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## A Qualitative Study of Coping in Mothers of Children with an Autism Spectrum Disorder

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**ABSTRACT.** A significant body of research exists that explores the stressors of raising a child with an autism spectrum disorder (ASD). There are fewer studies, however, that examine specific effective coping strategies of mothers of children with an ASD. This qualitative study explored mothers' perceptions of effective coping strategies for their parenting stressors. In-depth interviews were conducted with 11 mothers to inquire about their personal coping methods. Interviews were coded and emergent themes identified which included coping strategies such as "me time," "planning," "knowledge is power," "sharing the load," "lifting the restraints of labels," and "recognizing the joys." The information from this study may benefit mothers of children with ASD and inform pediatric therapists providing services to children with ASD and their families.

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**KEYWORDS** Autistic spectrum disorders, coping strategies, mothers, parenting stress, qualitative

20 Parenting a child with an autism spectrum disorder (ASD) can be challenging and increase parental stress (DeGrace, 2004; Montes & Halterman, 2007, 2008; Woodgate, Ateah, & Secco, 2008). Therapists who work with mothers of children with an ASD should be aware of the typical stressors these parents face, and the strategies that may be effective for each family unit. Because mothers appear to be particularly vulnerable to the stressors of child rearing, therapists must also be aware of effective strategies for

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mothers that will help support family functioning. There is evidence that certain coping strategies may be more successful than others for mothers of children with an ASD, and that some strategies may actually increase stress.

Many mothers of children with an ASD are highly stressed and some of the specific stressors that have been reported in the literature include social isolation, financial burden, and difficulty obtaining the appropriate diagnosis and services (Montes & Halterman, 2007, 2008; Woodgate, Ateah, & Secco, 2008). The high level of stress and the difficult behaviors of children with ASD can have a significant impact on family occupations (DeGrace, 2004). However, even in the face of significant stress, many families are resilient and parents cope effectively (Bayat, 2007).

Research suggests that both resilience and family coping depend upon a multitude of interacting factors such as the crisis event itself, the family's resources, and the meaning the family makes of the event (Bayat, 2007; McCubbin & McCubbin, 1996). Altered perceptions and the parents' ability to make meaning of their child's disability allow the family to adapt and structure the use of its resources to balance the demands of raising the child. These "reframed" perceptions may be the key to family satisfaction and well-being.

Specific coping strategies used by parents of children with an ASD that have been identified using a variety of research methods include social and family supports, professional supports and services, support groups, and religion (Boyd, 2002; Bristol, 1987; Gray, 2006; Hastings et al., 2005; Luther, Canham, & Cureton, 2005; Tway, Connolly, & Novak, 2007). Social and spousal supports have been found to be extremely important in reducing stress and improving adaptation for families of children with disabilities. Social supports, including support groups, appear to be particularly effective in reducing stress from parenting and are associated with better mental health (Boyd, 2002; Luther et al., 2005). Religion is frequently reported as an important coping strategy, and may include belief in God, a sense of spirituality, or attending church (Bayat 2007; Gray, 2006; Luther et al., 2005).

The current literature does not allow an in-depth understanding of how parents of children with ASD perceive specific coping strategies and why they believe certain strategies are successful. As mothers continue to be the primary caregivers in many homes, a more thorough understanding of the process of coping and the perceptions of mothers regarding effective coping strategies is warranted. The purpose of the study was to explore the perceptions of effective coping strategies among mothers of school-aged children with ASD using a phenomenological approach. Information regarding successful strategies might help other mothers in developing effective coping strategies and assist pediatric therapists to collaborate with mothers when providing services.

## ***METHODS***

### ***Participants***

Eleven mothers, each with a child with ASD, participated in the study. Mothers were recruited through an Autism Spectrum Support Group (ASSG), although not all participants were active members at the time of the study. The leader of the group was provided with information about the study to be shared with the members via phone, email, or in person at a group meeting. Interested mothers then contacted the researchers. To be included in this study, the mothers must have had at least one biological child over

Q1 TABLE 1. Selected Participant Characteristics

	N	Range (Years)	Mean (Years)
Age of mother	11	40–46	42.9
Marital status			
Married	9	*	*
Divorced	1		
Widowed	1		
Employment status			
Full-time	1	*	*
Part-time	6		
Not employed	4		
Socioeconomic status			
High	5	*	*
Average	4		
Low	1		
Religious affiliation			
Jewish	2	*	*
Catholic	5		
Congregational	1		
Episcopalian	1		
No of children			
ASD	14	*	*
Typically developing	11		
Race			
White	9	*	*
African American	2		
Age child with ASD	14	6–11	8.3

the age of 2 years with a diagnosis of an ASD. ASSG staff was not included in the study, nor were any individual results shared with the ASSG. All mothers who met the above criteria and volunteered were enrolled in order to include as many perspectives of coping as possible. The study was approved by the Sacred Heart University Institutional Review Board and mothers' provided informed consent. Characteristics of the participants are provided in Table 1. The mothers all lived in a suburban, affluent community in the Northeastern United States.

