Resilience in Families of Children With Autism and Sleep Problems Using Mixed Methods

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A B S T R A C T

Purpose: About 80% of children with autism spectrum disorder (ASD) have sleep problems that may disrupt optimal family functioning. We explored the impact of sleep problems on families' resilience.
Design and Methods: An explanatory sequential mixed methods design was used to discern whether resilience differed between families whose children with ASD have or do not have sleep problems, to seek predictors for family hardiness/resilience, and to determine whether narrative findings support, expand, or conflict quantitative findings.
Results: Seventy complete surveys were returned from parents of children with ASD to compare sleep and family functioning. Fifty-seven children had sleep problems and six interviews regarding eight of these children were conducted. Parents of children with ASD and sleep problems had lower levels of resilience than those who slept well. Predictors of hardiness were social support, coping-coherence (stress management), and lower strain scores. Qualitative content analysis revealed a journey analogy with themes: finding the trailhead, dual pathways, crossing paths and choosing travel companions, forging new paths, resting along the way, and seeing the vistas.
Conclusions: Qualitative findings supported quantitative findings regarding the impact of sleep problems but also expanded them by illustrating how families' resilience and children's socialization improved over time. Social support predicted family hardiness. Parents revealed that sleep issues contributed to family strains and described their progression to resilience and embracing their child.
Practice Implications: Findings support the need for community and provider advocacy and implicates a need for development of sleep interventions on behalf of families and children with ASD.

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Introduction

Autism spectrum disorder (ASD) is defined as "persistent deficits in social communication and social interaction" and "restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association, 2013, p. 50). Many children with ASD have co-occurring sleep problems. Resilient families, defined as those who are able to endure and transcend life's major difficulties (Walsh, 2003), foster strategies to help themselves and their children move toward their best potential. Finding resilience is especially daunting for families with the dual challenge of dealing with the behavioral issues of ASD and often co-occurring sleep problems. Despite stressors families of children who have ASD appear to adapt and demonstrate resilience but little is known about whether co-occurring sleep problems impact resilience (Bayat, 2007; El-Ghoroury, 2012). Sleep deprivation, an outcome of

sleep problems, can lead to emotional dysregulation for children and their families (Leger et al., 2010).

Sleep Problems

Children with autism often have co-occurring health conditions including attention deficit, obsessive compulsive, digestive, seizure, and sleep disorders. Sleep initiation and maintenance affects up to 86% of children with ASD has been confirmed by parental reports and polysomnography studies (Cortesi, Giannotti, Ivanenko, & Johnson, 2010). Children with ASD appear to have some abnormal hormones, including melatonin and cortisol, and circadian rhythm profiles resulting in sleep reduction (Glickman, 2010). Rapid eye movement (REM) sleep (when normal generalized paralysis occurs) is reduced in children with ASD, which increases the proportion of non-REM sleep and allows them more time to physically act out their dreams as seen in night terrors and sleep walking (Reynolds & Malow, 2011).

Sleep problems in children with ASD do not seem to disappear over time without sleep hygiene interventions (Sivertsen, Posserud, Gillberg, Lundervold, & Hysing, 2012). Medications such as melatonin can help promote onset of sleep, however, delayed sleep onset has not been

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found to exacerbate as much autistic behavioral symptomatology as other sleep problems, such as waking in the night and parasomnias (abnormal sleep behaviors; Hoffman et al., 2008).

Sleep deprivation has many deleterious effects including decreased energy conservation, cognitive functioning, and ability to regulate emotions and mood (Kotagal & Broomall, 2012). When compared to normative childhood sleep patterns, those with ASD had more trouble initiating sleep and experienced more daytime sleepiness (Allik, Larsson, & Smedje, 2006). Autistic behaviors exhibited by the child may lead to insomnia, further exacerbating hyperactive repetitive behaviors (Jeste, 2011).

Children's sleep problems often cause sleep deprivation for their parents (Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008). Poor parental sleep has been associated with higher fatigue levels, higher anxiety and depression, and lower levels of activity among parents of children with ASD (Giallo, Wood, Jellett, & Porter, 2013). Families of children with ASD have reported greater adjustment and stress issues than families of typically developing children and children with other disabilities (Hall & Graff, 2011; Vriend, Corkum, Moon, & Smith, 2011).

Family Adaptation and Resilience

Both qualitative and quantitative studies have confirmed that quality of life was often decreased in families of children with ASD (Hutton & Caron, 2005; Lee et al., 2009). Socialization is often the lowest adaptive skill of children with ASD and their behaviors may not be socially acceptable (Hall & Graff, 2011). The restriction of interests associated with ASD can prohibit families from enjoying a variety of social activities. Children may protest against changes in routines that, in turn, prohibit spontaneous family outings. Families may avoid social settings related to lack of understanding and ambivalent acceptance of their children by the public, therefore, becoming socially isolated (Higgins, Bailey, & Pearce, 2005; Manning, Wainwright, & Bennett, 2011). The resulting isolation can lead to further stress and/or depression for family members.

