parents who share their experiences or those affected as well (Barbera, 2009; Dillenburger et al., 2004). The nature of these empirical implications suggest that this study offers an environmental and situational outlook, direct concentration, and understanding about the beginning and continuing stages of the lived experience with in-home ABA treatment for their child with autism from a parents' perspective.

Recommendations for Practice

The purpose of this study was to increase a better understanding of parent's lived experiences with in-home ABA treatment for their child with autism. This study includes a recommendation for best practices. Additionally, this study recommends that parent readers are informed about the parent participants experience enough to understand and extend the knowledge the in-home ABA treatment for their child with autism. For clinical ABA practitioners, I recommend and encourage current and future in-home ABA

agencies to utilize the results of this study to modify and/or apply missing applications discovered by the results of parent participant responses.

Conclusion

The purpose of this qualitative, phenomenological study was to increase our understanding the lived experiences of parents whose child with autism receives in-home ABA treatment. Currently, autism spectrum disorder (ASD) is at least 1 in 54 children diagnosed (CDC, 2016; DeVibiss, & Lee, 2014). The current quantitative literature on in-home ABA treatment is highly supportive (Healy, Connor, & Kenny, 2008; McEachin et al., 1993) indicating that its value and importance has public resource implications. However, an investigation for qualitative, phenomenological studies were limited and unrepresented (i.e., a gap). Participants in this study shared their lived experiences with in-home ABA treatment for their child with autism. In turn, the results of this study confirmed the importance of capturing the lived experiences of parents and encouraging future phenomenological studies in this area. The determination and motivation by parents raising a child with autism, providing support for in-home ABA treatment, and learning from ABA clinicians is evident of ABA treatment as a positive social antecedent.

The following study was an attempt to discover the current state of in-home ABA treatment for a child with autism from the parent's perspective. This included the impact it had on their quality of life, willingness to continue in-home ABA treatment, facing challenges throughout the experience, and the influence on their parenting skills via ABA training from their child's clinician. The review of the literature revealed little to no phenomenological studies concentrated on this important subject. Instead, this study

extends the knowledge that a parent's perception confirms their support and dedication to providing their child with an in-home ABA treatment because it is a an evidenced-based practice (Granpeesheh et al., 2009; Romanczyk et al., 2014), provides a specialized training towards parent training (Davis & Carter, 2008; Grindle et al., 2008; Perry et al., 2006), and continues to receive positive public support (Blacklock et al., 2012; CDC, 2016; Silva & Schalock, 2011).

The knowledge gained from this study may contribute to helping other parents raising a child with autism to understand the effectiveness of using in-home ABA treatment, the knowledge gained through parent training specifically with their child, facing challenges during their child's service period, and the commitment and dedication to host in-home ABA treatment. This study may be an integral part of developing best practices for parents who are seeking assistance with providing support for their child and being trained to take over when their child outgrows or graduates from an in-home ABA treatment. In addition, the essence of this study provides current and future ABA clinicians to be a positive social change agent and evolve their professional practice to address deeper meaning of the parent's experience before, during, and after in-home ABA treatment, understanding the motivations and demands parents face, and invest and encourage parents to be a primary factor in their child's progress.

References

Agency for Healthcare Research and Quality. (2011). *Therapies for children with autism spectrum disorders*. Washington, DC: Author.

Ambert, A. M. (2001). An international perspective of parenting: Social change and social constructs. *Journal of Marriage and the Family, 56*, 529-543.

American Academy of Child and Adolescent Psychiatry. (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*(2), 237-257.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

American Psychological Association. (2016). Ethical principles of psychologists and code of conduct. Retrieved from http://www.apa.org/ethics/code/index.aspx

Angell, A. M., Frank, G., & Solomon, O. (2016). Latino families' experiences with autism services: Disparities, capabilities, and occupational justice. *Occupation, Participation, and Health, 36*(4), 195-203.

Asmus, J., Ringdahl, J., Sellers, J., Call, N., Andelman, M., & Wacker, D. (2004). Use of short-term inpatient model to evaluate aberrant behavior: Outcome data summaries from 1996-2001. *Journal of Applied Behavior Analysis, 37*, 283-304.

Baer, D. M., Wolf, M. M., & Risley, T. R. (1987). Some still-current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 20*(4), 313-327.