### *Design and Procedures*

A phenomenological qualitative approach was used to explore mothers' shared experiences with effective coping strategies when raising a child with ASD. Patton (1990) described phenomenological inquiry as "what people experience and how they interpret the world" (p. 69). He also asserts that people who have comparable experiences will share an "essential essence" of that experience (p. 70).

Data were collected through individual semistructured interviews with open-ended questions. The five-member research team met to develop the interview guide, identifying primary questions and follow-up probes prior to initiating the interviews. The primary questions included: "What stressors, if any, have you experienced raising a child with an ASD?" and "Can you describe the strategies you have found most

effective in dealing with these stressors? Have any strategies been ineffective?" On the basis of mothers' responses, investigators used probing follow-up questions to clarify comments and elicit in-depth explanations. Each mother was interviewed once by one of three interviewers (one of the authors) and each interview lasted for approximately 45 min. The interviews occurred at a time and place chosen by the mothers to encourage a sense of comfort and control. Nine mothers were interviewed in their home, one mother at her place of employment, and one interview took place over the phone. 90 95

Mothers were interviewed individually, and only one investigator was present during each interview. The mothers were encouraged to share any information they felt would help the researchers understand their experiences. Most interviews included discussions of the overall experience of raising a child with ASD; daily routines, stressors they experienced, coping strategies they found helpful, and strategies that were ineffective. 100

Interviews were audiotaped and later transcribed by the interviewers into MS Word. A portion of the interviews was transcribed by another interviewer, other than the one who had completed the interview. Given the mothers' busy schedules and difficulty completing the interviews while also caring for their child with ASD, only one interview was conducted with each participant. 105

### *Data Analysis*

Data analysis occurred in three major steps: (a) initial within-case coding or horizontalization, (b) identifying clusters of meaning across cases, and (c) thematic analysis (Cresswell, 1994). During the first step, three interviewers independently read and coded each transcript to identify key quotes and phrases within each transcript (horizontalization). Each of the three also independently clustered similar quotes and phrases across transcripts looking for similarities between respondents. Then interviewers met to discuss their individual findings and came to the consensus that each selected quote or phrase directly related to the research question. They named each of the groups of quotes with a code. The interviewers then independently collapsed these codes into broader categories related to the guiding questions. A full description of the phenomenon experienced by these mothers was developed from these data. After 11 interviews, no new information relevant to the study purpose emerged and the interviewers felt that saturation of data had been achieved. They discussed the categories, eliminated irrelevant data, identified overlapping categories, and finally identified the emergent themes that are discussed below (Miles & Huberman, 1994). 110 115 120

Next, the researchers described the phenomenon within the thematic labels using supporting detailed statements from the mothers. All five researchers completed the thematic analysis; one of whom is an expert in qualitative analysis (Darragh, Krieger, & Sample, 2001) and the other is an experienced pediatric therapist who has specialized in working with families of children with an ASD (Miller-Kuhaneck, 2010). The authors who had not participated in the interviews were able to comment on the face validity of the themes by reading and assessing all the transcripts prior to the meeting, examining the transcripts, themes, and supporting data (Patton, 1990). If these readers found information which did not support the themes or the experiences of the mothers, the theme was not included. Once consensus was achieved, the final themes were identified. 125 130

*Strategies Used to Improve Credibility of Data*

- 135 A variety of methods exist to improve the credibility of qualitative data. During data collection, the research team improved trustworthiness of the data by reviewing interviewing techniques with the three primary interviewers, especially how to ask the questions and use probes to elicit more detailed information (Lysack, Luborsky, & Dillaway, 2006). The research team attempted to prevent researcher effects on the
- 140 interviews by allowing the participants to choose an informal setting in which they felt comfortable (Miles & Huberman, 1994). In addition, the team used triangulation: multiple researchers conducted the interviews. This reduced the researcher bias associated with having one interviewer conduct all interviews (Patton, 1990; Miles & Huberman, 1994).
- 145 During data analysis, the research team used analyst triangulation to increase the credibility of the results. To ensure continued consistency across interviews, the investigators met with one another throughout data collection to reflect on the interviews and the topics that were covered. This also allowed the interviews to gain depth as they proceeded and to improve replication of important findings. The interviewers were in
- 150 frequent communication about the interviews as they evolved to maintain a common sense of the data and to identify points for replication.

