
8-18-2014

Relationships of Children with Autism Spectrum Disorders and their Fathers

Terry Keller

Lourdes University, tkeller@lourdes.edu

Julie Ramisch

Northern Illinois University, jramisch@niu.edu

Marsha Carolan

Michigan State University, Carolan@msu.edu

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>



Part of the [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#), and the [Social Statistics Commons](#)

Recommended APA Citation

Keller, T., Ramisch, J., & Carolan, M. (2014). Relationships of Children with Autism Spectrum Disorders and their Fathers. *The Qualitative Report*, 19(33), 1-15. Retrieved from <https://nsuworks.nova.edu/tqr/vol19/iss33/2>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



Qualitative Research Graduate Certificate
Indulge in Culture
Exclusively Online • 18 Credits
LEARN MORE

NSU
NOVA SOUTHEASTERN
UNIVERSITY

NOVA SOUTHEASTERN

Relationships of Children with Autism Spectrum Disorders and their Fathers

Abstract

This phenomenological study investigated the relationships between 7 fathers and their sons with autism spectrum disorder (ASD). Seven major themes emerged: Shared Activities, Developmental Sensitivity, Emotional Understanding, Fighting the Label, Fatherhood Expectations, Parent Responsibility, and Fatherhood Isolation. Fathers were sensitive to their sons' emotional needs and developmental milestones. Clinicians can help fathers to develop appropriate relationships with their children that involve shared activities. Clinicians can also assist fathers in coping with isolation and expectations regarding fatherhood, developing desired fatherhood roles, and finding appropriate shared activities with their children.

Keywords

ASD, Child Development, Fatherhood, Parenting

Creative Commons License



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 License](https://creativecommons.org/licenses/by-nc-sa/4.0/).



Relationships of Children with Autism Spectrum Disorders and their Fathers

Terry Keller

Lourdes University, Sylvania, Ohio, USA

Julie Ramisch

Northern Illinois University, DeKalb, Illinois, USA

Marsha Carolan

Michigan State University, East Lansing, Michigan, USA

This phenomenological study investigated the relationships between 7 fathers and their sons with autism spectrum disorder (ASD). Seven major themes emerged: Shared Activities, Developmental Sensitivity, Emotional Understanding, Fighting the Label, Fatherhood Expectations, Parent Responsibility, and Fatherhood Isolation. Fathers were sensitive to their sons' emotional needs and developmental milestones. Clinicians can help fathers to develop appropriate relationships with their children that involve shared activities. Clinicians can also assist fathers in coping with isolation and expectations regarding fatherhood, developing desired fatherhood roles, and finding appropriate shared activities with their children. Keywords: ASD, Child Development, Fatherhood, Parenting

Children with autism spectrum disorder (ASD) may have a range of social difficulties, which include impairments in social interaction, communication, and repetitive and stereotyped behaviors (Diagnostic and Statistical Manual [DSM-5]; American Psychological Association [APA], 2013). Researchers have demonstrated that children with ASD have more difficulties with social skills compared to children without ASD (Macintosh & Dissanayake, 2006). Specifically, communication difficulties include a lack of skills such as making appropriate comments about conversation topics (Paul, Orlovski, Marcinko, & Volkmar, 2009), making decisions about how much or how little to say in a conversation about a particular topic (Paul et al., 2009), the ability to maintain a balanced back-and-forth conversation by taking conversational turns (Jones & Schwartz, 2009; Paul et al., 2009), understanding implicit and explicit meanings of messages (Muller, Schuler, & Yates, 2008), and interpreting gestures and tone of voice (Muller et al., 2008).

Theoretically, the difficulty that children with ASD have with reciprocal social interaction may interfere with the development of secure relationships with family members, and specifically, with parents. In one meta-analysis, Rutgers, Bakermans-Kranenburg, van IJzendoorn, and van Berckelaer-Onnes (2004) determined that children with ASD, as compared to children without ASD, were less often securely attached to their parents. More recent studies have confirmed that children with ASD had less secure relationships with their parents (Naber et al., 2007; Rutgers et al., 2007; van IJzendoorn et al., 2007). In a 2007 study, van IJzendoorn et al. also measured parental sensitivity and found that parents of children with ASD did not differ significantly from parents of children without ASD in terms of sensitivity. For children without ASD, more parental sensitivity was associated with more security, but for children with ASD, more sensitivity was not associated with more security (van IJzendoorn et al., 2007).