Compounding socialization problems for families and children with ASD, are sleep problems. Despite the potential severity of sleep and related problems of children with ASD; longitudinal studies demonstrate decreased family stress, improved functioning, and resilience over time (Manning et al., 2011). Parents of children with ASD with non-violent behaviors demonstrated adaptation over 10 years including lower stress levels, decreased perception of stigmatizing reactions from others, and increased psychological well-being (Gray, 2006). Factors leading to these positive changes included developing support systems, diminishing child's troubling behaviors, and focusing on the child's positive attributes. Families seemed to rely on friends and spirituality for support and used techniques to reframe the situation in a positive light, such as minimizing the impact of other people's opinions about their child (Tunali & Power, 2002).

Theoretical Model

The Resiliency Model of Family Stress, Adjustment, and Adaptation, illuminates the process of differentiating families who move toward positive adjustment and adaptation instead of maladaptation (McCubbin & McCubbin, 1993). Resilience was used in the current study as the umbrella construct inclusive of positive concepts that reflect resilience such as: adaptation, regenerativity, hardiness, and coping/coherence (Gloria & Steinhardt, 2016; McCubbin & McCubbin, 1993). The focus of this model is not on the family's deficits, but on discerning what factors mediate the effects of stressors and enable families to recover and become stronger. According to the model, when families are confronted with a pile-up of stressors, families become vulnerable and work to regain a sense of balance and harmony. If families move to a level of bonadjustment, the process has resolved for that current situation. However, if the family does not initially adjust, they can move forward into adaptation by utilizing various mediating variables (e.g. problem solving,

social support, new patterns of functioning). This model has been used to explore adaptation in families of children with ASD by Hall and Graff (2011) and Manning et al. (2011).

Two studies specifically related to resilience in families of children with ASD have been described but none were specifically related sleep problems (Bayat, 2007; El-Ghoroury, 2012). Narratives of parents of adult children with ASD demonstrated how they became resilient over time as their children became autonomous (El-Ghoroury, 2012). Many participants reported that the family unit or individuals within the family had changed for the better (e.g. positive outlook, compassion, spiritual beliefs) as a result of raising a child with ASD (Bayat, 2007). The evidence that families of children with ASD can transcend difficulties and find resilience can be helpful to other families of children with co-occurring sleep problems.

The primary assumption of our proposed research is that we are measuring family resilience using individuals' responses. Although individual family members can be asked to report on their family as a whole, the data are limited in representing the *family* as the unit of analysis (DeHaan, Hawley, & Deal, 2013). Family resilience as a concept is dynamic and is composed of multiple factors. It is formidable to find and employ an instrument that measures resilience based on the unified family even if answered by each individual (Black & Lobo, 2008). Thus this research was based on literature regarding families, the theory of family resilience, and used family resilience measurements as seen from the perspective of individual family members; in this case the primary caretakers of children with ASD. McCubbin, Thompson, and McCubbin (2001) worked with the "premise that family processes interact with individual family members' psychological and physiological processes in discernable and predictable ways" (p. 821) in their inventories.

Purpose

The purpose of this study was to explore the impact of sleep problems on families of children with ASD and identify promoters of adaptation and resilience. The study aims were to: 1) compare family resilience for parents of children with ASD who have and do not have sleep problems using parent survey data; 2) identify which independent variables among sleep problems, resilience sub-indices, and demographics that are the best predictors for overall resilience; and 3) use in-depth interviews with parents of children with co-occurring ASD and sleep problems in order to explain, support, expand, or counter quantitative findings.

Design and Methods

An explanatory, sequential, mixed methods design provided a structure for the collection of initial cross-sectional quantitative data related to the child with ASD's characteristics, sleep problems, and family resilience; followed, sequentially, by in-depth interviews to add deeper understanding and contextualization to the quantitative data. In this approach, questions within the qualitative inquiry were based on the initial quantitative findings (Creswell & Plano Clark, 2011). Given the complexity of the heterogeneous spectrum of autism characteristics and sleep problems, a mixed methods design is needed to bring different perspectives and methodological expertise into data analyses.

Participants and Setting

To obtain a purposive sample of parents of a child with a diagnosis of ASD, recruitment was conducted over a 12-month period from two pediatric developmental clinics and a community-wide parent support group. The inclusion criteria were English-speaking parents of a child with an ASD diagnosis who was between 4 and 12 years. Parents of children with and without sleep problems were recruited in the quantitative arm of the study for post-analysis comparison. Participants were

individual parents although they were questioned about family characteristics and resilience in the surveys and interviews.

