

DEMONSTRATED STRESS IN LOW
SOCIOECONOMIC RURAL PARENTS OF
CHILDREN WITH ASD: COLLABORATION
AND IMPROVED SUPPORTS

Dr. Wendi Dunham
Marshall University

PARENTING STRESS

- Higher in parents of children with ASD—more than with typically developing children and children with other developmental disabilities.
- WHY????
- Thought to be due to the parent's perception is that the child's attributes are difficult to manage.
- Core deficits of ASD, specifically communication and repetitive/restrictive behaviors.
- Feel more distressed when trying to meet associated demands.
- ASD continues throughout the lifespan...culminately stressful.
- Psychologically impacts parents because extreme duties and necessities of parenting supersede individual resources (limitations in physical, financial, and personal resources=stress=development of mental health, negative feelings as a parent, and ultimately parenting dysfunction).

PARENTING STRESS

- Parents are unprepared to parent a child with ASD.

WHY?

- Lack of awareness of ASD symptomology and characteristics.
- Lack of awareness of accessible resources.
- Lack of knowledge about existing community resources.
- Lack of capacity to provide appropriate therapeutic and social support.

PARENTING STRESS AND LOW SES/RURAL AREA

- Parents who live in rural and low SES areas have additional stressors in addition to common place stressors related to ASD.
- Poverty
- Unemployment (includes not being able to be employed due to the needs of the child or excessive absenteeism)
- Expected cultural and socioeconomic rules (often in generational poverty)
- Incongruous services and supports to serve children with ASD in educational settings
- Medical health shortages (contribute to the underidentification of children)
- Lack of community support systems
- Lack of awareness of ASD symptomology and characteristics.

RESEARCH STUDY

- A bounded qualitative descriptive case study was used to explore the demonstrated stress of low socioeconomic rural parents of children with ASD based on their perceptions of stress. Ten parents who were raising a child with ASD were invited to participate in the study. Each parent represented one unit of analysis, or case, for this study. The data collection consisted of the PSI-SF for quantitative data and a semistructured interview for the qualitative data.
- Parenting stress was examined within the contexts of parent-child relationships, child behaviors, and parenting difficulties.
- The quantitative data were collected using the Parental Stress Index-Short Form, a 36-item Likert scale with items related to parent-child dysfunctional relationships, parenting distress, and child behavior. Descriptive analysis determined which domain and items were most stressful and were the basis for developing 6 semistructured interview questions. Interview data were open-coded and analyzed thematically to identify the greatest stressors to parents.

RESEARCH AND ROLE OF EDUCATORS IN PARENTAL STRESS

- With the rise in incidence in ASD, demands for increased awareness and understanding of the disorder are a priority, not only by parents but also by individuals who educate the children
- Parents in different contexts experience a unique set of stressors and to provide competent services, educators must know those parents' stressors.
- Additionally, how educators relate to, work with, and support the parents of ASD children can be a key way to relieve parental stress.

RESEARCH QUESTIONS

1. What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the PSI?
 - (a) parental distress subdomain and items,
 - (b) parent-child dysfunctional interaction subdomain and items, or
 - (c) difficult child subdomain and items.

2. How do low socioeconomic rural parents of children with ASD perceive parental stress?
 - (a) How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships?
 - (b) How do low socioeconomic rural parents of children with ASD perceive their child's behavior?
 - (c) What parenting difficulties do low socioeconomic rural parents of children with ASD experience?

RESEARCH QUESTIONS

- The first research question relates specifically with the data collected using the PSI-SF (Parental Stress Index-Short Form) and align with the three sections of the PSI-SF: parental distress, parent-child dysfunctional interaction, and the difficult child.
- The second research question and its sub-questions were answered using a combination of the PSI-SF data and the semi-structured interviews. Specifically, the PSI-SF data were used to generate questions and guide follow-up questioning during the semi-structured interview.