Although researchers have looked closely into the relationship between children with ASD and their mothers, less attention has been directed to the study of fathers of children with ASD. Researchers have pointed out the need to investigate fathers' experiences and perceptions about raising a child with ASD (Flippin & Crais, 2011; Parette, Meadan, & Doubet, 2010; Phelps, Hodgson, McCammon, & Lamson, 2009). Flippin and Crais (2011) reviewed the literature and discussed the importance of involving fathers in early ASD intervention. The authors emphasized the importance of father involvement in terms of communication with their children with ASD. This study was designed to investigate the relationship between children with ASD and their fathers.

Research Question

How do fathers interpret their relationships with their children with ASD?

Reflexivity

It is impossible to separate the researchers from their research or to be neutral or unbiased. It thus becomes important for researchers to be honest about their histories and reflect upon how that might influence the research. Daly's (2007) definition of reflexivity is: "the ways in which a researcher critically monitors and understands the role of the self in the research endeavor" (p. 188). For this project, the first two authors acted as the research team and the third author was a consultant to the team. Before beginning the work, and during the process of analysis, each member of the research team explored their biases and values and their understanding of the topic. The researchers examined their experiences with people with developmental disabilities and experiences growing up in connection with fathers in order to be more open to the process of research.

Terry Keller

Looking at the reasons for entering the social services field it is important to understand my background. I grew up in a very rural community with limited resources and very few individuals continued on to college. I have a father who was very limitedly involved with my brother and sister as well as myself. Deciding to go into this field was easy in knowing that I wanted to explore the family dynamic and become an advocate for healthy father involvement. Having limited resources I worked part time at a local community mental health hospital while in college and found my own research interests that would guide me through the rest of my graduate work.

Having two small children at home is important to mention because I feel they have a significant impact on how I approach my work in the field of attachment and fatherhood. Especially when exploring the father-daughter bond. I completed my master's in social work and master's in business administration in St. Louis, MO while working with both urban and rural families. I am a fully licensed social worker at both the clinical and macro level. I am also a member of the academy of certified social workers. I have worked with numerous families and have seen them struggle to make ends meet and successfully come out on top. I have also seen the downside of limited engagement of parents and the detrimental effect that it can have on children. I maintain a strong interest in the early childhood years and father involvement especially those that are under five.

In this project I expected to hear fathers describe how they are meeting their expectations of being a father. I anticipated that there would be a large number of fathers who talked about the stress and financial strain that having a child with ASD brings. I also

wondered as we progressed through this project the significance of the bond that developed and how the strength of that bond is shown in the social world outside of the home.

Julie Ramisch

While completing my bachelor's degree I worked in a group home for adults with developmental disabilities. I observed while working with these adults that most of them were disconnected from their family members and this affected them in negative ways. Holidays were especially difficult, as they did not get to go see their relatives as often as they wanted. One of the primary reasons that I entered a marriage and family therapy program was so I could help families with children with disabilities stay together and connected as much as possible.

Now, I am a trained marriage and family therapist who has worked with children with developmental disabilities and their families in various clinical settings. I have witnessed the difficulty that such families have to find and maintain suitable employment, elicit family support, and locate and utilize appropriate medical services. During my education I have studied numerous aspects of families with children with disabilities. I have investigated constructs such as caregiver strain, family coping, and marital satisfaction. My research and clinical practice has demonstrated to me that families of children with disabilities experience numerous stressors and have many obstacles to overcome. While I have witnessed some families successfully navigate through stressors, I have seen many more burdened by all of the pressures.

Prior to interviewing fathers for this project, I expected to hear that they were stressed by their child's ASD and lack of social support and resources. This expectation was developed from my own clinical experiences working with families with children with ASD. What I was most interested in learning, though, was how having a child with ASD affected the fathers' relationships with their children.

Method

The search to understand a phenomenon in-depth and develop rich descriptions of lived experiences fits best with qualitative methodology and specifically within the constructivist and interpretivist paradigms (Haverkamp & Young, 2007). The interpretivist/constructivist paradigm grew out of the philosophy of Edmund Husserl's phenomenology and Wilhelm Dilthey's and other German philosophers' study of interpretive understanding called hermeneutics (Mertens, 2005). Interpretivist / constructivist approaches to research have the intention of understanding "the world of human experience" (Cohen & Manion, 1994, p. 36), suggesting that "reality is socially constructed" (Mertens, 2005, p. 12). The interpretivist/ constructivist researcher tends to rely upon the participants' views of the situation being studied (Creswell, 2007) and recognizes the impact of the researcher and his or her personal beliefs and values on the construction of meanings (Haverkamp & Young, 2007).

To address the deficit in knowledge about fathers of children with ASD, a semi-structured, in-depth phenomenological interview was chosen. This method was used to expand the understanding of what men hold to be true about their thoughts, feelings, and behaviors directed toward their children with ASD. Using phenomenological methods allowed the researchers to explore and then describe the participants' experiences (Creswell, 2007).