Measures/Data Collection

The quantitative design employed three questionnaires: a PI developed demographic survey seeking basic child and family descriptors and two standardized and psychometrically tested instruments including the Family Index of Regenerativity and Adaptation-General (FIRA-G; McCubbin et al., 2001) and the Children's Sleep Habits Questionnaire (CSHQ; Owens, Spirito, & McGuinn, 2000).

The demographic survey included items about the primary caretaker, the child's sex, race/ethnicity, age, age at diagnosis, co-occurring diagnoses, therapies, medications, age when sleep problems began (if applicable), family's financial status, and number of people living in the home.

The FIRA-G is a measure of resilience, designed to coordinate with McCubbin et al. (2001) Resiliency Model described earlier (used with author's permission). The FIRA-G includes 73 items measuring both negative indices (family stressors, strains, distress) and positive indices (relative and friend support, social support, family coping-coherence, and hardiness) that are seen as mediators or outcomes of adaptation (see theoretical definitions of measures in Table 1, including psychometric properties). Individuals completed the items based on their perceptions of family functioning.

The CSHQ includes 33 measures of bedtime resistance within the seven overall categories of: sleep onset delay, duration, sleep anxiety, night wakings, parasomnias, sleep disordered breathing, and daytime sleepiness (Owens et al., 2000). These categories were drawn from children's common sleep symptoms in the International Classification of Sleep Disorders. Internal consistency ranges from 0.68 from a community sample to 0.78 in the pediatric sleep disorders clinical sample. The CSHQ is in the public domain (www.kidzzzsleep.org). Higher scores indicate greater sleep problems with an additive score of 41 as the cutoff between good and poor sleep.

Analysis

Quantitative Analysis

Data were entered into SPSS (version 22) for analysis. Descriptive statistics on demographic characteristics were generated. Variables of interest were the seven indices of the FIRA-G which were calculated as overall negative and positive scores. Measures of sleep habits from the CSHQ were coded as poor if they scored above 41 points. This dichotomous variable was used in the analyses as an independent variable to answer the research questions of this study. Attention deficit hyperactivity disorder (ADHD), medication use, and financial need were recoded into dichotomous variables to indicate their absence or presence and treated as independent variables in the analyses. Separate independent t-tests were conducted to show if sleep problems, ADHD, gender, medication use, or financial status had an effect on outcome resilience variables (e.g. hardiness and coping/coherence). Bivariate correlations between the outcome variables, age and time since the ASD diagnosis were estimated to study the relationships among them. Linear multiple regression analysis was conducted to model the positive outcome variables as response variables. Only significant predictors were included in the final model.

Qualitative Analysis

Parent interview questions included inquiries about any specific sleep problems and strategies the family used (Fig. 1). Participants were given the opportunity to reveal family stressors, resources the family used to adjust to stressors, family patterns of functioning, and how functioning had developed or changed over time. Based on aggregated quantitative findings, interviewees were asked to relate their child's story over time to account for changes. Audio-recordings were transcribed verbatim and meticulously validated by the PI. The PI sent each participant a copy of the final transcript for member checks. Thematic content analysis was conducted by two authors, involving reading and re-reading the transcripts, extracting statements, coding clusters of data, and finally grouping the codes into themes that reflected broad perspectives (Creswell & Plano Clark, 2011).

Integration of Quantitative and Qualitative Data

In this type of mixed method study, qualitative findings were used to explain quantitative findings. Inferences were made through integration (comparison, correlation, consolidation) of the two data types. The two strands of inquiry were merged and relationships within the theoretical framework were sought. The researchers had prolonged engagement with the data and used reflection strategies before integrating findings into a coherent whole (Creswell & Plano Clark, 2011).

Table 1
Measures from the Family Index of Regenerativity and Adaptation-General.

Indices of family functioning & psychometric properties	Definition of measures
Family stressors index (negative index) Validity[b] = 0.60	"Life events and changes that can render a family vulnerable to the impact of a subsequent stressor or change"[a] (e.g. work changes, death, new family member)
Family strains index (negative index) Reliability = 0.69 Validity = 0.87	"Life events and changes which can render a family vulnerable to the impact of a subsequent stressor or change"[a] (e.g. conflicts, finances, sickness).
Family distress index (negative index) Validity = 0.50	"Major difficulties families may experience which reflect a deterioration in a family's stability."[a] (e.g. substance abuse, violence, divorce)
Relative and friend support (positive index) Reliability = 0.82 Validity = 0.99	"The degree to which families call upon relative and friend support…to manage its stressors and strains."[a]
Social support (positive index) Reliability = 0.82 Validity = 0.80	"The degree to which families are integrated into the community, view the community as a source of support and feel that the community can provide emotional, esteem, and network support."[a]
Family coping-coherence index (positive index) Reliability = 0.71 Validity = 0.80	"The degree to which the families call upon their appraisal skills to manage stressful life events, strains, and changes."[a]
Family hardiness index (positive index) Reliability = 0.82 Validity = 0.15–0.23	"A stress resistance and adaptation resource in families, which would function as a buffer or mediating factor in mitigating the effects of stressors and demands, and a facilitation of family adjustment and adaptation over time."[a]

[a] McCubbin et al. (2001) p. 822–824.
[b] Validity coefficients were determined by correlations with original instruments.