Research Questions and Results to be Reported

Number.	Research Questions	Results to be Reported and Goal
RQ 1	<p>What stressors do low socioeconomic rural parents of children with ASD demonstrate as measured by the three PSI subdomains and their items?</p> <ul style="list-style-type: none">(a) Subdomain parental distress?(b) Average in subdomain parent-child dysfunctional interaction?(c) In subdomain difficult child?	<p>Report: The three subdomain average scores for each participant.</p> <p>Goal: Determine which <i>subdomains</i> are the most stressful for this sample and should be given the most weight in the interviews.</p> <p>Report: Within each subdomain, for each specific PSI-SF item, the averages of 3.0 or greater and modes of 3 or greater on the survey scale of 1-5.</p> <p>Goal: Determine which items are the most stressful for this sample, and should be given the most weight in the interviews.</p>
RQ 2	<p>How do low socioeconomic rural parents of children with ASD perceive parental stress?</p> <ul style="list-style-type: none">(a) How do low socioeconomic rural parents of children with ASD perceive their parent-child relationships?(b) How do low socioeconomic rural parents of children with ASD perceive their child's behavior?(c) What parenting difficulties do low socioeconomic parents of children with ASD experience?	<p>Report: For each subdomain research question all themes and subthemes that emerge from all of the participants' interviews.</p> <p>Goal: To understand the most stressful aspects of the parents' lives.</p>

THEORETICAL FOUNDATION-FAMILY SYSTEMS THEORY

- In family systems theory, any alteration to the family system may cause an imbalance of the whole family system. Family systems must sustain a delicate balance in relationship patterns to maintain family function and assuage family dysfunction.
- The justification for using the theoretical foundation of family systems theory in this study was to explore how the family system functions when the changes exhibited by a child with ASD create stress for parents living in low socioeconomic rural areas.
- Family systems theory includes both individual behavior and dyadic dynamics within the family and other systems that interact with the family (i.e., friends, extended family, community, and society) and other service agencies such as schools and medical professionals .

RESEARCH INSTRUMENTS

- PSI-SF (Abidin, 1995)- The PSI-SF is a self-reported Likert scale that measures origin and types of stress directly related to the parenting role. The PSI-SF is the abbreviated version of the full-length PSI. The PSI-SF consists of 36 statements. Parents respond to each statement using a five-point Likert-type scale to indicate the level of stress for each
- The scale selections include strongly agree (5 = SA), agree (4 = A), not sure (3 = NS), disagree (2 = D), and strongly disagree (1 = SD). The PSI-SF is divided into three subscales: (a) parental distress, (b) parent-child dysfunctional interaction, and (c) difficult child.

DESCRIPTIVE STATISTICAL ANALYSIS

The descriptive statistics occurred in two steps--subdomain analysis and item analyses.

In step 1, each participant's data were totaled as a raw score. Then the raw score was converted to a T-score using a conversion table and these would be entered into the bottom rows of individual subdomain tables and when all participants T-scores are in the bottom row of the subdomain data table, the mean would be calculated and entered. This allowed for the determination of which subdomain was the highest in stress for parents.

Step 2 of item analysis determined which items from the subdomains should be used to inform the interview questions because they were most stressful for the most number of people. The data were organized in a frequency table by item and participant. The mean and mode for each item's raw score were calculated to indicate the most stressful items (mean) for most of the participants (mode). Items that show a rating of three or higher on the scale show the most stress for the sample.

EX: Parental Distress Items Rated by Parents with a 3, 4, or 5—Determined to be most significant subdomain.

Item	3	4	5
I often have the feeling that I cannot handle things well.	0	4	2
I find myself giving up more of my life to meet my children's needs than I ever expected.	0	5	4
I feel trapped by my responsibility as a parent.	0	1	4
Since having this child, I have been unable to do new and different things.	0	4	3
Since having a child, I feel I am almost never able to do the things I like to do.	1	3	3
I am unhappy with the last purchase of clothing I made for myself.	1	3	4
There are quite a few things that that bother me about my life.	0	3	4
Having a child caused more problems than I expected in my relationship with my spouse/parenting partner.	1	6	3
I feel alone and without friends.	0	2	3
When I go to a party, I usually expect not to enjoy myself.	1	2	2
I am not as interested in people as I used to be.	1	2	5

EX: Parental Distress Subdomain, Mean Averages, and Modes

Items	Mean	Mode
I find myself giving up more of my life to meet my children's needs than I ever expected.	4.5	4/5*
There are quite a few things that bother me about my life.	4.2	4
Having a child caused more problems than expected in my relationship with my spouse/parenting partner.	4.2	4
I am unhappy with the last purchase of clothing I made for myself.	3.9	4
Since having this child, I have unable to do new and different things.	3.7	4
I am not as interested in people as I used to be.	3.7	5
Since having a child, I feel I am almost never able to do things I like to do.	3.6	2/4/5*
I do not enjoy things I used to do.	3.5	4
I often have the feeling that I cannot handle things well.	3.4	4
I feel alone and without friends.	3.3	2

QUALITATIVE INTERVIEW

- Six interview questions were generated to determine how low socioeconomic rural parents of children with ASD perceived stress. Questions were developed using the three PSI-SF subdomains in which descriptive statistics determined which domain would produce what number of questions.
- Results determined the Parental Distress domain would produce three questions; Difficult Child Domain would produce two questions; and Parent-Child Dysfunctional Interaction would produce one question. Relative to the research question 2 sub-questions, Parental Distress is equivalent to parenting difficulties, Difficult Child is equivalent to child behavior, and Parent-Child Dysfunctional Interaction is equivalent to parent-child relationships.
- The main interview questions were asked of every participant, but follow-up questions were specific to the individual. Interviews were transcribed, and thematic coding was used for analysis.

