



EXPLORATION OF EXPERIENCES OF PARENTS RAISING CHILDREN ON THE AUTISM SPECTRUM

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Abstract

The purpose of this qualitative study was to explore the experiences of parents raising children on the autism spectrum. Past research on the experiences of parents raising a child diagnosed with ASD indicate that the welfare of caregivers is adversely affected by the problems that they may experience daily (Brien-Bérard & des Rivières-Pigeon, 2023). This study is unique because it doesn't only focus on the mental health conditions but explores the lived experiences in all aspects completely. The research question of the present study is "What is the lived experience of a parent raising an autistic child?" The total number of participants used in the study were 2 key informants. The data collection method included semi-structured interviews over the phone. The open-coding displayed 3 themes: 1) Knowledge of autism, 2) Associated Emotions, and 3) Resources. Results indicated that parents raising autistic children do not experience any noticeable differences with their children in public or at home. It also indicates that parents raising autistic children need and desire an increase of sufficient resources to assist in their child's needs. This study can be improved by expanding the participant population and including the experienced thoughts and emotions of fathers raising children with autism spectrum disorder in comparison to mothers' experienced thoughts and emotions.

Keywords

Autism Spectrum Disorder, Parental Experiences, Raising Children

Autism spectrum disorder (ASD) is characterized as a developmental cognitive impairment caused by imbalances found in the brain. Those diagnosed with ASD tend to experience difficulties with social communication and interacting with others. They also can experience a narrow scope of interest or recurrent actions. The difficulties experienced often continue to some degree throughout one's entire life (Ali et al., 2023). Past research (Ali et al., 2023; Brien-Bérard & des Rivières-Pigeon, 2023; Demšar & Bakracevic, 2023; Grebe et al., 2022; Higgins et al., 2023; Marriott et al., 2022) on this topic all agree that parents raising children on the autism spectrum undergo elevated levels of stress, depression, anxiety, and responsibilities. All of these contribute to the existence of mental health problems, burnout, marital problems, and overload experienced by parents (Brien-Bérard & des Rivières-Pigeon, 2023; Demšar & Bakracevic, 2023; Higgins et al., 2023).

This topic of study is important because it will increase our understanding of the perceptions of parents raising autistic children. It will also enlighten us on sufficient support to better assist parents with a child on the spectrum. Lastly, we will become more aware of the lived thoughts and emotions that are often run into by parents with differently-abled children. The consequences that we risk facing if the topic is not investigated are an overwhelming decrease in mental health status for parents, contribution to the neglect of children on the spectrum and their parents, and increasing the marginalization of parents raising children diagnosed with autism. We do not currently know how the experiences of parents change during the development of their child's life. We need to better understand how the support of others and others' perceptions of ASD has modified their perceptions of their child's diagnosis of ASD. All parents, especially new parents of autistic children will benefit from this qualitative research study. Advocates for children on the spectrum will also benefit from the research.

Literature Review

The purpose of this literature review is to explore past research on the experiences of parents with a child on the autism spectrum. In this section, research related to the mental health status of parents, the contribution from mothers vs fathers as well as the effect it has on their marriages, and the responses and reactions of parents and their loved ones.

Mental Health

The prevalence of children being diagnosed with ASD has increased and is continuously increasing (Brien-Bérard & des Rivières-Pigeon, 2023; Higgins et al., 2023). According to Brien-Bérard & des Rivières-Pigeon (2023), past research has indicated that the welfare of caregivers is adversely affected by the problems that they may experience daily taking care of a child diagnosed with ASD. In comparison to parents raising non-autistic children, caregivers of children with ASD possess elevated amounts of stress, anxiety, and depression (Demšar & Bakracevic, 2023; Marriott et al., 2022). Remarks from parents in studies also indicate that parenting a child with ASD has proven to be psychologically and physically challenging (Urkmez et al., 2023). The presence of difficulties regarding social communication is not surprising for most children diagnosed with ASD. Even though parents are the first and main source of communication, mothers, and fathers still report communication with their children as a considerable stressor for them (Im-Bolter & de la, 2023). Notwithstanding the experienced struggles, caregivers with children on the spectrum still disclose favorable parenting gains such as enhancement, positive transformation, and great pleasure (Marriott et al., 2022). Demšar & Bakracevic (2023) conducted a study where they presented a questionnaire with 42 questions to parents of autistic children. They intended to assess the symptoms of anxiety, depression, and stress. Demšar & Bakracevic (2023) also intended to assess the number of parents who underwent any type of professional mental health assistance. Their results indicated that 85.7% of parents had not received any assistance, while 11.9% did. 54% of parents reported that they would receive mental health assistance if offered, while 38% reported that they would not (Demšar & Bakracevic, 2023).

