


The Lived Experiences of Low-Income Parents Raising Children with Autism


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Abstract

Previous studies indicated that parents raising children with autism spectrum disorders (ASD) experience higher rates of stress; however, no qualitative studies have addressed low-income parents' lived experiences of raising children with ASD. The purpose of this basic qualitative study was to understand the challenges that low-income parents of children with ASD face daily within the framework of family systems theory. Interview questions were used to focus on the impact of income and the core symptoms of ASD (social deficits, communication deficits, and repetitive behaviors) on marital and interpersonal relationships. Although the study was open to both mothers and fathers, only mothers participated in this study. Semi-structured interviews with 13 mothers were conducted, and transcripts were analyzed for themes. Results indicated some negative impacts on parents' marital, social, and professional relationships. Themes included reports of stress and depression, decreased social interaction, low levels of personal and professional satisfaction, and decreased marital satisfaction. Results indicated that increased empathy and understanding of mothers' challenges are needed to improve access to resources and services required for low-income parents of autistic children to enhance their family's quality of life.

Keywords: *parental stress, marital satisfaction, low-income, communication, developmental disabilities, poverty, and autism spectrum disorders*

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Introduction

Rates for autism spectrum disorders (ASD) have been on the rise for over a decade in the United States. Baio et al. (2018) reported rates of 1 in 59 in 2018, which is a 2.3% increase over the 1 in 69 rates reported in 2012 (Centers for Disease Control [CDC], 2012, 2018). An increase in diagnoses has led to an increase in desired services to assist children with ASD and their families. There is a lack of information about parents raising children with ASD who have low incomes who not only struggle to understand the diagnosis of ASD but also

struggle to seek affordable resources to enhance the quality of life for themselves and their children (Sullivan, 2017).

Raising a child with developmental disabilities can produce additional stress for parents when they face ASD-related stressors, particularly communication deficits, compared to parents raising typically developing children (Anderson, 2010; Bebko et al., 1987; Daniels et al., 2008; Davis & Carter, 2008; Moore & Vandivere, 2000). Other stressors for parents of children with ASD may include the child's problems with sensory, motor, emotional, behavioral, or cognitive functioning (Brobst et al., 2009; Davis & Carter, 2008). Mount and Dillon (2014) found that parenting an adolescent child with ASD presented unique parenting stresses. These stressors compromised the marital quality and overall marital satisfaction and led to a conflictual marriage for parents of a developmentally disabled child; even when the couple was satisfied with their marriage, they were often negative about the quality of their marriage (Parker et al., 2011). Hartley et al. (2012) found that a higher household income, as well as the closeness of the mother-child relationship, determined higher levels of marital satisfaction for parents of a child with ASD.

Previous quantitative studies have indicated that parents experience unique stressors when raising children with ASD, which included behaviors such as physical, impulsive, and verbal outbursts; food-related issues; social perceptual issues; lack of spontaneity for parents; inflexibility; views from other people about their child's behaviors or ASD; and communication difficulties with the child (Mount & Dillon, 2014). These difficulties also have an impact on relationships with partners, others in the family (e.g., siblings and other relatives), and communication with a child with ASD. These issues can lead to parental feelings of frustration, guilt, regret, uncertainty, and fatigue as parents struggle to cope with the ASD diagnosis (Mount & Dillon, 2014).

Very few qualitative researchers have addressed the lived experiences of lower-income parents raising children with ASD and the impact that a lack of finances has on parental stress and the marital relationship. Falk et al. (2014) found that significant factors affecting parental mental health included a lack of socioeconomic support and parental cognitions regarding raising a child with ASD, more so than ASD symptom severity and maladaptive behaviors, as reported in previous studies. Results from their study indicated that younger mothers reported increased levels of anxiety; also, child aggression toward adults led to higher levels of depression, along with a perceived lack of social support and an externalized parental locus of control. For fathers, results across variables were consistent; however, one variable that led to depression in fathers was dissatisfaction with parenting. Also, younger fathers reported higher levels of stress, and the child's aggressive behavior led to elevated levels of anxiety. The authors concluded that the severity of ASD symptoms and the child's externalizing behaviors did not directly influence parental psychological distress; rather, the combination of the two variables, along with parental cognitions and perception of socioeconomic support, led to higher levels of distress across both genders.

Hoogsteen and Woodgate (2013) reported that parents felt ASD was an invisible disorder to most people because they received comments that their child looked normal; however, when their child had tantrums in public, those same community members attributed the child's behaviors to poor parenting or to an uncontrollable child. Socioeconomic status, particularly the financial status of participants, was not addressed in this study. However, participants believed that because they lived in rural areas, resources to help them provide a better quality of life were absent, leaving them to raise their children without necessary resources and daily services that are present in more populated areas (Hoogsteen & Woodgate, 2013).

