

MEANINGFUL EXPERIENCES OF PARENTS WITH
CHILDREN WITH AUTISM

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in
Psychology

by
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DEDICATION

I dedicate this project to all the families that I have worked with in the past and present. Not only have you inspired my project, but you have ignited my passion for helping to make the world a more kind and empathetic place.

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ABSTRACT

MEANINGFUL EXPERIENCES OF PARENTS WITH CHILDREN WITH AUTISM

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Families can struggle to adjust to the pile-up demands of daily life raising a child with autism. When the demands persistently outweigh the capabilities of the family, such as raising a child with autism, this can result in a crisis for the family (Patterson, 2002). According to the Family Adjustment and Adaptation Response model (FAAR), in order to move through the crisis families must adapt either by increasing their capabilities or reevaluating the meaning in their experiences (Patterson, 2002). This preliminary study looked at the experiences of four parents raising children diagnosed with autism spectrum disorder. Each participant was interviewed over the phone for 45-60 minutes. The researchers looked at 3 aspects of parents' experience based on the FAAR model: Demands (what the family struggles with), Capabilities (what the family has going for it), and Meaning making. Each category had sub categories as displayed in table 2. Researchers found demands, capabilities, and meaning making. Meaning making presented 3 themes between the families: new meaning, family identity, and critical meaning. This study can be helpful for clinicians by emphasizing the importance on holistic family services. Families in this study described moving from a place of sadness and fear to one of acceptance and

adaptation. Not only can clinicians provide families some emotional support and education as they move toward better adjustment, but therapy plays a big role in creating new meaning out of experiences.

CHAPTER I

INTRODUCTION

As autism rates grow to 1 in 68, more and more families are faced with the demands of parenting a child with Autism Spectrum Disorder (ASD) (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). An autism diagnosis is characterized by difficulty with communication, difficulty connecting and maintaining relationships, repetitive behaviors, and stereotypical behaviors like hand flapping, jumping, and echolalia. Children with autism can also have sensory issues that can cause difficulty sitting still, sensitivity to sound, eating issues, and difficulty with motor skills. Each child on the spectrum can have any and all combinations of symptomology (American Psychiatric Association, 2013).

This disorder not only affects the child, but the entire family. This disorder presents high demands for families and caregivers including overcoming communication barriers and balancing multiple roles as parent, therapist, and advocate. Families can struggle to adjust to the pile-up demands of daily life raising a child with autism. Due to the wide range in symptoms, children may need special therapies, including speech, occupational, and behavioral as well as multiple medical interventions. When the demands persistently outweigh the capabilities of the family, such as raising a child with autism, this can result in a crisis for the family (Patterson, 2002).

According to the Family Adjustment and Adaptation Response (FAAR) model, in order to maintain family functioning parents and caregivers must adjust to the demands that

come with raising a child with autism (Patterson, 2002). This is not always an easy task. Studies show that parents of a child with autism have higher stress levels, higher reported mental health issues, fatigue, and more avoidant coping strategies (Gray, 2003; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006; Osborne & Reed, 2010; Pozo, Sarriá, & Brioso, 2014; Seymour, Wood, Giallo, & Jellett, 2013). Parents reportedly feel out of control or like they are not effective as parents, which increase stress and risk of depression and anxiety disorders (Falk, Nicholas, Norris, & Quinn, 2014). When parents and families cannot adapt after a diagnosis of autism, the presence of these risk factors decreased the family's overall quality of life and emotional well-being (Pozo et al., 2014).

According to the FAAR model, in order to move through the crisis families must adapt either by increasing their capabilities or reevaluating the meaning in their experiences (Patterson, 2002). This study uses the FAAR framework to study the how autism affects the entire family experience by looking at what demands are placed on the family and what capabilities they have to combat these demands. Most importantly, the researchers were curious how the families made meaning out of their lived experiences. The researchers collected data from recorded, semi-structured, qualitative interviews asking four parents of children with autism to describe their family's experiences of raising a child with autism.

CHAPTER II

LITERATURE REVIEW

Family Life with Children with Autism

The severity of the child's symptoms makes the stress of caregiving for that child all the more challenging. In general, stress levels for a parent of a child with autism are higher in comparison not only compared to typically developing children, but also for parents of children with other disabilities (Herring et al., 2006). Parental stress can be higher as a result of the severity of the child's emotional and behavioral challenges (Falk et al., 2014; Herring et al., 2006; Osborne & Reed, 2010; Rao & Beidel, 2009; Seymour et al., 2013). These challenging behaviors include tantrums, aggressive behaviors, and strict adherence to routines (Johnson, Frenn, Feetham, & Simpson, 2011; Ludlow, Skelly, & Rohleder, 2011; Seymour et al., 2013). Caring for a child with autism can make the daily routine more difficult when you have to keep to a strict schedule and any change in that routine, planned or unplanned, could result in screaming, crying, and possibly self-injurious behavior. This leaves parents to be hypervigilant at times of unpredictability in order to prevent or prepare to manage the child's behaviors (Safe, Joosten, & Molineux, 2012). This constant vigilance and preparation for problem behaviors can cause fatigue and exhaustion for caregivers (Gray, 2003; Seymour et al., 2013).

Parents have also reported increased stress when trying to manage the child's behaviors out in public. Parents described being more stressed when they felt that they were being judged by others (Ludlow et al., 2011). One study found that parents felt rejected and

judged by others when their child was experiencing challenging behaviors in public (Kinnear, Link, Ballan, & Fischbach, 2016). This type of stigma in the community can make the family feel more isolated as parents have to decide whether to stay home or take the child to a public place (Kinnear et al., 2016; Ludlow et al., 2011). Safe and colleagues (2012) found that mothers of children with autism were often confronted with ignorance about ASD. This is especially difficult as autism is not a physical illness, and children can look or seem “normal” to others when you consider the spectrum of severity in diagnosis.

