Parenting a Child with Autism: Parents' Perspectives at Different Stages

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Abstract

Raising a child with ASD involves unique challenges. This poster presents research involving focus groups of parents of children with ASD at different stages, investigating the experience of parenting children with ASD, and the different needs brought about by the multiple transitions that occur throughout the lifespan of a child.

Background

In recent years, the prevalence of Autism Spectrum Disorders (ASDs) has increased (CDC, 2011). ASD is a disorder that affects not only the child, but the family as well (Bevan-Brown, 2010). Parents of children with ASD experience a higher amount of stress and are more susceptible to negative outcomes when compared to parents of typically developing children and parents of children with other disabilities (Bowers, Burbine, Dunn, & Tantleff, 2001), which may impact on family welfare and functioning of the nuclear family unit. Raising a child with ASD involves unique challenges such as the severity and duration of the disorder, and the child's inability to adhere to social norms (Altiere & von Kluge, 2008). In addition, as in the life of every child, there are multiple transitions that occur, not only from school to work, but also from early intervention to school, through the grade levels from early elementary to secondary elementary to middle school to high school, and from adolescence to adulthood. It is important to determine what needs exist for supports at each of these stages for parents of children with ASD.

Purpose

The aim of this study is to explore the perspectives of parents of individuals with an ASD from early childhood through adulthood and how these perspectives change over time. Six groups of parents of children with ASD at different ages representing a different transition stage in the life of a child with ASD participated in this study:

- First diagnosed
- Early elementary (K-2 grades)
- Secondary elementary (3-5 grades)
- Middle school
- High school
- Adult

Methods

An online focus group methodology was used for this investigation. The focus groups were conducted over the Internet over a period of weeks. This allowed for a more distributed geographic sample of parents, and also allowed for data collection to take place within a time frame that was reasonable for busy families. A password-protected Wiki site was used for the online focus groups.

The participants in each of the six focus groups were asked to explore and discuss issues and variables that they perceived to be central to the experience of raising an individual with an ASD as a factor of their current stage of development. The focus groups spanned a period of 7-8 weeks, and participants were asked to respond to a new question/topic each week, which included:

- Describe what's going on right now in your life as it relates to parenting a child with an ASD.
- Of the issues you described, which would you consider to be the issues that weigh on you the most? What are the things that you worry about the most right now?
- What successes have you experienced recently, as a parent of a child with ASD?
- How do you feel having a child with ASD is making your experience as a parent different at this point in your life than it otherwise would have been?
- What aspects of being a parent of a child with ASD seem like they will never go away (positive and negative)?
- What are your hopes and dreams for your child?

Participants were asked to respond to the online discussion topic at least one time per week, and to reply to another parent's response at least one time per week.

Analysis

- Participant exchanges were transferred from the Wiki site to a word processing document.
- The information from the focus group discussion was broken into the smallest units of meaningful information that expressed a complete idea or thought (McNaughton et al., 2001; Vaughn et al., 1996).
- These thought units were coded according to an overall coding scheme based on the work of Bronfenbrenner (1979).
- The researchers determined reliability for 20% of the data. The research group discussed any disparate coding decisions until agreement was reached and reliability was greater than 90%.
- All remaining thoughts units were coded for main themes and sorted across groups by broad code, at which point the broad coded themes were subcoded for the presence of subthemes.

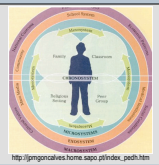
Coding Scheme

Urie Bronfenbrenner (1979) described an ecological model of development, which summarized the different levels of interrelationships between individual and environment within which development occurs. In this approach, the developing individual (e.g., the individual with ASD) is considered in the context of his or her central role in a series of increasingly larger environmental settings.

This poster presents a discussion of the preliminary subthemes that emerged from the data at the level of the **family**, an important part of the mesosystem as described by Bronfenbrenner (1979), which includes the interrelations between the systems in which the developing individual directly participates.