Part I: Autism symptoms and diagnosis

When and how was your child diagnosed with autism?

What has been challenging for you or your child?

What strategies have worked or not worked?

How does this affect each family member, positively or negatively?

Part II: Co-occurring sleep problems

Can you tell me the story of your child's sleep within the context of the whole family?

Over time, what has each member of the family done to make the problem better?

What would you want to share with other families with similar issues?

Part III: Family adaptation

What are the positive and negative things that have changed in your family since

diagnosis?

Do you feel like you have adapted over time?

Fig. 1. Summary of interview guide.

Procedures

Quantitative Procedures

Parents were recruited though a letter explaining the study and inviting participation. About 350 recruitment letters were either electronically mailed or handed to parents in clinics and community meetings. For those parents considering participation in the study; surveys were delivered by mail or in person, information about the study provided, and consent was implied by completion of surveys. Surveys were returned to the PI in self-addressed stamped envelopes through postal mail. Parents had the option to include their return address to receive a gift card.

Qualitative Procedures

After each survey packet was returned and scored, the PI sent a new recruitment letter to each participant whose sleep survey indicated that the child had sleep problems (n = 57). The letter explained the qualitative arm of the study and asked if they (inclusion of their partner) would agree to participate in an interview. Written consent was obtained prior to data collection. The interviews included open-ended questions, informed by survey findings, relating to the child's behaviors and history of ASD diagnosis and sleep problems (Fig. 1). All interviews were conducted in private settings and audio-recorded. Participating parents received a gift card. All transcripts were de-identified. Institutional Review Board (IRB) approval for the research was granted from the university of the principal investigator (PI) along with two Midwestern urban hospitals across state lines.

Results

Quantitative Findings

Parents of 84 children with a diagnosis of ASD returned the surveys, 70 of which were complete and met inclusion criteria. Clinic and community agency personnel did not track how many survey packets were actually delivered. The response rate was roughly 24%. All respondents were the primary caretaker of the child with ASD and all were mothers (n = 70/100%), including one foster mother. Thirteen (18.57%) mothers reported no father in the home. The average age of the child was 7.32 years and most were boys (n = 53/75.71%). Most participants were Caucasian (n = 56/80%). The average age at diagnosis of children in these families was 4.44 years. Among co-occurring diagnoses, slightly over half of the children were also diagnosed with ADHD (n = 37/52.86%). Almost all of the children (n = 63/90%) were involved in occupational, speech, or behavioral therapies. Most children (n = 48/68.57%) were taking medication, 44 (62.86%) of these children took either psychotropic or sleep medications. Of the 70 participants, only six (8.57%) responded that they could not meet their family's financial needs and 27 (38.57%) felt they could consistently meet them. Sleep problems as reported in the CSHQ occurred in the vast majority of children (n = 57/81.43%).

Parents of children who had sleep problems as determined by the CSHQ, scored statistically significantly higher in family strains (p = 0.003) and family distress (p < 0.001), and higher on the combined negative resilience sub-inventories (p = 0.020; Table 2). Child age, time since the ASD diagnosis, and medication use were not significantly related to any sleep or resilience scores. Female sex, without regard to CSHQ scores, was significantly related to higher (worse) scores in the overall negative resilience scale (p = 0.031), specifically on strains (p = 0.023).

Results of the regression analysis found that strains (β = −0.271, SE = 0.074), social support (β = 0.549, SE = 0.096) and coping-coherence (β = 0.770, SE = 0.285) were all significant predictors for hardiness, a positive outcome variable of the FIRG-A. Social support (community network support) contributed the most to the regression model with the largest beta estimate. Relationships were discovered among the resilience indices. Relative and friend support was significantly correlated with social support (r = 0.309, p = 0.009). Social support was significantly correlated with hardiness (r = 0.566, p < 0.001), and hardiness had a significant negative correlation with distress (r = −0.396, p = 0.001) and strains (r = −0.448, p < 0.001).

Table 2
Comparison between resilience measures for families of children with and without sleep problems.

	Sleep problem		p Value
	Yes	No	
	Mean (SD)	Mean (SD)	
Stressors	9.2127 (7.33)	8.1200 (10.14)	0.701
Strains	14.0891 (8.78)	6.3400 (7.26)	0.003*
Distress	8.4944 (7.07)	2.2533 (3.73)	<0.001*
Social support	45.4000 (6.92)	48.6667 (6.80)	0.108
Coping-coherence	16.1273 (2.25)	15.4667 (2.50)	0.329
Hardiness	43.9818 (6.77)	47.4667 (9.21)	0.108
Relative and friend support	25.8182 (5.82)	24.6667 (8.40)	0.541
Overall negative	31.6418 (16.67)	16.7133 (15.96)	0.003*
Overall positive	131.3273 (16.02)	136.2667 (16.79)	0.298

* $p < 0.05$.

