

2021

Advocacy, Intervention, and Coping: A Qualitative Study of High Functioning Autism from a Mother's Point of View

John Rausch

Follow this and additional works at: https://collected.jcu.edu/fac_bib_2021

 Part of the [Psychology Commons](#)

ADVOCACY, INTERVENTION, AND COPING: A QUALITATIVE STUDY OF HIGH FUNCTIONING AUTISM FROM A MOTHER'S POINT OF VIEW

Mothers' views of their experiences with their child with high functioning autism (HFA) have not been thoroughly investigated in previous research. Thirty mothers of children with high functioning autism participated in a semi-structured interview in the present qualitative study. The collected data were generally coded into five broad categories: diagnosis, intervention, social dynamics, advocacy, and coping skills. Diagnosis of HFA typically was not made until ages nine to 13. The participants created individualized interventions that were reality and strengths-based. Social dynamics included both the child's social interactions with peers and the social dynamics within the family system. The participants related having to advocate for their children with HFA with school, social service, and medical professionals. The participating mothers also found their own techniques for coping. The present study provides insights into mothers' experiences with each of these areas that would be useful for professionals to understand when working with families who have children with HFA.

There is much debate among professionals as to the nature of the disability in high functioning autism (HFA). While some people claim that there is a real severity to this diagnosis, others claim that HFA should be recognized as a "difference" rather than a disability (Baron-Cohen, 2002). This idea of "difference" tends to take the negative labeling off of individuals with HFA, freeing them from the stigmatizing perception that they are incapable and powerless. Regardless of how HFA is labeled, it is generally accepted that this diagnosis carries

with it a multitude of difficulties including communication barriers, inability to read social cues, and social isolation that these individuals must overcome in order to feel like they are contributing members of society (Muller, Schuler, & Yates, 2008).

Those youth with HFA may have been previously diagnosed with Asperger's Syndrome (AS) by the DSM-IV-TR guidelines (American Psychiatric Association [APA], 2000). Nevertheless, the authors of the DSM-IV-TR did not comment on the quality and style of communication of children with AS. The authors of the DSM-5 (APA, 2013) looked to remedy this issue by reducing the three dimensions of behavior as described in the DSM-IV (i.e., deficits in social reciprocity, deficits in communication, and presence of restricted, repetitive behaviors and interests) to two domains: social communication/social interaction and restricted, repetitive

behaviors and interests (Lord & Jones, 2012). Because most individuals diagnosed with HFA function within the average parameters of cognitive development, this disability often remains “hidden” or undiagnosed until a later age. HFA is rarely diagnosed before the age of six, although parents of children with HFA will generally confirm that their child did show signs of social impairments as early as toddlerhood (Baron-Cohen et al., 2006). Other authors conclude that this diagnosis may not be given until children are, on average, between nine and 11 years old, and suggest that it may not occur until as late as adulthood (Gray, 2003; Scott, Baron-Cohen, Bolton, & Brayne, 2002). Having a late diagnosis is very disconcerting since the results of other research demonstrate the negative, long-term impact a late diagnosis of HFA can cause. Some consequences of late diagnosis are poor communication skills, negative peer interactions, psychopathology, and social ostracization (Muller et al., 2008; Scott et al., 2002).

A key concern for mothers of children with HFA is social isolation. Youth with HFA have difficulty regulating their interactions appropriately in social settings which causes substantial concern for parents when taking their child on public outings. For example, Lee, Harrington, and Newschaffer (2008) indicated that families with children with HFA are 70% less likely to attend religious services once a week and participate significantly less in extracurricular activities than families without an HFA diagnosis. They also concluded that parents have substantial concern for their child’s ability to interact socially and believe their child has a diminished quality of life (Lee et al., 2008). This concern is especially true when the child with HFA has more extreme behavioral issues, aggression, and violent outbursts. Thus, parents tend to limit their social contact to others who are empathetic of their child’s disability and avoid going to public places. This reluctance to go into public places increases the family’s sense of isolation (Gray, 2002). It also contributes greatly to a mother’s sense of her own social isolation as a way to avoid these negative attitudes and cynical estimations of her character (Kim, Kim, Kim, Nichols, & Kang, 2020; Kim, Kim, Voight, & Minjoon, 2018; Pisula & Porebowicz-Dorsmann, 2017; Ryan & Cole, 2009).

Not only does the family experience an extreme sense of isolation, but parents also expressed worry and embarrassment regarding how they are perceived by outsiders when their child misbehaves (Gray, 2002; Kim et al., 2018; Lee et al., 2008). Parents felt that others judged them to be bad parents and rejected them as parents, deeming them to be failures in maintaining the family unit. This sense of stigmatization extended greatly to the mothers who felt that they were perceived even by their husbands to be the parent liable for the child’s difficulties. Mothers, in general, were also more likely than the fathers to deal with the child in public settings and were more sensitive to the public’s reactions to their child’s behavior. Most commonly, this social stigma occurred through evasion since outsiders tried to circumvent any interaction with the child or the child’s family. However, parents experienced more extreme stigmatization from others in the visible forms of blatant, rude stares and impolite remarks. This stigma even occurred at times when the parent was not with his or her child but others perceived them differently simply because of their association with the child (Gray, 2002; Jackson, Keville, & Ludlow, 2019; Kim et al., 2018, 2020).

