



Review article

Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review

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ABSTRACT

Having children with developmental disabilities (DDs) requires a high level of caregiving responsibilities, and existing studies support that mothers of children with DDs experience high levels of maternal stress as well as poor sleep and well-being. Given the fact that the number of children with DDs has increased, an up-to-date literature review is necessary to identify factors associated with maternal stress, sleep, and well-being. In addition, understanding these factors and their relationships may provide better strategies in designing effective interventions that can reduce the burden in mothers of children with DDs. This review summarized 28 scientific research papers that examined maternal stress, sleep, and well-being in mothers of children with DDs in past 12 years. The study findings indicate that mothers of children with DDs experience higher levels of stress than mothers of typically developing children, and it remains high over time. In addition, these mothers often encounter depressive symptoms as well as poor sleep quality. The study results also reveal that there is a bidirectional relationship between maternal stress and depressive symptoms as well as between poor sleep quality and depressive symptoms. For example, higher stress mothers experienced more depressive symptoms. Mothers of children with DDs with poor sleep quality are significantly associated with more depressive symptoms. Child behavior problems were significantly associated with both maternal stress and depressive symptoms, but cautious interpretation is warranted due to the shared variance between child behavior problems, maternal stress, and depressive symptoms. Methodological guidelines for future research involve the use of reliable and valid instruments for the measurement of child behavior problems, maternal stress, and sleep. Recommendations for future research are included.

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1. Introduction

According to Public Law 106–402, the Developmental Disabilities and Bill of Rights Act, developmental disabilities (DDs) are defined as a group of severe chronic mental and/or physical conditions that result in substantial limitations in at least three of the following areas; self-care, receptive and expressive language, learning, mobility, self-direction, capacity of independent living, and economic self-sufficiency. Developmental disabilities are lifelong conditions that are typically originated during childhood ([Developmental Disabilities Assistance and Bill of Rights Act of 2000](#)). Examples of DDs include intellectual disabilities (IDs), neuromuscular disorders such as cerebral palsy, blindness and deafness, epilepsy, and autism, genetic disorders such as Down syndrome and Fragile X syndrome, and other developmental delays ([Boulet, Boyle, & Schieve, 2009](#); [Developmental Disabilities Assistance and Bill of Right Act of 2000](#); [McCallion & Nickle, 2008](#)). About 15% of US children aged 3–17 years, or 10 million children, experience DDs, and the number of children with DDs has significantly increased in the past 15 years (from 12.84% in 1997–1999 to 15.04% in 2006–2008) ([Boyle et al., 2011](#)). Due to the multiple physical and intellectual limitations, DDs have a profound impact on a child's health and function as well as health care utilization. For example, 41.4% children with DDs reported they have multiple disabilities ([Boulet et al., 2009](#)). In addition, children with DDs reported (1) greater limitation in their ability to walk, run, or play; (2) more needs for special equipment and home health care; and (3) higher long-term (>3 months) use of prescription medication than children without DDs ([Boulet et al., 2009](#)). Thus, raising children with DDs requires a high level of long-term caregiving far beyond the usual needs of typically developing children as they grow.

Having children with DDs often requires a high level of caregiving responsibilities due to complex limitations in activities of daily living as well as prolonged medical conditions ([Boulet et al., 2009](#); [Raina et al., 2004](#)). In most studies of children with DDs, mothers are the primary caregivers and play a pivotal role in managing their child's care and needs. The evidence also showed that mothers experienced more stress associated with child rearing and parenting than fathers. For example, in a study with parents of children with IDs, mothers' perceived daily parenting stress increased significantly across the preschool to early school-aged period, but fathers' level of perceived daily parenting stress was not only lower, but more stable over time ([Gerstein, Crnic, Blacher, & Baker, 2009](#)). Similarly, mothers of children with DDs reported higher levels of parenting stress scores falling within the clinical range (84%) than fathers of children with DDs (67%) ([Oelofsen & Richardson, 2006](#)).

Caregiving and raising children with DDs often described in terms of stress. Stress is a multi-dimensional construct and can be operationalized in various ways ([Crnic, Arbona, Baker, & Blacher, 2009](#)). Within the context of families of children with DDs, stress is often related with having children with DDs (child related) or parenting and child rearing. The stressful experiences are considered as person–environment interactions, in which both external stressors and available psychological, socioeconomic, and cultural resources influence on the person's appraisal of the stressor ([Lazarus & Folkman, 1984](#)). Thus, understanding factors associated with maternal stress is a necessary step toward the expanding current knowledge of stress in mothers of children with DDs.

In general, exposure to prolonged or chronic psychological distress has shown to result in negative health outcomes, ranging from impaired sleep to negative psychological and physiological well-being. When the body is unable to respond effectively to stressful challenges, this ineffective response is believed to produce a harmful effect due to activation of neural, endocrine, and immune systems ([McEwen, 1998](#)). Behavioral changes such as increased smoking and drinking alcohol, decreased physical activity, or decreased sleep also often occur as adaptations or coping mechanisms to stress response

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