Data that were coded at this level fit the following description:

Feelings related to the functioning of the nuclear family, including discussion of sibling issues, parental issues, spousal relationships, or family functioning. Feelings about the impact on the family of having a family member with ASD or about being a family member of a person with ASD are included in this area.



http://jpmgoncalves.home.sapo.pt/index_pedh.htm

	Code	Code Definition
Benefits	2.1	Any comments related to the successes, positive outcomes, or advantages associated with being a parent or family member of an individual with ASD.
Negative Impact	2.2	Any comments related to the negative experiences or feelings associated with being a parent or family member of an individual with ASD.
Supports	2.3	Any comment directly related to a strategy, characteristic, action, or attitude occurring at any level of the system that supports the parent in parenting their child with ASD.
Barriers / Challenges	2.4	Any comment directly related to a characteristic, action, or attitude occurring at any level of the system that creates challenges or serves as a barrier preventing the parent from effectively parenting their child with ASD.
Recommendations	2.5	Any comment that includes a description of ideas for ways to overcome barriers and challenges, ideas for supports that could be beneficial, or advice to other parents of individuals with ASD that relate to parenting an individual with ASD.
Future Hopes	2.6.1	Any comment that includes a description of a hope that the parent expresses related to the future of the family, spousal relationships, or siblings of the individual with autism.
Future Worries	2.6.2	Any comment that includes a description of a worry that the parent expresses related to the future of the family, spousal relationships, or siblings of the individual with autism.

Results

Benefits

Positive Changes: parents discussed positive changes in their attitudes and in the family as a whole, and the role of their child with ASD in making life more interesting

"I am a better person now. More tolerant with others, more understanding and kind too."

"The burdens may be more complex within our family, but we sometimes are so thrilled by something that another family might take for granted."

Special Bond: some parents emphasized the bond between parent and child and within the entire family

"The love for my daughter is each day bigger. She is the most wonderful girl in the whole world for me and I am so proud of her. I know every mom loves your child, but when your child has special needs it is possible to love even more."

"But really solving something together as a family, growing that way--well, we get maybe more of those moments than others."

Child's Progress: parents were able to see the benefits of their child's successes

"I think his biggest success has been that he can get himself out of bed to get to work during the week when I am not home to do so."

Learning about Autism & Supporting Others: some parents felt they could use what they've learned to help others

"I just love helping a fellow parent, because if I can help them avoid the run around we experienced than I will, because it was not fun and a waste of valuable time."

Negative Impact

Doubt About Doing Enough: parents discussed fears about doing enough and the potential for failure

"My biggest fear is that I fall short in preparing him for life, helping him utilize his talents and live up to his highest potential."

Exhaustion: they expressed the difficulties in keeping up with needs and feeling worn out

"It's the 24 hrs/day, coordinating/dealing with everything, figuring out what works, what doesn't, the emotional toll of it all and on and on."

Isolation: parents expressed feeling isolated from others that don't understand and giving up on a previous life

"I never pictured myself in the place where I am now, I truly feel dead inside and constantly on auto pilot."

Strain on the Family: many parents discussed the impacts of a child with autism on the family resulting in strain on themselves and the family as a whole

"So I guess my feeling is that it really gets harder, and the rewards are definitely dwindling. I might expect that things will even out over time, but I'd like to be able to enjoy some stuff now, not just look forward to looking backwards at having done the 'right thing.' It's a rough time."

"I don't think that any of us who are going through this can say that we have come out of it with our marriages unscathed! It absolutely takes a toll on all relationships! We can only do what we can and move on."

Supports

Family Supports: many parents identified their family members as a positive support

"My marriage - the most precious thing in the world to me right now. He talks me in off the ledge and helps me keep my sense of humor when things just get too overwhelming"

Coping Strategies: parents identified strategies that they have developed to help cope, such as hope, taking time for themselves, positive attitudes, etc.

"One thing that will never go away for me is hope! I don't know what the future brings but I have hope that one day the autism puzzle will be solved. I have hope that there is a cure or a medication on the horizon that will reverse the effects of autism"

Encouraging their Child's Independence: some parents discussed encouraging independence

"Whenever he starts to do stuff on his own it can take him ages to do it. I have had to learn patience and to be accepting of the result of his efforts even if they may not be upto [sic] my standards."

Being an Advocate: many parents felt that advocacy was critical

"We are their advocates, their support system, their world...and as such must be stronger, more supportive, and more loving than those parents that are not faced daily with the challenges their needs pose."

