

Walden University

College of Social and Behavioral Sciences

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Abstract

Exploring Barriers to Fathers' Implementation of Behavioral Interventions for Nonverbal

Children with Autism

by

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MSEd., Touro College, 2007

Advanced Certificate, Queens College, City University of New York, 2004

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Many families, regardless of their ethnic and cultural background, find it challenging to raise a nonverbal child with autism. Parent-implemented behavioral interventions can contribute to positive behavior change related to joint attention, imitation, and communication. However, many parents face barriers that prevent them from implementing behavioral interventions in the home. Very little research has been conducted on fathers of nonverbal children with autism to ascertain their perspectives on these barriers. In this qualitative study, a phenomenological design was used to obtain input from 12 fathers of diverse ethnic and cultural backgrounds residing in New York City regarding barriers to implementing behavioral interventions in the home with their nonverbal child with autism. Behavioral and humanistic theories constituted the theoretical framework. Thematic analysis resulted in the identification of themes and patterns within and across cases. Recommendations for parents and professionals include on-going in-home parent training from preschool to age 21 that focuses on acquiring instructional control over behavior and establishing effective communication with the nonverbal child with autism in the home. Study findings may help psychologists, counselors, parents, advocates, and autism treatment organizations improve parent training and counseling methods with the goal of promoting positive therapeutic outcomes.

PREVIEW

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Dedication

I would like to dedicate this to my mother and father, who continued to support me throughout my academic endeavors and life goals. To my sister Angela, who will always be my hero and true inspiration in my life. To my wife, who put up with long work hours and held down the fort at home with our sons and daughter while I attended residencies or spent consecutive days finishing coursework requirements. To both my sons and daughter, who are the true joys of my life, I love you so much! You are my world, you mean everything to me!

I also would like to dedicate this to all nonverbal children with autism and their families, who through my work, have taught me about some of the true meanings of life. Lastly, to my Father in Heaven; my Lord and Savior Jesus Christ, who helps me stay in Grace. Without Your Unconditional Love, I wouldn't have the Ultimate Example to look up to and try to emulate.

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PREVIEW

Table of Contents

List of Tables	vi
List of Figures	vii
Chapter 1: Introduction to the Study	1
Problem Statement	1
Nature and Purpose of the Study	3
Research Questions and Theoretical Framework	4
Definition of Terms	5
Assumptions	6
Scope and Delimitations	7
Limitations of the Study	7
Significance	7
Summary	9
Chapter 2: Literature Review	12
Introduction	12
Literature Search Strategy	15
The Nonverbal Child with Autism	15
Symptoms and Characteristics	15
Treatment Findings	17
Parental Involvement	19
Parenting a Child with Autism	19
The Inclusion of Parents in the Special Education Process	20
Changes in Legislature	20

Parent Implemented Interventions & Therapeutic Outcomes.....	22
Barriers Faced by Parents of Children with Autism.....	25
Communication with Treatment Providers.....	25
Poverty.....	26
Fatigue.....	27
Gender Roles.....	27
Family Disruption.....	28
Perceptual Differences.....	28
Disability.....	29
Lack of Child Progress.....	29
Language.....	30
Cultural Factors.....	31
Behavioral and Humanistic Based Interventions.....	32
Behavioral Skills Training.....	32
Humanistic Counseling.....	33
Summary.....	35
Chapter 3: Research Method.....	41
Introduction.....	41
Research Design and Rationale.....	42
Research Questions.....	42
Research Tradition.....	44
Role of the Researcher.....	45

Methodology.....	46
Participant Selection Logic.....	46
Site Selection.....	47
Ethical Concerns and Participant Protection.....	48
Methods of Data Collection.....	48
Document Collection.....	48
Interviews.....	49
Data Analysis.....	49
Validity and Reliability.....	52
Ensuring Reliability.....	52
Validity Concerns.....	52
Validation of Findings.....	53
Summary.....	54
Chapter 4: Results.....	56
Introduction.....	56
Setting.....	57
Demographics.....	58
Data Collection.....	59
Data Analysis.....	60
Evidence of Trustworthiness.....	60
Credibility.....	60
Transferability.....	61

