

**SYSTEMATIC REVIEW OF QUALITY OF LIFE FOR FAMILY MEMBERS OF CHILDREN  
WITH AUTISM SPECTRUM DISORDER IN ASIA  
AND  
MINDFULNESS BASED INTERVENTIONS FOR CHILDREN WITH AUTISM SPECTRUM DISORDER  
AND THEIR PARENTS: MECHANISM, EVIDENCE, AND FEASIBILITY**

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## **Abstract**

Autism Spectrum Disorder (ASD) is a lifetime neurodevelopmental disorder with presence of symptoms early in development. About 1 in 68 children have been identified with ASD globally. Parents of children with ASD face diverse hurdles that can have a significant impact on their quality of life (QOL), and interventions may be able to improve these outcomes. A systematic review was conducted to assess the QOL for family members of children with ASD in Asia and to elucidate interventions that can impact QOL outcome measures. This study sought to synthesize QOL outcomes for parents of children with ASD across Asia by drawing from currently available primary research. It also sought to examine interventions that have been used in this population to investigate their impact on QOL outcomes in order to unveil the most efficacious interventions for impacting a given outcome. A total of 34 studies were included for review; 17 were used for quantitative analysis and 17 used for qualitative review. Parents of children with ASD in Asia were found to have lower QOL in the areas of general health, role physical, social, vitality, mental health, stress, and overall well-being than parents of typically developing (TD) children. High sense of coherence was shown to be associated with higher parental QOL and lower parental stress. Certain factors were found to be associated with higher sense of coherence including: male gender, parent age greater than 45, and child age greater than seven. Mothers were broadly found to have lower QOL than fathers. Mothers had a lower sense of coherence, lower health-related QOL, poorer overall well-being, and higher stress levels. Coping strategies that parents of children with ASD were found to use most often were religion and a focus on positive growth to create meaning. Not all interventions resulted in positive outcomes. A Mindfulness Based Intervention in Jordan positively impacted QOL outcomes. A Multidisciplinary Parent Education program in China had a significant positive impact on family functioning, while a Cognitive Behavioral Therapy (CBT) intervention for children with ASD decreased parental stress. Additionally, parents having and maintaining contact with parents in a similar situation helped improve well-being, parental stress and family functioning, following an intervention. This preliminary work investigating QOL for family members of children with ASD emphasizes the importance of discovering QOL outcome targets and pairing these with efficacious interventions that are specific to the needs of the population.

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### Mindfulness Based Interventions for Children with Autism Spectrum Disorder and their Parents: Mechanism, Evidence, and Feasibility

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## **Background**

### *Autism Spectrum Disorder*

According to the CDC, about 1 in 68 children have been identified with ASD, although numbers vary based on the study. ASD is seen across racial, ethnic, and socioeconomic groups, and is five times more common among boys than among girls.<sup>7</sup> The term “Autism Spectrum Disorder” (ASD) encompasses a group of lifetime neurodevelopmental disorders.<sup>16</sup> The Diagnostic and Statistical Manual of Mental Disorders, fifth edition, discusses the following components of ASD used for diagnosis: social communication and social interaction deficit, restrictive, repetitive patterns (behavior, interests, activities), presence of symptoms early in development, clinically significant impairment, and impairments that are not better explained by intellectual disability or global developmental delay.<sup>1</sup>

### *Impact on Parents*

It has been consistently commented that parents of children with ASD experience greater levels of stress, anxiety and depression than parents of typically developing (TD) children.<sup>5, 6, 17, 28, 29</sup> Each of these individual outcomes play a role in the larger concept of one’s quality of life (QOL). Although ASD is a lifelong disorder, various interventions can help families adapt to and cope with this diagnosis, the goal of many of which is to improve QOL for these families. Diverse forms of support and resources for families are available including, but not limited to: education about ASD, support groups for family members, and Mindfulness Based Interventions.<sup>24, 30, 32</sup> Those mentioned, along with others, have been implemented and studied in order to assess their effects on QOL and well-being of family members of those with ASD. Evaluating the effectiveness of such interventions can be challenging. Nevertheless, the necessity to impact QOL for family members of children with ASD demands a meaningful intervention with a correlated evaluation.