Parents also experience isolation and exclusion from friends and family members (Kinnear et al., 2016; Ludlow et al., 2011). Some children with autism have difficulty coping with unfamiliar adults and children. This can make it difficult to set up play dates, or have friends casually over for dinner. Also, friends and extended family do not always understand what life is like with a child with autism. Even those who may be supportive at times, might not fully understand the diagnosis or what the parents are going through on a daily basis. In a qualitative study by Ludlow and colleagues (2011) a parent described the grandparents not fully understanding the autism diagnosis and attributing the child’s behaviors to “bad parenting” (pg. 705).

Not only can it be difficult to connect with friends and family, but the child’s symptoms can also make it difficult to connect with their child. The lack of communication and social reciprocity can make having a relationship with their child more complex. It can be difficult for parents to communicate with their child, or for their child to communicate back. This leads to a lack of a relationship, or that they have “lost” their child (Ludlow et al., 2011, pg. 707). For some children, sensory issues could mean not even being able to hug your child. This can make having a meaningful and loving relationship difficult (Ludlow et al., 2011).

Parents have to manage daily life and multiple roles as a caregiver, scheduler, therapist, advocate, and teacher (Hoogsteen & Woodgate, 2013). Typically the stress of their demands was increased when they were described as chronic, ongoing, or constant (Ludlow et al., 2011; Weiss, Wingsiong, & Lunsky, 2013). Meaning, parents' days revolve around the child with autism, using all their time and energy to put the child's needs above their own (Hoogsteen & Woodgate, 2013; Rao & Beidel, 2009; Safe et al., 2012). In one qualitative study, parents expressed most, if not all, of their energy was focused on their child with autism (Hoogsteen & Woodgate, 2013). McGrew and Keyes (2014) found that in that first year after the diagnosis parents report an increase in "pile-up demands", meaning they have an increase in appointments, therapies, worries, stress, and changes in every aspect of their life. This includes talking to doctors and other healthcare providers throughout the course of their child's diagnosis. This in itself can be stressful as, not only does it take years to get an autism diagnosis for their child, but after the diagnosis parents may have to fight against barriers to gaining services (Bultas, 2012; McGrew & Keyes, 2014). Parents often report that they do not feel supported by their health care providers (Bultas, 2012; Ludlow et al., 2011).

Parents also have to manage external stressors that come with everyday life regardless of having a child with autism. Families describe struggling with health problems, family problems, stress from school and work, child's behavioral and emotional problems, life changes, and having multiple life stressors (Weiss et al., 2013). Parents have to balance work, paying bills, extracurriculars, and giving attention to other children in the family. These demands are stressful outside the realm of having a child on the spectrum. The excess of these demands in a family's life is associated with higher levels of parent mental and physical health issues, fatigue, and

maladaptive coping strategies (Falk et al., 2014; Herring et al., 2006; Johnson et al., 2011; Seymour et al., 2013).

But when you add daily stress on top of the stress of caring for a child with autism, parents can feel overwhelmed. It can also negatively influence a parent's perception of their ability to handle the stress. Even with everything parents do for their child and families, they may still not feel like they are doing enough (Osbourne & Reed, 2010). Parents often feel guilty about their child's diagnosis and even feeling inadequate as a parent (Gray, 2003; Ludlow et al., 2011). Studies have found that both mothers and fathers had increased stress when they had lower levels of perceived parenting ability, such as involvement with child and setting limits for their child (Falk et al., 2014; Osbourne & Reed, 2010). Parents can even have difficulty justifying taking a break or personal time for themselves (Safe et al., 2012).

But raising a child with autism is not all bad; studies have also looked at what strengths these families have. Many studies have looked at what types of coping skills are used by parents such as: problem-focused coping, use of social support, positive reframing, emotional regulation, and compromise coping (Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005; Pottie & Ingram, 2008; Pozo et al., 2014). Parents using one more of these coping skills reported increased positive daily mood and decreased risk of depression as well as anxiety (Hastings et al., 2005; Pottie & Ingram, 2008; Pozo et al., 2014).

Parents' use of social support was an important factor in parent emotional and physical health. Gray (2003) found that parents, particularly mothers, relied on support from others. They noted the benefit of seeking out emotional support from family members and friends. Parents also utilized support groups with other parents of children with autism (Gray, 2003; McConkey & Samadi, 2013). Parents valued these groups as they learned skills to better

help their child, how to help themselves, and they could listen to other parent's experiences (McConkey & Samadi). Parents who stayed in contact with parents after the group had ended reported an increase in health and family functioning after one year (McConkey & Samadi). Parents also gained a sense of empowerment as advocates for their child. Parents with increased rates of self-empowerment were found to have higher rates of satisfaction with services received for their child (Resendez, Quist, & Matshazi, 2000). Finding the right services for their family can help the family to feel supported too. Parents report after bad experiences with service providers, including schools and therapists, they did find some professionals that were invaluable helpful and supportive (Ludlow et al., 2011; Safe et al., 2012).

Family Adjustment and Adaptation Response Model

Families who are exposed to significant risk, such as parenting a child with autism, must go through an adjustment process in order to successfully navigate the unique challenges of living with this stress. Patterson (2002) has introduced the Family Adjustment and Adaptation Response (FAAR) model as a way to understand this adjustment process in families and what it means to be resilient. Resiliency is a process of balancing the family demands with the family's capabilities as it relates to family meanings (Patterson, 2002). When a family goes through a crisis, demands persistently outweigh the family's capabilities. Family adjustment and adaptation is the process of restoring that balance.

Families can restore balance by increasing their capabilities and, more importantly, by constructing family meaning. Family meanings play a significant role in readjusting the balance by the family's evaluation of the difficulty of the demands and how capable the family is at handling those demands. Evaluations are interpretations that have been formed over time as the family interacts with each other and talk about their experiences (Patterson, 2002). This

family history can become a protective factor if the family narrative is one of strength and capability. These families tend to be more resilient in the face of crisis.