Semi-Structured Interview Questions by Domain

Interview Questions	Domain
Why do you believe you find yourself giving up more of your life to meet the needs of your child?	Parental distress
How does rarely being able to do the things you like to do bother you in your life?	Parental distress
How has having a child with ASD caused more problems than you expected in your spouse/parenting partner relationships?	Parental distress
Why do you believe your child reacts very strongly when something they do not like happens, such as getting used to changes in schedules or changes around the house?	Difficult child
Why do you believe your child makes more demands on you than another child would make on their parent?	Difficult child
Why do you believe your child is very emotional and gets upset easily?	Parent-child dysfunctional interaction

FINAL CODES

- Final codes
- How relates to literature
- Several common stressor themes emerged during the development of this study, specifically during the interview process. Among the many stressors experienced by parents raising a child with ASD.
- Four Common Themes: parental respite, marital disconnection, child unpredictable behavior, and parent isolation

PARENT RESPONSES TO FOUR CODES (EXAMPLES)

Parent Respite:

During the interview process of this study, the absence of parental respite was a common theme among parent participants. Parents related their stress to the inability to have time for themselves due to the needs or demands of their child. The ability to find someone to watch or “babysit” their child was the common reason the parents believed they did not have respite for themselves.

EXAMPLES

“Basically, I cannot do anything for myself because no one wants to babysit for him. I can leave him at childcare during certain hours of the day but after those hours there is no one to watch him. No one wants to watch him. He is urinary and bowel incontinent, is nonverbal, and unless you know him very well it is really hard for people to know what his wants and needs are because they cannot read him. I am very protective. I wouldn't leave him with just anybody because his is nonverbal and he couldn't tell me if someone hurt him or is mistreating him.”

“That has probably been the biggest thing that is “me” time. Because we really don't have a lot of that, but like I said, my mom has really been the only person who can handle my child so she does help us when she can. But we have difficulty finding babysitters. He just doesn't do well with other people, he is just uncomfortable, and we don't want to leave him in an uncomfortable situation.”

MB/D

Marital Breakdown/Disconnection

Another common theme among the parent participants from this study was the breakdown of their marriage relationship or a disconnection with their spouse. Parents believed that the demands of their child were so high that the relationship with their spouse becomes disconnected. Examples of marital breakdown or marital disconnections expressed during the interviews included a breakdown in spousal time shared, paternal denial of diagnosis, maternal responsibility, spousal resentment, and divorce.

EXAMPLES

“Well, I’m divorced. I don’t think; I think for the most part there is so much denial there that his dad doesn’t take him anywhere outside of the home. When he has him, he doesn’t take him outside of the home anywhere, like Walmart, or the grocery store or out to eat. He will take him to a drive through and then take him home. It did cause so much stress that we did get a divorce so because he couldn’t deal with the fact that his child was different.”

“I think it has a lot of challenges like my husband when he found out (child) had autism and stuff he really didn’t understand it. He was denying it and fighting me with it and didn’t want to do the therapies and stuff. It was really challenging cause (husband) thought it meant (child) was stupid and that everyone would call his son stupid. He was like flipping out and saying he’s not stupid, and I’d just tell him that he was just had challenges that need to be met. He also got mad at me because I baby him and stuff and I always let him do stuff and stuff like that. We always get in fights about this and that too.”

CUB

Child Unpredictable Behavior

Parents communicated during the interview that not predicting their child's behaviors or reactions to situations was a stressor that was two-fold, first, stress from not predicting their child's actions or reactions to situations and, second, parental distress when their child does not understand the parent's behavior.

