

Systematic Review of Quality of Life for Family Members of Children with Autism Spectrum Disorder in Asia

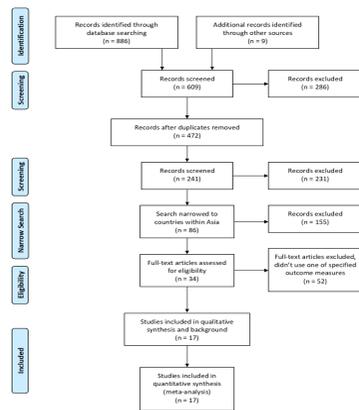
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Abstract

Parents of children with Autism Spectrum Disorder (ASD) face varied challenges significantly impacting their quality of life (QOL), and interventions may be able to improve these outcomes. A systematic review of primary research was conducted to assess the QOL for family members of children with ASD in Asia and determine which interventions can impact QOL. A total of 34 studies were included, 17 for quantitative and 17 for qualitative analysis. Parents of children with ASD in Asia were found to have lower QOL when compared with parents of Typically Developing (TD) children, with mothers having lower QOL than fathers. Higher sense of coherence is associated with higher QOL and lower stress. The most commonly used coping strategies were religion and a focus on positive growth to create meaning. Interventions that impacted QOL measures include Mindfulness Based Intervention, Multidisciplinary Parent Education and Cognitive Behavioral Therapy (CBT). Parents having and maintaining contact with other parents following an intervention also improved multiple QOL measures. This preliminary work emphasizes the importance of addressing QOL outcome targets and pairing these with efficacious interventions specific to the needs of the population.

Introduction

ASD is a lifetime neurodevelopmental disorder effecting 1 in 68 children, crossing racial, ethnic and socioeconomic boundaries, and associated with significant impairment in social communication functioning.^{1,7,16} Its pervasive, lifelong nature impacts parents of children with ASD, resulting in overall lower scores on markers of QOL.^{5, 6, 17, 28, 29} This study focuses on factors impacting diagnosis, access and QOL for families in countries in Asia. Regional ideas and barriers include a belief that speech delay signals higher intelligence, burdens of stigmatization, the one-child policy in China, shame and blame resulting in isolation, and belief that this is a sign of karmic demerit.^{8, 34, 18, 16, 24} These unique factors impact QOL for family members of children with ASD in Asia. This systematic review considers the following question: what is the QOL for family members of children with ASD in Asia, and how does it differ from that of family members of TD children; what interventions can impact these QOL markers? This broad assessment seeks to identify QOL deficits, with a focus on efforts to improve outcomes, including: general QOL, stress, relationships and family functioning, coping styles and general health.



Flow Diagram 1: Process of Article Selection for Inclusion in Systematic Review

Methods

Evidence from review of the literature was systematically retrieved and analyzed. Articles were identified in the following databases with five similar search strands: PubMed, CINAHL, and Embase, with additional background and cultural belief articles identified through bibliographies and prior research. Primary research articles meeting inclusion and exclusion criteria included the following designs: cross-sectional questionnaires, interviews, quasi-experimental pre-, posttest design, and case-control studies. Preliminary screening removed those clearly outside the scope of the question or in the U.S., with duplicates then eliminated. The five QOL outcomes of interest were overall QOL, stress, relationships and family functioning, coping styles, and general health. The search was narrowed to Asia, in order to draw a more meaningful conclusion. For each of the 5 major outcomes, 1-2 of the most commonly used QOL instruments was selected for inclusion. Flow Diagram 1 shows the selection process and Table 1 shows included measurement tools. Data was extracted for quantitative analysis when available. Without sufficient data, qualitative analysis was completed. Additionally, a within-group comparison of mothers to fathers was included.