Previous studies that have looked at meaning focus on specific traits in parent's lives. Weiss, Cappadocia, MacMullin, Vecilli, and Lunsky (2012) looked at how acceptance mediated mental health in parents of children with autism. They found that parents who had higher rates of acceptance of difficult thoughts and emotions regarding the relationship with their child with autism, had lower rates of psychological distress. Positive perceptions were also found to decrease depression in mothers of children with autism (Hastings, Kovshoff, Ward, Espinosa, Brown, & Remington, 2005). These positive perceptions included the belief that the child with the disability has had a positive impact on the parent and the family as a whole as well as the child having positive attributes. Parents even describe raising a child on the spectrum as 'rewarding' (Ludlow et al., 2011, pg. 708). Another study by King, Zwaigenbaum, King, Baxter, Rosenbaum, and Bates (2006) held focus groups to research belief systems in parents of children with autism or Down syndrome and found that parents experienced raising a child with a disability as a life changing experience that impacted their values and world view. Some families experienced loss after the initial diagnosis, but they emphasized adjusting their values and beliefs to include hope and seeing possibilities for their child and family. Researchers in the study also found that parents talked about their own personal growth to include better understanding, patience, acceptance, tolerance, perseverance, compassion, and love (King et al., 2006, pg. 361).

Few qualitative studies have studied meaning making in families dealing with autism. Bayat (2007) studied 175 parents of children with autism by asking them to write a response to three questions. The three questions each participant answered was: 1) to describe the positive and/or negative effects of autism on their family life; 2) to describe the positive

and/or negative effects of autism on the personal life; and 3) to describe the child. The study used Walsh's theory of resilience which is defined by the ability of families to become stronger in the face of difficulty (as cited by Bayat, 2007). Bayat found four aspects of resiliency factors in parent statements: making meaning out of adversity, pulling resources together, being connected, spirituality or belief system, and affirmation of strength and becoming more compassionate. Parents in this study wrote about their change in world view and the positive aspects of raising a child with autism.

Bayat's (2007) study was limited in its interview process and did not allow for follow-up questions. As a result, the researchers were unable to get a full scope of the families' experiences good and bad. Bayat noted that the study only looked at factors that fit their theoretical framework although they saw other family strengths in their interview. The present study sought to extend Bayat's research and look at parental perceptions and their view of quality of life to show resiliency factors in the parents studied. The present study uses qualitative interviews to study how autism affected the family experience of four parents raising a child(ren) with autism and what meaning they made out of those experiences. The primary researcher conducted detailed interviews to gain insight on the full scope of what these families struggled with (demands), how they managed those difficulties (capabilities), and what types of meaning they created out of their experience.

CHAPTER III

METHODS

This study looked at the lives of four parents raising children diagnosed with autism spectrum disorder. The researchers used a semi-structured interview to gain better insight to the families' demands, capabilities, and meaningful experiences. Transcripts of the study were analyzed to determine if families' experiences with autism were aligned with the model of resilience outlined in the FAAR model (Yin, 2011).

Participants

Researchers interviewed four parents who all had children between the ages of 4-9 diagnosed with ASD. A fifth interview did not record and that data was not used in the final results. Participants included two mothers, one father, and one step-grandmother. All participants were between the ages of 31-53, were married, and had attended some college. The three women identified as Caucasian or white and the one man participating identified as Hispanic/Mexican American. Participants were recruited through fliers that were distributed by local agencies, non-profit organizations, and respite workers that serviced families in the autism community. Participants then contacted the researcher in order to participate. Participants were contacted through email and/or telephone. Criteria for inclusion in the study included: must be a parent (self-defined) of a child with Autism Spectrum Disorder, parents must be willing to be interviewed and audio recorded, parents must sign and agree to the research informed consent (Appendix 1). There was no incentive for participation. Participants were asked at the end of every interview to refer another parent they know to participant, only one participant was contacted through another parent. Further participant information is located in Table 1.

Table 1

Participant Demographic Information

Family	Age	Gender	Marital status	Ethnicity	Highest level of education	Total number of children	Number of children with autism	Age of child with autism	Gender of child with autism
Family A	53	F	Married	White	Some college	1 Step Grandchild	1	6	F
Family B	34	F	Married	White	MA	2	1	5	M
Family C	31	M	Married	Hispanic/ Mexican American	Associates	2	2	6;4	M;M
Family D	40	F	Married	Caucasian	BA	2	1	9	M

Procedure

Qualitative data was collected by audio recording of telephone interviews. The interviews were 45-60 minutes long. The interview was semi-structured and the interviewer asked questions from an outline, but would ask follow-up questions based on the participant's answers. The interviewer took written notes during the conversation as well as made an audio recording of the interview, which was later transcribed.

Data Collection

The researcher started each interview with basic demographic questions. The interviewer asked questions about the participant's age, gender, ethnicity, marital status, highest level of education, number of children, and number of children with autism. The bulk of the interview focused on the experience of the family and included what type of demands the family struggled with (i.e., How stressful is your weekly schedule? What do you struggle with most as a parent?), what capabilities the family have used (i.e., Who is your main source of support? How do you reach out when you need help? How do you typically cope with stress?), and how they make meaning of their experiences (i.e., Can you tell me a bit about your family? What have you gained as a parent of a child with autism? How do you feel successful as a parent? In what ways do you feel incapable of handling the stress?). All interviews were conducted by the author of this paper.

Coding and Analysis

Coding analysis was conducted by the author of this thesis as well as the thesis Chair. The researchers followed a similar coding procedure as outlined in the Grounded Theory methodology (Glaser, Barney G., & Strauss, 1967). Each transcription was read multiple times, looking for different elements in the data with each iteration. The first time researchers engaged with the transcripts was in the Open Coding process, or a process of highlighting text and making marginal notations with initial interpretations to meaning. Then, researchers followed the Axial coding process where data was read a second time within the lens of the FAAR model, looking for statements of demands, capabilities, and meaning making. Then, researchers compared the first two coded results to develop themes and sub-categories within themes. Although most statements only exhibited one theme, there were some statements that represented

multiple themes. The researchers compared coding data and the dominant theme was then chosen for that statement. Statements were selectively coded and reorganized into the themes of demands, capabilities, and meaning then coded again using the sub-categories.

Ethical considerations

Each participant was sent an informed consent (see Appendix B) through email to sign and sent back either by mail or email. Before each interview the researcher went over the informed consent and asked for verbal consent for participation and to audio record the interview. Each participant was assigned a letter and all identifying information was removed from the data. This includes participant names, and names of children and relatives. There was no compensation for participation in the study.