Since mothers have a protective instinct for their children, they are often thrust into the role of advocate for their child (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2018). They often feel as if they are called upon to battle for the equal treatment of their child (Boshoff, et al., 2018). The nature of advocacy for mothers of children with HFA is not simply defined as speaking on behalf of their child. Advocacy is linked to a form of activism on the child’s behalf in that mothers fight to ensure their child is not misrepresented, to encourage their child’s ability to succeed, and to guarantee their child is given the best prospects there are to offer (Ryan & Cole, 2009). Researchers have not discussed how advocacy develops in mothers over time. Understanding how this advocacy develops is a central feature of the present research study.

While mothers go through a mixture of emotions throughout their experiences raising a child with HFA such as sadness, depression, guilt, and grief (Gray, 2003; Medina, Rios, Aleman-Tovar, & Burke, 2020; Schnabel et al., 2020; Tsermentseli & Kouklari, 2019), research

findings show that mothers develop strong coping skills throughout this process. Gray (2003) distinguished two core coping methods mothers utilized in order to deal with their child's disability. The first method involves the mothers taking a proactive approach in dealing with their child by attempting to foresee potential problems and ameliorate those issues before they escalate to an extreme level. The second approach, in contrast to the previous method, is to deal with the child's disability one day at a time, placing their interventions on a needs-focused basis. Gray (2003) also demonstrated that mothers felt that a strong support network of friends, family, and spouses were especially helpful in order to vent their daily frustrations and feelings. Last, Gray (2003) found that religion plays a key role in coping strategies. In a different study, Gray (2006) noted that coping strategies evolve over time as mothers adapt to the restricted routines their child imposes, the child overcomes some of their more difficult behaviors, and both parents accept the permanence and longevity of the disability.

Topics addressed in the current study cover a variety of issues mothers deal with in raising a child with high functioning autism. While many researchers note the lengthy diagnostic process, issues of misdiagnosis, and the increased stress levels parents encounter through this process, they do not detail how this process occurs, nor the long-term effect this process has on the overall family system (Gray, 2002, 2003; Lee et al., 2008). There is also a paucity of research regarding the role and development of parental advocacy and how mothers approach this issue. While social isolation and stigma are often noted, their overall consequences on the family system and inter-relational dynamics are often overlooked. The present study seeks to discover how mothers develop coping skills over time in order to cope with the challenges presented as a result of having a child with HFA.

Method

Mothers were specifically chosen for the current study for several reasons. First, previous authors demonstrate that mothers tend to be the parent designated as the primary caretaker of a child with HFA (Gray, 2003; Ryan & Cole, 2009). Being the primary caretaker means that these mothers take the lead in the diagnostic

process, the lengthy referral process, and intervention strategies. Second, mothers also tend to be the parent who is more likely to venture into public outings with their children and thus deal with any negative experiences that sometimes accompany these outings. Third, mothers have a higher potential to experience the role of the mediator for their child when dealing with healthcare professionals, school administrators, and in extracurricular activities. Last, mothers tend to be the parent who is held accountable for maintaining the public image of a healthy, functioning family unit and preserving household order between family members (Gray, 2002, 2003; Ryan & Cole, 2009).

Participants

We recruited participants through purposive and snowball sampling from a large metropolitan area in the Midwestern United States. We selected mothers with children between the ages of 12-30 who were diagnosed with HFA. We conducted the initial purposive sampling through various community programs upon referral from the directors of those programs. We also recruited participants through three local school districts. In regards to the snowball sampling, the initial participants we recruited from the community programs and school sites were then asked if they would pass along the study information and consent forms to any other families they knew with a child diagnosed with HFA. The snowball sampling proved helpful in recruiting mothers from other cities, mothers who homeschooled their children, and mothers with children older than the high school level.

Sample Description

By using these sampling methods, we had 30 mothers volunteer to participate in the present study. They were asked to provide pseudonyms for themselves. The participants were primarily White ($n = 20$), seven were Black, and three were Asian American. The women's ages ranged from 33-62 and they ranged from middle to upper-middle class. The mothers' education levels ranged from high school graduates to doctoral degrees. Four of the participants' children with HFA also had diagnoses of Attention Deficit Hyperactivity Disorder

(ADHD) and one had an additional diagnosis of sensory integration disorder.

The majority of the participants were either teachers or in some educational profession. Each mother had at least one child with HFA who was over the age of 12 years old. The ages of the mothers' children with HFA ranged from 12 to 30. Each of these children attended public or private schools while in K-12 education and they had an Individualized Education Plan (IEP) or 504 plan in place. Only one family had an additional child with an autism diagnosis.

Data Collection

We gathered data through in-depth, semi-structured individual interviews with participants. We conducted one interview total per participant that lasted approximately one hour. The interviews were audio-recorded and we subsequently transcribed them. The participants were asked a series of open-ended questions addressing the core topics of the present research project (i.e., social stigmatization, isolation, developmental issues, interventions, advocacy, and mother's coping strategies). All identifying information pertaining to participants remains confidential and we have changed all names in the reporting of the data. Prior to the interviews, participants also filled out a general background information form regarding their age, socioeconomic status, child's diagnosis, number of children, and education levels.

Data Analysis

Following Strauss and Corbin's (1998) procedure, we conducted open, axial, and selective coding with the set of 30 transcribed interviews. We chose Strauss and Corbin's (1998) method of data analysis since it entails three distinct stages of coding. These stages are designed to uncover the main interview categories/themes and provide a detail regarding the properties and dimensions of each main theme. This process helped us develop each of the main themes with enough depth and interview quotes in order to support the results that emerged from the data. Strauss and Corbin's (1998) method evolved from the seminal work of Glaser and Strauss (1967), who first proposed the constant comparative method for qualitative data

analysis. We felt this technique was the best fit for our research problem in order to explore the in-depth experiences of mothers with a child with HFA.

