

Mothers of Children on the Autism Spectrum Experience High Levels of Fatigue and Mental Distress



Studies indicate that the demands placed on parents caring for a child with autism contribute to a higher overall incidence of parental stress, depression, and anxiety and adversely affects family functioning and marital relationships compared with parents of children with other intellectual, developmental, or physical disabilities. Mothers of children with ASD, in particular, appear to face unique challenges that potentially have an impact on their health and wellbeing.

Parents of children with an autism spectrum disorder (ASD) are increasingly involved in the provision of early intervention and learning activities to promote positive outcomes for their children. However, several studies have documented that parental stress as well as a lack of time and energy are barriers to providing early intervention activities. Because autism impairs social relatedness and adaptive functioning, parent stress can decrease helpful psychological processes and directly influence the parent or caregiver's ability to support the child with special needs. Consequently, understanding factors, such as lack of energy or fatigue that may limit the capacity of the parent to assist in promoting their child's development is critical.

A study published in the journal *Autism* examined the extent to which parents experience fatigue and its relationship to other aspects of wellbeing and parenting. Fifty mothers of children ages 2-5 years with ASD participated in the study and completed questionnaires assessing level of fatigue, parenting self-efficacy (belief about the ability to parent successfully), children's behavioral and emotional problems, sleep quality, parent support needs, and overall physical activity. The study found that compared with mothers of typically developing children, mothers of children with ASD reported significantly higher fatigue, with overall scores in the moderate range. Factors associated with high levels of fatigue were poor maternal sleep quality, a high need for social support and poor quality of physical activity.

Fatigue was also significantly related to other aspects of wellbeing, including stress, anxiety and depression, and lower parenting efficacy and satisfaction.

These findings were somewhat expected given the additional caregiving demands, parenting challenges and pressures of managing family life when raising a child with an ASD. Likewise, It is also probable that symptoms of depression, anxiety, stress and worry (body tension, increased heart rate and rumination) can be mentally taxing and contribute to, or exacerbate fatigue. The researchers also note that it was not surprising that poor sleep quality was associated with higher levels of fatigue given the large amount of research indicating that inadequate sleep and poor sleep quality is associated with a range of physical health and wellbeing difficulties. Parents of children with ASD are at particular risk of sleep disruption and poor sleep quality owing to the high rate of sleep problems in their children. Parents reported that their child waking was the primary reason for sleep disruption. For other parents in the study, stress, anxiety and not being able to wind down were stated reasons for sleep disruption.

Implications

What are the implications of this study? The findings clearly indicate the need for interventions to specifically target parental fatigue and its impact on families affected by ASD both in the present and longer term. In addition to interventions targeting child sleep problems, parents are likely to benefit from psycho-education about fatigue and its potential effects on wellbeing, parenting and caregiving. This includes information about strategies to minimize and/or cope with the effects of sleep disruption, increase health and self-care behaviors, and strengthen opportunities for social support. It is well established that social support is protective of optimal parent wellbeing and, therefore, is an important component of any intervention to address fatigue and wellbeing of parents of children with an ASD. Parents with limited assistance to share the daily demands of caregiving and family life are likely to be at greater risk of fatigue than parents with more support. For parents with limited support, there might also be fewer opportunities to engage in self-care behaviors that are likely to alleviate or protect them from fatigue.

From a clinical perspective, professionals working with families of children with an ASD should be aware of negative effects of fatigue in addition to other wellbeing difficulties, such as stress and anxiety. An assessment of the presence and severity of

the physical, cognitive and emotional symptoms of fatigue, as well as the perceived impact on daily functioning, mood, relationships, parenting and other aspects of caregiving is important. Lastly, future work in this area should involve the development and evaluation of information resources and intervention approaches to assist parents of children with an ASD to manage fatigue and promote their overall wellbeing. The longer-term benefits for parents in terms of strengthening their overall health, wellbeing and parenting should also be a focus of research.

Giallo, R., Wood, C. E., Jellett, R., & Porter, R. (2013). Fatigue, wellbeing and parental self-efficacy in mothers of children with an Autism Spectrum Disorder. *Autism*, 17, 465-480. DOI: 10.1177/1362361311416830

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