The author would also like to note the personal stance of the primary researcher. The researcher is a student of marriage and family therapy and is a working therapist in the community. The researcher has also worked prior in the autism community as an ABA (applied behavior analysis) paraprofessional, and respite worker with autism families for many years. This lens may be helpful in knowing what questions to ask and listening to nuanced answers, but could also slant the data with pre-conceived ideas about this population. The interviewer was careful not to conduct therapy during the interview process, but chose a more neutral stance when asking initial and follow-up questions by using the participant's own words throughout the interview.

CHAPTER IV

RESULTS

Each participant was interviewed over the phone for 45-60 minutes. The interviews were then transcribed, coded, and reorganized into themes and sub-categories. The researchers looked at three aspects of parents' experience based on the FAAR model: Demands (what the family struggles with), Capabilities (what the family has going for it), and Meaning making. Meaning making presented 3 themes between the families: new meaning, critical meaning, and family identity. Each category had sub categories as displayed in Table 2.

Table 2

Themes Found in Parent Interviews

Demands	Capabilities	Meaning
Daily hassle	Use of available resources	New meaning New perspective/understanding
Symptom coping	Social network	Acceptance Adapting
Lack of support	Partner/Family relationship	Family identity Optimism
Difficulty in spousal relationship	Coping skills	“Fighter” mentality Pride/Teaching
		Critical meaning Guilt Feeling alone/misunderstood Unpredictability Low self-efficacy

Demands

Families have to deal with the regular stressors of life as well managing the challenges of a child with special needs. Parents in this study reported many stressors in their lives including: daily hassle, symptom coping, lack of support, difficulty in spousal/partner relationship.

Daily hassle includes parents' daily routines of work, school, carpool, dinner, extracurriculars, bedtime and everything else that makes the daily life stressful or difficult. Having a child with autism can add to the list of appointments in a day. Parents described taking their kids to multiple therapies and doctors' appointments. Family B stated:

Every week has to be planned out very carefully. We are double booked two nights a week and so that means that if my husband's not home, some one, I have to find a way to get my kids where they're supposed to be while I get the other one where he's supposed to be. I work, my husband may be gone, he may be doing classes or other things. And the kids have school, I work while they're in school, then we come home and we pick them up, and their fried and exhausted, I have to get food in them, get them rested, power rest. And then we have to go to lessons, therapies and all back to back and we get done at 6 o'clock. So, dinner has to already have been made at some point in the week when I was probably not home, and homework has to get done, but they're tired and crabby, and have been going from one thing to the next. And we are doing the bare minimum of what we can do.

Every parent interviewed expressed stress over having to manage the families' daily demands to include autism. One mother mentioned that her child had 30 hours every week of interventions. Parents said they had to plan ahead and were always thinking about the next item in order to manage their time.

Every parent in the study also described the difficulty of dealing with the symptoms of autism. Parents in this study expressed being exhausted and frustrated by the tantrums, difficulty eating, and lack of communication with their child. Parents frequently compared their

experience to that of parents with “typical” children, describing difficulty in completing ordinary tasks like that of needing to go grocery shopping. Family B stated:

I think parents of children with autism, [we] are so unbelievably beat down, tired, exhausted, every single thing they do is a battle. And parents of regular kids, typical kids, they don't realize that they take for granted that their kids are gonna eat when they put food in front of them, they take for granted that their kids are gonna sleep because it's 2am, why wouldn't they be asleep?, they take for granted “oh we need food, we'll just go to the store.” They don't understand that in our world, especially in those first few years, I couldn't go to the store unless my husband was home or I got a babysitter. It was not possible. My child slept two hours a night, my child had severe feeding disorder, which we tackled, but that was a nightmare... So my husband and I were just unbelievably exhausted, chronically sick, chronically sleep deprived, crabby and all of these things.

These parents also worried about being out in public when their child with autism was having a difficult time. One mother expressed not wanting to take her son out to restaurants unless there are “autism people” around because others would judge when her son would have a tantrum.

Balancing all these demands can be more difficult when parents do not have to proper support to help them. When interviewed about their struggles with parenting a child with autism, lack of professional and social support was the most common response. Parents expressed difficulty in obtaining quality services for their child. Including being upset at how difficult the road to diagnosis was for their child. Almost all the parents expressed frustration at how long it took professionals to accurately diagnose their child with autism. Family D reported:

He was originally diagnosed with a speech delay. Which now just to say it out loud boils my blood. But, you know, he was diagnosed with a speech delay at 20 months and was supposed to be reassessed in 6 months, but the assessment process took another 3 [months] and [...] we went from 18 months [...] to hearing the word autism [...] 3 months before his 3rd birthday. And so the process was terrible and slow.

When their child did finally get a diagnosis, services were not always easy to obtain. Parents had to deal with insurance companies, regional agencies, and an overwhelmed system. Parents have to push to get services by calling multiple agencies and paying expensive fees in order to find

help for their child. Even when they do have the financial means to get services, professionals are not always skilled or reliable. The mother from Family B felt frustrated and taken advantage of by the lack of support by a certain company in town:

I gave up on the behaviorist, because it was a joke, and I was getting, really just getting lead on by [company] and after the two behaviorists that we paid all that hundreds of dollars, thousands of dollars to, and then dumping us and then [they] lost our file, and then this and that... I'm just kind of like, alright, I'm done. And they're really one of the only games in town unless you want to pay privately. And you're looking at 350\$ a week if you were to privately pay a behaviorist. And that's just crazy.

Parents also expressed a lack of support to help them personally. All parents expressed difficulty finding childcare. They could not hire a typical babysitter and found it difficult to find respite workers that they felt comfortable with to leave their child with. Also, they expressed wanting professional help to teach them skills to better help their children when professionals were not around. They felt that reading and internet resources were not enough to get by. Parents also had difficulty utilizing local support groups. Some reasons given were the burden of childcare, but also that the group itself was not helpful to support them through their own emotional processes.