Family Systems Theory

A plethora of research exists on ASD but there have been no research studies that have explored the lived experiences of parents of autistic children who have lower incomes. In this study, we addressed the personal

and individual accounts and beliefs of mothers raising children with ASD, and the lived experiences of these mothers, as well as their stress and marital satisfaction while raising children with ASD from a family systems perspective. Cridland et al., (2015) pointed out that family systems theory should be incorporated when working with families who have a child with a disability such as ASD because each member has a specific role within the family system, and roles may change as members assume more responsibility to care for the child.

The family is a system, meaning that when one person is not functioning well (e.g., has received a diagnosis of ASD), it has a direct impact on the rest of the family members who may experience challenges such as changes in daily routines, lack of spontaneity, the presentation of sudden mood changes in the child with ASD, and the need to serve as mediators in social interactions (Cridland et al., 2014; Cridland et al. 2015; Goepfert et al., 2015; Neely-Barnes & Dia, 2008). The three major characteristics of ASD include deficits in the areas of social interactions, communication, and repetitive behaviors, and all three may have a direct impact on family members, especially the parents who experience unique stressors as they cope to manage the symptoms of ASD. The family is a system, in which each person serves a role and when a person has a disability, it can mean that members within the family system may have to change their roles to accommodate the person with the disability (Goepfert et al., 2015). Cridland et al., (2014) pointed out that about one-third of individuals with ASD require daily assistance with self-care, mobility, communication, and cognitive or emotional tasks (e.g., ways in which the child with ASD either expresses his or her thoughts and feelings or does not express them at all, leaving the parents to try to figure out how to fulfill the child with ASD's needs), which leads families to experience higher levels of stress overall.

What happens in a person's environment can have a significant impact on their physical and emotional well-being. Parents are reported to experience a host of medical (Borrell-Carrio et al., 2004) or psychological problems (Bayat, 2007; Benson & Dewey, 2008; Schieve et al., 2007), including anxiety and depressive disorders (Bolman, 2006; Cappe et al., 2011) due to their striving to understand and accommodate the specific needs of the child with ASD (Lakhan, 2006). Cridland et al. (2014) identified several challenges for families with a child who has ASD. For example, relying solely on the mother's perspective as indicative of other family members' perspectives may lead to family or marital discord, particularly amongst the couple who may share different perspectives. Parental conflict could lead to increased sibling adjustment problems as siblings may have to renegotiate their roles in the family, including sharing their time and attention with the child with ASD, which may alter the other children's social and family activities since the child with ASD may require more parental attention.

The parent's experience within the family system can be impacted by environmental, physical, or emotional factors with the potential for dysfunction as adjustments are made to accommodate the needs of the child with ASD (Lakhan, 2006). Each family member undertakes a unique role and set of responsibilities within the family. According to Cridland et al. (2014), when a child within the family has a chronic illness or a disability such as ASD, parents assume the bulk of the household and caretaking responsibilities. In the same study, some parents transferred household responsibilities to others in the family to allow themselves more time to meet the demands of caring for the child with ASD (Cridland et al., 2014). We used a family systems theoretical approach to focus on ways family members interact with other systems, such as the community, other families, schools, and social groups, all of which are important subsystems within the family (Cridland et al., 2014).

As family members of a child with ASD take on additional responsibilities and step into roles they may not ordinarily fulfill in a family, stress can increase and thus lead to higher levels of psychological problems, more emotional reactivity instead of problem-focused coping strategies, and more family conflict overall. Cridland et al. (2015) reported that this is particularly likely for older sisters, who often assume additional responsibilities to help their parents in caring for the child with ASD. Also, families of children with ASD often must work with a variety of service providers (e.g., doctors, speech and occupational therapists, teachers, and

other specialists) which can impose time demands and reduce the family's opportunity for social activities, thus exacerbating feelings of frustration (Cridland et al., 2015).

Although it is apparent that ASD requires extensive and expensive treatment and support, it is unknown how low-income parents experience raising a child with communication deficits or how low income and ASD affect the family system. Providing low-income parents the opportunity to share their feelings, express their concerns, and suggest possible solutions for coping with an uncommunicative child has the potential to enhance the understanding of professionals and other parents living with these difficult children. The research question for this basic qualitative study was: What is the lived experience of low-income parents of a child with ASD?

