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Health-Related Quality of Life of Parental Caregivers of Children With Autism Spectrum Disorder

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Purpose: The rate of Autism Spectrum Disorder (ASD) is increasing, where one in 68 children are now diagnosed with the disorder. The ASD spectrum includes autism, Asperger's syndrome, and pervasive development disorder. Symptoms of ASD can vary in severity and include difficulty communicating, sleep disturbances, social impairment, and behavior problems. Individuals with ASD may also have other comorbidities, which can contribute to the level of care needed.

Parents of children with ASD have high levels of stress and burden, which may lead to lower quality of life (QOL) outcomes. Parental caregivers are given no choice in the caregiving role and may feel that the caregiving duties are forced upon them. Additionally, parental caregivers have a greater risk for poor health due to limited time spent on personal health promotion tasks like diet and exercise. Also, because there is no cure for the individual with ASD, there is a need for a lifetime of parental caregiving. This stress may compound over time, contributing to poor QOL outcomes. The purpose of this presentation is to examine the state of the science of QOL in parents of individuals with ASD and to outline future research, clinical, and policy implications.

Methods: A comprehensive, electronic search of CINAHL, MEDLINE, the Cochrane Database of Systematic Reviews, and PsycINFO was performed. Seven hundred and twenty-nine articles were retrieved. Evaluation included inclusion and exclusion criteria, subject terms, title review, and abstract review. Fifteen relevant articles were kept for analysis. Both quantitative and qualitative articles were included in the articles kept. The articles represented studies conducted in 10 countries and included 5565 participants. Articles were evaluated for level of evidence and quality. Significant data were extracted to determine emergent themes.

Results: Quality of life was found to be lower in parents of children with ASD in five out of six World Health Organization (WHO) domains: physical health, psychological health, social relationships, environment, and spirituality. The domain of level of independence was not significantly affected. Physical and psychological QOL were most negatively impacted. The strongest risk factor for QOL was severity of behaviors of the child with ASD. Protective factors for QOL included increased parental income and education level, and independent activity levels of the child with ASD.

Conclusion: This review reinforces previously published guidelines suggesting early intervention for the child with ASD to decrease behaviors and to promote independence, which may ease the burden for parental caregivers. Parental caregivers would also benefit from programs and policies offering financial support in the way of funding to support therapies, medications, and respite care.

Gaps in this review include that there were a significantly lower number of male participants. This may be due to gender differences, where the female parent may be considered the primary carer. There were no studies comparing caregivers of children with ASD with other caregivers, which may aid in determining the unique needs of this population. There were no studies exploring the changes in family dynamic and progression of the disorder over the lifetime of the child with ASD. The needs of a toddler, a school-aged child, an adolescent, and a young adult may be very different and may include different stressors for the parental caregiver, such as potty training, school issues, puberty, and transitioning to adult services. Also, parents may either learn to better cope or may have compounded stress, both of which could impact QOL outcomes, long-term. Limitations of this review include the high number of descriptive studies ($n = 11$) with lower levels of evidence, which weakened the overall strength of the review and low number of fathers as participants.

Future areas of research include studies on fathers of children with ASD, exploration of coping as a mediator, and studies examining the impact of the age of the child on parental stressors and QOL outcomes. Clinical implications include the need for better screening tools to recognize caregiver burden, including tools to screen for physical health and psychological health. There is also a need to better educated caregivers on the importance of self-care and health promotion. Policy implications include the need for policies to assist with the financial burden of care for parents of individuals with ASD, particularly therapies and respite care. Also, there is a need for work related benefits to support missed time from work due to caregiving.

In summary, parental caregivers of children with ASD have increased stress and a potential for impaired physical and mental QOL. The research, clinical, and policy implications for nursing may help to improve parental QOL, may aid in the prevention of chronic physical and mental illness, and may secondarily improve the QOL of the individual with ASD.

Title:

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Abstract Summary:

The purpose of this presentation is to delineate the state of the science of health-related QOL of parents of individuals with ASD and discuss implications for future research, clinical practice, and policy.

Content Outline:

Health Related Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder

- Introduction
 - Caregivers of children with Autism Spectrum Disorder (ASD) have increased stress
 - Stress can negatively affect quality of life (QOL)
- Background and Significance
 - ASD "spectrum" includes autism, Asperger's syndrome, and pervasive developmental disorder
 - Symptoms range in severity
 - Communication
 - Sleep disturbances
 - Social impairment
 - Behavior problems and repetitive behavior
 - Other comorbidities may add to severity of symptoms
 - Parents as caregivers
 - No "choice" in caregiver role
 - Greater risk for poor health due to limited time to care for self
 - No cure for ASD means a lifetime of caregiving; compounding poor QOL outcomes
- Incidence and Prevalence
 - Significant increase in diagnosis; one in 68 children
 - Significant economic cost
- Method
 - Electronic, systematic review of 5 databases
 - Evaluation via inclusion/exclusion criteria, subject terms, title review, abstract review
 - Level of evidence and article quality analysis
 - 729 articles reviewed; 15 articles kept for analysis
 - Both qualitative and quantitative
 - 10 countries represented (N = 5565)
- Emergent Themes
 - Risk factors for decreased parental QOL
 - Severity of behaviors of the child with ASD
 - Protective factors for QOL
 - Higher parent income
 - Higher parent education level
 - Domains of QOL
 - Analyzed using 6 World Health Organization domains of QOL (physical, psychological, level of independence, social relationships, environment, and spirituality)
 - Physical and psychological QOL were most negatively impacted
- Gaps
 - Significantly lower number of male participants
 - No studies exploring changes with the age of the child/compounded parent stress over time
 - No studies comparing ASD with other disabilities
- Limitations

- Article quality, where 11 of 15 articles were descriptive studies
- Research Implications
 - Need for more rigorous studies, more studies with fathers, longitudinal studies or comparison of age groups to analyze compounded stress of parental caregivers
 - Interventions to promote QOL
- Clinical Implications
 - Need for caregiver burden screening tools
 - Physical and psychosocial
 - Need to educate caregivers on self-care and health promotion
- Policy Implications
 - Need for policies to support caregivers
 - Respite care
 - Financial assistance
 - Work related benefits to allow missed time from work due to caregiving
- Conclusion
 - Parental caregivers have increased stress and potential for impaired physical and mental QOL; implications for research, practice and policy change have been presented
 - Improvements to parental QOL may aid in prevention of chronic physical and mental illness and may secondarily improve the QOL of the individual with ASD

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