EXAMPLES

“Basically, (dealing with behavior) it is a lot of hit or miss. I had to, you know, I was really a pushover when he was little. Then one day I had to say “no you’re not going to act like that, because if you act like that you are going to be in time out.” Or “you’re going to be on your bed, or you’re just going to be in trouble.” I did have some advice from a pediatrician when he was seven or eight years old. She said, “Treat him as you treat (her other child). If you are going to put her in time out, put him in time out. If you are going to spank her, then you need to spank him.” It seems to have really worked because, you know, he knows that he had consequences the same as she did. So it is just a little bit different but I do try to treat them the same, but it is frustrating. He has learned that when he gets angry, I mean really really angry, sometimes, I have to. . . I get up. . . I say, “You are not going to do that, and you’re going to act like you got some sense.” “You’re going to stop smacking” and if he continues to do it, I actually put him in the shower because that calms him. So I do that, or I make him go sit on his bed, which he doesn’t like. . . but I do make him do that”

EXAMPLES

“I have to stay at home with him and if we go to the store, for example, the last time we took him shopping. We went to Kmart, and he picked out a video game supposedly. I mean, he recognized it was a game, but as far as X-box or Play Station he didn't recognize that and all he knew was that it was a SpongeBob video game. So I sidetracked him, gave him a video game...not a video game, a movie, because we used to buy him a five-dollar movie. Then it went from a five-dollar video to sixty dollar dinosaurs. The video game at Kmart, I sidetracked him and gave him something else, and he found it (video game) again in a different game version. I think the one he found first was Play Station. I hid that and then he found the exact same game for the X-box same picture on it and, of course, we couldn't buy it. Of course, he started screaming from the electronics all the way to the parking lot. He screamed bloody murder and ever since then we don't take him to the store.”

PI

Parent Isolation:

Parents related that due to the high needs and challenges of a child with ASD they found themselves isolated from their family members, friends, and community. While caring for the needs and behaviors of their child, parents also have to deal with the stress of being unable to attend family gatherings or trips into the community. This leads to an overwhelming feeling of isolation.

EXAMPLES

“I have to do that (give up my life) because my son has autism and is nonverbal. He has to have all of my extra time. To be able to figure what he wants to eat, what he wants to do, a lot of extra stresses. With the aggression, outbursts and the pacing, we are not able to do a lot of the things normal families go and do. So it's a little more, so it's a lot more stressful to live in his world, basically”

“I feel like my child's life is more important than mine. I feel like I need to be there to give him guidance because he is not completely aware of things that are right or wrong. Where I am an adult, I feel like things are right there before I go on with my own my life if that makes sense? Probably (given up) some of my hobbies like singing or I used to sing different places. Giving up things like clothing or getting my nails done or getting my hair done or going out to lunch with a girlfriend. Heck, even going out for date nights with my husband.”

HOW CAN WE HELP?

- It may be beneficial if educational professionals stay consciously aware of the needs of the families as a unit and extension of the child's education. The parenting stress findings from this research can provide educators with the knowledge of the stressors parents experience when trying to cope with the child's demands, abilities, and educational needs with limited support.
- A large part of the problem stems from the lack of formal and informal supports and then the limited knowledge families have to access the existing ones. This dilemma creates parents who demonstrate their stress based on perceptions, which includes the perception of not having supports to assist with raising their child.
- Many parents expressed that they are the only ones who provide support for the specific needs of their children creating frustration and often breakdown within the parents' own life.

RECOMMENDATIONS

My recommendations are:

- For educators to create and provide a parent needs assessment to be completed by parents of children with ASD twice per year (fall/spring). Educators could become aware of the needs of their parents, which in turn impacts how services, supports, and resources are provided to students. Keeping and tracking the individual needs can help teachers develop ways to target specific goals and objectives for the child. Once educators have tracked the needs of their parents they can research and compile a list of formal and informal supports within the school district and within the community. Examples could be directories of medical health professionals, community autism support groups, autism support websites, childcare programs that accept children with disabilities, and afterschool programs.
- Discuss with the school superintendent and school board members during monthly board meetings about how to find funding to support families. An example could be to create a small “parent library” in which parents can take pamphlets or have access to magazines and literature about autism.
- Provide parents with phone numbers and emails to state agencies, such as OCALI in Ohio, which provide support to parents who have children with ASD.

IMPLICATION FOR CHANGE

Challenges expressed by parents, based on the findings of this research, were that parents of children within a low SES rural area were unaware of or had limited information about formal and informal supports available to them. Parents indicated that formal supports, such as finding competent professionals who did not accurately diagnose children with ASD or having to wait for services and informal supports, such as limited childcare resources negatively impacted the family functionality and the possibility that their child would be educationally underserved.

Once educators assist parents in identifying their stressors, educators can begin the process of developing supports, and lastly, show parents how to access and implement supports.

QUESTIONS