Barbera, M. L. (2007). *The verbal behavior approach*. Philadelphia, PA: Jessica Kingsley.

Barbera, M. L. (2009). The experience of "autism mothers" who become behavior analysts: A qualitative study. *Journal of Speech Language Pathology and Applied Behavior Analysis, 4,* 56-72.

Barlow, K., Tiger, J., Slocum, S., & Miller, S. (2013). Comparing acquisition of exchange-based and signed mands with children with autism. *The Analysis of Verbal Behavior, 29,* 59-69.

Battaglia, D., & McDonald, M. (2015, Winter). Effects of the Picture Exchange Communication System (PECS) on maladaptive behavior in children with autism spectrum disorders (ASD): A review of the literature. *Journal of the American Academy of Special Education Professionals,* 8-20.

Beavers, G., Iwata, B., & Lerman, D. (2013). Thirty years of research on the functional analysis of problem behavior. *Journal of Applied Behavior Analysis, 46*, 1-21.

Behavior Analyst Certification Board. (2012). Board Certified Behavior Analyst (BCBA). Retrieved from http://www.bacb.com

Bennett, M., & Goodall, E. (2016). A meta-analysis of DSM-5 autism diagnoses in relation to DSM-IV and DSM-IV-TR. *Review Journal of Autism Developmental Disorder, 3,* 119-124.

Biddle, B. J. (1986). Recent developments in role theory. *Annual Reviews Sociology, 12,* 67-92.

Blacklock, K., Weiss, O., Perry, A., & Freeman, N. (2012). Parents' perception of progress versus children's actual progress in intensive behavioral intervention. *Journal on Developmental Disabilities, 18*(3), 60-62.

Burden, J., & Roodt, G. (2007). Grounded theory and its application in a recent study on organizational redesign: Some reflections and guidelines. *Journal of Human Resource Management, 5*(3), 11-18.

Callahan, K., Methta, S., Magee, S., & Wie, M. (2010). ABA versus TEACCH: The case for defining and validating comprehensive treatment models in autism. *Journal of Autism Developmental Disorders, 40*, 74-88.

Cautilli, J., Rosenwasser, B., & Hantula, D. (2003). Behavioral science as the art of the 21st century philosophical similarities between B. F. Skinner's radical behaviorism and postmodern science. *The Behavior Analyst Today, 4*(2), 225-264.

Centers for Disease Control and Prevention. (2016). Autism spectrum disorder (ASD). Retrieved from https://www.cdc.gov/ncbddd/autism/facts.html

Connolly, M., & Gersch, I. (2016). Experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school. *Educational Psychology in Practice, 32*(3), 245-261.

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

Creswell, J. Q., & Poth, C. N. (2017). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Thousand Oaks, CA: Sage.

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism Developmental Disorders, 38*, 1278-1291.

Dawson, G., & Burner, K. (2011). Behavioral interventions in children and adolescents with autism spectrum disorder: A review of recent findings. *Current Opinions in Pediatrics, 23,* 616-620.

DeVibiss, E. A., & Lee, B. K. (2014). Brief report: trends in U.S. national autism awareness from 2004 to 2014: The impact of national autism awareness month. *Journal of Autism Developmental Disorder, 44,* 3271-3273.

Dillenburger, K., Keenan, M., Gallagher, S., & McElhinney, M. (2004). Parent education and home-based behavior analytic intervention: An examination of parents' perceptions of outcome. *Journal of Intellectual & Developmental Disability, (29)*2, 119-130.

Fogt, B., Miller, D.N., & Zirkel, P.A. (2003). Defining Autism: Professional best practice and published case law. *Journal of School Psychology, 41*(3), 201-216.

Eldevik, S., Hastings, R., Hughes, J., Jahr, E., Eikeseth, S., & Cross, S. (2010). Using participant data to extend the evidence for intensive behavioral intervention for children with autism. *American Journal on Intellectual and Developmental Disabilities, 115,* 381-405.

Gale, C. M., Eikseth, S., & Rudrud, E. (2011). Functional assessment and behavioral intervention for eating difficulty children with autism: A study conducted in the natural environment using parents and ABA tutors as therapists. *Journal of Autism Developmental Disorders, 41*, 1383-1396.