Children who had ADHD had a significantly higher parent-reported CSHQ mean score of 52.58 (SD = 11.08) when compared to those without ADHD (mean score of 47.4324, SD = 8.43, p = 0.031). Parents of children who had ADHD scored significantly lower on the family stressor score (M = 6.5515, SD = 6.79) when compared to parents of children without ADHD (M = 11.1432, SD = 8.36, p = 0.015).

Qualitative Findings

Interview recruitment letters were sent to all survey respondents whose child's CSHQ score indicated sleep problems (n = 57) and six parents responded (9.5% response rate). The PI conducted six interviews (five mothers plus one couple) regarding eight children (two sets of siblings) with ASD and sleep problems. The interviews lasted between 45 and 75 min each. The parents (all married, one separated) discussed their children who were currently between 5 and 13 years old. All children were male except for one female. There was a wide range in socioeconomic status with one family having the resources to employ a nanny and one mother who reported that her husband was homeless. All families had support services and most of the children had other co-occurring disorders including ADHD. No new insights were gained by the sixth interview; therefore the researchers determined that data saturation was reached among this sample of primary caregivers who receive autism services in this geographic area.

Interviews revealed numerous, complex, and dynamic themes that we have aligned with a journey analogy. The themes within *Journey toward Family Resilience* include: *finding the trailhead*, *dual pathways*, *crossing paths and choosing travel companions*, *forging new paths*, *resting along the way*, and *seeing the vistas*. The themes represent the journey the participants traveled as aligned with the Resiliency model. During the adjustment phase, parents described the *trailhead* (appraisal of the diagnosis), *dual pathways* (resistance, differing patterns of functioning), and *rest* issues (pileup of stressors). Themes also demonstrated movement into the adaptation phase through *travel companions* (social support), *forging new paths* (new patterns of functioning), and finally *seeing the vistas* (situational appraisals) as families transcend. The restoration goal, *resting along the way*, illustrates how families sought to deal with the child's sleep problems that created sleep deprivation for all.

Finding the Trailhead

In this schema, the trailhead is the child's ASD diagnosis. Before diagnosis, many families are on a path of observing atypical behaviors. Sometimes, the parents identified the differences. "We always felt like there is something not right with the older child." "He was the fourth [child] and…there was a lot of physical things that were just slightly different." Other times, immediate family members saw the uniqueness of the child, but parents justified it as a normal variation. "I mean I was almost four when I started talking. He was almost four when he started talking and I was like, I think you people are just being paranoid." Often, someone outside the family identified abnormal behaviors and encouraged

testing. "[W]e had a friend that kept him for a week that was really strongly encouraging us to get him evaluated."

Eventually this led to the ASD medical diagnoses. As a trailhead marks the beginning of a fairly defined path, a diagnosis does likewise. It gives a name, a description, affirmation of parental observations, and access to family education and therapeutic resources. "He wasn't getting services until I got the autism label. It was a night and day difference for him." "I think it's good that with a diagnosis you get lots and lots of help from all those tax dollars that you so graciously…pay." Although the processes involved in finding the trailhead were similar, there was much diversity among paths.

Dual Paths

The journey can be conceptualized as consisting of two paths; the child's path of developmental and behavioral changes and the parents' path of seeking to effectively respond to the child's needs. The two paths essentially run parallel, although they continually merge and diverge. *Dual paths* are conceptually simplified, considering that each parent will have a distinct path. For instance, some mothers said their husbands had more difficulty with the diagnosis than they did.

Along the child's path, a large variety of behaviors were described. One parent commented, "Kids with autism are all different. They are alike – but they are different." All parents spoke about their children's socialization, "The most debilitating thing about autism is the social aspect." An account was given of a child "wandering around the classroom aimlessly for two hours at a time." Other examples of social problems were the child's odd speech patterns, disinterest in others, forceful physicality, and inability to form casual friendships. Play often became extreme and even obsessive, self-centered, with little reciprocity. One mother described her child with ASD on play dates was "not really interested in what the other person has to say" or was "repetitive talking to them." As children got older, parents were concerned about social issues, the child's defiance, or the fear of leaving teenagers at home unattended.

Thus, the parental response path was often frustrating. Parents often found an effective way to deal with an issue (merge), but then it stopped working or the behaviors changed (diverge). Merging and diverging are well described: "[Her] moods are up and down. One day she'll be running all over the house, she won't listen, she'll be screaming…The very next day she'll be sitting down, she'll be calm, she'll be talking to you normally." For each phase, parents had to improvise. "We have to keep a very strict schedule and can't deviate from that very much. That's part of our lives that we do miss."