**RESULTS**

- Six themes emerged from the data analysis related to maternal coping: (a) “me time,” (b) planning, (c) sharing the load, (d) knowledge is power, (e) lifting the restraints of
- 155 labels, and (f) recognizing the joys. The following discussion will provide detail about the reported strategies. All names have been changed to protect the children’s identities.

**“Me Time”**

- Mothers reported their children with ASD needed significant attention, supervision, and direction. Time with their child was intense, emotionally and physically draining,
- 160 and all consuming. Mothers therefore reported needing “me time” and described a variety of activities they used to achieve time for themselves. “Me time” was often spent in exercise, which was described as a way to keep up mental and physical energy. Peter’s mom reported, “If I don’t exercise my life would be crazy.” “Me time” could also be spent with friends. Nick’s mom said, “To relieve stress I have to escape, escape the
- 165 family, you know, try to make plans with friends.” Often the two methods of “me time” were combined as many of the mothers exercised with friends. Other activities included shopping, going out to lunch, and going out for the evening. Kevin’s mom stated, “At least once a week I will try to meet a friend for lunch.” For mothers with more than one child, one method of “me time” included spending time with the sibling(s) of the
- 170 child with ASD, whom they worried felt neglected. Nick’s mom commented, “I make an effort to alternate doing special things with the other kids.” This satisfied a need for time away from the child with ASD and allowed them to spend quality time with their other children.

***Planning***

The mothers reported that they kept a hectic schedule. In addition to the typical tasks of mothering such as driver, cook, housekeeper, playmate, and disciplinarian, these mothers also had to coordinate alternative schooling, attend extra school meetings, tend to relentless healthcare and insurance issues, and schedule and travel to therapy. The busy schedule and the tendency of their child with ASD to have outbursts or tantrums when routines were altered, required continual planning. “I get ahead of the issues that are coming up and keep a routine because that reduces Philip’s stress and mine as well,” reported Philip’s mom. Kevin’s mom reported she is constantly planning. “You’re planning ahead, you’re so far ahead, that you forget what you were supposed to do today.” The mothers described that it is effective to keep set routines in order for the child to transition from one activity to another. The mothers also felt that it is important for them to warn their child of transitions to ease anxiety and decrease the likelihood of tantrums.

***Sharing the Load***

All of the married mothers reported that participation of their spouses in the parenting and care coordination activities associated with raising a child with an ASD was critical. Some reflected that they did not know how they would manage without their husbands. Jason’s mom described sharing household responsibilities with her husband as a system. “We have become organized in the distribution of responsibilities as to who does what.” Having a supportive spouse also allowed for there to be “me time” as discussed above. Seth’s mom, a divorced single mother, stated, “I don’t do babysitters. I just don’t feel comfortable with that kind of situation” and without a spouse to share in the workload, “you just don’t have the down time.” The mothers felt a spouse also served as a significant emotional support and sharing the experience was a relief. Nick’s mom reported, “Having someone that is supportive and understands and can pick you up when you’re down and vice versa is definitely helpful.”

Mothers who stressed the importance of spousal support also mentioned that support groups were not effective. While all of these mothers were recruited through a local support group, Nick’s mom stated that support groups do not meet her needs because the children are all so different. As she described, “You hear people complain about things you really wish your child could be doing.” These mothers also reported support groups to be ineffective in terms of coping because of the lack of true emotional connection. Many of the mothers, although still members, did not regularly attend the support group meetings.

***Knowledge is Power***

Mothers reported that as a mother of a child with ASD, it was imperative not only to know the facts and information regarding their child’s condition but also to be educated on state and federal laws, resources and services that are available, processes and structures within the school system, and the insurance industry. The mothers reported a variety of stressors in regard to the lack of knowledge of others and the continual fight to obtain services. Their own knowledge was the key to their being a successful advocate for their child. While discussing the importance of this information gathering,

Philip's mom reported knowledge "helps you to relieve stress . . . because it gives you knowledge to deal with the situations that come up." When their children were diagnosed with ASD, many of the mothers were unaware of what autism was. As the mothers did  
220 research and learned on their own, they continuously worked to educate their family members and members of the community as well. But in their ability to cope with and advocate for the needs of their child, their own knowledge was instrumental.