Giangreco, M., & Broer, S. (2005). Questionable utilization of paraprofessionals in inclusive schools: Are we addressing symptoms or causes. *Focus on Autism and Other Developmental Disabilities,* 20(1), 10-26.

Golnik, A., Ryaboy, N., Scal, P., Wey, A., & Gaillard, P. (2012). Shared decision making improving care for children with autism. *Intellectual and Developmental Disabilities, 50*(4), 322-331.

Granpeesheh, D., Tarbox, J., Dixon, D. R., Carr, E., & Herbert, M. (2009). Retrospective analysis of clinical records in 38 cases of recovery from autism. *Annals of Clinical Psychiatry, (21)*4, 195-204.

Grindle, C.F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism Developmental Disorders, 39,* 42-56.

Gulati, S., & Chakrabarty, B. (2013). Diagnostic and treatment options in autistic spectrum disorders – An overview. *Journal of Special Education and Rehabilitation, 15*(1-2), 43-58.

Heyvaert, M., Maes, B., Van Den Noortgate, W., Kuppens, S., & Onghena, P. (2012). A multilevel meta- analysis of single-case and small-n research on interventions for reducing challenging behavior in persons with intellectual disabilities. *Research in Developmental Disabilities, 33,* 766-780.

Healy, O., Connor, G., & Kenny, N. (2008). Three years of intensive applied behavior analysis: A case study. *Journal of Early Intensive Behavioral Interventions, 15* (1), 4-21.

Kazdin, A. (2010). *Single-case research designs: Methods for clinical and applied settings* (2nd edition). New York: Oxford University Press.

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.

Kirkham, P. (2017). The line between intervention and abuse – Autism and applied behavior analysis. *History of the Human Sciences, 30*(2), 107-126.

Kuo, D. Z., Bird, T. M., & Tilford, J. M. (2011). Associations of family-centered care with health care outcomes for children with special health care needs. *Maternal Child Health Journal, 15*, 794-805.

Kulik, L., Shilo-Levin, S., & Liberman, G. (2015). Multiple roles, role satisfaction, and sense of meaning in life: An extended examination for role enrichment theory. *Journal of Career Assessment, 23*(1), 137-151.

Levitt, H. M., Moutulsky, S. L., Wertz, F. J., Morrow, S. L., & Ponterotto, J. G. (2017). Recommendations for designing and reviewing qualitative research in psychology: Promoting methodological integrity. *Qualitative Psychology, 4*(1), 2-22.

Levy, M., Merhar, I., & Pinto, M. (2003): Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 24*, 18-423.

Lyons, A. M., Leon, S.C., Phelps, C. E., & Dunleavy, A. M. (2009). The impact of child symptom severity on stress among parents of children with ASD: The moderating role of coping styles. *Journal of Child and Family Studies, 19*, 516-524.

Lovaas, O.I. (1987). Behavioral Treatment and normal educational and intellectual

functioning in young autistic children. *Journal of Clinical and Consulting Psychology, 55*(1), 3-9.

Maccoby, E. E. (1992). The role of parents in socialization of children: A historical overview. *Developmental Psychology, 28*(6), 1006-1017.

Maurice, Catherine (1993). *Let me hear your voice.* A family's triumph over autism. NY: Fawcett Columbine.

McEachin, J. J., Smith, T., & Lovaas, O.I. (1993). Long-Term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation, 97*(4), 359-372.

Michael, M. E. (2009). Establishing a translational science for autistic spectrum disorders for children and their families: Optimizing function, participation, and well-being. *The Journal of Pediatrics, 154*(3), 319-321.

Mello, M. P., Goldman, S. E., Urbano, R. C., & Hodapp, R. M. (2016). Services for Children with autism spectrum disorder: Comparing rural and non-rural communities. *Education and Training in Autism and Developmental Disabilities, 51*(4), 355-365.

Morse, J. M. (1998). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (2nd ed., pp. 56-85). Thousand Oaks, CA: Sage.

"NVivo 12 Pro: Import and analyze data from the widest range of sources in virtually any language" (n.d.). Retrieved from http://www.qsrinternational.com/nvivo/nvivo-products/nvivo-12-pro

Nelson, C. & Huefner, D.S. (2003). Young children with autism: Judicial responses

to the Lovass and discrete trial training debates. *Journal of Early Intervention, 26*(1): 1-19.