Outcome	Measurement Tool
Overall QOL	WHOQOL-BREF: World Health Organization Quality of Life Scale-Brief
Stress	CBI: Caregiver Burden Index
Stress	PSI-SF: Parenting Stress Index-Short Form and PSI: Parenting Stress Index
Relationships	FAD: McMaster Family Assessment Device
Coping	WCC-R: Ways of Coping Checklist-Revised
Coping	SoC: Sense of Coherence
Health	GHQ-12 or -28: General Health Questionnaire
Health	SF-36: Health-Related Quality of Life Short Form-36

Table 1: QOL Measurement Tools

Results: WHOQOL-BREF

For the WHOQOL-BREF, higher scores denote higher quality of life. Figure 1 meta-analysis compares intervention to control group for a 5-week Mindfulness Based Intervention in Jordan and a 10-week support group in Taiwan and shows an insignificant inverse relationship between interventional status and score.^{30, 32} Figure 2 meta-analysis shows mothers in Jordan had a bigger effect on total WHOQOL-BREF scores compared to fathers, with insignificantly higher pooled scores in mothers.^{13, 14} Figure 3 cross-sectional data shows mean scores for each component of the WHOQOL-BREF were significantly higher within the High SoC group compared to Low.³³ Figure 4 cross-sectional survey data for caregivers in Thailand and mothers in Iran shows significantly higher means in Thailand.^{37, 22}

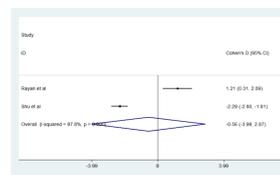


Figure 1: WHOQOL-BREF Meta-Analysis: Intervention vs. No Intervention

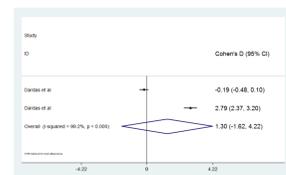


Figure 2: WHOQOL-BREF Meta-Analysis: Mothers vs. Fathers

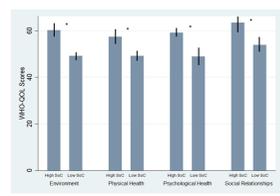


Figure 3: WHOQOL-BREF: Relation to Sense of Coherence

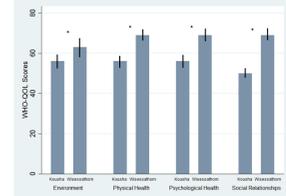


Figure 4: WHOQOL-BREF Components by Article

Results: PSI-SF

For the PSI/PSI-SF, higher scores indicate higher levels of stress. Figure 5 shows that mothers in Iran, Jordan and India were found to have higher PSI-SF scores than fathers.^{31, 14, 9} Figure 6 shows studies in Taiwan, Singapore, Jordan and Japan had no significant score difference on the PSI-SF across countries.^{19, 23, 12, 25} In China, parents of children with ASD had significantly higher scores on the PSI compared with parents of TD children.³⁹ Parents in Singapore had lower levels of stress on the PSI following CBT intervention for children with ASD.²⁷ An informational session with mutual support for parents in Iran found that parents who maintained contact with other parents had lower parenting stress on PSI-SF at three and twelve months post-intervention.²⁴

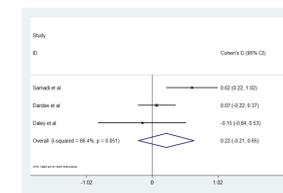


Figure 5: PSI-SF Meta-Analysis: Mothers vs. Fathers

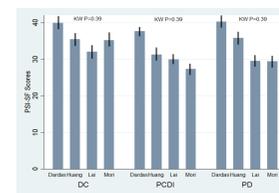


Figure 6: PSI-SF Components by Article

Results: SF-36

For the SF-36, higher scores indicate higher QOL. Figure 7 shows that following a Multidisciplinary Parent Education program in China, there were no statistically significant differences in either component score between intervention and no intervention group, without significant increase in longitudinal scores.²⁰ Figure 8 shows that fathers have higher mean component scores than mothers in Japan.³⁸ Figure 9 shows that family members of TD children in Japan have higher scores compared to family members of children with ASD.³⁵