Participants noticed that raising a child with autism also can cause some difficulties in the spousal relationship. Some of the parents interviewed explained that their spouse had different ways of coping with the stress of autism. This made it difficult sometimes to communicate and support each other. This leads to arguing and more stress. One parent expressed worry about the high divorce rate and the struggle of different perspectives on how to raise their children. The parent from Family B called it a "trial by fire," when asked how raising a child with autism impacted her relationship with her husband. "You will either stay married, or

you will not. And it becomes pretty clear within a year or two I think whether or not you have what it takes.”

Capabilities

Although raising a child with autism has its difficulties, families also have many external and internal resources available to them as a family. When interviewed, parents talked about the strengths and resources of their family. Four themes of capabilities were discovered: use of available resources, social network, and partner/family relationship and coping skills.

Parents noted the struggle and fight to find support for their children, but once they find the right services parents push to take advantage of the available resources provided. Some parents were lucky to have autism services at their school, while others did their research and asked for the best therapists for their child. All parents in the study described themselves as advocates for their child. Meaning, each one of the parents interviewed described always looking for more services and resources to help their child. Family A stated, “We were just kind of seeking out resources, and find out what groups are out there, and what we could be involved in to learn more”. These resources included speech therapists, Applied Behavior Analysis (ABA) therapists, occupational therapists, teachers, social groups, and even service dogs. And when parents find those therapists or teachers that are helpful, parents strived to keep that connection and continued to use them as resources. For example, Family C stated:

[professional name] is one of our wonderful workers who comes over, she a tutor. Well, actually she, used to be an ABA therapist for [first child] who was our older son and they’ve always had that connection and we’ve always felt that because of that connection we felt like she understood our children.

Each parent in the study also reported utilizing therapy services for themselves. Parents sought out marital and family counseling as well as autism parent groups to find emotional support. Parents described finding better ways to personally cope with the stress of

raising a child with autism, as well as the success of improving how they communicate with their spouse, “It was good for him [my husband] and I to talk, the counselor would create conversations that we probably needed to have, but we just could not get to having.” (Family D)

Parents also described leaning on family and friends to help support them. Family B reported:

I would say that my husband and I support each other a lot. It would be him and then the main support for my family is my mom, definitely. She’s amazing, both of my parents live here and they are really really great at helping out when we are double booked with speech therapy and karate practice.

Although not all families had relatives nearby to help, everyone described extended family and their spouse as their main source of support. When family was not available parents had friends that would help by listening and being supportive. While some parents used friends as a time to take a break from being a parent, other friends provided support by giving advice and exchanging information about autism. Family D said:

I do not know if it’s an autism support group, but it’s like a group of moms that were, who were at that time trying ‘bio-med’, and since then we all kind of stayed friends, and gone off in these other directions or other different things that we’ve tried, but we’ve all kind of stayed connected. Like whenever anyone finds something that, I don’t know, “works” or is working or is helping, then we all email or call or get together and talk about it. And it’s been great.

Another thing these parents have going for them is their use of coping skills. Parents in this study described many ways in which they took care of themselves in the face of stress. Multiple parents cited the use of exercise, taking a break, seeking out quiet time for themselves, music, spirituality, keeping a positive attitude, and making fun plans with the family. Family A stated:

It’s kind of one of those things were you may not get that release that day, but you know, ok this weekend we are going to go out to kid’s park, we are going to go out to lunch, so you have something that you know, that light at the end of the tunnel, so to speak. Ok it’s stressful today, but Saturday we are going out, and that will be fun.”

The mother from Family D even acknowledged that she asks for help when she is feeling overwhelmed, stating, “I’ve learned to try to ask for help before I get angry or frustrated. [...]Get the support I need. I ask early. You know, ask sooner rather than later.”

Meaning

Meaning is how the family defines their experience and places themselves in the context of their demands and capabilities. Meaning was categorized into three themes: new meaning, critical meaning, and family identity.

For the most part, parents saw raising a child on the spectrum as having a positive impact on their lives. They created new meaning for themselves and their family. Part of that new meaning was adapting to the demands of raising a child with autism. Adapting is when a parent makes changes to adjust to the new demands of raising a child with special needs. Parents in this study reported increasing their coping skills, changing work to fit a new schedule, even changing how they communicate and connect with their spouse. Multiple parents described wanting to give their child a “normal” life and they adjust to accommodate the child with autism such as Family B:

We used to be very adventurous, and we would travel all over. And we did all kinds of adventure sports and camping all the time, and that has all changed. So we have had to kind of adjust to a different norm, a new norm. But we try every year to get back a little bit of what we used to be like, and what we used to do, and just try to help [child] sort of stretch what he’s comfortable with without making it a bad experience. Yeah, so we are probably pretty average family. We love to swim and love to take the boys hiking; we go on a lot of hikes with them.

Some parents had multiple children and wanted to include the child with autism in as many activities and outings as the typical child, including family dinners and chores. Parents also learn how to have a relationship with their child. They take more of an interest in their child,

learning how to play, how to teach, and how to communicate with them such as Family D who stated:

...They are different, they do things in different ways, but it doesn't mean that they're less intelligent. [...] People think that because [my child] doesn't talk a lot, that he can't talk, that he's not intelligent. And that's not the case at all, he's very intelligent, he just doesn't always use his words. Until you know, or he uses words, with his baby talk or unintelligible [speak], but if you listen to him long enough you can make out what he's saying. You know I almost hate the phrase that he's non-verbal because he's not non-verbal, he talks a ton, you just have to know how to listen to him or you have to know how to ask him things to get him to talk.

Parents in the study also expressed acceptance of their new life and the unique needs of their child. A few parents described their experience accepting the child's diagnosis. They mentioned grieving for a time period before being able to fully accept that their child had autism.

The father from Family C was in denial, but eventually accepted this life-changing news:

I originally thought, you know he just a slow starter, he's really just getting to know his environment in a different way [...] I was pretty in denial because, you know, [I was] proud to have a kid and when you have a kids and your proud to have him you don't really, [...] think about something's wrong with my child. It's just, he's my child, you know, it doesn't matter what is going on, it's, what matters is he's going to grow out of it and he's strong like I am and, you know, just that kind of mentality. Yeah, and my wife was, like I said she's very analytic, there was tall-tell signs,[...] we go back and forth, but eventually I snapped out of it and realized she was right and we were able to get him to therapy.