Method

Participants

Upon approval from the university's Institutional Review Board, participants were recruited using a flyer posted on a local college campus, on social media in online ASD support groups, and shared within the first author's social network. Participation was open to both mothers and fathers who have lived with their child for at least one year after receiving a diagnosis of ASD; however, only mothers volunteered in this study. Interviews continued until saturation was reached at 13 female participants, who met all the eligibility criteria for participation in this study; one had two children, one age 4 and the other, age 10, both of whom have ASD, thus making a total of 14 children.

Procedure

Interested participants responded to flyers by requesting more information when they contacted an email address set up specifically for this study. Although the study was open to both mothers and fathers, only mothers of children participated. After receiving emails of interest for participation, eligibility prescreening forms were emailed. To determine eligibility, children must have been between ages 4 and 10; a child must have been diagnosed with ASD for at least one year; parent must have lived with a child at least one year after the ASD diagnosis was received; and parental annual income must be equivalent to or below the federal poverty level based on family size. Two interested participants were excluded because their income was higher than the federal poverty level based on their family size and one was excluded because the child had not yet been officially diagnosed with ASD. Upon receipt of these completed forms, we scheduled a telephone interview with those eligible to participate and mailed consent forms with a self-addressed, stamped envelope to sign and return. Once received, participants were sent another email with the option of conducting the interview in person or via telephone. Three participants chose to meet in person in a private room at a local college library and the remaining nine participants chose to be interviewed via telephone. After consenting to the study and giving permission to digitally record the interview for transcription accuracy, each participant was interviewed individually.

Analysis

All responses were recorded with permission from participants, and we later transcribed the recordings into a Word document. To analyze the data, we used a content analysis table for each interview question to categorize participant responses (see Appendix A for a list of interview questions). In the content analysis table in Word, we created and divided the table into three columns. In the first column, we coded the identified participants by their first and last initials; the second column included participant answers to the interview question, and a third column was left blank so codes and emerging themes could be listed. Key

words, phrases, or emerging patterns, as well as the main point of each individual's quotes were recorded as codes, particularly words repeated by participants. There were 12 tables, one for each interview question, which allowed codes and emerging themes to be easily identified from each answer and for each interview question. Themes were identified by highlighting reoccurring or similar code words in parental feedback to detect similarities and differences, underlying meanings, correlations, or trends in parental experiences that led to the development of themes and the establishment of trustworthy conclusions.

Results

As shown in Table 1, the ages of the 13 participants ranged from 22–50, with a mean age of 33.6 years. Four (30%) of the participants were African American. Three (23%) completed high school, four (30.7%) 2 years of college, five (38.5%) some college, and one (7.7%) graduate school. The majority (eight or 61.5%) were not employed outside the home, three (23%) worked part time, one (7.7%) both part time and full time, and one (7.7%) full time. Incomes ranged from less than \$10,000 a year (two or 15.3%), four (30.7%) were between \$10,000–20,000, one between \$20,000–30,000 (.05%), and three (23%) over \$30,000. The children with ASD ranged in age from 4–10, with an average age of 6.8 years. All but one of the children were male (92.3%).

Emerging themes indicated that due to the costs involved, many parents were unable to provide various treatments that might be helpful to their children. For example, some parents indicated that they had either tried or considered equine therapy but were unable to acquire or continue with the therapy due to the high costs involved, especially since equine therapy was not covered by insurance. Nine participants indicated that income was a factor in their ability to raise their children with ASD and 10 reported difficulties in acquiring resources such as speech and occupational therapy outside of the school system, even though they believed their child would do better with additional services.

Lived Experience

The essence of raising a child with ASD was described with the words “stressful,” “overwhelming,” and “emotional.” Participants were able to describe their children in a positive manner such as (e.g., “a loving, sweet, sensitive child,” “the sense he has is just ridiculous compared to other kids his age,” “very playful and he likes kids,” “very smart and highly, I mean highly intelligent,” “amazing. He is very smart in math.”). Themes related to challenges that were shared included parental stress, some of which was attributed to inadequate incomes and the inability to provide necessary resources for their children, difficulty understanding their child's needs due to communication deficits, social isolation and separation from extended family members, unsupportive community responses to ASD, and differences in parenting techniques and understanding of ASD by spouses, which harmed the marital relationship.

All participants described the positives and negatives of raising a child with ASD and a common theme among all participants was it is “stressful” and “challenging” and requires “a lot of patience” and is a very “emotional” experience, especially as “behaviors get worse” and as the child gets older and lacks appropriate social skills to form close friendships with other children.

