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

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ABSTRACT

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.

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 melantonin 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, regenerativitiy, 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

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