Despite the frustration of divergences, the times of merging between the child's path and the parental response path was often joyful. "I think that they enjoy that I'm kind of more on the same page with them than I used to be... he wants to be a normal young man, so bad. [W]e just got to be here to catch him when he falls." Merging resulted from finding effective responses. These creative responses can be "stored away" like *tools in the backpack* that one takes along on the journey. Various tools can be employed as needed to help the child. "The social stories have been real helpful." To help promote appropriate behaviors another parent worked with a teacher to "put together a book with pictures about how there's times when it's okay to be Spiderman and other times when he has to be Peter Parker." Parents also described occasional *leaps of progress* that made the difficult parental path even more rewarding. "He wasn't going to do it. Then, one day, he just did it." One father expressed, "He's exercising; changed the ways he's eating." The mother interjected, "He's discovered girls, I think." The sentiment was captured in "[W]e danced for joy."

Crossing Paths and Travel Companions

This theme represents other relationships that may simply cross the parental-child dual paths or travel along side for a time. *Path crossers* can include friends, extended family members, teachers, or health care providers; many who are able to understand and provide needed support.

The family chooses their *travel companions* to join or visit, their core paths.

Overall, respondents were pleased with school and health services. They preached the merits of early intervention and health care providers that listened and advocated versus doubting them. "I was so blessed to have a pediatrician who said, '[I]f you're still worried about it, I trust you…let's get him the evaluation." Other families needed to persevere to get help. Many stated that diagnosis opens doors to support, but that neither services nor parents can "do it all."

Forging New Paths

Some people or places are not helpful or accepting. These "paths" are often left behind and a new path begun, although the new path is sometimes more isolating. "Nothing is as challenging as family members. We just learned that they have their opinions…we leave them, we go back to our normal little box, then do what we've got to do to maintain and for our family's survival…we've kind of just shut them out, because they don't live with them [children with ASD] day to day." One father's response to other people, judging him about over-reacting, was "Don't accept it." The mother responded, "Well, then we're isolated, but [you] just do what you got to do to cope and get through it."

Most parents discussed the effect of other people's implied or expressed thoughts about their child with ASD. The tenor of offside comments by other adults made some parents feel a need to apologize when in public settings. "It hurts the parents much more than the child." Families avoided public outings and became more isolated or rehearsed "public behavior a hundred times" before leaving home. Some parents described school situations. "They both were bullied horribly [at the old school]…the [new] school…is small but it's a country school. The kids are much more accepting [at the new school]…they've really blossomed." Other children had to change schools to get therapy and therefore were separated from their siblings.

Resting Along the Way

Perhaps the most important part of the merging-diverging dual paths is families finding ways to get rested and revitalized, to be enabled to continue the journey. Sleep is the obvious solution, but perplexing when children with ASD have co-occurring sleep problems. Issues ranged from the extreme need for consistent routines, transitions to bed, staying asleep, and safety of nighttime awakenings and wandering. Getting the child to sleep was exhausting. Many children could not self-soothe back to sleep. Parents expressed that they would appreciate freedom from these night routines but that over time they learned to "deal with it."

Some of the children had sleep problems starting at birth. "When the oldest was a baby, he never slept. I thought I was going to lose my mind. We were just like zombies." Others stated, "We decided the only way we're going to get sleep [is if] he's right here [in bed] with us. And that's what we did." "I mean he was six or seven years old before he finally slept through the night on his own." "He never took naps as a child."

Parents described their child's nighttime anxieties. "They have some background noise. They still need a night light. That's just their insecurities…they're scared. The oldest one runs up the stairs like someone is chasing him. No self-calming." A variety of measures helped children sleep, maybe just temporarily, such as contact with another person. A mother with two sons with ASD stated "my eight year old likes to fall asleep holding my hair…my nine year old likes to hold my ear."

Many parents described specific behaviors related to sleep problems. For example, one child got out of bed 20 to 30 times before sleep, finally falling asleep late and awakening early. Another child wet the bed each night and then roamed the house and went outside, prompting the parents to get an alarm system. Other activities were frightening as well. One young non-communicative child got into destructive and dangerous things including spray-painting the carpet, climbing on top of the refrigerator, and getting into cleaning supplies. This 5 year old could unlock safety locks and untie ropes. "She'd be destroying the room before she'd go to sleep and screaming and yelling, 'I don't want to go to sleep.'" Parents spoke about getting no sleep for a long time. "Most of the time if they're awake, I need to be awake."