During the open coding process, we individually read and coded the interviews and then we met in order to discuss our coding until we reached agreement. During all of the coding stages, we utilized the constant comparative method described by Glaser and Strauss (1967). This process helps build each code and theme by constantly comparing pieces of data to each other that we saw making up those codes/themes.

We then examined all of the open codes in order to find whether individual codes could be combined into higher conceptual categories as a part of the axial coding process. Once these higher conceptual categories were developed, we examined each category's properties and dimensions. During axial coding, connections were made between the categories and their sub-categories through the process of considering the conditions, context, action and interaction processes, and the consequences of each category. Through the process of selective coding, we then analyzed the axial categories in order to investigate their relationships to each other across the participants' interviews. All three coding stages helped us uncover the participants' experiences of being a mother of a child with HFA.

We reached theoretical saturation (Strauss & Corbin, 1998) after collecting and analyzing the 30 interviews, which meant we were no longer receiving new information from our coding process. From our data analysis, five axial categories emerged that were comprised of several sub-categories. With the data analysis approaches employed, the collected data were generally coded into five broad categories: diagnosis, intervention, social dynamics, advocacy, and coping skills.

Reliability

We compared our coding of the interviews at each stage of the coding process in order to establish an indication of the reliability of the emergent categories. Initially, we independently coded the interviews. Then, we met to discuss our coding until we reached agreement by utilizing the constant comparative method

(Glaser & Strauss, 1967). This process was done at the open, axial, and selective coding stages. Member checking was also conducted by presenting the analysis and the results to the participants to establish whether the results represented their experiences. The completed written data analysis and results sections were sent to all of the participants to ask for their feedback. All but three of the participants provided feedback through the member-checking process. The participants who did respond confirmed that the analysis and the results did represent their overall experience.

Interrater Reliability

Additionally, two faculty members with qualitative research experience, who were not involved in the present study, served to establish a measure of interrater reliability of the five axial categories. The external raters were given operational definitions and one example interview excerpt for each category. Then, they rated 15 unmarked interview excerpts into these five categories. The interview excerpts were placed on note cards so the raters could move them around until they placed them into the categories in which they thought the cards belonged. Significant interrater reliability was observed using Cohen's (1960) kappa coefficient ($\kappa = .88$, significant at .001).

Although using Cohen's kappa may be interpreted as more of a positivist notion of reliability, it has been documented as one means of establishing interrater reliability in qualitative research (Cohen, 1960; Conger, 1980). This technique may not be appropriate for all qualitative designs but it does seem to fit with the specific coding strategy utilized by Strauss and Corbin (1998). Cohen's kappa computes an interrater reliability coefficient and it also factors out chance agreement, which is not addressed in pure percentage of agreement.

The goal of conducting the interrater reliability procedure was to ensure that the data analysis reflected the participants' data as accurately as possible. Lincoln and Guba (1985) presented the idea of stepwise replication, which involves utilizing multiple people to conduct a study. They described this process as similar to the positivist idea of replication. In the present study, we utilized the idea of stepwise replication in order to examine how

multiple raters interpreted qualitative information and whether there was agreement among their interpretations.

Results

Through the coding process, we found five main categories that emerged from the participants' data: diagnosis, intervention, social dynamics, advocacy, and coping skills. Each of these main categories had other sub-categories, presented below. The five main categories were represented in each of the 30 participants' interviews. The quotes that are included represent the majority of the participants' experiences.

Late Diagnosis of an Invisible Disability

The results of the present study indicated that the majority of the participating mothers' children received a later diagnosis of HFA, around the ages of nine to 13. While one mother, Marie, received her child Rob's diagnosis at age four, such an early diagnosis was rare. Elaine, mother of 17-year old Joe, noted the process it took in order to have her son diagnosed. Her experience is consistent with each of the mothers who experienced a late diagnosis:

He was not diagnosed with HFA until later. I would say [the diagnosis took] three to six months of working with the psychologist. She had to get to know him, she had to get to know us, and really get a whole big picture. And, at that time, she was able to say: "You know, I think it's this but, again, it's still just a guess."

Elaine related the length of time it took to receive a diagnosis, as well as the ambiguity that can be involved when professionals are trying to make that diagnosis.

Consistent with the HFA diagnostic criteria, all of the children exhibited splintered symptoms throughout their early childhood development. These symptoms were incongruent with their overall ability to function. Several of the mothers identified noticing these symptoms at ages three and four. Elaine's sentiment was illustrative of the group when she noted:

Joe's fine motor skills weren't that good but his gross motor skills were good. He could ride a bike but he couldn't do something else, so he could do very high-functioning skills, gross motor

skills, but then other things he couldn't do. He could read at a very high level but his comprehension was low. So, it was just very splintered all over the board, although he was never delayed in any of his milestones.

While some HFA symptoms were observed by these mothers in toddlerhood, the mothers who received a later diagnosis felt that it was difficult to gauge what was simply normal development and what their child would eventually grow out of as they aged. These mothers commented that it was a challenge early on before their children were diagnosed with HFA.

Part of the overall difficulty in obtaining an HFA diagnosis appears to be the general ambiguity of the diagnostic criteria. Because the diagnostic criteria contain such a wide range of variation in symptomatology, degrees of severity, and loosely defined descriptions of HFA, it can be difficult to ascertain how and where a child fits into the HFA diagnosis. This ambiguity was experienced by all of the participants and was reflected in Jill's statement: "It's hard because the kids don't always get into that nice pigeon-holed spectrum. They could be very good in one area and not very good in another."