Mothers vs. Fathers and Marital Distress

Though mothers and fathers both have experience as parents of autistic children, past research has displayed an overwhelming difference in contribution from mothers in comparison to fathers (Grebe et al., 2022). Mothers are commonly the main parental figure that participates in research regarding ASD (Grebe et al., 2022). Brien-Bérard & des Rivières-Pigeon (2023) pointed out that numerous mothers of autistic children tend to decrease the number of hours that they work or cease working completely. This reality does contribute to the financial tension within a family and tension within a marriage (Brien-Bérard & des Rivières-Pigeon, 2023). Grebe et al. (2022) conducted a study intended to inquire about father variables such as perception, coping, and stress. Their study was inspired due to the lack of father representation in studies regarding parents of autistic children. Their study consisted of 361 parent participants with only 67 of the participants being fathers (Grebe et al., 2022). Though there have been studies that indicate that fathers disclose experiencing stress about behavioral elements expressed by their children that cause unwanted attention in public (Grebe et al., 2022), perceptions of their child's diagnosis differ from the mothers (Brien-Bérard & des Rivières-Pigeon, 2023). The differences in their realization of ASD tend to cause strife and separation within marriages (Brien-Bérard & des Rivières-Pigeon, 2023). On the other hand, some mothers have reported seeing a difference in their spouse's contribution (attending an appointment, reaching out to their child's school, reaching out to a specialist, etc.) to their child with ASD, after disclosing feelings of burnout or unhappiness (Brien-Bérard & des Rivières-Pigeon, 2023).

Responses and Reactions

Former research has found that parents experience feelings of guilt, denial, or anger in response to becoming aware of their child's diagnosis of ASD (Ali et al., 2023). In addition, research has also collected evidence and reports that parents of children with ASD have to cope with antipathetic or unsympathetic feedback from their loved ones and their communities (Brien-Bérard & des Rivières-Pigeon, 2023). Marriott et al. (2022) indicated that numerous parents undergo seclusion from the community and intense criticism. Despite viewing themselves as unqualified to handle the diagnoses, favorable outcomes such as a decline in guilt do present themselves through the positive responses, support, and lucidity offered by doctors and other health professionals (Ali et al., 2023). Marriott et al. (2022) utilized Interpretative Phenomenological Analysis (IPA) to investigate the experiences of autistic parents or parents who possessed autistic characteristics who were raising a child with ASD as well. All participants in the Marriott et al. (2022) study scored at least a 32 on the Autism Quotient. The study resulted in seven parents disclosing that their loved ones and residences were safe havens from the critical community that surrounded them (Marriott et al., 2022).

Purpose of Study

The purpose of this study is to explore the experiences of parents with a child on the autism spectrum. This study intends to better understand the thoughts and emotions of parents with a child diagnosed with ASD. The study also intends to learn how to support parents raising an autistic child more efficiently.

Research Question/s

The following research question guided this study: What is the lived experience of a parent raising an autistic child?

Qualitative Research Orientation

Given the research question for this study, a qualitative research method is appropriate because it provides adequate comprehension of the subjective reality of participants as well as their thoughts, emotions, and ambitions. The phenomenological approach was utilized to investigate this study topic. The phenomenological approach is appropriate because the strategy examines the experiences of individuals from their subjective point of view. The use of this approach grants other people who may not possess the lived experiences knowledge about what it is like to be a parent raising a child with autism spectrum disorder.

Research Design

Role of Researcher

As the researcher, my goal is to collect accurate data on the experienced thoughts and emotions of the study's participants. I have family members who are raising children diagnosed with autism spectrum disorder and find parents' satisfaction with resources important. I have also sat in a behavioral health assessment for a child with autism spectrum disorder. Some bias that I possess is the belief that raising a child with autism is sometimes difficult and stressful. I also think that children with autism can be unpredictable. To account for these biases, I will utilize four validation strategies to maintain data trustworthiness.

Sample Size

Two individuals raising children diagnosed with ASD participated in the study.

Sample and Context

Both participants in the study were African-American females. Participant 1 was the age of 26 with a one-year-old daughter with ASD and Participant 2 was the age of 50 with a 15-year-old daughter with ASD.

Sampling Procedure/Ethical Considerations

The method of sampling utilized for the study was the snowball/chain method. This method of sampling was used to gain access to participants who met the inclusion criteria. Access was granted to participants by asking if they knew of anyone else who also met the inclusion criteria and providing a name or contact information. The inclusion criteria consisted of being a parent or primary caregiver for a child with autism spectrum disorder. The participants were each provided a consent form to read and sign. After consent was confirmed with both participants, semi-structured interviews were conducted via the phone and were audio recorded.

Data validation

This study uses four validation strategies to maintain data trustworthiness. The strategies utilized were rich thick descriptions, bracketing, member checking, and peer review. Before the conduction of any interviews with participants, the researcher wrote down any biases they may possess regarding the subject to suspend any judgment and to focus more on the analysis of the experiences collected. During interviews, the researcher reiterated all the notes taken from the participants' responses after each interview question. The participants assured the researcher that the information and interpretations collected were interpreted correctly. Once data collection methods were complete, the researcher reviewed the findings with qualified qualitative research experts to ensure that the data was interpreted correctly.