Each interview was slightly different as both of the researchers conducted the interviews. Additionally, the researchers wanted to explore the experiences of the individual

fathers and the relationships that they had with their sons. Some of the interview prompts that were developed prior to the interviews to be used if needed were:

- What are the first things that come to mind about your relationship with your child with ASD?
- How has your relationship with your child changed since s/he was diagnosed with ASD?
- Is there anything that you would like to do with your child that you are unable to do?
- Describe how your relationship with your child affects other relationship that you may have with others?
- What else would you like people to know about your experience with your child?
- How do you define your role as a father of a child with ASD?
- What are your favorite things to do with your child with ASD?
- How do you and your child show affection to each other?
- How do you and your child communicate with each other?

Participants

After the Michigan State University Institutional Review Board (IRB) approved this study, participants were recruited through the Michigan State University special needs listserv. Inclusion criteria for participants in this study were:

- a) the participant was the biological father of a child diagnosed with ASD;
- b) the participant was married to the biological mother of the child with ASD;
- c) the child with ASD was between four and six years old; and
- d) the participant had at least one other child.

The researchers decided that married biological parents provided a starting point in which future research could build upon. Non-biological fathers and unmarried fathers were not included in the sample due a potential for unforeseen stressors related to divorce, separation, remarriage, or adoption. Single fathers would also potentially not have the assistance of the mother in caring for a child with ASD, which also could increase the potential for stressors for such families. The researchers chose to include fathers with children with ASD between four and six years old to give fathers and children time to develop relationships with each other. Finally, the researchers chose to select participants with at least one other child so fathers could reference a relationship with a child or children without ASD.

Participants were recruited using a university-based listserv for parents of children with special needs. The email solicited participants who fit the inclusion criteria, and requested a response via e-mail or phone. After participants replied, a researcher called or e-mailed the prospective participants to verify that all of the inclusion criteria were met, and explained the study. Researchers set up interviews with participants at locations of their own choosing. Seven fathers participated in this research study. All of the fathers and children diagnosed with ASD were white males. Fathers were all employed outside of the home and were over 35 years of age.

Procedure

The researchers conducted separate interviews with each father. After informed consent was obtained, the interviewer followed the interview guide that was developed to maximize fathers' reflections and perceptions about their relationship with their children with ASD. The interview guide consisted of a set of questions to guide the interview, but which also allowed for freedom to ask spontaneous questions as indicated by the direction of the interview. The open-ended dialogue fostered a collaborative relational experience between the researcher and the participant, representing a technique shown to uncover new ideas and perspectives on the research questions (Smith & Osborn, 2003).

Interviews took about 1 to 1.5 hours to complete and were audiotaped. Following the interview, each participant was given a \$10 gift certificate for his time. One researcher transcribed each interview verbatim and then the other researcher double-checked the transcription for accuracy. All identifying information was removed from transcripts and names were replaced with pseudonyms to protect the identities of the participants.

Data Analysis

Colaizzi's (1978) method of phenomenological analysis provided the structure for data analysis. The primary purpose of this study was to develop a deep understanding of the phenomenon of being a father of a child with ASD. To address the deficit in knowledge and understanding about fathers of children with ASD, a semi-structured, in-depth phenomenological interview was chosen as the best method to expand the understanding of what men hold to be true about their thoughts, feelings, and behaviors as demonstrated toward their child who has ASD.

For each interview, both researchers carefully and independently read the transcripts multiple times in order to identify significant statements. Significant statements were identified as those containing meaningful descriptions of the fathers' perceptions of their lives and relationships with their children with ASD. The researchers then came together to develop the final list of significant statements. Each researcher then independently formulated meanings for each statement. Meanings for statements were developed as a way for the researchers to infer the meanings fathers give to their experiences. The researchers came together again to develop a final list of meaning statements. Together, the researchers then completed the final step, clustering meanings common to all transcripts into themes.

During data collection, the researchers reflected on what they were learning, they talked with each other about emerging understandings, and read relevant research and theory to enlarge and deepen their understandings. This allowed the researchers to develop new insights into the meanings of the material. The researchers identified promising patterns of meanings and identified tentative core concepts, which were early areas to organize the material from the transcripts. The researchers then identified, named, and coded core concepts through notions that were part of general knowledge but were not part of the literature review or reflexivity statements. Glaser (1978) calls the practice "theoretical sensitivity." The names the researchers chose were both the product of what the participants used as well as the interpretation of those words.