Table 1: *Demographic Characteristics of Parents of Children with Autism Spectrum Disorder*

Sub Initials	Mom's Age	Ethnicity	Education	Employed*	Annual Income	# Children with ASD	Age of Child	Child Gender
JB	43	AA	2 yrs. College	NE	<\$10,000	2	4/10	M/M
AC	28	C	2 yrs. College	NE	<\$10,000	1	4	M
AD	34	C	Some College	NE	\$30,001-40k	1	9	M
JD	34	C	Some College	NE	\$10,001k-\$20k	1	5	M
MD	30	C	Some College	NE	\$10,001-\$20k	1	5	M
CG	37	C	High School	FT & PT	\$10,001-\$20k	1	10	M
MF	34	C	High School	NE	\$20,001-\$30k	1	8	M
CH	28	AA	High School	NE	\$20,001-\$30k	1	4	M
BJ	32	C	2 yrs. College (AA)	PT	\$30,001-\$40k	1	7	M
AP	30	C	Graduate School	FT	\$40,001-\$50k	1	4	M
BS	50	C	AAS Nursing (2 yrs. College)	PT	\$10,001-\$20k	1	10	M
CW	35	AA	Some College	NE	\$20,001-\$30k	1	10	M
BW	22	AA	Some College	PT	\$10,001-\$20k	1	5	F

*Employment: PT = Part Time; FT= Full Time; NE = Not Employed

Daily Experience

Participants described their daily experiences of raising a child with ASD. Participant initials were used to maintain confidentiality. One participant not only has a child who has been diagnosed with ASD but during the diagnostic process, her husband was also diagnosed with Asperger's Syndrome. She described her daily experiences as follows:

It is hard.... it is very hard. My part-time job is that I am a family support partner for families who have children with mental disorders, and I have my ASD support group for parents of kids with ASD online. When there's a meltdown or he's upset it's heartbreaking because he cannot tell you what he needs so you can fix it; you just have to wait until it gets better. His improvements over the years have made it better but it's still hard. He is a very loving child, but he doesn't like to show affection because

it is very uncomfortable for him and my husband is the same way... so it is very lonely it's very lonely.
(JD, age, 34, married, son, age 5)

Another participant described her experiences as sometimes being sad to watch, especially when her son is left out because he cannot play with his same-aged peers because he is so slow in figuring out what they are doing. This participant described her son as:

capable of playing “next to” others and not “with them” because he has processing disorders and a social-communicative disorder, by the time he figures out what the other child is doing, that child is done and has moved on to something else. He reads emotions and feelings but because he's almost always overloaded on sensitivity to where I cannot cry because I am not allowed because it will upset him. If I am having a disagreement with someone or if I get angry and start to cry or get too loud, he gets upset on my behalf. (AP, age 30, Never Married, son, age 4)

Another participant described her daily experiences as follows:

Some are really bad days, all day to me, some days we have really good days. She is very meticulous about some things to me; she likes her routine; she has to have a routine. So, when we do things off her routine, she gets really upset. We have a routine and I try to stick to it much and I can. (BW, age 26, Never Married, daughter, age 5.)

Another participant described her child as having a difficult time leaving the house, especially in the mornings for school because he does not want to leave so he tries to waste time.

It is very stressful because he does not understand feelings; he cannot tell a joke from the truth so you have to be very serious with him. Everything has to be on a routine; if you do not show up at 5 o'clock to get him, he panics. He likes structure and routine and if he does not have it, we will have issues!... He will have a meltdown! We cannot go anywhere because getting him to leave the house is like pulling teeth. In school, he had to repeat the third grade because he was behind in math. He gets numbers mixed up in his head. This year, so far, everything is going fine at school and it's much better now than it was in the previous years. (MF, age 34, Married, son, age 8)

Household Income

When asked to describe the relationship between their current household income and their ability to raise their child with ASD, 10 respondents indicated that income was a problem when it came to providing for their child. Three respondents either lived with others who helped financially, or they had their own private insurance that helps cover some of the expenses involved with caring for a child with special needs.

It's real hard.... The children get disability, SSI, and the amount they get each month.... by the time, I buy food out of their income, and the medicines they are on, so that little bit left of the income goes to buy groceries and then they gain weight so I constantly have to buy new clothes... and they love electronics.... So, I have to buy things to keep them occupied... (JB, age 43, Married, has two boys, ages 4 and 10; both have ASD.)

If money were no option, some of the additional services participants would like to increase or obtain for their children and their families include specialized daycares, more speech, occupational, and physical therapy, music and art therapy, more resources in the schools, equine therapy, and more counseling for parents. One participant recommended increased funds for athletic programs and electronic toys, while another participant recommended the legalization of cannabis oil “just to try to see if it helped anything.”