Another challenge in diagnosing HFA is the inherent invisibility that occurs with this diagnosis. It is not a diagnosis that others can visually see. HFA is masked by its very nature because these individuals are able to blend in with other children academically, even excelling at times. Yet the major social deficits are not always evident at first glance; it may take a change in routine or an anxiety-provoking situation in order to really detect this diagnosis. Each mother in the present study agreed that the invisibility of HFA did affect how special services were provided, how outsiders perceived them, and the lateness of the diagnosis. Gwen's perspective was common for the rest of the participants:

It is an invisible thing. You don't see it. And honestly there have been times when, it's terrible to say, but it would be easier if he had something like Down Syndrome where you could look at the child and you can tell there's something. John looks like a perfectly regular 16-year old kid.

As Gwen related, having this "invisible" disability was difficult when the mothers were trying to receive an accurate diagnosis.

Mothers' Individualized Interventions

This thematic category outlines intervention approaches that were consistent with all of the mothers in the present study. The data shows a wide variation in specific techniques used depending on the child's needs. Therefore, there is minimal correlation or commonality in the types of techniques utilized. The important element this category emphasizes is the overarching methods the mothers used in planning their technique strategies. Thus, the interventions are based on providing individualized, child-centered planning. This process involved these mothers understanding what needs their child has and then using creativity in applying various techniques. For each of these mothers, this process starts with a desire for their child to understand basic life skills like social interaction, organizational skills, and effective decision-making skills. Marie explained her approach this way, which represents the common experience of the participants:

I try to create opportunities for my son, to create examples so he knows how to interact. When we go to the store and he wants to buy something, I get in a line with him so that he can go through and take out his money and ask how much it is. Every interaction with a person is a memorized process so that he knows how to interact and what to ask, how to move in society. So, it's been a slow learning process in terms of understanding that you have an independent life but he gets it.

Additionally, in this individualized approach these mothers were consistent in their belief of challenging their children to step outside of their comfort zones, which was demonstrated in Julie's interventions with David:

So, I'm always pushing [David] because his tendency is to draw back, to stay by himself. But I'm always pushing to at least try, to just go in and see what you think. And, most of the time, he'd have fun. He'd go in and forget what he was worried about. But yes, it's constantly having to make him try it.

As Marie and Julie related, the mothers found that they had to be very concrete in developing interventions that would help show their children a step-by-step method for interacting with others.

A core feature of this individualized approach is the process of trial and error with intervention techniques. Each of these mothers described intervention techniques they found to be successful long-term, successful short-term, or unsuccessful overall. The important issue for these mothers was that it is vital not to become overly worried or anxious about the potential success or failure of a technique. Kia explained the majority of the mothers' experiences this way: "You're never going to know what works. You're just going to try a bunch of stuff and you don't know whether it's working or not quite honestly."

Reality-based interventions are another shared core feature of the present study. Each mother takes a strong stance about the need for preparing her child for the realities of life. A reality-based approach implies that interventions focus on not only teaching the fundamentals of life, but also concentrating on skills the child needs in order to be successful, providing a cushion of support for the child now, and teaching the child to take responsibility and ownership for his life. Denise represented the participants since she was very adamant about this aspect of her child's intervention process:

I think parents of children with special needs need to allow them to fail more than we want them to because nothing teaches a child better than natural consequences. And if you really want your child to be in the world as best as possible and functioning then you need to let them fail *now* so they can grow into it before they go off to college. If we sugar-coat it all for them all the way through and they go off to college, they're not going to be able to survive because the pressures are just going to be too much.

The mothers wanted their children to be prepared for the realities of life, especially for an eventual time when the mothers would not be around to help solve issues daily life might present to their children.

Reality-based interventions are closely linked to a strengths-based approach as well. During the interviews, each of these mothers appeared to avoid focusing on their child's weaknesses and difficulties. Rather, these mothers concentrated on the child's strengths. This approach implies that the child is given affirmation for his capabilities and talents.

The last helpful intervention strategy involved maintaining a team approach throughout the intervention process. This team can involve a variety of resource networks, schools, doctors, counselors, family members, and support groups. The present study found that the stronger the team is in implementing interventions, the better the prognosis for the child and the less stress and anxiety felt by the mother.

Social Dynamics of their Children with Peers and Family Members

Since HFA is largely considered a social disability, many individuals with HFA have considerable difficulty in social situations and interactions with their peers. As discussed previously, many families experience social isolation due to the HFA diagnosis. However, the present study found that while some of the mothers experienced distress over their children's behavior in public when they were younger, all of them expressed a low level of current concerns regarding being socially isolated. Monique represented the participants when she noted that social isolation was a "choice" and mothers have to take initiative to stay connected. She also stated: "I've learned over time that explaining my child's behavior in public to people is a waste of time."

It appeared that the issue for these mothers was a concern for their children's desire and ability to initiate relationships with their peers. Each of the mothers relayed that their children have difficulty taking initiative in building and maintaining friendships. Generally, their children would not take that first step on their own. Julie described David's social life in this way, which was very common among the participants:

[David] doesn't really *need* friends, he doesn't need to have anybody over or anything like that. But he enjoys the camaraderie and being together, especially when he's at school. And

sometimes kids will reach out to him and say: "Let's get together, let's do this." And he'll go with it but he would never be the person to initiate that.

The other mothers also related this experience that their children did not seem to need friends but they would interact with friends when they were present.