Trustworthiness

To ensure reliability in qualitative research, examination of trustworthiness is crucial. Seale (1999) stated that the "trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability" (p. 266). An audit trail was created and

maintained throughout the progression of the study that incorporated the literature review, research question development, theory and method selection, Institutional Review Board process, data gathering events, reflexivity recordings and writings, coding procedures, transcription, and data analysis. Reflexive statements were written prior to data collection to identify assumptions and biases of the researchers. Reflexive memoing was also done during the project.

An essential requirement of phenomenological research is that researchers bracket their pre-understanding of the topic (Dahlberg & Dahlberg, 2003). The researchers were aware of potential bias due to their pre-understanding. For example, from the reflexive statements, the researchers described how they expected to hear fathers discuss themes about how they are meeting their expectations of being a father, stress of having a child with ASD, financial strain of having a child with ASD, lack of social support, and lack of resources. As the researchers analyzed the data, if a father mentioned any of these themes, the researcher would make a reflexive memo to refer to later to discuss potential places for bias. Finally, data analysis was strengthened through the use of two coders and peer debriefing between the researchers.

Results

The researchers conducted the data analysis procedure following the third interview and then following each subsequent interview. After the seventh interview, no new themes were developed, and the researchers decided that saturation within the themes was achieved. From the seven verbatim transcripts, the researchers identified 195 significant statements. Meanings were inferred from significant statements, and then were clustered into themes. Seven themes were developed from the significant statements: Shared Activities, Developmental Sensitivity, Emotional Understanding, Fighting the Label, Fatherhood Expectations, Parent Responsibility, and Fatherhood Isolation.

Theme 1: Shared Activities

“Shared Activities” represents the variety of activities that fathers described that they enjoy with their sons. Many fathers mentioned outdoor activities, such as swimming and playing on playgrounds. Interacting with water in some capacity was mentioned by most of the fathers.

I enjoy doing it with him especially visiting the beach...and playing in the water. Really it's any place with water because he absolutely loves it. It really does get the body experience, which is really the main thing. (Michael)

My parents have a place on a lake so we do like to go and play in the water, and go for boat rides, and fish. (Doug)

Indoor activities that fathers described usually involved some sort of physical touch such as snuggling or wrestling with their children.

A lot of hugs. Squeezing you know. He'll come up and get right in my face. (Tom)

...he likes to engage in kind of physical play. Like we were doing yesterday I was...wrestling with him and he tried to get away with me then I'd let him go and he'd come back a few minutes later. (John)

He will snuggle with me on a regular basis... 'I want to lay with you daddy'... (Doug)

No matter what activities the fathers were engaging in with their sons, they seemed to enjoy the moments together.

...we were playing the Wii, you know we were on the same team...we were doing the same goal and he looked at me and said 'You're the best daddy, you're the best.' 'Thanks buddy, you are too.' 'Yeah, yeah we're the best, we're a good team.' And we high fived and did the knuckles. (Doug)

I really like taking him swimming, playing hide and go seek with him, outdoor activities like going to the zoo, going to the park, going to the lake...(Michael)

Theme 2: Developmental Sensitivity

“Developmental Sensitivity” describes that fathers appeared to recognize the need to attend to their children’s development and understand how their children learn and develop.

...its ASD 24/7, it never goes away and we try to take every opportunity to help him function more and learn more. (Michael)

It was us learning how he learns. It wasn't him doing anything different. It was us learning and letting him learn that way. (Carl)

...his brain is just wired in a different way than...most other kids I guess. But at the same time it can be very rewarding as well. He's you know he's been making a lot of progress learning his alphabet and learning to read and spell words. (John)

Fathers seemed to cope with the fact that ASD was always present by staying positive, choosing battles, and looking at their relationships as constant learning experiences.

I guess it's just a constant learning experience, we understand each other pretty good, I don't know if I would add anything or if there is anything else, it's just a learning experience, watching what he does...(Michael)

We are kind of fortunate for having a son that is autistic to be as well off as he is. We just count our blessings and back. (Robert)

Being sensitive to their children’s developmental abilities seems to lead to appreciation of the small achievements of their children – small achievements that may be overlooked in children who are typically developing.

There is always that unknown, there are always milestones, you know there are milestones in everyone's lives, these are different now. It's not something

he chose or we chose - they are just different and we don't know what those milestones are yet until they actually happen. Is he going to graduate kindergarten? We don't know, we are hopeful, so you know, it is always something different always something new. (Doug)

Carl told a story about how his son jumped for the first time:

...then I said, "[Son] jump" and he did, and it was only like a quarter of an inch. But, this is the kid who wouldn't even bend his knees, right, like not even go down. So, those things are the most prized things in the world and I get those and other people don't.

Theme 3: Emotional Understanding

In this theme, "Emotional Understanding," fathers described being aware of their children's emotional abilities and different ways of expressing feelings. Fathers exuded confidence that their children loved them despite a lack of verbal affirmation.