### *Lifting the Restraints of Labels*

The mothers reported that perhaps for others, the term autism may bring to mind a  
225 specific set of characteristics or attributes. However, the mothers did not see their child as "autistic," instead they saw them as "Steve" or "Charlie." When David and Doug's mother was told that her children were diagnosed on the spectrum, she was told not to expect them to be affectionate. She was also told, "they probably won't tell you that they love you." She reports that today, her children are two of the most loving kids she  
230 knows. They both communicate and tell her they love her. The mothers spoke of the importance of expectations and one of the best ways to reduce the impact of the label of autism was to socialize their child with children who are typically developing.

### *Recognizing the Joys*

While all of the mothers discussed their stressors with raising their children, the final  
235 theme that emerged was the joy of raising a child with ASD. Kevin's mom reflected on the simple feeling. "The joy is when he is happy there is not a happier kid in the world, and that makes me so happy." There is "nobody like him," stated Kevin's mom. "He is just such an awesome little boy," said Nick's mom. Tyler and Allison's mom boasted, "They are really beautiful kids." David and Doug's mom added, "They are great kids. I  
240 think they were sent to me for a reason. I have two, after all, who have been labeled." Derek's mom said, "He's very affectionate, probably more than a typical eight-year old child." As Kevin's mom reflected, "It makes you stop and think of every little step. With a typical child you expect it, but when Kevin accomplishes something it's amazing." Steve and Amy's mom added, "Now it makes me stop and smell the roses." She grows  
245 with the kids each day and no longer takes life for granted. "Each day is a miracle."

## **DISCUSSION**

This study was restricted to mothers in a suburban, affluent community in the North-eastern United States. Services, educational systems, and infrastructure do not reflect  
250 the United States as a whole, or the experiences of mothers in different geographic regions. Mothers were also recruited from one single source. Given their association with an Autism Spectrum Disorder Support Group, the mothers in this study also may not represent other mothers who are not affiliated with support groups. Although findings should not be generalized, they contribute to the knowledge of how mothers experience and cope with parenting a child with ASD.

255 The themes support the literature in identifying a variety of stressors in parenting a child with ASD and, more importantly mothers' reported a variety of coping strategies that based on their experiences were effective. One theme that emerged was the mothers



need to for “me time,” particularly through exercise. To our knowledge, this has not been previously reported for mothers of children with ASD, and could be an important strategy for stress management intervention. Exercise has been studied in many populations of individuals in relation to psychological states and well-being and is frequently found to be related to improved mood and reduction of stress (Penendo & Dahn, 2005). In addition to exercise, our mothers generally stressed the importance of being able to take time away from their child. Similarly, Higgins, Bailey, and Pearce (2005) reported that caregivers felt it important for them to go out with their spouse on a regular basis.

Another important coping mechanism for these mothers was planning. Planning and having a consistent or at least predictable routine is the typical advice offered to parents of children with autism (see websites such as [http://www.helpguide.org/mental/autism\\_help.htm](http://www.helpguide.org/mental/autism_help.htm)). While we know little about the effectiveness of planning in families with a child with ASD, Weisner, Matheson, Coots, and Bernheimer (2005) have found that sustainability of routine was an important outcome for families and one with considerable variation between families of children with a disability. Examining the efficacy of planning for family functioning may be an important avenue of research in the future.

The ability to share the workload with a spouse, in particular, was quite important for the study participants. The sample of mothers reported that they relied on their spouse to know the routine and split the responsibilities. Similarly, Bayat (2007) found working together, being flexible, and communicating to be important characteristics in resilient families of children with autism. The mothers in the current study also felt a sense of relief knowing that in their spouse, they had someone who they could relate to. Higgins et al. (2005) reported that primary caregivers felt that it was important to talk over personal feelings and concerns with their spouses; spousal support was considered at least moderately helpful for coping.

The mothers in our study reported the importance of obtaining knowledge about autism and sharing that knowledge with others. Kuhn and Carter (2006) found that the more time that had passed since the family received the diagnosis the greater were the feelings of self-efficacy, and they suggested this was due to a mother having more time to gain knowledge about autism. The body of literature on self-efficacy suggests that this strategy of educating oneself may improve self-efficacy and thereby allow a mother to feel more control, more confidence in the parenting role, and less stress in the parenting experience (Kuhn & Carter, 2006; Weiss, 2002).