All of the mothers also expressed some concern regarding their children being socially isolated and ostracized by their peers. This worry felt by the mothers was triggered by a general desire for their children not to experience peer rejection and wounded feelings. Susie related this common concern among the participants: "The stigma that maybe he had in younger grades and he misbehaved carries with him and those kids remember that." Vera knew of current, active bullying and ostracization occurring with her son. She described John's struggle with interpreting his peers' behaviors, which was common for the other mothers as well:

So, he doesn't always put it together that this is *why* they're doing it. Sometimes he recognizes they *are* doing it but he doesn't quite get the why. What about his behavior are they picking up on? It's the social cues he doesn't catch. He knows they're making fun of him sometimes. I don't want his feelings to be hurt.

This experience of not understanding social cues, especially ones that are not stated, can impact those individuals with HFA throughout their lifetime.

While struggles occur within peer relationships, family dynamics have a large impact on the overall effectiveness of family functioning. Every relationship within the family affects each member individually and collectively. Therefore, conflict between siblings affects the siblings, the mother and father in their parenting roles, the mother and father in their marriage roles, and the individual relationship of the mother and father to each child. All of the mothers related these strains in the family, as Marie described:

There are times when a special needs child will cause stress on the entire family. And you won't necessarily get the chance to do what exactly what you want to do all the time. And you have

responsibilities that you wouldn't have had otherwise.

All families experience stress and conflict. However, having a child with HFA presents unique challenges within the family dynamic.

While these participants acknowledged the toll having a child with HFA can take on a family, they identified some crucial elements that can lessen the overall distress the family endures. First, they discussed the importance of the mother and father accepting the HFA diagnosis and working as a team in managing the effects of the diagnosis. All of the mothers discussed the impact their husband's support (or lack of) had on their ability to maintain family cohesion, as Sidney related: "We've learned to share responsibilities. There was a certain amount of sharing of responsibility and coverage. So, we've invested in it." Julie stated: "So (my husband) was not on board at first at all. But then, when his diagnosis just fit (David) so perfectly, then he realized he had to be a part of it." Elaine explained a common experience among the participants:

[My husband's] been very good. It maybe took him a little longer to come around; he wasn't always at all the meetings. So, then a couple of times I think what you have to do is say: "You take him, you take him to the doctor, you take him to the group, you go talk to Dr. X." And that way he would hear strategies and techniques. So, get them up to speed and keep them in the loop. And, it's really different if [the husband is] seeing firsthand and you have to create opportunities for them to do that. Or just educate them on different techniques. But I guess I'm lucky because mine just wanted to get up to speed.

The reason mothers were chosen for the present study was that they are often the parent who takes charge in most of these situations. However, having the support of another adult in the home provides a great deal of relief for the mother and it helps them form a team to face whatever situations may arise.

What occurs within the spousal relationship then trickles down to their children. When the mother and father are on the same page regarding discipline, intervention strategies, and

parenting styles, their child is able to overcome difficulties more effectively. Another crucial element is the ability of the parents to allow their children to be distinctly individual from one another, which involves the parents viewing each child separately for who they are as a person.

The last key concept regarding family dynamics involves the enduring family bond that exists between members regardless of conflict or harmony. Each of the mothers in the present study had positive things to say regarding the unconditional love and protectiveness their family exhibits to one another, as Gwen noted how her children will “defend” one another in any outside situation, even if they argue at home. Denise discussed the participants’ common experience of the family overcoming the challenges of an HFA diagnosis in order to “make it work.” While the mothers with school-age children may question their parenting abilities, they believe first and foremost in doing what is best for their family unit.

Mothers’ Advocacy for their Children

The role advocacy plays for the mothers in the present study is characterized by intrinsic motivation. This concept generates the idea that advocacy is an inherent quality within the role of “mother” that supersedes refusal, yet does not constitute deliberate choosing. It is like an innate reaction that necessitates taking action. The position of “advocate” seems to also stem from the child’s inability to advocate for himself. Mariel represented the participants’ experiences with the following statement: “I tend to get a little defensive when it comes to Jarod because he’s not going to speak for himself. No one is going to stick up for him if I don’t.” Evie related the lifelong nature of the advocacy role which was expressed by all of the participants: “The problem with all of this is that it doesn’t stop. You have to just keep dealing with what has to be done and support what has to be done.” All of the mothers also specifically stated they would continue their advocacy role in supporting their children as they aged past adolescence.

Another aspect of advocacy that is noteworthy is the battle these mothers undergo in order to ensure their children have the services they require and are treated with equality among their peers. All of the mothers acknowledged

that they had to push to secure certain services for their children, although the degree to which they had to fight varied. Shantelle related her struggle with a school system about teaching her child, which was common among the participants:

Depending on the commitment at the school system, there is a fight about nothing or everything or anything in-between. We had points in time where his initial interaction with the public schools [was negative]. He had the particular teacher who said until his behavior was in order she couldn’t teach him anything. That was nonsense. And we fought with them for a year.

School bullying was another area most of the participants experienced and Michelle explained her reactions to her son being bullied in fifth grade:

When he was being bullied, I came to school one day and I said: “I’m not leaving until we get this resolved.” And the teacher at the time was completely unaware that he was being bullied. So, I said: “Well, I’m not leaving, I’m standing right here.” That was probably really the only time I had to dig in and say either straighten it around or [else]. That’s where the parents have to step in and really put their foot down and say: “Wait a minute.”

All of the mothers reported advocating for their children in a number of different ways. Although it was not always easy, the participants drew strength from their advocacy.

The last issue pertaining to advocacy has to do with the mothers’ role in creating social awareness for HFA. The mothers reported they have taken on community advocacy roles and feel it is their duty to educate others about HFA. All of the mothers expressed a desire to educate people who work closely with their children about HFA and Julie explained her position: “Sometimes it helps when I can explain more about HFA to somebody so they can understand the big picture.”

