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Respite Care and Stress Among Caregivers of Children With Autism Spectrum Disorder: An Integrative Review

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Review

Problem: While parenting, in general, can be stressful, mothers of children with autism spectrum disorder (ASD) experience chronic stress comparable to combat soldiers. Research suggests that respite care may potentially reduce stress among caregivers. However, greater understanding of this relationship is needed. The purpose of this integrative review is to examine the relationship between respite care and stress among caregivers of children with ASD.
Sample and Eligibility: A final sample of 11 primary research reports were located using several databases. Articles were included that were: related to the focus of the review, written in English, and published within the last 10 years.
Results and Conclusion: While most studies found that respite care was associated with lower stress, several found that respite care was associated with higher stress. One study found no association. A model is presented that contributes to a new understanding of this relationship. Overall, the results of this integrative review provide some evidence that respite care use may be associated with a decrease in stress among caregivers of children with ASD. However, due to the lack of consistency and quality across the studies, these findings must be interpreted with caution.
Implications: Healthcare providers must recognize the importance of tailoring respite care services to the unique family needs. Additionally, policy changes and innovative ideas are needed to help improve the quality of respite care and help expand access. Finally, additional research is necessary to better understand the relationship between respite care and stress among caregivers of children with ASD.

Background and Significance of the Problem

While parenting, in general, can be stressful, mothers of children with autism spectrum disorder (ASD) experience chronic stress comparable to that experienced by combat soldiers (Smith et al., 2010). Previous research has shown that stress is more prevalent in caregivers (especially mothers) of children with ASD when compared to caregivers of children with other disorders and typically developing children. In addition to typical parenting demands, caregivers of children with ASD also have added demands related to their child's condition. These additional demands can cause increased stress, which can cause physiological changes, lower the immune response and place caregivers at risk for serious health risks, including depression. Caregivers who are under stress are also more likely to have disrupted relationships and experience difficulty caring for their child. This can impact the child's functioning and can also put the child at a greater risk for abuse or neglect.

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Autism spectrum disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges (Centers for Disease Control and Prevention [CDC], 2015). ASD includes several conditions, including: autistic disorder; pervasive developmental disorder not otherwise specified (PDD-NOS); and Asperger's Syndrome. According to estimates from the Autism and Developmental Disabilities Monitoring (ADDM) Network, about 1 in 68 children has been identified with ASD (Centers for Disease Control and Prevention, 2014). The increasing prevalence of ASD is a significant public health concern.

Respite Care

Respite care is an important support service for caregivers. Respite care is simply a break from caregiving that is designed to serve caregivers and families who are caring for people with disabilities or other special needs such as chronic or terminal illnesses; or are at risk of abuse and neglect (Respite Care Association of Wisconsin, 2016). Respite care has also been defined as planned or emergency care provided to a child with special needs in order to provide temporary relief to family caregivers who are caring for that child (ARCH National Respite Network, 2016).

Studies related to respite care began to be published in the early 1980s primarily in social work journals and focused on respite care to help reduce child abuse (Cohen, 1982; Subramanian, 1985; Cowen & Reed, 2002). While research in the area of respite care for caregivers of children with ASD is limited, a variety of other caregiver populations have been studied, including: children with chronic illnesses (Thurgate, 2005); physical disabilities (Doig, McLennan & Urichuk, 2008; Palisano et al., 2010); cognitive disabilities (Preece & Jordan, 2007; Wilkie & Barr, 2008); and developmental disabilities (Cowen & Reed, 2002; Mullins, Aniol, Boyd, Page & Chaney, 2002).

Respite care can be provided in various settings, including: in-home (Corkin, Price & Gillespie, 2006); community-based (Dawson & Liddicoat, 2009); hospital-based or in a residential facility (Mullins, Aniol, Boyd, Page &Chaney, 2002; Wilkie & Barr, 2008). The providers of respite care can be formal, such as nurses (Barrett et al., 2009) or in-formal (family and friends). Respite care can also occur in varying frequencies and durations (Corkin, Price & Gillespie, 2006; Wilkie & Barr, 2008). Respite care services can be short-term, intermittent, long-term, on-going, or provided as an emergency intervention (Corkin, Price & Gillespie, 2006; Wilkie & Barr, 2008). For example, respite care might occur in the form of a short-term, intermittent, community-based respite event sponsored by a local church with volunteers providing the care. In contrast, respite care services might also be provided in a hospital-based facility, staffed by trained nurses, for regularly scheduled long-term stays.

Researchers have also identified barriers to respite care use, including: lack of knowledge of available services (Harper, Dyches, Harper, Roper, & South, 2013); limited options and services and lack of trust in respite care providers (Wilkie & Barr, 2008). The results of several qualitative studies suggest that there needs to be a match between the type of respite care service and the unique needs of the family. Timing of services, as well as frequency of services, have influenced parents' perceptions of services as providing what they would consider a true 'break' (Corkin, Price, & Gilespie, 2006; Wilkie & Barr, 2008). Overall, there is no consistency related to what components are needed to make respite care services adequate from the perspective of the caregivers.

Stress Among Caregivers

Stress is defined as an individual's perception of the degree to which they find their life to be unpredictable, uncontrollable, and overloaded. This is consistent with the definition provided by Cohen, Kamarck, and Mermelstein (1983). In this definition, subjectivity is important, recognizing that one's perception is their reality. The intentional decision was made to not study *caregiver stress* because of the philosophical view that one cannot separate the stress caused from caregiving from other stress in an individual's life. If someone feels stressed, they feel stressed.

Several researchers have examined the impact of respite care use on stress among caregivers. A systematic review by Strunk (2010) found that respite care may be an effective intervention to decrease stress among family caregivers. However, the author concluded that studies are needed to examine the impact on parenting stress over time with a focus on non-maternal caregivers, such as fathers. A review by Chan and Sigafoos (2000) described the characteristics related to the use of respite care among families with children with developmental disabilities. They found that caregiver stress was a significant predictor in the decision to use respite care, indicating that stress levels may be higher, initially, among those who use respite care. Cowen and Reed (2002) found that participation in a county respite care program resulted in significant reductions in parent stress when comparing pre and post intervention data; however, parent stress level remained high, possibly suggesting a need for a more intensive intervention. Harper et al. (2013) found that stress mediated the relationship between respite care use and relationship quality among married parents of children with ASD. McLennan et al. (2012) examined stress before and after participation in a center-based respite program and found that, while stress levels decreased, there was no significant difference between the pre and post-test score among the intervention group. However, qualitative analysis suggested that, at least temporarily, stress was greatly reduced.

Conversely, several researchers have found that respite care, specifically when not meeting the individual needs of the family, can ultimately lead to an increase in caregiver stress (Hoare et al., 1998; Treneman, Corkery, Dowdney & Hammond, 1997). MacDonald and Callery (2007) found that parents expressed a need for a break but were too worried about the quality of the care to enjoy the time away. Caregivers in one study even expressed feelings of guilt and embarrassment about having to send their children to respite