I love him and he loves me. Every night before we go to bed there is always a hug and he gives a hug and a kiss and we've done that forever and he gives kisses now and they are the biggest open-mouth-wettest-nastiest-wet-tongue thing that you can get but they are beautiful. (Carl)

Fathers also expressed the ability to respond to nonverbal language. Often fathers are sometimes thought of as lacking emotional intensity but as described below there is a strong bond.

Yeah I feel that I know him the best out of anybody. I can understand his body language and just what he wants to do. If he says a word that nobody else understands I will be able to understand it. I see myself as pretty good at that. (Michael)

Carl discussed an incident when his son was sick:

So he was crying and as soon as I open the door he grabs my hand and walks me over to his bed and he crawls in and he drags you and what he likes to do is be on his shins and his knees and he gets there and then he takes your head and he pushes it down right next to his so you are both curled up and then he reaches over and gives you one of those big wet kisses and then pushes your head back down and you know after about 15, 30 seconds like that he'll roll over to his side and you'll snuggle like that. You know it is just something like that...it is awesome. You know, I'm sick and I need you. Thanks for coming.

Theme 4: Fighting the Label

The theme, "Fighting the Label," reflects that fathers expressed that they have to advocate for their children to be treated as unique individuals who did not necessarily fit stereotypes held by other individuals about children with ASD.

...you want people, whether it's now or down the road to be open-minded and see him for what he is, and give him a chance. You know he's a good kid, he has a good heart, he's just a little different than most. (Doug)

For Carl, ASD appeared to be a diagnosis that did not really mean much to him. Before his son was officially diagnosed with ASD, he was more concerned with getting his son the appropriate treatment rather than finding the “correct label.” At one point in the interview, Carl reflected back to his state of mind regarding diagnosing his son:

You know we talked about ASD...but the thing for us was that it could always be this [ASD], but it didn't really matter at this time because whatever we do is going to be exactly the same thing. So let's not label it right now, let's just treat it, because it doesn't matter...the label at this time just doesn't matter.

“Fighting the label” also seemed to encompass how fathers described some relationships with individuals outside of the family.

We have fought very hard and believe very strongly that he should be in general [general education classroom] as much as possible, so we have fought for that. It doesn't matter which school district you are in, you fight...everybody fights. They can tell you how great their programs are but they also don't fight, so we've been fighting for the last two and a half years...the teachers are good, but the system is bad. (Carl)

Carl further discussed how he and his wife worked as a team to advocate for their son's education and services at school:

So maybe I've become a little more protective of him and fighting for the fact that he gets it [understands]. So it took him three and a half years to jump above normal, but he did it!...Part of what I would tell people is that just because he can't talk or he is not talking yet doesn't mean that he's not listening or seeing or picking up what is going on around him and maybe he is not doing it the same way that you or I do, but it is still happening. It is still there. And we have...after going through the ABA [Applied Behavioral Analysis] training...proof of that. It is not just us saying...he gained 10 months in two [months]. It was three months of training and when he started he was at two months for most of his stuff and for all of his stuff he made a 10-month jump.

Theme 5: Fatherhood Expectations

Despite a unique understanding of their sons' developmental levels and a sense of protectiveness regarding other people in society, it also appeared as though fathers battled with their own “Fatherhood Expectations.” Carl discussed how he was really looking forward to some of the activities that he and his father enjoyed while he was growing up. Some of the activities, such as revisiting landmarks, can be accomplished, but others, such as spontaneously taking a road trip, cannot.

There were things that I did growing up with my dad that I was hoping that we could experience...like go up north and hang out at our cabin...I'd like to be a

little more spontaneous with him but it is difficult to do some of that stuff with him. (Carl)

Many of the fathers talked about how they would like to do more activities together with their sons:

Yeah I'd like to bike ride with him where he's actually riding next to me. Or be able to, you know, we kick the soccer ball back a forth a little bit, but be able to do more of that kind of stuff with him. (Tom)

The hardest thing is not being able to...throw a baseball, or throw a football, or have him stand still for a second to do something... (Michael)

Some of the fathers shared about their personal experiences when they first found out that their children had ASD. Michael had to overcome denial and thoughts that his son would eventually grow out of ASD:

I was in denial for a long time, and also I didn't realize how serious it was. I thought that if we did some therapies and some vitamins...he would start to get better. It has been a lot harder than I thought.

There appears to be a sense of loss that occurred with these fathers. The expectations and build up to those created a life and dyadic relationship that they expected to have with their child. Not having the possibility of living out those expectations was a powerful feeling the fathers had as if they were reworking their own perceptions. Doug described the grieving process that he experienced:

There is a grieving process when you find out, because this child who you want to be who you think is [typically developing], and you are told otherwise, there is a bit of a grieving process for that and you have to understand that, accept it, and deal with it however people deal with things like that.