Dependability.....	61
Confirmability.....	62
Peer Debriefing Results.....	62
Member Checking Results.....	63
Results.....	64
Research Question Analysis.....	64
Research Questions.....	64
Summary.....	89
Case Assertions.....	89
Chapter 5: Discussion, Conclusions, and Recommendations.....	96
Introduction.....	96
Key Findings.....	97
Successes and Challenges.....	97
Barriers and Experiences.....	98
Thoughts and Emotions.....	99
Interpretation of Findings.....	100
Conceptual Framework Analysis and Interpretation.....	106
Limitations of the Study.....	106
Recommendations.....	107
Recommendations for Educators and Autism Treatment Professional.....	108
Recommendations for Fathers and Parents.....	114

Recommendations for Advocates and Policy Makers.....	116
Recommendations for Future Research.....	118
Empirical Implications.....	118
Potential Impact for Positive Social Change.....	118
Empirical Implications.....	120
Recommendations for Practice.....	120
Conclusion.....	121
References.....	123
Appendix A: Letter of Study Information.....	142
Appendix B: Invitation to Participate in Research.....	143
Appendix C: Interview Protocol.....	144

List of Tables

Table 1. Demographics	58
Table 2. Interrater Agreement.....	63

PREVIEW

List of Figures

Figure 1. Overview of themes discovered – cross-case analysis.....	65
Figure 2. Emergent themes based on each participants’ identified barriers.....	73
Figure 3. Overview of themes discovered.....	92

PREVIEW

Chapter 1: Introduction to the Study

According to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed., [DSM-5]), children with autism spectrum disorder (ASD) exhibit delays in their ability to interact socially and acquire functional speech and language skills (American Psychiatric Association, 2013, p. 53). Between 25-61% of children with autism may exhibit little or no functional speech by the time they reach 2 years of age (Schlosser & Wendt, 2008). Moreover, as many as 50% of children with autism may not develop communicative language by age 13 (Kasari, Paparella, Freeman, & Jahromi, 2008) and 25% may fail to produce communicative speech at all (Koegel, Shirotova, & Koegel, 2009). Because of these data, many parents of nonverbal children with autism seek quality behavioral treatments as part of early intervention and preschool special education for their children (Kasari et al., 2008).

Problem Statement

Parents of children with autism report higher levels of stress than parents of children with any other conditions (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Parent training, which has been found to help parents adjust immediately after a child has received an initial diagnosis, is one behavioral intervention for nonverbal children with autism (Estes et al., 2014). Training parents to implement behavioral interventions can also improve parental interactions with children with autism and reduce parenting stress levels (Bendixen et al., 2011). However, most research has focused on mothers because they are often the parent that intervenes the most (Elder et al., 2011). Little is known about fathers' interactions with their children (Donaldson, Elder, Self, & Christie, 2011).

As parental roles become more alike, fathers are increasingly caring for children with autism (Boström & Broberg, 2014). Coinciding with the increasing diagnosis of autism in the United States (US), the Centers for Disease Control and Prevention (CDC, 2014) have highlighted the need for psychologists to examine the experiences of parents of children with autism. In response, Dardas and Ahmad (2015) found that quality of life amongst fathers of children with autism can be impacted by their perception and abilities applied to their situation. Studies suggest that some parents may either fail to implement behavioral interventions with their children with autism, or do so with low procedural fidelity (Schultz, Schmidt, & Stichter, 2011), defined as the extent of which each step of the procedures are conducted correctly.

Common barriers to parental implementation of home-based behavioral interventions children with autism include lack of time and financial support (Leyser & Dekel, 1991). Families of different ethnic and cultural backgrounds may face other barriers (Kissel, Nelson, Dulaney, Bing, & Currans, 2010). For example, Matthews (1998) found that some Jewish families of children with autism face barriers related to a lack of child care and social support. Dardas and Ahmad (2014) discovered that Arab parents are impacted by cultural factors. A study of fathers in Ireland indicated that the difficulty of tasks can be a factor when engaging in interactions with their children with autism (O'Halloran, Sweeney & Doody, 2013). Australian parents have been found to experience challenges when addressing their children's externalizing behavior (McStay, Trembath & Dissanayake, 2014). Similarly, difficulties in addressing behavior problems of children with autism living in China were found to be a major aspect of parent-child

interactions (Gong et al., 2012). Swedish fathers reported that managing the responsibilities in their lives around their child's disability was a recurring factor for the first 5 years after the initial diagnosis (Boström & Broberg, 2014). These examples indicate that regardless of ethnicity and cultural background, parents face challenges when caring for their child with autism.