Mothers’ Self-Coping Skills

The last segment of the present study has to do with the development of coping skills for these mothers. Each mother acknowledged that

the passage of time was a key element regarding their ability to cope with their children's HFA diagnosis. Also, keeping a present-focused mindset was found to be helpful in keeping the mothers from dwelling on past mistakes or issues. Lori described it this way: "I think you just have to have a short memory and move on. Because you can't beat yourself [up]."

Another crucial feature of coping skills development has to do with acceptance. The ability of these mothers to accept the HFA diagnosis was found to be a vital part of them being able to move past the anger, frustration, and anxiety produced by the HFA symptomatology. Linda represented the participants since she had the following to say about coming to terms with the diagnosis:

I guess the hardest part for any parent is trying to figure out how life looks now that the young man that was born isn't going to throw a football and be on a sports team or whatever your dream was about. But rather they'll be the person they decide to be based on the talents that they have.

Another common experience dealing with acceptance was related by Diana as she talked about her initial desire to fix her son's disability:

For a long time, I wanted to fix him. I can fix this if I figure it out enough. I'll be able to fix this. But you can't. So, at some point in time you have to go, "It is what it is," and you just have to be the parent. And everything can't be focused in on the developmental issues.

For these mothers, acceptance can take a while since the diagnosis process typically takes a long time. After the diagnosis, acceptance is a gradual process that develops over the course of time.

While acceptance is a vital part of the coping process, normalizing the HFA diagnosis is essential as well. Normalizing means that the mothers began to think about their children in terms of how they are similar to every other child instead of how they are different. Each of the mothers in the present study felt that the issues they were dealing with as parents were not much different than what other parents handle. Being able to identify oneself as just a "normal, everyday" parent seemed to be an excellent tool for these mothers in overcoming the enormous

challenges of raising a child with HFA. Katie took this common perspective:

Being the parent of a special needs child is no different than being the parent of any child. You have a lot of responsibility, it's just *different* responsibility. It means that you have to go off in different directions, you have to ask for different things, you have to learn about what's available. Every parent has responsibilities for the child no matter what they are. I don't think I'm that different, I really don't! I can't say that my experience was any different than any other parents, it's just that you do different things.

Once acceptance happened, all of the mothers were able to see more clearly how their parenting experiences were not always that different from what other mothers were encountering.

While normalizing their situation, these mothers also found common ground in their personal perspective-taking. The more these mothers were able to look at the "big picture," the better equipped they were to deal with the daily frustrations of their role as mothers. As an example for the participants, Marie talked about how she learned this life lesson:

One of the things a special needs child does for you is it changes your perspective about what's important. I think that you understand that being supportive and connecting to the world and having a community is probably what's most important for that child and that's what you work for all the time.

Through the acceptance and normalizing processes, the mothers were able to develop a wider view of what was important for them and their families.

So far, these coping skills have focused on internal methods of dealing with the HFA diagnosis. However, there are two external sources of coping skills that all of the participants found to be very helpful. The first external coping skill has to do with self-education, which includes the idea that "knowledge is power." Each of the mothers in the present study embarked on an extensive journey to learn as much about HFA as possible. Educating themselves proved to be a fundamental piece to this puzzle and it was inherently linked to the development of the

internal coping mechanisms. Each of the mothers also gave many different examples of ways they self-educated (e.g., books, articles, seminars, doctors, etc.).

The second external coping strategy is evident through support. Support includes having supportive spouses, extended family, and friends. It also includes having a support network. For the mothers in the present study, this support group was comprised of people such as parent support groups, education teams, and doctors, among others.

Discussion

The five main themes that emerged from the mothers' interviews centered around the diagnosis process, interventions that they had tried, social dynamics of the family and their child's peers, the mothers' need to advocate for their child, and the coping skills that the mothers had developed. Through their interviews, the mothers provided more detailed insights regarding these areas. Previous researchers have not provided this type of in-depth qualitative examination into the lives of mothers who have a child with HFA.

As Baron-Cohen (2002) related, the mothers saw the diagnosis as a "difference" rather than a "disability." The mothers went through a long diagnosis process and most of their children were diagnosed with Asperger's syndrome before the newer DSM-5 (APA, 2013) would identify them with HFA. Some of their children had other previous diagnoses before they were identified with a form of autism, which was most commonly ADD/ADHD. Later diagnoses can lead to increased issues with communication skills, peer interactions, psychopathology, and social ostracization (Muller et al., 2008; Scott et al., 2002). There have been instances when diagnoses have not happened until young adulthood.

As noted previously, the diagnostic process for HFA is often extensive and long overdue, which was experienced by the majority of the participants in the present study. The long diagnostic process can cause much distress for mothers, both emotionally and physically, and mothers sometimes required counseling and medication (Gray, 2003; Medina et al., 2020; Schnabel et al., 2020). As noted by the participants, a negative outcome of this late diagnosis was that, prior to the HFA diagnosis,

mothers were often blamed for their child's behavior and were labeled as ineffective parents by the public and sometimes even by their families (Tsermentseli & Kouklari, 2019). The unfortunate reality of this situation is that individuals with HFA are often misperceived as not having a disability and are expected to be "normal" like everyone else; the participants clearly related the challenges with an invisible disability. As Gray (2002) noted succinctly: "They are people with a disability who must deal with the social world as if they were not disabled" (p. 735). In this regard, mothers tend to shoulder a heavy share of this burden for their children and feel as if they must alleviate the wounds their children may suffer when outsiders do not accept them (Kim et al., 2020).