Theme 6: Parent Responsibility

“Parent Responsibility” reflects that although fathers realized that being involved fathers to their sons was an important responsibility, they balanced their other roles within the family. When asked about his role in the family, Ryan saw himself as the disciplinarian:

...knowing that you have to come home every night, knowing that you have to be a dad first...discipline I would say.

Carl's role was to stay positive:

My wife is very strong, but I'm also the positive part of it. So I have to stay positive.

The role of parenting their other children also was discussed. Ryan emphasized wanting to make sure he gave equal attention to both of his children:

I try to treat them both...the same...so it doesn't seem like I'm...favoring the other...it's just a matter of...dispensing my attention to not just one child...Trying to...make them both happy.

Carl talked about how he felt guilty that sometimes he pushed his younger son away and wondered how that affected him:

That is something that I keep in my head. I want to make sure that with everything that we're doing that he's still getting time too...and I think that he is...but it is definitely a concern that I still have often.

Carl would further explain how important it was that he was a part of all of his children's lives:

So that is one of my biggest successes is being a part of their lives. You know my wife, last night, told me that she went to one of her meetings..."and I appreciate how involved you are with the kids...you know I have all of these ladies and they have husbands who don't do anything...they are out golfing on Sunday and they just leave." And I don't understand how that happens. That part just doesn't click in my brain.

Lastly, fathers discussed their role in protecting their children from harm.

I held him in my arms and I realized that at moment that I...I mean I'm not a person who likes to get into altercations. I've had them but you know...but I realized in that moment I could kill somebody. I mean if somebody really intentionally tried to hurt him...you know it would be a very short ride from calm parent to [snapping] that's it. (Tom)

Theme 7: Fatherhood Isolation

"Fatherhood Isolation" represents the times when the fathers expressed sadness and isolation about being the father of a child with ASD. The wives of some of the husbands were involved in groups of mothers that met regularly. None of the fathers, however, talked about having a group of other fathers who gathered on a regular basis. Carl talked about how he could not call someone on the phone to celebrate a positive moment, such as his son jumping for the first time:

Who am I going to call on the phone...[wife] can...right, dads don't. I would, but there just isn't. So what do I do? So I put on my Facebook, '[Son] jumped!' And people are like, 'Hey, what does that mean?' See, it doesn't mean that much to many people. They don't get that it was the biggest inch in the world.

For Michael, his isolation caused him to feel discouraged and jealous:

I think that it is the most discouraging part...like I will see other five or six year old kids playing, playing normally, it makes me feel a little jealous. I am not going to lie about it, it really bothers me.

Some fathers also talked about how having a child with ASD negatively affected their relationship with their spouses. Tom did not feel that he could get a sitter to spend alone time with his wife because of his son's behavioral problems:

But you feel guilty when you're always sharing the duties especially when I was on the road you come home and spend a little time with him [son] to say, 'Ok now I'm going to get a sitter and we're going to go out.' ...the other thing is when he is having issues he just you can't say, 'Well I'm just going to get a sitter,' because you can't pay somebody enough to chase a kid around who's harming himself.

Tom also talked about how he and his wife used to be involved in sporting activities. When their son was diagnosed with ASD he described it as a “kick in the teeth.” As the ASD progressed they were able to do less and less of the things that they enjoyed.

So our lives pretty much revolve around the ASD now. It used to revolve around mountain biking and water skiing and things like that and now we have to watch ourselves when we're in groups of friends that we don't spend the whole time talking about ASD. (Tom)

Even though fathers felt isolated from their peers, some fathers expressed the importance that others did not feel sorry for them.

No, no. You know, my life is my life. I was trying to tell one of my best friends...when you talk to me and you complain about the hockey games that you take your kids to, I'm not sad that I'm not that guy. What I'm sad about is that I can't talk to you about [son] jumping because in your head you want to feel sorry for me. You want to go, 'Oh, God, that sucks, it's horrible.' And I'm like, 'No! It's my life...I just need to be able to tell you about it.' I just want to tell you that I had to go to ABA (Applied Behavioral Analysis) for 40 hours this week. That's my life, it is not yours, your problems are still problems, there is no difference in levels, just don't feel sorry for me, unless I ask you to. But, you know, it is hard for most people. They want to [sad face], and it is just like, no! This is my life. (Carl)

Discussion

The seven fathers interviewed for this research study are all intensely dedicated to their children. They have a mission to help their children with ASD be successful in whatever capacities possible. However, this dedication and passion is delicately balanced with the father's personal life. In other words, these fathers are clearly motivated to help their children to be successful, but sometimes there is a cost to their own personal well-being. For some fathers this means fewer peers to socialize with, while for other fathers this means less time with other children or spouse.