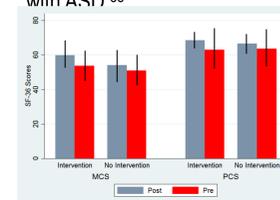


Figure 7: SF-36: Intervention vs. No Intervention

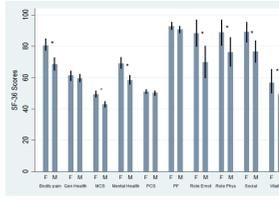


Figure 8: SF-36: Mothers vs. Fathers

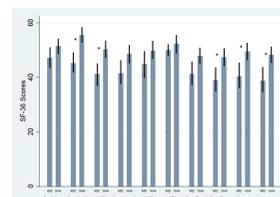


Figure 9: SF-36: No ASD (TD) vs. ASD

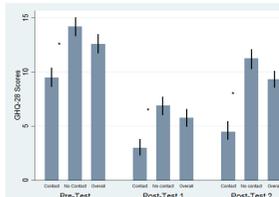


Figure 10: GHQ-28: Maintained vs. No Maintained Parental Contact

Results: GHQ-28

For the GHQ-28, higher scores indicate poorer well-being. Figure 10 shows that parents who did not maintain contact with other parents following an information and support training course in Iran had significantly poorer well-being than those that maintained contact, at three and twelve months post-intervention.²⁴ Parents of children with ASD in Lebanon had poorer well-being than parents of TD children.²⁶ Mothers in Iran had poorer well-being than fathers.³¹

Results: SoC and Relationships

Parents with high sense of coherence (SoC) had significantly higher QOL compared with parents who had low SoC.³³ Predictors of higher SoC include: male, aged ≥ 45 years, and child with ASD ≥ 7 years.³³ There is an inverse relationship between parental stress and SoC.⁴ Parents are most likely to use positive reappraisal to cope, creating meaning through religion and a focus on personal growth, and are least likely to use distancing or accepting responsibility.^{10, 11, 12} Following Multidisciplinary Parent Education in China, family functioning significantly improved, without significant impact on caregiver burden.²⁰ A parent training and support course in Iran found parents who maintained contact with others following the course had better family functioning at three and twelve months post-intervention than those who did not maintain contact.²⁴

Discussion and Conclusions

Parents of children with ASD in Asia have lower QOL than parents of TD children. They face unique, culture-specific challenges. These outcomes are targets for improvement. SoC has a strong influence on a parent's QOL and stress, allowing parents to draw meaning and breed confidence. Mothers have lower SoC and QOL, higher stress, lower health-related QOL, and poorer overall well-being. Overall, mothers may carry a heavier burden than fathers in childrearing, which may be culturally dictated. Coping strategies including religion and focus on positive growth allowed parents to make meaning, an important part of the human experience and one with potential to create resiliency. Identifying and impacting predictors of QOL, particularly in mothers, is valuable, as they experience lower QOL than parents of TD children. Mediators and predictors of QOL can be elucidated and targeted in future studies.

Not every intervention resulted in improved outcomes. It is critical to evaluate an intervention's efficacy in each setting and population in which it is used, taking care to avoid assumptions. Each intervention may have particular power in impacting one outcome while not impacting or even worsening outcomes in other realms. Pairing QOL outcomes with interventions that target a specific need is vital. Parents' maintaining contact with other parents for support positively impacted many QOL outcomes and is a feasible, replicable intervention.

This study focused on Asia as a whole, which grossly oversimplifies the region. There are similar QOL deficits in each country, but the unique contexts cannot be addressed by one solution. Outcomes with homogeneous results across many countries are high-impact outcomes of focus, which this study clarified as areas for future research and targets of intervention.

Acknowledgements

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