The mothers in the present study developed their own intervention strategies. Although other, perhaps more formal, strategies were attempted at schools or agencies, the mothers came up with their own interventions that they thought worked for their children and their families (Frankel, Gorospe, Chang, & Sugar, 2011). Some of their strategies came through trial and error. Others involved more reality or strengths-based approaches. They also sought to participate in a team approach. They felt that having everyone on the same page would be the best solution to help their children.

Other informal and formal interventions may also be utilized as related by the mothers in the present study. Ghanadzade, Waltz, and Ragi (2018) found that interventions for social communication difficulties and challenging behaviors are among the top of mothers' intervention priorities, which was true for the participants in the present study. An increase in play dates has been found to increase behaviors such as mutual offering of objects, conversing, and other turn-taking activities with peers on the school playground (Frankel et al., 2011). The mothers in the present study related initiating play dates to increase their children's social skills. A more formal intervention such as Developmental Reciprocity Treatment is promising in order to help children with HFA and increase parental empowerment and quality of life (Gengoux et al., 2019).

Social isolation is common among those children with HFA. The mothers reported instances where their child was isolated and

when the child themselves did not seek out peer/friendship relationships, which could also impact how social and outgoing the whole family is due to stigmas in society (Lee et al., 2008). How social the family could be impacted the mothers' own feelings of isolation since they sometimes had to avoid situations where they felt their parenting skills were being judged (Kim et al., 2020; Ryan & Cole, 2009).

This social isolation and stigmatization can negatively impact the family unit as a whole (Kim et al., 2020), which was related by the participants in the present study. Due to the difficulties a child with HFA has in social settings and the stress it causes on the family to embark on public excursions, many parents limit how often they go to public functions (Kim et al., 2018). The participants related to being less likely to participate in activities and conduct social outings, and more likely to avoid people who are unsympathetic to their situation (Gray, 2002; Lee et al., 2008). Another study demonstrated that family discord and conflict is directly related to an increase in HFA symptomatology, especially an increase of anxiety and depression (Kelly, Garnett, Attwood, & Peterson, 2008).

Advocacy was very important for the mothers in the present study. They saw it as a form of activism to seek out the rights for their child and their family (Ryan & Cole, 2009). The participants related having to advocate with doctors, teachers, and administrators, sometimes over a long period of time, in order to receive the right diagnosis and services for their children (Boshoff et al., 2018). These mothers were the primary caretaker of their children, which is common (Gray, 2003; Ryan & Cole, 2009). The participants also saw themselves as being responsible for how their family was viewed by others (Gray, 2002, 2003; Ryan & Cole, 2009).

For the participating mothers, advocacy often started with the pathway to diagnosis, which required resiliency and commitment (Boshoff et al., 2018). Advocacy itself seemed to serve as a coping strategy for the participants (Ewles, Clifford, & Minnes, 2014). Advocacy can involve seeking self-education, using support services, engaging with the community, and educating others (Boshoff et al., 2018). For these mothers, advocacy is a life-long, all-encompassing challenge as they work to create a

future for their children and their families (Boshoff et al., 2018). There are also personal and societal benefits that emerge from the mothers' advocacy (Boshoff et al., 2018). Most important of all, advocacy involves taking action, even when many others may fail to do so (Boshoff et al., 2018).

The mothers in the present study also developed their own coping skills in order to help themselves through this whole process. Increased information for parents helps them manage their stress and fears and gain adaptability to their child's needs (Tehee, Honan, & Hevey, 2009). Ryan and Cole (2009) found that advocacy also helped mothers in developing their own identities. Supporting their children can provide a sense of purpose and help them feel "selfless."

Another notable coping strategy the participants in the present study related involved the impartation of resources, information, and support networks (Boshoff et al., 2018). One study found a direct correlation between the amount of resource information given and parents' ability to manage their stress levels, address fears, and gain adaptability to their child's changing needs (Tehee et al., 2009). The mothers in the present study related that educating themselves with such information was crucial in order to help their interactions with their children with HFA. Ryan and Cole (2009) suggest that advocacy may also play a key role in helping mothers articulate their own purposes and solidify their identity as parents. Advocating for their child allows some women to feel they have a purpose in a way that conveys a "selfless" approach that outsiders can respect, which in turn helps these mothers in coping with their complex role as a mother of a child with HFA. The women in the present study agreed with the importance of this advocacy for themselves and their children.

The results from the present study should be very helpful to educational, social service, medical, and other professionals who work with families who have a child with HFA. They need to be aware of what the family goes through during the diagnostic process. They should be educated as to the social impacts the diagnosis has on the developing family. They should support mothers' advocacy by asking what the family needs and by providing timely and thorough

services. Coping strategies should be explored with the mothers and their families. Professionals should find out what interventions have been successful for the mothers and try to replicate aspects of those interventions in their agencies. The mothers in the present study have related what their lives are like and they should be regarded as equals by professionals who are interacting with their children.

Limitations and Future Research

We acknowledge that there were limitations to the present study. First, the data were gathered only in one large metropolitan area in the Midwestern United States. Collecting data in other states and countries would provide a more holistic overview of mothers' experiences. Second, the sample was mainly White, largely due to the area where we recruited participants. There was some diversity in the sample but more diverse viewpoints are always helpful in order to explore the ways different people might experience having a child with HFA. We did not explore how cultural background may have impacted the participants or their families. However, our view of qualitative research is that it rarely has the goal of providing a representative sample from a whole country. Rather, the reader interprets the study based on the participants' data and decides how they may be relevant to their experience or setting.