For the seven fathers who participated in this research study they connected with their sons through “Shared Activities,” “Developmental Sensitivity,” and “Emotional Understanding.” Not all of the themes were about the father-son relationship, though. The last four themes, “Fighting the Label,” “Fatherhood Expectations,” “Parent Responsibility,” and “Fatherhood Isolation”, were related to the fathers' relationships with other individuals, or were about individual processes.

Findings of the current study concur with van IJzendoorn et al. (2007) in that parents of children with ASD are sensitive to their children. Specifically, fathers in this study were sensitive to their sons' emotional needs and developmental milestones. Such sensitivity appears to be especially important, considering the varying levels of verbal abilities of the children. When the children were nonverbal, fathers had to work harder to learn to communicate with their children.

A limitation of the current study was that all of the children with ASD were white males, and future studies should seek fathers who have female children diagnosed with ASD. Also, although the phenomenological approach allowed for in-depth interpretation of the data, it is necessary for the researchers to take into account that the presence of the recorder could have affected the fathers' interpretation of their relationships with their children (Riessman, 1993). Expanding the sample size to include non-married fathers or possibly single fathers with custody and without could provide further analysis for comparison of how fathers define their relationship with their child with ASD outside of marriage.

Implications for Research and Practice

Despite the fact that the findings are not generalizable to all fathers in every societal context, the findings of this study reveal significant information about the relationships that fathers have with their children with ASD. These findings also highlight the need for further research in this area. More specifically, what are the individual characteristics of fathers and their children with ASD that predict positive relationships? How can uninvolved fathers become more involved? How would uninvolved fathers explain their lack of involvement?

Clinicians can use the information from this study to help fathers foster healthy relationships with their children with ASD. First, it is important for clinicians to recognize and accept the personal processes of such fathers and to allow them to move through acceptance of an ASD diagnosis at their own pace. Fathers in this study discussed being in denial and having to grieve that their children would always have ASD. Clinicians should be patient with fathers who are in various stages of this process. Fathers who have children with ASD also "look" different from each other. All fathers had ideas about their roles in their families and felt a sense of pride and ownership over these roles. Asking about and honoring the roles that a father perceives himself to be in can be empowering for the individual. For example, for fathers adapting to an "advocate" role, clinicians familiar with special education law can be a resource to fathers trying to navigate the school system.

As for their specific interactions with their children, all fathers who participated in this study had shared activities that they enjoyed with their children. These activities may or may not have included other children or spouses, but more importantly, they were activities that both the father and child enjoyed. It is important for clinicians to help fathers develop sensitivity around their children's physical development and emotional expressiveness so they can develop shared activities with their children. It can be difficult to overcome the expectations that a father might have of his child and his child's development, but the fathers who participated in this study were able to balance their expectations and at the same time recognize and celebrate the developmental milestones that their children were reaching.

It is also important for clinicians to recognize that fathers appear to balance these shared activities with their children with ASD with a sense of guilt about their relationships with other children and spouses. Relationships with other children were important to fathers in this study. Clinicians can help fathers to develop healthy relationships with all of their children and normalize family experiences in that some children require more energy at certain times in the family life cycle. Clinicians also can help fathers to attend to their relationships with their wives by helping them find time to spend time alone with their wives,