A variety of adjustments helped parents. One mother adapted to her child's early waking as incentive to get herself out the door to Yoga each morning. Another effective way that parents obtained some rest and restoration was to "tag team" with each other, or trusted persons so they could "step off the path" temporarily. Communication appeared to be strong in the more adapted families, particularly those with older children. As stated, it is about "our family's survival." "It made our relationship stronger, because we've had to rely on each other."

Seeing the Vistas

Vistas represent a larger worldview, one that allows for parents to find the positive and see the beauty in their child; "Focus on the positives." Some participants developed a sense of humor about the situation and allowed other people to have their own opinions and subsequently ignored them. "We have friends that…also have autistic children and they're not the same and we laugh about it." One mother stated "[I] tell people how to deal with him, I don't tell them he's autistic."

The most poignant comments were related to acceptance of the child. Parents understood that their child was "never going to be like everyone else" or that they "can't fully communicate with them." Nevertheless, every single participant expressed comments such as: "I don't want to cure my kid from being my kid." "You love them with all your heart and you don't give up." "There's a reason he is here. There's a reason we're here." "I wouldn't have them be any different. It's part of who they are and I just wouldn't change that at all." The road to resilience seemed very closely linked to increasing acceptance of the child. Parents appeared to move from original denial of the child's differences to acceptance and more frequent merging of the paths or more comfort with divergence. This growing understanding and advocacy voiced by parents was well described by one mother: "It goes from denial, to the full on…marching parade."

Discussion

Integration of Mixed Findings

The survey findings identified relationships among demographic characteristics, measures of sleep, and family resilience. Families of children who had sleep problems scored significantly higher on the combined negative resilience indices. The interviews provided further explanatory evidence, with details and life contexts. Although survey data showed that family resilience was not affected by the child's age or time since diagnosis, this was not the case with our interview data. Cross-sectional surveys could not portray the time element involved in family progression toward resilience, nor could they adequately tease out social issues of the child including how socialization proceeded.

In surveys, family hardiness (an active orientation to stressors) was predicted by social support, coping-coherence (family's positive appraisals), and lower levels of strains (related to family conflicts; McCubbin et al., 2001). The coping-coherence findings supported studies indicating that faith and positively reframing problems can lead to hardiness (Bayat, 2007; Gray, 2006; Manning et al., 2011). Interview data were consistent with previous qualitative and longitudinal studies that showed increasing resilience over time (Bayat, 2007; El-Ghoroury, 2012; Gray, 2006; Tunali & Power, 2002). Descriptions are shown in the *dual paths* theme of the parental responses to the child's behaviors and needs, involving constant appraisals.

The findings of this mixed study confirm earlier research in terms of socialization challenges of children with ASD, difficulties with changes in routine, and the social unacceptability of some ASD behaviors that cause families to avoid public activities and become more socially isolated (Hall & Graff, 2011; Manning et al., 2011). Interview findings in this study were consistent with increased family stress related to lack of

understanding from health care providers (Higgins et al., 2005). As in previous studies (El-Ghoroury, 2012; Gray, 2006; Manning et al., 2011), parents interviewed in this study, especially those of older children with ASD; reported increased adaptation, decreased stress, and improved psychological well-being over time. Social support by school and health care personnel helped these parents respond more effectively. Our participants' family functioning was positively influenced by support systems, decreasing of the child's troubling behaviors over time, and parental acceptance and focusing on positive attributes, despite significant challenges.

In the survey analysis, biological sex and ADHD were meaningfully related to sleep or resilience variables. Families of girls with ASD had higher strains indicating more difficulties. There is no easy explanation for this relationship, except that girls of average to higher intelligence may be diagnostically underrepresented due to potential assertation bias. Children who had ASD along with ADHD had worse sleep but, surprisingly, families had fewer stressors (i.e. life events that can increase families' vulnerability). Stimulant medications may improve ADHD while disallowing good sleep. This is a case for divergence of the two methods. Interviewed parents did not differentiate strains in families who had boy or girl children on the autism spectrum. Most of the interviewees reported that their child(ren) had a diagnosis of ADHD and did speak about medications helping overall, but not specifically regarding stimulant medication and changes in sleep. Quantitative methods may be able to highlight relationships that parents do not directly perceive.

The title of McCubbins' FIRA-G measure of resilience emphasizes adaptation and regenerativity. These processes are well reflected in our thematic analysis, which depicts functioning of families with a child with ASD as a dynamic, constantly adapting life path; along which rest and restoration are needed to continue the journey. Parents described progression toward resilience related to sleep problems, however, in that as sleep got better, strain was reduced. Descriptions corroborated survey findings that sleep problems contributed to family strains, a pile up of stressors that could move a family toward maladaptation. Each parent spoke about accepting and loving their child despite difficult issues and related how their family adapted. The journey model introduced here shares similar concepts with the Resiliency Model, but provides an image that is arguably easier to understand and relate to, making it a potentially useful analogy for families of children with ASD as well as a framework for health care providers caring for them (McCubbin & McCubbin, 1993). Overall, the combination of the mixed methods findings enhanced the understanding gained about the topic beyond what could be learned by either a quantitative or qualitative approach alone.