Results

Atlas Ti was used as a tool for analyzing the data. The audio recordings collected during the interviews with participants were uploaded to Atlas TI. After analyzing the data, 14 codes were created in total. The categories for the codes were created by the researcher. The essence of the 15 codes was then condensed to create three themes.

Themes

The three themes that surfaced from the codes were knowledge of autism, associated emotions, and resources used/available.

Knowledge of Autism

Three codes were combined to establish this theme. The codes were lack of knowledge, sufficient knowledge, and parents' intuition. When asked about the meaning of autism, participant one mentioned, "I really don't know, first time having a child with autism." Regarding sufficient knowledge, Participant Two stated that "there is no single definition for autism because all autistic individuals are very different." Participant Two continued to share a plethora of knowledge on autism that has been learned through 15 years of parenting. Lastly, participant one and two reported that they were aware something was different about their child early on in their development. Participant One shared "I knew something was a little different about my child when she was one year old."

Associated Emotions

Five codes were condensed to create the theme of associated emotions. The codes were denial, fear, guilt, grief, and privilege. Participant One disclosed that once making her family aware of her child's diagnosis she said "Some people didn't believe that she had Autism."

Concerning fear, Participant One stated that when she initially became aware of her child's diagnosis "I didn't have any emotions, but her dad freaked out and had mixed emotions." Regarding the feeling of guilt, Participant Two shared "I felt that I was being punished." She also shared that her husband experienced feelings of guilt due to having difficulties reading when he was younger. Her husband felt his difficulties may have contributed to their daughter's difficulties and diagnosis. When it comes to grief, Participant Two needed to grieve the life she initially envisioned for her daughter. Participant Two said "I remember nights I just cried. I was very sad at first that my child would never be on the cheerleading team or she would never get to do prom like everybody else would." Lastly, when it comes to privilege, Participant Two said "I felt very privileged and believe that God entrusted my husband and myself to handle it."

Resources

Seven codes were combined to establish this theme. The seven codes were lack of resources, early intervention, goals, advice, Duty/purpose, congruency, and support. The seven codes were also condensed into three sub-themes. The sub-themes were external resources, internal resources, and parents as a resource. External resources accounted for early intervention, lack of resources, and support. Participant Two said, "While in daycare, a daycare instructor suggested Babies, Can't Wait. Through that program, she was evaluated and began occupational therapy a couple of times a week." Regarding the lack of resources, Participant Two stated, "In elementary school, there were no programs available nearby, and she had to take a bus to a school and another district." When it came to support, Participant Two shared many avenues for support, one being her group of friends. Participant said, "I have always been supported by my group of friends. Anything that I have for my daughter, they are always there. Anytime I put on a fundraiser, whether Girl Scout cookies or selling onions for the basketball team, my daughter is always the number one salesperson." The sub-theme of internal resources consisted of spiritual resources/faith, duty/purpose, and congruence. Participant Two spoke highly of her spiritual resources. When asked what she would recommend to other parents with children on the spectrum she responded, "Faith in Jesus Christ is my support group." Participant Two also expressed that it is her duty to be an involved parent and to be her child's best advocate. She stated, "It is my purpose to find my daughter's weaknesses, assist them, and prepare my daughter for the workforce." Both participants one and two discussed congruency with their behavior as well as their child's behavior in public settings, and at home. Participant One shared "She is still the same. She acts normal in public until she sees her brother acting up or running around." The sub-theme of parents as a resource encompasses the codes of goals and advice. Participant Two expressed that she has goals for her daughter. She wants her to learn how to count money and how to tell time. Participant Two stated, "10 PM is the same thing as 12 noon to her. Saying those means absolutely nothing. The same thing goes with money. If you give her \$20 or \$50, she's still going to be excited." Participant Two advised parents who are raising children on the autism spectrum to "read everything, take advantage of resources, ask questions. Knowledge is power."

Discussion

This study aimed to explore the experiences of parents raising children with autism spectrum disorder. The study suggests that parents raising autistic children do not experience any noticeable differences with their children in public or at home. Findings from the study suggest that parents raising autistic children need and desire an increase of sufficient resources to assist in their child's needs. 100% of the participants in this study were mothers. According to Grebe et al. (2022), mothers are more likely to willingly participate in research studies focused on autism spectrum disorder. The results of this study can benefit new parents raising a child with autism, the school system, and applied behavior analysts. Information found from the study can help initiate positive change in adequate and local resources for the children and for the parents. In the future, researchers could explore the experienced thoughts and emotions of fathers raising children with autism spectrum disorder in comparison to mothers' experienced thoughts and emotions.

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Appendix Interview-Questions

1. What is the meaning of autism to you?
 - a. How did you discover the meaning of autism?
2. Can you describe the thoughts and emotions you experienced when you became aware of your child's diagnosis?
3. What responses did you receive from family and friends after you disclose your child's diagnosis?
4. What experiences have you had in public settings since your child's diagnosis?
5. How have your experiences in public settings changed since the development of your child's diagnosis?
6. How have the perceptions of others changed your perception of the autism spectrum?
7. What do you recommend to other parents with children on the autism spectrum?
 - a. Advice?
 - b. Support groups?