With the income thing... it is kind of a big problem.... It's very stressful on my marriage; it's very stressful on a lot of things.... it's very stressful for me.... I have real bad anxiety now, ... my financial problems come into effect. We only have one vehicle due to financial problems. Our rent gets 6 to 8 months behind and we end up owing lots and lots of money because we cannot pay our rent on time, so... knowing that you are just getting more and more behind in rent is just not a good thing. (AC, age 28, Married, son, age 4)

Trying to pay for his medications and everything is hard. I'm in the process of trying to find a second job. His medications can range each month from \$100 to \$120, depending on what he needs and what he is out of in terms of his prescriptions. (MF, age 34, Married, son, age 8)

It's very hard... I try to have a job where I can have some flexibility... I get paid more than minimum wage so I do not feel I cheat myself out of what I can do... I just know that because I am her caregiver, I do a lot of things that are very unrealistic. (BW, age 26, Never Married, daughter, age 5)

Strengths

Participants were asked to identify any strengths they feel they have developed as parents of children with ASD and indicated unanimously that patience is a must. Other strengths mentioned included becoming a kinder, more empathic person towards others who have special needs, flexibility in learning new coping strategies to decrease their own frustration levels, becoming more personally resourceful in terms of increasing their knowledge of ASD, becoming a better listener, becoming more loving, and learning how to become a better advocate at school, in the community, and even in their own families to educate others about the needs of their child and the unique symptoms of ASD.

Weaknesses

Weaknesses identified by parents included increased or the development of parental anxiety, short tempers, not just with their children, but more so with members from the community who lack an understanding of autistic symptoms and the special needs of a child who may be exhibiting behaviors the person may not understand and think are simply the result of poor behaviors or poor parenting skills. Another weakness was being overly sensitive when others criticized the child or when the child was compared to same-aged typically developing peers, being more emotional and crying more easily, sometimes due to not being able to communicate effectively with the child to determine the child's needs, or just out of sheer frustration in not being able to do more to help the child progress. The one element that most parents agreed they could use more of was sleep, as many fail to get adequate sleep consistently because they worry about their child getting up in the night and perhaps leaving the house or because their child experiences sleep problems as well and the parent has to monitor the child closely to ensure his or her safety.

Support and Marriage

BJ was the only participant in the study who actively participated in a support group for parents of children with ASD, although there are many local and Facebook groups available. Nine of the participants stated that their children are with them most of the time, thus making it difficult for them to be involved in community support groups. Most of the participants in the study turned to friends and family members for support. One participant, CW, viewed her son's ASD in a much more positive light than the other participants and stated that "most people cannot even tell." Family and friends were described by participants as having a limited understanding of their life with ASD, and most participants described feelings of frustration about perceived judgmental attitudes of those outside of their home. All 13 participants described life with limited or nonexistent social relationships with anyone outside their family or work for those who were employed.

When asked to describe how ASD had affected her personally, JB (Married, age 43, two children, ages 4 and 10) stated,

Actually, it delayed my career. I had to stop working. I became very depressed. I lost all my friends. My marriage went downhill. I kept telling their Daddy that something was wrong with (the children) but he kept saying no, nothing was wrong. It hurt me because I am the mother and a mother just knows about her children.

JB stated that it was not until her husband had to stay with the boys while she was at work and at school, that he realized that something was really wrong with the boys. She stated that “counseling has helped” and that it has “helped their marriage overall.” AC (age 28, Married, son, age 4) reported:

I’d say (ASD) has kind of impacted our relationship a lot because I get stressed out and it’s kinda stressful. For me and my husband, we don’t see things eye to eye and you know, it’s kinda of different with him because he operates differently than I do or whatever. Our marital relationship or whatever.... we are not on the best of point right now with that.

AD (age 34, Married, son, age 9) reported “My husband and I have been together for 18 years. We started dating when I was 16 and we got married when I was 22 and then I had my son when I was 25 or so.” When asked if she and her husband ever got time to themselves, she responded “once or twice a month” when her supportive parents helped out with the children.

MD (Not married, age 30, son, age 5) was not married at the time of the interview but stated that she does believe ASD had an impact on her previous marriage because of the energy it took to meet the needs of her son. She stated that “all of my attention was on” my son because of his behaviors. “If we went somewhere and he got a bad vibe, like in a grocery store, he would go crazy and start to scream and it was really tough.” She stated that she believed her ex-husband was better able to handle the stress of raising a child with ASD because “he was at work all the time.” She denied any impact of ASD on her marriage.