Barriers faced by fathers from diverse ethnic and cultural backgrounds has been scarcely examined in research on parental implementation of home-based behavioral interventions for nonverbal children with autism (Kissel et al., 2010). No studies were found that have explored how fathers of diverse ethnic and cultural backgrounds residing in New York City (NYC) personally experience such barriers. Therefore, this study identified barriers to the implementation of behavioral interventions for nonverbal children with autism by fathers of diverse ethnic and cultural backgrounds living in NYC. In the study, the researcher examined how these fathers experience and feel about these barriers.

Nature & Purpose of the Study

The purpose of this exploratory qualitative study was to analyze the narratives of fathers from diverse ethnic and cultural backgrounds residing in NYC. Participants were asked to identify and describe their experiences with barriers to implementation of behavioral interventions for their nonverbal children with autism. The researcher collected data by conducting one-time, semistructured interviews with participants. Open-ended questions were used in the interview. A thematic analysis highlighted

themes across participants' narratives. Each interview lasted 60 minutes. The thematic analysis was completed by reading the interview transcripts line-by-line.

Research Question(s)

In order to obtain a deeper understanding of the perspectives of participants, the researcher investigated several phenomena through the following research questions:

RQ1. What are barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their child with autism?

RQ2. How do fathers of diverse ethnic and cultural backgrounds residing in NYC experience barriers to implementing behavioral interventions with their child with autism?

RQ3. How do fathers of diverse ethnic and cultural backgrounds residing in NYC feel about these barriers to implementing behavioral interventions with their child with autism?

Theoretical Framework

When working with parents of children with autism, integrative psychologists and counselors often draw from behaviorism principles and humanism concepts (Hannon, 2014). Training parents to implement behavioral interventions can address the behavioral symptoms exhibited by children with autism (Miltenberger, 2011). However, counseling interventions that use humanistic approaches such as narrative interventions and person-centered interventions may provide parents with opportunities to share their experiences in an effort to facilitate change, improve "self-capacities", and feel enabled when faced

with daily stressors (Rogers, 1986). When a parent develops their capacity to cope with stress in a positive and healthy manner, their quality of life may significantly improve.

Practices in psychology such as counseling involves six conditions that are necessary for psychologists to understand the lived experiences of their clients (Rogers, 1957). One key principle of humanistic counseling is understanding that individuals actively assign meaning to their experiences (Mize, 2003). When providing therapy, humanistic counselors seek to relate to clients in an empathically respectful and growth-producing manner (Scholl, McGowan & Hansen, 2012). Therefore, in this exploratory study, the researcher sought to gain a more in-depth understanding of how fathers identify, describe, and experience the barriers to implementing behavioral interventions with their nonverbal children with autism. With empirically-supported data, practitioners may be better able to understand the experiences of fathers of children with autism. Study findings may inform interventions for fathers who seek parental training and counseling support. Findings of this study may also provide insight for future researchers investigating related areas.

Definitions

The following terms are defined due to their repeated usage throughout this study and the importance of their precise meaning:

Autism spectrum disorder (ASD): is diagnosed in early childhood and characterized by persistent deficits in social interaction and social communication across multiple settings and restricted repetitive patterns of behavior, interests, or activities,

which cause clinically significant impairment in social, occupational, or other important areas of current functioning (APA, p. 53, 2013).

Generalization: occurs when behavior is emitted under conditions that are different from the training setting (Stokes & Baer, 1977).

Imitation: is a nonverbal type of learning associated with the observation and reproduction of another human being's movements, sounds, or intended actions (Moore, 2013).

Joint-attention: involves the sharing of attention with others, through eye-contact, facial expressions, nonverbal gestures, pointing, showing, and coordinated looks between a person and object (Kasari, Freeman & Paparella, 2006).