Expectations: many parents expressed the importance of changing their expectations

"As he has grown into a little boy, I still feel inclined to want to fix things, but my expectations are evolving into the realization that this is a slow, steady process of adaptation and acceptance for everyone involved."

Results, cont.

Barriers/Challenges

Child Specific Challeges: parents in all groups discussed the variable nature of the daily functioning of children with autism

"I love my son and bend over backwards for him. ASD is much more of a burden because an ASD mind is so different from a neuro-typical mind so that I don't know what to expect on a day-to-day basis. One day he is completely 'on' and I wouldn't even know that he is an ASD kid, but other days, he is so 'off' that we can't address anything with him because his responses/actions are completely off text."

Parent Specific Challenges: many parents shared challenges specific to themselves

"And I'm not handling it very well myself -- I'm impatient and haven't been very understanding. We are more or less just trying to get through the day as a family at this point."

Others Don't Understand: some parents shared that many people could not help or understand

"It is so embarrasing in public. My husband and I dont know what to do, we were told by his psychologist to ignore it. Its very hard to do that....especially in a public setting when everyone is starring at you or your child."

"My son and his dad are usually at odds because his dad believes that he can overcome his autism. He is in such denial. So he pushes him beyond his capabilities and then it ends badly."

Recommendations

Recognize Progress/Keep Track of Successes: parents recommended being aware of successes and taking things one day at a time

"So progress. Isn't that what we dream about and work for. Any progress, sometimes measured in calendar notes. Was this month better then [sic] last month? This year better then [sic] last? That's something the behavioralist taught me. Take notes and look for trends because the up and down of daily living can make you hopeless and that makes you feel helpless."

Seek Balance: parents recommend finding time for themselves and/or their spouses, and accepting help from others

"Don't forget you. You still exist and that is a big problem we all face, we forget ourselves and put everyone in front and then we are left empty. Take care of you first and foremost."

Know Your Child: they recommend knowing the child's individual needs and trusting instincts

"The best piece of advice the doctor game me after Owen's diagnosis was delivered to me was 'Owen hasn't changed any from the time you walked in here, you now just have a lot more information about him.' And she was so right."

Hopes and Worries

Hopes: parents expressed hopes for their child and their family, which tended to be general in nature

"I am hopeful that as our sons get older, we will be able to have a social life again"

"Now, I would consider that I did a good job as a parent if [child] is a happy child and adult, and if he has the social and emotional skills to take him through life. Not that I don't still dream that he will go to college, but I think that his emotional growth and happiness is more important to me."

Worries: parents worried about many things, such as the long term impact on the family and what will happen when they're gone

"I think our fears and worries as parents are magnified with children who we feel will always need us. I sometimes wonder what will happen when my husband and I are no longer around, if he will be okay without us. I think it is perfectly normal for us to worry, who else knows and loves our children as much as we do!"

Discussion

Benefits

- Many of the benefits were reported by parents of children at younger ages (elementary school age)
  - Positive changes were primarily discussed by parents of children through middle school
  - All parents celebrated the successes that their children had achieved

Negative Impact

- The strain on the family was a theme that resonated with parents at all ages
- The themes of exhaustion and isolation were primarily discussed by parents of the youngest ages (first diagnosis and early elementary)

Supports

- Family supports, coping strategies, and changing expectations were discussed by all parents except those whose children had reached adulthood
- All groups of parents discussed the importance of being a strong advocate for their children

Barriers/Challenges

- Parents in all groups recognized the challenges presented by their own children's specific needs
- The feeling that others don't understand or can't help seemed to be more prevalent for parents in the middle ages (elementary and middle school)

Recommendations

- Parents' recommendations echoed the strategies that they have found to be helpful, such as celebrating successes (identified in Benefits), seeking balance (identified in Supports), and knowing their children (a theme throughout)

Hopes and Worries

- Parents identified far more worries and fears than hopes.

Parenting a child with ASD, at any age, can be a challenge. As one parent said,

"Of course, not losing your mind may be the greatest success of all because who knew that being a parent was so hard."

However, they do recognize:

"…relish the good moments and I bet you, like me, just love your kid, and the joy you have at the good moments sustains you through the frustrating times."

We have no relevant financial or nonfinancial relationship(s) to disclose.

Presented at the
ASHA Convention
November 17, 2012
Atlanta, GA

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