

Risk and Protective Factors for the Health of Primary Care-Givers of Children with Autism Spectrum Disorders or Intellectual Disability: A Narrative Review and Discussion

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Abstract : Background: Primary care-givers of children with autism spectrum disorder (ASD) or intellectual disability (ID) have poorer health and quality of life (QoL) than primary care-givers (hereafter referred to as just care-givers) of typically developing children. We aimed to review original research which described factors impacting the health of care-givers of children with ASD or ID and to discuss how these factors might influence care-giver health. Methods: We searched Web of Knowledge, Medline, Scopus and Google Scholar using selections of words from each of three groups. The first comprised terms associated with ASD and ID and included autism, pervasive development disorder, intellectual disability, mental retardation, disability, disabled, Down and Asperger. The second included terms related to health such as depression, physical, mental, psychiatric, psychological and well-being. The third was terms related to care-givers such as mother, parent and care-giver. We included an original paper in our review if it was published between 1st January 1990 and 31st December, 2016, described original research in a peer-reviewed journal and was written in English. Additional criteria were that the research used a study population of 15 persons or more; described a risk or protective factor for the health of care-givers of a child with ASD, ID or a sub-type (such as ASD with ID or Down syndrome). Using previous research, we developed a simple and objective five-level tool to assess the strength of evidence provided by the reviewed papers. Results: We retained 33 papers. Factors impacting primary care-giver health included child behaviour, level of support, socio-economic status (SES) and diagnostic issues. Challenging child behaviour, the most commonly identified risk factor for poorer care-giver health and QoL was reported in ten of the studies. A higher level of support was associated with improved care-giver health and QoL. For example, substantial evidence indicated that family support reduced care-giver burden in families with a child with ASD and that family and neighbourhood support was associated with improved care-giver mental health. Higher socio-economic status (SES) was a protective factor for care-giver health and particularly maternal health. Diagnostic uncertainty and an unclear prognosis are factors which can cause the greatest concern to care-givers of children with ASD and those for whom a cause of their child's ID has not been identified. We explain how each of these factors might impact caregiver health and how they might act differentially in care-givers of children with different types of ASD or ID (such as Down syndrome and ASD without ID). Conclusion: Care-givers of children with ASD may be more likely to experience many risk factors and less likely to experience the protective factors we identified for poorer mental health. Interventions to reduce risk factors and increase protective factors could pave the way for improved care-giver health. For example, workshops to train care-givers to better manage challenging child behaviours and earlier diagnosis of ASD (and particularly ASD without ID) would seem likely to improve care-giver well-being. Similarly, helping to expand support networks might reduce care-giver burden and stress leading to improved health.

Keywords : autism, caregivers, health, intellectual disability, mothers, review

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