Panagiota, R. (2015). Teaching strategies for children with autism. *Journal of Physical Education and Sport, 15*(1), 148-159.

Perry, A., Prichard, A. E., & Penn, H. (2006). Indicators of quality teaching in intensive behavioral interventions: a survey analysis of parents and professionals. *Behavioral Interventions, 21,* 85-96.

Regehr, K., & Feldman, M. (2009). Parent-selected interventions for infants at-risk for autism spectrum disorders and their affected siblings. *Behavioral Interventions, 24*, 237-248.

Reichow, B., & Volkmar, F. (2010). Social skills interventions for individuals with autism: Evaluation for evidence-based practices within a best evidence synthesis framework. *Journal of Autism and Developmental Disorders, 40*, 149-166.

Rivard. M., Terroux, A., Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*, 1609-1620.

Robertson, R. E. (2016). Effectiveness and acceptability of parent-implemented behavior interventions for children with autism in three African American families. *Education and Training in Autism and Developmental Disabilities, 51*(2), 107-121.

Romanczyk, R. G., Callahan, E. H., Tuner, L. B., & Cavalari, R. N. (2014). Efficicacy of

behavioral interventions for young children with autism spectrum disorders: Public policy, the evidence base, and implementation parameters. *Review Journal of Autism Developmental Disorders, 1*, 276-326.

Saldana, J. (2016). *The coding manual for qualitative researchers (2nd ed.)*. London EC1Y: Sage.

Sanjari, M., Bahramnezhad, F., Fomani, F. K., Shoghi, M., & Cheraghi, M. (2014). Ethical challenges of researchers in qualitative studies: The necessity to develop a specific guideline. *Journal of Medical Ethics and History of Medicine*, 7-14.

Shean, G. D. (2015). Some methodological and epistemic limitations of evidence-based therapies. *Psychoanalytic Psychology, 32*(3), 500-516.

Silva, L. M. T., & Schalock, M. (2011). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism Developmental Disorders, 42*, 566-574.

Skinner, B.F. (1974). *About Behaviorism*. New York: Knopf.

Smith, T., & Antolovich, M. (2000). Parental perceptions of supplemental interventions received by young children with autism in intensive behavior analytic treatment. *Behavioral Interventions, 15*, 83-97.

Smith, T., Eikeseth, S., Klevstrand, M., & Lovaas, O. I. (1997). Intensive behavioral treatment for preschoolers with severe mental retardations and pervasive developmental disorder. *American Journal on Mental Retardation, 102*(3), 238-249.

Smith, T., & Eikeseth, S. (2011). O. Ivar Lovaas: pioneer of applied behavior analysis and intervention for children with autism. *Journal of Autism Developmental Disorder, 41*, 375-378.

Smith, T. & Lovaas, O. I. (1997). The UCLA Young Autism Project: A reply to Gresham and MacMillan. *Behavioral Disorders, 22*(4), 202-218.

Smith, T. & Lovaas, O. I. (1998). Intensive and early behavioral intervention with autism: The UCLA Young Autism Project. *Infants and Young Children, 10*(3), 67-78.

State of California, D. (2020). Support Services. Retrieved October 08, 2020, from https://www.dds.ca.gov/general/eligibility/support-services/

Strunk, J. A., Pickler, R. P., McCain, M. L., Ameringer, S., & Myers, B. J. (2014). Managing the health care needs of adolescents with autism spectrum disorder: the parents' experience. *Families, Systems, & Health, 32*(3), 328-337.

Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in intellectual Disabilities*, *22*, 34-42.

Tellegen, C. L., & Sanders, M. R. (2014). A randomized controlled trial evaluating a brief parenting program with children with autism spectrum disorders. *Journal of Consulting and Clinical Psychology, 82*(6), 1193-1200.

Up To Date. (2017). Autism Spectrum Disorder in Children and Adolescents: Overview of Management. Retrieved from www.uptodate.com

Warren, Z., McPheeters, M., & Sathe, N. (2011). A Systematic Review of Early Intensive Intervention for Autism Spectrum Disorders. *Pediatrics 127*(5), 1303-1311.

Welch, C. D., & Polatajko, H. J. (2016). Applied behavior analysis, autism, and occupational therapy: A search for understanding. *The American Journal of Occupational Therapy*, *70*(4), 1-5.