Once the parents accepted the diagnosis, they all expressed matter-of-factly that this was their job as parents to do what it takes to care for their child. Each parent made a statement with the sentiment of "you got to do, what you got to do". These parents also expressed acceptance that their days are hard and stressful, but they are doing the best they can for their child. Parents described the importance of being loving and caring parents that put their child first and that some days may be more successful than others such as when the parent from Family B said, "If he's got clothes on, that was the triumph that day. He wasn't naked, and he ate fish sticks, so we're just going to call it a day."

New meaning for parents included a new perspective or understanding. Each parent had a different defining moment, but everyone described how they have been changed for the better by their child with autism. Family B best represented this concept by stating:

I feel like it [having a child with autism] has completely changed, who I like, who I appreciate, who I value and I really look at now, like families of special needs kids are so different from families that have difficult kids. And it just opened my eyes to how amazing life is with these kids in our world and in our family, and how much they grow and change it. And I feel such a kinship to other special families and being special because I really feel like it's such a gift to know [my child] and love [my child] and understand [my child]"

Some parents realized that it's not all about academics, but enjoying life, others were surprised by their own strength and ability to handle a child with a disability. Parents described having more patience, and being more appreciative of the things and people they have in their lives. One mother described changing from someone who would judge other parents to a person who is now more understanding of others. Family D emphatically stated, "Different doesn't mean less. I think that we're able to see the value in people and not necessarily, I don't know, judge or pre-judge people."

Critical meaning comprised of two main themes, guilt or feeling misunderstood. Parents expressed guilt about not realizing the signs of autism earlier and not getting them into treatment earlier. One parent even expressed guilt over potentially being the genetic cause of his son's autism. Parents also expressed guilt about not always being able to handle all the stress of taking care of a special needs family, for not having enough patience, for taking a break, or guilt for not including the child with autism in every family event. Family D recalled an incident:

We are going to this tournament and stay overnight, if he's not there it would be less stressful until about Sunday afternoon and it hits me, and so you've pawned [your child] off on relatives all weekend and then the whole drive home, it's like, now I've got to do more for [child], I didn't have him this weekend.

Parents seemed to take responsibility for the success and failures of their child. This stress of fighting for your child with special needs also made the parents feel alone and misunderstood by others. Parents described not being able to talk about their lives with friends and family because they did not understand what they were going through. Family C shared, “I know it wouldn’t help me going to talk to any friend or family members, [...] I want to tell them my problems and they don’t really know how to react in a lot of situations.”

Some parents even described how they struggle with not having typical lives with friends who can watch their children, having play dates, or the ability to go out without being “gawked” at. The father from Family C talked about “mourning” the life he used to have:

I mean there is times where I feel kind of, [I] fall into a depression, but I think that’s also because I kind of mourn the stuff I used to do and the change [...] That happens to be very difficult. You know, being a marine and working and being responsible for so many things and [now] to being a father who transports his kids back and forth to therapy, [it] doesn’t clash. It’s quite different.

Parents also described the difficulty with that unpredictability that comes from caring for a child with autism. The parent from Family A spoke of the struggle to keep up with all the new and changing challenging behaviors from her granddaughter, “it’s just a little but harder with her because you don’t know what you are going to get every day”. Parents also worried about an uncertain future and if their child would ever be independent or lead a semi- typical life, such as Family C who stated. “[I’m] always thinking about my sons and how it’s going to happen to be when they grow up and they go through the process of going through high school, through life...and how people are going to react”.

Families also had a strengthening of identity. Family identity themes found in the responses are being “fighters”, optimism, and a sense of pride. Even though parents described their struggles, they also expressed how they are able to make it through it all. Two parents in the

study described how their difficulties are life changing for them, they used words “strong”, “fighters”, and “survivors” to describe their family. The mother from Family B even described how some days in the beginning were like a “battle”, but they made it through it, “Everything was a battle, and so for a couple years, my god it just felt like a warzone, like everything was fighting. We had to fight for every damn thing we did.”

Parents expressed how important it was to them that they continue to push their children and families to do their best, to never give up, and to continue to advocate for the best care to help their child with autism. Parents also noted how optimism plays an important role in their family. Parents such as the one from Family B expressed hope, gratefulness, and the idea that things will always be ok:

I feel confident that I’m always going to be ok no matter what happens. And I’m always going to be happy no matter what happens because I am choosing to be, not necessarily because my life is easy or my life is filled with good things, but because I am choosing to focus on the good things.

The most responses noted for family identity communicated a sense of pride for parents. Parents were excited at how much their child has grown and improved with all the hard work. For example, the father from Family C expressed the family’s surprise and delight in building a relationship with their child, getting to see their personalities come out and being able to share interests with them: “I like to know about my kids... yesterday [his favorite color] was red and now today [it’s] blue. I like to ask those kinds of questions, and by knowing my kid, I feel much more connected with them. That’s the most important thing to me. I love that.” Parents also took pride in teaching them life lessons, like respect, hard work, care, compassion, and honesty. Parents enjoyed watching their child play and learn from their other children. Having fun as a family was an important value that parents wanted to share with their child and Family D shared that:

Spending time with the kids, they're so much fun. And we get to go on vacation or whatever, we spend time together. It's wonderful, I love watching them be happy and have fun and do the things that they enjoy doing. [My child] loves to swim and in the summer the kids will spend hours out at the pool together just laughing and having a good time. And it's amazing to watch, and watching them together."

And most of all parents expressed love for their child and how much they value being their parent, which was eloquently stated by the parent for Family A:

I think those moments when you are really proud of being a parent, is just when you get that special little smile, or twinkle in her eye, or you get that curling up in your lap at the end of the day and she's saying ' I want to snuggle with you'. You know, I think it's those moments you are proud to say, 'yeah I'm your parent.'"

CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

This study aimed to capture a full scope of experience for parents of children with autism under the framework of the FAAR (family adjustment and adaptation response) model by looking at what these families struggle with, what they have going for them, and what meaning they make out of their experience (Patterson, 2002). Parents spoke at length about the struggles they face on a daily basis and how they were able to manage the demands placed on them. Parents noted managing the stress of daily hassle, challenging symptoms of autism, lack of support, and difficulty in their spousal relationship. Parents were able to manage these stressors with the help of coping skills, use of available resources, their social network, and family relationships.

The types of demands found in this study were similar to findings in previous studies. Every family in the study reported stress in their daily lives due to balancing multiple roles and following tight schedules to incorporate the entire family's appointments (Hoogsteen & Woodgate, 2013). Families expressed that their lives were more challenging than that of typical families, not only did they have more appointments to manage throughout the day; they have the job of taking care of a child with special needs (Safe et al., 2012). Every parent in this current study also expressed stress in coping with their child's symptoms of autism. They struggled with coping with tantrums, sensory issues, eating and sleeping disorders as well as connecting and communicating with their child. Similar to other studies, these parents reported not always being able to take their child out in public due to worry about behaviors and fear of judgment from others (Ludlow et al., 2011). Parents in the current study also expressed a lack of professional

and social support in helping the family as well as navigating struggles in their relationship with their spouse.

Our research also had similar findings with current research in terms of strengths and capabilities of parents with children with autism. Families in this study took advantage of the available resources and relied on their social network as well as their relationships with their partner and close family for support (Ludlow et al., 2011). They also advocated for services for their family and utilize coping skills (Hoogsteen & Woodgate, 2013; Ludlow et al., 2011; Safe et al., 2012). Extensive research has looked at the different types of coping skills exhibited by parents of children with autism, and although this study did not specify types of coping skills, the findings add to the literature that parents utilize multiple forms of coping skills and self-care including exercise, listening to music, planning fun trips, talking to friends and family, and asking for help from others (Gray, 2003; Hasting et al., 2005; Hoogsteen & Woodgate, 2013; Ludlow et al., 2011; Pottie & Ingram, 2008; Pozo et al., 2014; Safe et al., 2012; Seymour et al., 2013).

Capabilities are not enough to overcome the stress of increased demands, meaning making plays an important role in balancing the scale (Patterson, 2002). The parents interviewed in this study told stories filled with rich and meaningful descriptions of life experiences that included new meaning, critical meaning, and family identity. This is important because families utilize their personal meaning to assess the presenting situation in terms of how difficult it will be and if the family is capable of handling said situation (Patterson, 2002). For parents in this study, the daily hassle might be seen as less stressful because parents are optimistic that they can successfully manage each day. Whereas, symptom coping might be seen as more stressful if

parents do not feel have the skills to manage challenging behaviors nor do they feel supported enough by services providers.

Themes regarding meaning making found during these interviews included new meaning, family identity, and critical meaning. New meaning comprised of statements of gaining a new perspective or understanding, statements of acceptance, and statements of adapting. Parents gained new perspectives as a result of parenting a child on the spectrum. Parents mentioned lowering/changing expectations of parenting, putting more emphasis on the values of love, caring, and fun, and they expressed a change in themselves, whether it was being more open and non-judgmental, to being more appreciative of the life that they had. These statements of a new perspective were similar to that found in other qualitative studies where common statements were making meaning out of adversity, a change in their world view, and personal growth (Bayat, 2007; King et al., 2006).

Acceptance was another theme found in statements of new meaning. Not surprising, parents went through a process of acceptance where they acknowledged that their life was different from how they imagined it would be, but they have to “embrace it” as one parent stated. Parents accepted that not every day was going to be perfect, but they kept moving forward no matter what. Part of that moving forward was adapting to the changes in their life. Raising a child with autism means making accommodations for their unique needs and parents expressed the importance of change in order to include the child in a more “normal” family life. Parents wanted to keep going out to eat, and going on hikes or fun outings, and even include the child in household chores, but they had to adapt to accommodate the child with autism. Parents also expressed changing how they parent, including being more involved in teaching, play and making more of an effort to communication with their child.

Part of making meaning of experience includes shared constructs of the family's identity (Patterson, 2002). In this study, parents talked about their family traits of optimism, where parents express the value in keeping a positive attitude, and having a "fighter" mentality. The fighter mentality was expressed by two out of the four families. Here, parents described fighting for their child no matter the odds, and fighting for what they have. The mother from Family B talked about teaching her children to never give up in the face of illness and disability, "You're gonna get up, and you're gonna go to work and you're gonna do it anyway. And I think that our strength is just that, we are kind of survivors."

But the most common statement found for family identity was about the family pride and being able to teach family values. The values identified were similar to a study by King et al. (2006) where parents focused on values of openness, understanding, respect and positivity and less on more 'typical' values of success and accomplishment. But, what was unique in the current study was the pride they felt in being able to teach these values to their children. Parents also expressed pride in the strength of their family and particularly the growth of their child with autism.

The most surprising find in this study is the statements of critical meaning. Parents, of course, expressed so much joy, love, and hope, but they also expressed feelings of guilt, feeling misunderstood by others, unpredictability, and feelings of low self-efficacy. Parents felt guilty for potentially being the genetic cause of their child's disability, not doing enough for their child, and for taking breaks for themselves. Parents also experienced feeling misunderstood by other parents, friends, and even family members. Although there have been great strides in bringing awareness about autism, most people do not know what it is like to raise a child on the spectrum. Parents felt misunderstood by friends and other parents with 'typical' children. Parents even

talked about grandparents being helpful with emotional support, with childcare, and carpooling, but those same parents mentioned that because the grandparents are not around every day they do not always understand what they go through or why the child behaves the way he does.

For parents, there is also a level of unpredictability in their lives due to autism. Parents described not knowing if the child is going to have a good day or a bad day, or how the child will react to any slight change in the day. There is also uncertainty in the future. Parents do not know if there will be continued services as the child ages or if their child will ever be independent. These critical meaning statements are different from demands because these statements are interpretations of either the demands they face or their ability to handle certain demands. Critical meaning can create stress on the family, but it is also a natural part of the adjustment process.