Language: is a body of words, signs, symbols and/or gestures of particular meaning in a system by which human beings communicate (Algeo, 2013).

Speech: is considered one or more vocalized utterances, vocal sounds, or spoken words, which are used as an oral communicative method for people to interact with each other (Serra, Ribeiro, Freitas, Orvalho, & Dias, 2012).

Assumptions

In the present study, it was assumed that data provided by each participant were based on their understanding of the open-ended questions asked during the interview. It was also assumed that participants' responses were truthful in all respects. Since eligibility to participate in the study required the participant to reside with their child with autism in the same household, there was another assumption that each father had

knowledge of their child's diagnoses and multiple experiences with their child's symptoms.

Scope and Delimitations

The focus of this study was to (a) identify barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their nonverbal child with autism and (b) explore how these fathers individually experience and feel about these barriers. Data included the fathers' narratives, which were obtained in semistructured interviews using open-ended questions. Research on mothers and fathers are included in the literature review. The results of this study provided much knowledge and insight to practitioners who aim to individualize parent training methods to the needs of families from diverse ethnic and cultural backgrounds with nonverbal children with autism.

Limitations of the Study

One limitation of this study involved the methods of sampling, as fathers were chosen based on having a nonverbal child with autism. Another limitation involved generalizability of data from the number of participants. Since the sample size of fathers from diverse ethnic and cultural backgrounds residing in NYC was 12, it is possible that the results of the present study were limited to similar populations living in similar urban areas in the US or abroad.

Significance

This study is unique because it addressed an understudied area of research. Firstly, fathers of children with nonverbal children with autism are underrepresented in

both parent research and parent implemented intervention studies (Flippin & Crais, 2011). This is discouraging because fathers have been argued to display interaction styles that contribute to social and language development in their children with autism. Second, parents of children with autism have been found to experience a variety of long-lasting stressors that can impact marital satisfaction and family functioning (Solomon & Chung, 2012). Fathers who reported higher levels of stress than mothers indicated that their paternal stress was associated with symptom severity, their child's age, intellectual quotient, gender, and failure to acquire adaptive behaviors (Rivard et al., 2014). In addition, Kissel et al. (2010) argued that ethnic and cultural factors may be contributing to parent-child interactions in the home. Parent training methods that are individualized to incorporate the identified barriers while considering the parents' ethnic and cultural background along with their personal experiences with these barriers may facilitate parent implementation of behavioral interventions in the home. Moreover, father implementation of behavioral interventions can promote increases in social interaction and functional speech and language by their nonverbal child with autism in the home (Elder et al., 2011). If social and communication skills are acquired, it is possible for fathers and families in general to experience a significant improvement in their quality of life. This therapeutic outcome is meaningful because fathers have identified that communicating with their child with autism is one of the most rewarding aspects of engagement (Hannon, 2014).

Therefore, the results of the present study indicated ways to help practitioners improve their parent training methods, especially for fathers. As a result, father

implementation of behavioral interventions will increase and improve. Center- and home-based autism treatment and special education programs that target deficits related to social interaction and functional communication in nonverbal children will experience more success in promoting changes in behavior. Increases in child correct responding associated with the ability to interact socially and acquire communication skills will be observed to facilitate behavior changes in others (e.g., primary caregivers, siblings), which in turn will foster additional learning opportunities across individuals and settings. These changes in behavior will reduce parent stress and will have a profoundly positive effect on the quality of life for these children with autism and for their families.

Summary

Children with autism exhibit symptoms that impact their ability to communicate and engage in functional skills, which has prompted parents to seek services from autism treatment professionals. When compared to other childhood disorders, parents of children with autism experience greater stress levels. Parent training can improve interactions in the family, which can alleviate stress but a large percentage of studies have been conducted on mothers while very little research has been done with fathers of children with autism. Fathers' roles in the treatment process have increased due to the rise of autism in the US and changes in parenting roles. Therefore, it is important to understand the experiences of parents of children with autism, especially fathers.

A child's quality of life and that of their family's can improve when fathers use their abilities to assist the treatment process; however, some fathers have been found to make errors or fail to implement behavioral interventions with their nonverbal child in