Future research should explore these five main themes in more specific depth. Each of these five areas could entail a full research study. We would like to see more examination of the influence of cultural background on a mother's experience. We also see the need to explore the experience with more formal interventions that are utilized in schools and agencies. Additional research could examine family relationships in more depth, such as marital, sibling, and extended family interactions.

In the present study, we presented an overview of the experiences of mothers with children diagnosed with HFA. The present study's findings will contribute to the current knowledge base of the education and human services fields. By using a qualitative approach, we represented much more personal experiences of mothers compared to a quantitative approach to research. We hope more research, qualitative and quantitative, will take place in the future

in order to help illuminate the worlds of youth with HFA and their families.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, D.C.: American Psychiatric Association Publishing.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, D.C.: American Psychiatric Association Publishing.
- Baron-Cohen, S. (2002). Is Asperger's syndrome necessarily viewed as a disability? *Focus on autism and other developmental disabilities*, 17, 186-191.
- Baron-Cohen, S., Scott, F., Wheelwright, S., Johnson, M., Bisarya, D., Desai, A., & Ahluwalia, J. (2006). Can Asperger syndrome be diagnosed at 26 months old? A genetic high-risk single-case study. *Journal of Child Neurology*, 21, 1-12.
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). Parents' voices: "Our process of advocating for our child with autism." A meta-synthesis of parents' perspectives. *Child: Care, Health and Development*, 44, 147-160.
- Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, 20, 37-46.
- Conger, A. J. (1980). Integration and generalization of kappas for multiple raters. *Psychological Bulletin*, 88, 322-328.
- Ewles, G., Clifford, T., & Minnes, P. (2014). Predictors of advocacy in parents of children with autism spectrum disorders. *Journal of Developmental Disabilities*, 20, 73-82.
- Frankel, F. D., Gorospe, C. M., Chang, Y. C., & Sugar, C. A. (2011). Mothers' reports of play dates and observation of school playground behavior of children having high-functioning autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 52, 571-579.
- Gengoux, G. W., Schapp, S., Burton, S., Ardel, C. M., Libove, R. A., Baldi, G., Berquist, K. L., Phillips, J. M., & Hardan, A.Y. (2019). Effects of a parent-implemented developmental reciprocity treatment program for children with autism spectrum disorder. *Autism*, 23, 713-725.
- Ghanadzade, M., Waltz, M., & Ragi, T. (2018). The intervention priorities of parents of children with autism spectrum disorders in Iran. *Research in Autism Spectrum Disorders*, 55, 14-24.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine de Gruyter.

- Gray, D. (2002). "Everybody just freezes. Everybody is just embarrassed." Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24, 734-749.
- Gray, D. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, 56, 631-642.
- Gray, D. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50, 970-76.
- Jackson, L., Keville, S., & Ludlow, A. K. (2019). Mothers' experiences of accessing mental health care for their child with an autism spectrum disorder. *Journal of Child and Family Studies*, 22, 534-545.
- Kelly, A., Garnett, M., Attwood, T., & Peterson, C. (2008). Autism spectrum symptomatology in children: The impact of family and peer relationships. *Journal of Abnormal Child Psychology*, 36, 1069-1081.
- Kim, K., Kim, J., Voight, A., & Minjoon, J. (2018). Listening to the screaming whisper: A voice of mother caregivers of children with autistic spectrum disorder. *International Journal of Qualitative Studies on Health and Well-being*, 13, 1-8.
- Kim, S., Kim, H., Kim, J., Nichols, S. C., & Kang, V. Y. (2020). Experiences and impact of having children with autism spectrum disorder on the lives of their Korean-American mothers. *Exceptionality: A Special Education Journal*, 1, 1-17.
- Lee, L., Harrington, R., & Newschaffer, L. (2008). Children with autism: Quality of life and parental concerns. *Juvenile Autism Developmental Disorder*, 38, 1147-1160.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Lord, C., & Jones, R. M. (2012). Annual research review: Re-thinking the classification of autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 55, 490-509.
- Medina, J. A., Rios, K., Aleman-Tovar, J., & Burke, M. (2020). Exploring patterns between school perceptions, child behavior, and maternal well-being among Latina mothers of children with autism spectrum disorder. *International Journal of Developmental Disabilities*, 1, 1-20.
- Muller, E., Schuler, A., & Yates, G. (2008). Social challenges and supports from the perspective of individuals with Asperger's syndrome and other autism spectrum disabilities. *The National Autistic Society*, 12, 173-190.
- Pisula, W., & Porebowicz-Dorsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLoS ONE*, 12, 1-19.
- Ryan, S., & Cole, K. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22, 43-53.
- Schnabel, A., Hallford, D. J., Stewart, M., McGilivray, J. A., Forbes, D., & Austin, D. W. (2020). An initial examination of post-traumatic stress disorder in mothers of children with autism spectrum disorder: Challenging child behaviors as Criterion A traumatic stressors. *Autism Research*, 13, 1527-1536.
- Scott, F., Baron-Cohen, S., Bolton, P., & Brayne, C. (2002). The CAST (Childhood Asperger Syndrome Test) preliminary development of a UK screen for mainstream primary-school-age children. *Autism*, 6, 9-31.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Newbury Park, CA: Sage.
- 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.
- Tsermentseli, S., & Kouklari, E. C. (2019). Impact of child factors on parenting stress of mothers of children with autism spectrum disorder and intellectual disability. *Early Child Development and Care*, 1, 20-30.