In contrast to prior research that has indicated the importance of support groups (Luther et al., 2005), the mothers in our study reported support groups to be an ineffective coping strategy. Although some of the mothers attended these groups at least occasionally, they felt them to be less than helpful. Shu and Lung (2005) have also reported that support groups did not improve mental health in mothers of children with ASD. Similarly, although prior research has indicated religion to be important in the coping of parents of children with a disability, and 10 of 11 mothers in our sample reported belonging to a religious sect, our sample did not report religion to be a method of coping.

Our sample of mothers identified a process of “recognizing the joys,” and reframing the “small things” as successes. Their joy and peacefulness in their family came from these new found perspectives. Similarly, in Luther et al. (2005), one of the most successful coping strategies reported was reframing (i.e., defining problems in more positive ways to avoid becoming discouraged). The use of reframing by our mothers supports these recent studies regarding the positive aspects of parenting a child with a

disability. Parents report effects such as increased sensitivity, increased confidence and assertiveness, greater opportunities to learn, a feeling of strength in the face of adversity, a change in perspective regarding life, improved family dynamics, and greater spiritual  
310 faith from having a child with an ASD (Bayat, 2007; Luther et al., 2005; Tunali & Power, 2002).

### ***Implications for Pediatric Therapy Intervention***

The results support the role of occupational and physical therapists in assisting mothers in obtaining the knowledge they need about autism and their child. Since time  
315 spent with primary care physicians is often limited (Tai-Seale, McGuire, & Zhang, 2007), parents may feel unable to gather the information they need from their primary care doctor. In certain practice situations, pediatric therapists may be able to spend more time with parents while providing intervention (i.e., during home visits). A pediatric therapist's holistic approach to intervention and wide base of knowledge may prove  
320 beneficial for mothers early in the process of learning about autism. Therefore, therapists working with this population should ensure they remain up to date and current with the newest information, research, legal debates, and controversies.

Therapists can also assist parents in creating routines that work effectively for the family and can assist mothers in creating planning and organizational methods, bedtime  
325 routines, morning ADL routines, and methods of using visual schedules to help the child learn these routines. Visual schedules may be effective in helping ease transitions (Mesibov, Browder, & Cameron, 2002). Therapists should also work with the family to schedule therapy sessions at times that are not disruptive to family routines, given the impact of schedules on family functioning and the potential importance of routine for  
330 these families.

Assisting mothers to achieve "me time" may require some method of providing respite or alternative and creative scheduling. The lack of availability of respite care has been previously reported (Abelson, 1999); however, therapists can assist the mother  
335 in finding quality respite care in the community or assist in creating a local group of well-trained respite providers. Pediatric therapists can encourage the spousal teamwork discussed by these mothers (if the mother is married), and can offer suggestions for exercise or other leisure activities that might help a mother reduce her stress and feel recharged and ready to parent again. Additionally, many states have parent-to-parent networks that may be helpful for families in achieving "me time."

340 Lastly, therapists can support mothers in contemplating the positive aspects of their experiences, assisting them to move toward reframing their situation and making meaning out of the event of having a child with ASD. There is a growing body of research suggesting the importance of spirituality and reframing for adaptation (for example see Kaye & Raghavan, 2002). Therapists therefore may also promote coping by entering  
345 into discussion with the mother regarding the role of spirituality in the family's life. These types of conversations must be handled delicately and mothers must be emotionally ready. The therapist must also be comfortable with the discussion and well prepared to engage the mother in this way.

350 Future research is needed to further evaluate these strategies. First, a more diverse population would be an important follow-up to this study. Then, survey development in order to capture and describe the experience of mothers on a national level would allow greater generalization of findings. In addition, research evaluating the relation between

stress, coping, and health in mothers of children with ASD would be particularly useful. Finally, research on fathers of children with an ASD and their particular stressors and coping mechanisms is critical. Therapists practicing in this field can benefit from the knowledge of evidence-based recommendations they can provide to parents about how to reduce their stress. 355

### CONCLUSIONS

The results of interviews with 11 mothers of children with ASD indicate that the participants perceived that they had a variety of ways to cope effectively with parental stress. Mothers reported that time alone, planning ahead, educating themselves, reframing difficulties in a more positive light, and working with their spouse in partnership were the key coping strategies. Formal support groups were reported to be less helpful. The strategies these mothers reported as helpful could easily be incorporated into therapy interventions. The themes lifting the restraints of labels and recognizing the joys' supported recent findings regarding the positive aspects of raising a child with a disability and provides a framework from which pediatric therapists can assist mothers of children newly diagnosed to cope effectively. These results must be used cautiously however, until future research enables generalization to larger population groups. 365

**Q4** *Declaration of interest:* The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper. 370

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