talking about topics other than ASD. Additionally, fathers might not feel as isolated if clinicians can help them find ways to meet other fathers who have children with ASD through activities such as support groups.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: APA.
- Cohen, L., & Manion, L. (1994). *Research methods in education* (4th ed.). London: Routledge.
- Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. Vaile & M. King (Eds.), *Existential phenomenological alternatives for psychology* (pp. 48-71). New York: Oxford University Press.
- Dahlberg, H., & Dahlberg, K. (2003). To not make definite what is indefinite: A phenomenological analysis of perception and its epistemological consequences in human science research. *The Humanistic Psychologist*, 31, 34-50. doi:10.1080/08873267.2003.9986933
- Flippin, M., & Crais, E. (2011). The need for more effective father involvement in early ASD intervention. *Journal of Early Intervention*, 33, 24-50. doi:10.1177/1053815111400415
- Haverkamp, B. E., & Young, R. A. (2007). Paradigms, purpose, and the role of the literature: Formulating a rationale for qualitative investigations. *The Counseling Psychologist*, 35, 265-294. doi:10.1177/0011000006292597
- Jones, C. D., & Schwartz, I. S. (2009). When asking questions is not enough: An observational study of social communication differences in high functioning children with ASD. *Journal of ASD and Developmental Disorders*, 39, 432-443. doi:10.1007/s10803-008-0642-y
- Macintosh, K., & Dissanayake, C. (2006). Social skills and problem behaviours in school aged children with high-functioning ASD and Asperger's disorder. *Journal of ASD and Developmental Disorders*, 36, 1065-1076. doi:10.1007/s10803-006-0139-5
- Mertens, D. M. (2005). *Research methods in education and psychology: Integrating diversity with quantitative and qualitative approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Muller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *ASD*, 12(2), 173-190. doi:10.1177/1362361307086664
- Naber, F. B. A., Swinkels, S. H. N., Buitelaar, J. K., Bakermans-Kranenburg, M. J., van IJzendoorn, M. H., Dietz, C.,...van Engeland, H. (2007). Attachment in toddlers with ASD and other developmental disorders. *Journal of ASD and Developmental Disorders*, 37, 1123-1138. doi:10.1007/s10803-006-0255-2
- Parette, H. P., Meadan, H., & Doubet, S. (2010). Fathers of young children with disabilities in the United States. *Childhood Education*, 86, 382-388. doi:10.1080/00094056.2010.10523174
- Paul, R., Orlovski, S. M., Marcinko, H. C., & Volkmar, F. (2009). Conversational behaviors in youth with high-functioning ASD and Asperger syndrome. *Journal of ASD and Developmental Disorders*, 39, 115-125. doi:10.1007/s10803-008-0607-1
- Phelps, K. W., Hodgson, J. L., McCammon, S. L., & Lamson, A. L. (2009). Caring for an individual with ASD disorder: A qualitative analysis. *Journal of Intellectual and Developmental Disability*, 34, 27-35. doi:10.1080/13668250802690930
- Riessman, C. (1993). *Narrative analysis*. Newbury Park, CA: Sage Publications.

- Rutgers, A. H., Bakermans-Kranenburg, M. J., van IJzendoorn, M. H., & van Berckelaer-Onnes, I. A. (2004). ASD and attachment: A meta-analytic review. *Journal of Child Psychology and Psychiatry*, *45*, 1123-1134. doi:10.1111/j.1469-7610.2004.t01-1-00305.x
- Rutgers, A. H., van IJzendoorn, M. H., Bakermans-Kranenburg, M. J., Swinkels, S. H. N., van Daalen, E., Dietz, C.,...van Engeland, H. (2007). ASD, attachment, and parenting: A comparison of children with autism spectrum disorder, mental retardation, language disorder, and non-clinical children. *Journal of Abnormal Child Psychology*, *35*, 859-870. doi:10.1007/s10802-007-9139-y
- Seale, C. (1999). Quality in qualitative research. *Qualitative Inquiry*, *5*(4), 465-478.
- Smith, J. A., & Osborn, M. (2003). Interpretive phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). Thousand Oaks, CA: Sage Publications.
- van IJzendoorn, M. H., Rutgers, A. H., Bakermans-Kranenburg, M. J., Swinkles, S. H. N., van Daalen, E., Dietz, C.,...van Engeland, H. (2007). Parental sensitivity and attachment in children with autism spectrum disorder: Comparison with children with mental retardation, with language delays, and with typical development. *Child Development*, *78*, 597-608. doi:10.1111/j.1467-8624.2007.01016.x

Author Note

Terry M. Keller, MSW/MBA, LMSW is an Assistant Professor and Chair of the Social Work Department at Lourdes University. He primarily teaches students at the undergraduate level at Lourdes University. Correspondence regarding this article can also be addressed to Terry Keller at e-mail: tkeller@lourdes.edu

Julie L. Ramisch, Ph.D., LMFT is Assistant Professor in the School of Family, Consumer, and Nutrition Sciences at Northern Illinois University. She primarily teaches and supervises students in the Specialization in Marriage and Family Therapy program at NIU. Correspondence regarding this article can also be addressed to Dr. Julie Ramisch at e-mail: jramisch@niu.edu

Marsha Carolan, Ph.D., Associate Professor, Human Development and Family Studies, Michigan State University, teaches and advises dissertations in Family Therapy and Family Diversity. Correspondence regarding this article can also be addressed to Dr. Marsha Carolan at e-mail: Carolan@msu.edu

Copyright 2014: Terry Keller, Julie Ramisch, Marsha Carolan, and Nova Southeastern University.

Article Citation

Keller, T., Ramisch, J., & Carolan, M. (2014). Relationships of children with Autism spectrum disorder and their fathers. *The Qualitative Report*, *19*(66), 1-15. Retrieved from <http://www.nova.edu/ssss/QR/QR19/keller66.pdf>