When asked to describe the impact that raising a child with ASD has had on her marital relationship, MF (Married, age 34, son, age 8) responded that “it’s been a strain because we bump heads sometimes, but it makes us stronger.” She reported their differences are over their son and stated that because her husband has ADHD himself, he and their son “sometimes bump heads so I am like the mediator between the two of them.”

BJ (Married, age 32, son, age 7) reported that her husband was diagnosed with Asperger’s about the same time that her son was diagnosed with a Pervasive Developmental Disorder and, because of that, she stated that “my husband took my son’s diagnosis a lot harder than I did because, to him, it was his fault because all the studies show that it is genetic” and he thought that his son was on the spectrum because he was on the spectrum himself. She stated that ASD does “wear on my energy levels” and that she “gets sick more often than anyone else in the house,” but she realizes that in addition to being a parent, she also works two jobs to help pay bills and to meet the needs of her child. She stated that it has taken a toll on her personal life and that “you wouldn’t believe how many people just back away from you when they realize you have a special needs child, so it’s worn on me physically and mentally.... it’s tough.” She stated that she and her husband have been married for 10 years but they do not argue often. She believed that much of the frustrations she and her husband experience are due to having to juggle responsibilities to accommodate their work schedules, as well as their son’s schedules.

AP (Divorced, age 30, son, age 4) reported that her ex-husband “doesn’t like me to use the word ‘ASD’ around our son and he is opposed to me having him evaluated at all.” Her frustrations with her ex-husband include the fact that he denies anything is wrong with their son. She and her husband divorced when their son was 13

months old but reported that he sees his father about twice a year since he lives in another state and that they call each other on the phone a couple of times per week.

CW (Divorced, age 35, son, age 10) stated that when she was married, ASD negatively impacted their relationship. She stated, “he was one of those dumb, country people that don’t believe anything is wrong and that a child shouldn’t take medicine and that you can just whip it out of him.”

BW (Never Married, age 26, daughter, age 5) was not married at the time of the interview but has a significant other and stated that they have discussed marriage. She does not believe ASD has impacted their relationship but does state that “sometimes it’s hard because I don’t think he understands either; even though he goes to some of the appointments and specialists too, he is like, “she’s okay...it’s just the way you present it.” BW reported that her daughter has mild symptoms, but she does not believe that her significant other is in denial because “he has been there since she was about 5 and wasn’t talking and not walking.... he has seen her progress.”

Discussion

The present study confirmed DePape and Lindsay’s (2015) observation that parents of children with ASD often experience increased financial risks compared to parents of typically developing children because they often have to pay for services out of pocket or may have to travel or move to areas with specialized treatment providers. The participants being low-income, the financial issues were intensified, with most participants reporting daily hardships and frustration with not being able to provide needed services to the child. All participants in this study reported annual incomes of less than \$42,000 and 77% indicated that income is a factor in their ability to raise their child with ASD because it adds to their overall stress level for the same reasons it would for any other parent, but also because it limits the frequency and types of resources they can provide for their children to ensure a better quality of life overall. Only one 4-year-old child had not yet received services, although his mother reported that he needs speech therapy. The remaining 92% were currently receiving or had received speech and occupational therapy, and only one had received physical therapy. One child had received music and art therapy although the parent-reported she does not have the money to continue those services. Two parents reported that equine therapy had been recommended to them by therapists or physicians but is not covered by Medicaid, insurance, or other financial providers, so none of the children are currently participating in equine therapy. Other therapies that were recommended included specialized daycare, counseling for the family, education for parents on ASD, ABA therapy, social skills and behavioral therapies, cannabis treatment, music and art therapy, summer camps, and more resources in the school system.

DePape and Lindsay (2014) found that parenting a child with ASD has a profound impact on family life, including roles and responsibilities that parents assume, especially when the child has abnormal communication, repetitive and restrictive interests, and impaired social functioning. One parent in the current study had two children with ASD and appeared to be the most distressed of all participants, particularly given the severity of symptoms of her oldest child, who has been hospitalized on three separate occasions due to his aggressive behavior toward his mother and his grandmother. Consistent with Ingersoll (2010), who reported that communication problems presented the most challenges for parents raising children with ASD, nine participants agreed that communication deficits, particularly when a child is non-verbal, were the most challenging issues because they do not always understand when the child is in pain or what the child wants, which they believe leads to a meltdown. One parent pointed out a huge distinction between a tantrum identified as misbehavior that a child engages in when he or she does not get their way and a meltdown which she described as the result when a child with ASD has no way of clearly expressing their frustration as they attempt to express their needs, including pain, or wants to their parents.

