Quality of Life of Parental Caregivers of Children with Autism Spectrum Disorder: A State of the Science Review

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Problem Statement
Parental caregivers of individuals with Autism Spectrum Disorder (ASD) are exposed to stressors associated with the daily care of raising a child with a developmental disability. These stressors can negatively affect parental quality of life (QOL). The problem to be addressed is the daily stressors of parental caregivers of children with ASD, which may lead to a decrease in parental QOL.

Search Strategy

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<tr>
<th>Database</th>
<th>Search Terms</th>
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<tr>
<td>PubMed</td>
<td>Autism Spectrum Disorder AND Parental Caregivers</td>
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<td>CINAHL</td>
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Study Characteristics
Ten countries were represented in this study. Total participants were 5565. Eleven of 15 articles were quantitative-descriptive studies. One article was a mixed method study. One article was a non-randomized controlled trial. One meta-synthesis of 50 qualitative studies. One systematic review of 12 quantitative studies.

Emergent Themes

- **Domains of QOL**
  - Physical health
  - Psychological health
  - Social relationships
  - Environment
  - Spiritual

- **Predictors of QOL**
  - Risk factors
  - Aberrant behaviors of the child with ASD
  - Parental caregiver perceived loss
  - Protective factors
  - Lower severity of ASD
  - Improved communication
  - Independence with ADLS
  - Increased family income
  - Increased social support

- **Limitations**
  - Small sample size of studies
  - Lower level of evidence where 11 of 15 articles were descriptive

- **Gaps in Knowledge**
  - Further research is needed in the following areas:
    - Parental caregiver studies comparing differences present dependent on the age of the child with ASD
    - Stressors
    - Coping
    - Resilience
    - QOL outcomes
    - Longitudinal studies
    - Fathers of children with ASD
    - Siblings of children with ASD

Summary and Implications

- Parental caregivers of children with ASD have lower physical, psychological, social, environmental, and spiritual QOL.
- Risk factors for decreased QOL include behaviors of the child, severity of ASD diagnosis, and parental perception of loss.
- Protective factors include improved communication of the child with ASD and increased social support.
- This study supports current guidelines for early interventions in speech and behavior therapy.
- There is a strong need for clinical guidelines for caregiver health screening in all domains, where no guidelines currently exist.
- Improvements made in the QOL of parental caregivers may aid in the prevention of chronic illness and depression and may also improve the QOL of children with ASD.