Implications

Sleep is not only crucial for cognitive executive processes needed by parents to deal with challenges of children with ASD, but also for effective family dynamics (Byars, Yeomans-Maldonado, & Noll, 2011). Stress and insomnia can lead to family dysfunction. Insomnia and family discord appear to become a vicious cycle, when insufficient sleep causes children's behavioral problems leading to an increase in negative parental moods, causing decreased sleep efficacy (Dahl & El-Sheikh, 2007). The results of this study demonstrated that families of children with better sleep were more resilient. The strong implication is for strengthening interventions to help promote better sleep for families and children with ASD. Based on these findings, services for children with ASD and insomnia are essential and must include well-designed, accessible community support services. First, clinicians should be educated regarding sleep strategies that help parents help their children such as through the Autism Speaks toolkit (Weiss, 2017) and collaboration with experts such as child psychologists who specialize in sleep. The sleep toolkit is accessible to parents as a download from Autism Speaks and is a guide to sleep hygiene strategies to help their children sleep; such as sleep settings, bedtimes, and sleeping alone. Accessibility to services has many barriers

including travel and childcare and could be alleviated by online formats or telemedicine techniques.

It was clear from the interviewees, that poor sleep was a significant challenge and that support services were key to families' progress toward adaptation and resilience. Community social support was the most powerful predictor of hardiness and as a mediator in the model, and should be a primary intervention. Thus, one priority for health care personnel is assessment of sleep patterns of children with ASD and their families. Another is to help those families find relevant, responsive, specialized services (Johnson, Giannotti, & Cortesi, 2009) as well as to maximize informal family and friend support. Educational programs can emphasize the importance of group support, help the family's social network (including school personnel) learn about ASD and co-occurring sleep problems, and teach evidence-based strategies for successful sleep (Katz & Malow, 2014). Developmental departments of children's hospitals and ASD support groups can offer programs that teach these sleep strategies to parents. Very few studies have been conducted using rigorous methodologies to determine the efficacy of sleep interventions but of those reported; interventions appear to ameliorate sleep problems with long-term success (Vriend et al., 2011). Reported interventions included behavioral changes; particularly, teaching parents how to use sleep hygiene practices, ignore bedtime disruptions, and to schedule wakings for children with night terrors. Prescribing clinicians should be aware that stimulant medication may not improve sleep but may provide a relief to families from stressors related to ADHD.

The concepts and relationships from the Resiliency Model along with the Journey framework can guide clinicians and future researchers (McCubbin & McCubbin, 1993). Clinicians can assess for characteristics intrinsic to this model and formulate a plan that helps achieve families' desired outcomes. Specifically, while collecting the child's history the nurse can assess the sources of stress, strain, or distress such as: work changes, death, new family member, conflicts, finances, sickness, substance abuse, violence, divorce (as listed in Table 1). It would be essential to assess friend/family support and community support systems that are accessible to the family. Family members can provide *rest* for parents along the journey. Support groups or social media can help families find *tools in the backpack* (helpful strategies). Family counselors can investigate further into the family's coping strategies and help them reappraise their patterns.

Limitations

Limitations are that participants were from only one Midwestern geographic area, a likely response bias because of participant incentives or research interest, and that parents of children without services had no access to recruitment. Less than 20% of the surveys reported that the child did not have a sleep problem. This is consistent with the literature indicating the low proportion of children with ASD who do not have sleep problems. The FIRA-G surveys do not measure change over time; we found that length of time since diagnosis did not show statistical significance with resilience scores. The interview participant number was small, although this is not a limitation in qualitative research, rather, it allows for in-depth inquiry into experiences (Patton, 2015). Additional limitations are that interviews were only reflective of the participants' perspective. These mothers spoke about their spouse's journey, but non-present fathers' perceptions were missing. All data that were collected was by self-report (parent perceptions) and therefore does not contain any objective measures.

Conclusions

This study is meaningful, as no other studies exist that have specifically examined how sleep problems of children with ASD impact family resilience, as expressed by primary caretakers. Considering the proportion of children with ASD and sleep problems, these issues could potentially affect a large number of families. Effective treatment for sleep

problems in children with ASD can result in improved sleep for the whole family and potentially less behavioral manifestations for the children. Treatments derived from children's behavioral ASD assessments are sorely lacking if they do not concurrently account for and treat sleep problems. Ultimately assisting families resolve sleep problems will help children with ASD integrate into their community and social settings by ameliorating behaviors that may be exacerbated by sleep disruptions. Well-designed social support services could be key interventions. These findings are foundational to future interventional research helping families achieve resilience through improving the sleep of children with ASD.

Acknowledgments

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