Eight participants reported that their child's autistic symptoms have hurt their social relationships outside of the home, as well as their marital relationships; the three participants who were currently divorced reported that ASD was a factor. For example, all three indicated that differences in parenting styles, as well as their husband's denial of the autistic diagnosis for their child, was a significant factor involved in their decision to divorce. These findings in the current study are consistent with Hartley et al. (2012) who reported that stress and depression can negatively impact marital satisfaction in couples.

Participants described family and friends as having a limited understanding of their life with ASD, and most participants described feelings of frustration about perceived judgmental attitudes of those outside of their home. All 13 participants described life with limited or nonexistent social relationships with anyone outside their family or work for those who were employed. This is consistent with the family systems perspective; Cridland et al. (2014) suggested that some families may struggle with boundaries in understanding overall family functioning, especially in terms of the permeability of boundaries, which is necessary for managing life events such as job changes or family members moving in and out of the house. This was observed with participants JB, JD, and AP. For example, each family expressed a fair amount of chaos, with JB's being the most severe. JB stated that a great deal of her frustration stemmed from her husband being in denial about her children's diagnoses; although once he realized that both boys had ASD, he began to better understand some of her daily frustrations. Still, JB and her husband struggled with establishing boundaries to reduce some of the chaos in their family.

JD expressed some chaos but has learned to utilize outside resources such as speech therapy, in addition to what her child receives at school. JD seemed to have established some boundaries and believed that having another typically functioning child in the home has helped her to manage her child with ASD. AP struggled with feelings of hopelessness and stated that it is difficult to watch him play because he tends to play by himself as he is unable to respond to other children in the way that he should so the other children drift away from him and he ends up playing alone. AP appeared to have established some effective boundaries with her child but was quite protective of him, perhaps because he also suffered from some health issues stemming from a premature delivery.

Families who function at their optimal levels develop a balance between open and closed boundaries. These families are flexible in their roles and responsibilities and communicate with each other regarding personal needs, but those families with poor boundaries may experience more problems regarding family functioning overall. CG is a single mother who lives with her parents and her child with ASD. She appeared to be one of the most well-adapted of all participants, possibly because she has the support of her live-in parents to help with her child. CG reported that her son goes everywhere with her and that she has taught him that when they are out, and he becomes overstimulated by the environment, to use his earplugs and to watch a video to keep his mind occupied.

Cridland et al. stated that some parents may expect more from siblings regarding household chores or caregiving responsibilities, roles that are typically assumed by parents. This was not observed from the current study's participants. JD, CW, and AD all stated that they try to spend quality individual time with their typically developing children and are very aware of not trying to "put more responsibility on them."

Cridland et al. stated that families who fail to establish effective boundaries run the risk of becoming enmeshed, especially when the parent is unable to view their own lives independently from the experiences of the child with ASD. Several families appeared to struggle with enmeshment, irregular boundaries, or seemed unable to separate their lives from the lives of their children. For example, JB only attended school when her children were in school. If the children were out of school for any reason, she reported that she was unable to attend classes herself. She also quit her job to attend to the needs of her children.

MF seemed to struggle with enmeshment as she reported that she does not leave her child with others and that she only goes where he goes; if he cannot go, she does not go. MF and her husband even purchased a new four-door car because her son did not like to ride in the back seat of the two-door car they had been driving. MF stated that her “life centers around him.” BS is a registered nurse but stated that due to her son’s behaviors, she “cannot work” full time, although she can work some “on a very part-time basis.” BW works part time while her daughter is in school.

Families who struggle with ambiguity may experience mixed feelings as they hold on to hope that a cure will be found versus feelings of hopelessness which can lead to increased frustrations during difficult times, including mixed feelings of love, pride, and joy, or feelings of guilt because of these same negative emotions. Several parents expressed some feelings of hopelessness, or perhaps some mixed feelings about their child’s diagnoses, especially as the child ages. For example, MD stated she does not trust others with her child and is “always with him.” AP reported that it is difficult raising a child with ASD and that when she cries, her son “does not understand why” she is crying. JB reported feelings of hopelessness, and perhaps some guilt, as she stated, “I am the mother; I’m supposed to know what to do for my children, but I don’t know how to help them.” She also pointed out that because of their behaviors, as they have gotten older and as their behaviors have “gotten worse,” she no longer has her mother to help her out because her mother “cannot handle them.” JB feels that the only support system she has is a friend or two at school who also have children with ASD, but, outside of school, she does not feel that she has any support.