Yanqing, G. (2006). Training parents and professionals to help children within autism in China: The contributions of behavior analysis. *International Journal of Psychology, 41*(6), 523-526.

Zaidman-Zait, A., Mirenda, P., Zumbo, B. D., Wellington, S., Vikram, D., & Kalynchuk, K. (2010). An item response theory analysis of parenting stress index-short form with parents of children with autism spectrum disorder. *The Journal of Child Psychology and Psychiatry, 51*(11), 1269-1277.

Appendix A: Electronic Recruitment and Invitation on Social Media

Are You a Parent of a Child who Receive an in-Home ABA Program?

If you are a parent or legal guardian of a child with autism receiving in-home ABA services, this study may be for you.

Study for Parents Whose Child Receives in-home ABA Services

I am looking for adults 18 years and older who are parents or legal guardians of a child with autism currently receiving in-home ABA services to capture their experiences and views with their child's in-home ABA services

Participant will be asked to participate in:

- One 30 to 60-minute one-on-one interview with the assessor by phone
- One follow-up appointment with interviewer

Participation in this study is voluntary. There are no monetary compensations or reimbursement provided for participation in this research.

Location

All interviews will take place by phone. The interviewer lives in XXX, California where he will schedule all appointments.

Are you Eligible?

- 18 years or older
- Parent or Legal Guardian
- Care and raise a child diagnosed with Autism Spectrum Disorder under the age of 18 years old
- Your child receives in-home ABA services

If you are interested in participating in this study or unsure if you meet the requirements, call or email at:

Gerald Lavarias

- Email address is:
- Phone Number: XXX-XXX-XXXX, call or text messages accepted.

Appendix B: Email Demographics Information Form

Dear (their name or Sir or Madam),

Please respond to the information below, you may reply by deleting or marking your response to the information below:

1. Are you the parent/caregiver/legal guardian of the child receiving services? Yes or No

2. What is your age range?
   A. 18 – 28yrs old
   B. 29 – 38yrs old
   C. 39 – 48yrs old
   D. 49 – 58yrs old
   E. 59 – 68yrs old
   F. 69 – 80yrs old
   G. 81yrs old and over

3. Level of Education Completed (only your highest):
   A. GED or High School
   B. Some college, but not completed
   C. Bachelors
   D. Masters
   E. Specialty (Credentials, Licensure, Post Bachelors Certification, etc.)
   F. Doctorial or above

4. Age your child first received in-home ABA services.
   A. 1 – 3yrs old
   B. 3 – 5yrs old
   C. 6 – 8yrs old
   D. 9 – 11yrs old
   E. 12 – 15yrs old
   F. 16 – 18yrs old
   G. 21yrs old and over

5. How many ABA companies has your child received in-home ABA services (only in-home, not school) since start to current?

6. How long has your child received in-home ABA services (only in-home, not school)?

7. What state do you reside?

8. Do you consider yourself a working parent?
   A. Yes, full-time
   B. Yes part-time
   C. No, do not work

Again, thank you for your participation. The information will be used only for the purposes of this research.

Sincerely,
Gerald B. Lavarias, MS
Doctoral Student and Researcher at Walden University

Appendix C: Guiding Interview Questions

1. What did you do before you knew about in-home ABA treatment for your child?
2. Tell me how you sought out and received in-home ABA treatment for your child.
3. Describe a situation that you remember about the first weeks of receiving in-home ABA treatment. Choose any early memories from that time and be sure to provide as much details as you can remember.
4. How does this memory affect your life now? In other words, describe the impact it had on you and what it means to you.
5. Describe a typical day, on the day your child receives in-home ABA treatment, and some of the things you do to prepare for it if any.
6. Describe your child's in-home ABA treatment in your view.
7. Describe your experiences with the ABA providers such as the behavioral therapists that work with your child and the other team members that come to your home.
8. Describe any concerns and assumptions regarding challenges you might have faced with having in-home ABA treatment for your child.
9. Regarding these concerns and assumptions, provide me a detailed example of a concern or assumption as best as you could describe.
10. Describe any positive experiences you had with your child's in-home ABA treatment.

11. Regarding these your positive experiences, provide me a detailed example of this experience as best as you could describe.
12. Describe how you think your experience would change if you did not have in-home ABA treatment for your home.