Strengths and Limitations

This was a preliminary study looking at meaning making and resilience in families of children with autism. Past qualitative studies have explored the struggles of families with a child with autism, but few have looked at how they construct meaning out of those experiences. The current study expands on those previous findings to include the meaning they see in their lived experience. Participants felt comfortable enough to give in-depth descriptions of their experiences and even disclosed some vulnerable moments in their lives that provided rich and meaningful data. But, this study is limited in scope for only having interviewed four parents. The inclusion criterion was very broad as a result of the limited and non-systematic recruitment process. The parents were very similar in gender, age, and ethnicity. It would be difficult to expand their statements to fit all mothers, fathers, and grandparents. Also, the interpretations of one parent has been generalized to the entire family, but in order to fully extrapolate the themes

to encompass the entire family's view it might be worthwhile to interview both parents in the future. Although the researchers do not emphasize the generalizability of the study, it should also be noted that most of the themes found in this study do overlap and expand on the current literature.

Clinical Implications

When a member of the family is diagnosed with a disability, it affects the entire family. And since parents are such an integral part of the diagnosed child's care, this leaves parents vulnerable to mental and emotional problems for themselves. This study can be helpful for clinicians by emphasizing the importance on holistic family services. Families in this study described moving from a place of sadness and fear to one of acceptance and adaptation. Not only can clinicians provide families some emotional support and education as they move toward better adjustment, but therapy plays a big role in creating new meaning out of experiences. Parents in this study described both positive and negative experiences. Experiencing feelings like guilt, being misunderstood, and unpredictability are normal emotional responses, but could potentially cause more stress on the family. Therapy can be helpful because therapy in itself is the process of exploring the experiences in our lives and reevaluating how we think and feel about those experiences. This process changes the way we act and how we experience future events.

Parents and even the entire family could benefit from therapeutic services in order to construct shared meaning. This study provides preliminary evidence of the importance of more holistic and strength-based interventions for families, such as narrative therapy or acceptance and commitment therapy (ACT). The narrative therapy approach deconstructs the family's struggles and amplifies the families' successes in order to construct a new narrative based on a family's

preferred way of living. Families create new meaning through giving voice to values and experiences that are most meaningful to their lives (Madigan, 2011). ACT is another useful therapeutic approach that combines the practice of mindfulness and defining of family values in order to live a more present and meaningful life. Families discuss which values they cherish the most and focus on building more meaningful experiences in the context of those family values (Harris, 2009).

When looking for a more holistic therapeutic intervention, Solomon and Chung (2012) suggested clinicians use a combination of action, emotion, and meaning as a treatment guide in the therapy room. Action includes empowering parents to take a more active role in their lives by educating parents on managing all appointments, behavior plans for their child, IEPs, as well as self-care and staying connected as a couple. Clinicians must help families deal with the difficult emotions that come up such as guilt, shame, sadness, anger, and grief. By strengthening coping skills, and creating an open dialogue about emotions, parents can then co-construct what this experience *means* to them as a family. Most importantly, it builds a thick family narrative that connects the members together as a solid unit. Through the process of meaning making, families can find strength, healing, and grow closer together.

Parents raising a child with autism have increased demands that include daily hassle, symptom coping, lack of support, and difficulty with spouse, but they show strength and growth in the face of adversity. These families also utilized available resources, their social network, and rely on family and friends for support. They also have many coping skills in order to manage the stress of demands placed on the family. But most importantly, families created meaning as a way to make sense of their world and balance the stress of demands while strengthening capabilities. Families create new meaning, strengthen family identity, and deal with critical meaning. This

study adds to the literature that families go through an emotional and meaningful process in order to adjust and adapt to the demands of autism.

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APPENDIX A

Informed Consent Form

STUDY TITLE: Resiliency factors in Parents of Children with Autism (title later changed)

PRINCIPAL INVESTIGATOR: CO-INVESTIGATOR(S): Heather Zipper

CONTACT AND PHONE FOR ANY PROBLEMS/QUESTIONS: heatherzipper@gmail.com; 918-814-8780

PURPOSE OF THE RESEARCH: The aim of this study is to better understand how the factors of social support, empowerment, stress, and meaning influence the lives of parents of children with autism.

PROCEDURES OR METHODS TO BE USED: Participants will be asked questions about their beliefs and behaviors surrounding their daily lives. The interview will be audio recorded.

LENGTH OF STUDY: 30 minutes

RISKS ANTICIPATED: Although we do not anticipate any risks associated with participating in this study, you may experience distress by hearing and discussing personal subject matter. We do not anticipate the amount of distress experienced will exceed that of a typical interview setting. You are not required to share any information that you are uncomfortable with. Participation in this study is voluntary and you may withdraw your consent at any time.

BENEFITS ANTICIPATED: Data collected from this study will be used to advance research in the field of study and could potentially further inform practitioners to better help the autism community and their families.

ALTERNATIVE RESOURCES: Should you need further assistance during or after participation in the study, you may contact the primary researcher (as stated above) or may contact other local agencies for individual or family therapy; this includes the individual or family services at the Counseling Training Center at the CSU-Chico Campus, Butte County Behavioral Health, or Chico Creek Counseling.

COMPENSATION: No compensation will be given for participation.

EXTENT OF CONFIDENTIALITY: The complete confidentiality of your responses is very important, and multiple steps are taken to keep your results confidential. No identifying information will be asked of you. We will ask you to provide an email address or phone numbers in order to maintain contact during the length of the study. After the data are collected, all identifying information will be removed from the data file, and you will instead be given an anonymous identification number. All data will be securely stored digitally on a USB which will be kept in a lock box.

I understand this project is research, and that my participation is completely voluntary in participating in the study and I am not required to answer any item or disclose any information I do not feel comfortable with. I also understand that if I decide to participate in this study, I may withdraw my consent at any time, and stop participating at any time without explanation, penalty, or loss of benefits, to which I may otherwise be entitled.

Printed Name

Date

Signature