When families can make time for each other individually, including the child with ASD, manage daily routines and chores, adopt flexible roles, utilize support services, and openly communicate with each other, particularly during challenging times, they are capable of being resilient and, despite the diagnosis of ASD, they can grow as a family, as well as individually, as they learn to understand and accept having a family member with ASD (Cridland et al, 2014). An assessment of all participants illustrated that JD and CG demonstrated more flexibility in their roles than other participants, with more established daily routines and the ability to seek resources beyond those provided in the school system. For example, CG’s son plays baseball at a local recreation department and JD started her online support group for parents of children with ASD. JD has also developed photography skills that allow her to photograph her child without the use of a flash, which she has found aggravates ASD. These participants appeared to be well-adjusted in terms of their daily routines and seemed to have open communication with each other, as well as those outside the family, and about ASD and their child’s individual needs. JD appeared to work in partnership with her spouse to provide for their children’s needs and reported that while her husband regrets that his son is unable to “do boy things with him, such as hunting, playing ball, etc.,” that he tries to spend “one-on-one quality time” with each of their children individually so “neither of them feel left out.”

Limitations of the Study

A limitation of the current study was that participants were all mothers. Results may differ if fathers had participated or if only fathers were interviewed, as their perceptions may differ from the mothers who participated in this study, particularly those who assume primary responsibility for the child with ASD’s overall and daily well-being.

As opposed to face-to-face interviews, the use of telephone interviews had several disadvantages as body language and facial expressions were unable to be observed during the interviews and tone of voice and inflections had to be relied upon to determine emotional distress. Because telephone interviews were conducted at convenient times for the participant, some had to stop to address the needs of their child during a conversation, which extended the time needed to complete the interview.

Recommendations

Given the stressors associated with the specific symptoms of ASD, more emphasis could be made by professionals to educate parents and to provide professional services to include individual and family therapy to address any mental concerns that may develop during, as well as after, a diagnosis of ASD has been received. Also, a list of available services and resources, including referrals to local and online support groups for parents of children with ASD could be provided to parents to help decrease their stress and frustration levels as they learn about ASD and its effect on their child and explore the most conducive resources for their child. Future research could address the differences in parental psychological and physical well-being when resources, including income, are adequate or plentiful.

Several participants indicated that having a child with ASD has impaired their ability to work or to work as frequently as they did before the child was born because of a lack of specialized daycare due to the symptoms of ASD. Future research is needed to determine how specialized daycares could benefit society as parents of children with ASD may be able to return to the workforce as full-time employees. Also, future research could assess the benefits of respite care for all parents of children with ASD, even those who chose not to work outside the home.

Given the unique symptoms of ASD and the impact that raising a child with ASD has on the nuclear family, opportunities exist for mental health professionals to work in partnership with other professionals, as well as with parents, as a team to develop programs that can address both the needs of parents and children with ASD, particularly for low-income parents. Although many parents may be initially unfamiliar with ASD, parents know their children and families better than others and may be instrumental in the development of the most conducive programs to improve overall family functioning and satisfaction which could lead to significant social change as low-income parents of children with ASD may develop improved self-esteem, higher levels of confidence in knowing that they have contributed positively, regardless of their income levels, and that their voices have been heard. This may also encourage more social interaction which would decrease their feelings of social isolation and may, in turn, eliminate or decrease levels of depression as they are taught to participate and to advocate more for themselves and their child's needs.

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Appendix A: Interview Questions

1. Tell me about your child. Include the quality of your pregnancy, the birthing process, to whom you first turned once you suspected a problem, who diagnosed and at what age, and how long it took to receive a diagnosis of ASD.
2. Describe your daily experiences of raising a child with ASD.
3. How did you get your education on ASD?
4. Describe your relationship between ASD and your income.
5. ASD affects everyone differently in terms of the three primary symptoms of communication deficits, social deficits, and repetitive behaviors. Tell me how these three symptoms have affected your child and which one(s) has been challenging? Describe changes in these symptoms over the years, if any.
6. Describe your child's communication abilities and any struggles that you experience as a result.
7. Describe the impact ASD had on you as a parent personally, physically, psychologically, and socially.
8. Describe how ASD has impacted your social and professional experiences outside the home, including extended family members and friends.
9. Describe any resources your child is currently receiving and the impact this has had on you both. If money were no option, what resources would you add and why?
10. Describe the impact that raising a child with autism has had on your marital relationship. What changed? When you are feeling overwhelmed, what coping techniques do you use? When your spouse is feeling overwhelmed, what coping techniques does he/she use?
11. Describe your family's level of functioning when your child with ASD is away (e.g., in respite care, at school, with extended family members, etc.).
12. Describe any strengths you feel you have developed as a parent of a child with ASD. Describe any weaknesses. Is there anything else I did not ask that you would want others to know about what it is like to raise a child with ASD?



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