## *Global Context*

QOL for family members of children with ASD has been studied most heavily in Western countries. However, as statistics on ASD diagnosis continue to rise, its global impact cannot be overlooked, both on individuals with ASD as well as their family members. There are various, culture-specific barriers faced globally with ASD. As such, there must be careful consideration of more focused regions of the world when researching this topic. Similarly, there are regional differences in feasibility and efficacy of interventions. Interventions that are performed in regions with greater resources may not be viable in areas with lesser resources for numerous reasons. Similarly, interventions that may impact individuals in countries with greater resources may not have a paralleled effect in countries of lesser resources or with dissimilar cultural contexts.

Countries in Asia, the focus of this study, possess unique and multi-faceted dynamics that can impact ASD diagnosis and access to resources for the child and the family alike. This, in turn, impacts QOL for all in the family. In the article by Sun et al, discussing service provision in Mainland China, some specific cultural barriers to diagnosis, treatment and support are described. One belief Sun et al explains is the idea that a child who speaks later during childhood will ultimately be more intelligent than their peers. As such, when speech delay is present, parents may delay seeking care and ultimately delay diagnosis.<sup>34</sup> This can have impacts both on the child and the family. Daley and Sigman found similar beliefs in India.<sup>8</sup> Also noted is the social and economic burden on families that can result from stigmatization; psychiatrists categorize autism as a mental disorder, therefore many parents consider their child's ASD diagnosis undesirable. As a result, parents may be stigmatized due to their child's condition, which in turn impacts their child's and their own QOL. Similarly, during the implementation of the one-child policy, a single child embodied the future of an entire extended family. As such, expectations were high, in academic and other arenas; when children failed to meet expectations, the stigma may have been further exacerbated.<sup>34</sup> Holroyd et al also discusses cultural influences on caregivers of children with ASD in China. This article explains that disability in China is viewed as arising from something a woman or her side of the family did. Social messages of shame and blame follow parents throughout their lives and often result in

protection and shielding of themselves from the outside.<sup>18</sup> This belief mirrors that discussed in Ha et al's article, which explains that within Vietnam disability is viewed as a consequence of an ancestor's karmic demerit.<sup>16</sup> A similar belief is also expressed in an interview with a parent in Iran in McConkey et al's article, who discusses others looking at them as though they had committed a sin or very bad deed, which deserved punishing.<sup>24</sup> Although China is discussed at length here as an example, each country and cultural context has its own barriers and factors that impact QOL for family members of children with ASD. Similar, though not identical, beliefs may exist in countries within the same region (Asia), as is elucidated in the articles mentioned above, in which analogous or related beliefs found in China exist in India, Vietnam and Iran. Viewed through this lens, as an example, one can begin to imagine the intricate and unique factors that may impact QOL for family members of children with ASD in non-Western countries.

#### *Aims of this Study*

Although various studies have looked at QOL measures for family members of individuals with ASD, these results have not been synthesized in a meaningful way. In particular, results from studies of this sort conducted in Asia have not been brought together and collectively considered. This study aims to assess quality of life for family members of individuals with ASD in Asia and consider how it compares to families with TD children. This will be assessed across various countries in Asia. The impact of interventions on various outcomes will be studied. While each country is unique, the motivation in approaching this question is revealing areas of QOL deficits that span multiple countries throughout Asia; with this information a more concerted effort to improve these specific outcomes of focus across multiple countries can be implemented.

This study seeks to answer the following research question: what is the quality of life (QOL) for family members of children with Autism Spectrum Disorder (ASD) in Asia, and how does it differ from that of family members of typically developing (TD) children; what interventions can impact QOL for these families in Asia? This study will be a systematic review of the literature to investigate various measures of QOL in family members of children with ASD in Asia. Quality of life will be considered across various outcomes, including: general QOL, stress, relationships and family functioning, coping styles, and general health.

## **Methods**

### *Search Strategy*

Evidence regarding the QOL for family members of children with ASD in Asia was systematically retrieved and analyzed through a systematic review of the literature. The following Databases were used for identification of articles: PubMed, CINAHL, and Embase. In addition to the specific searches conducted by the method discussed below, additional articles were located to obtain background information and evidence related to cultural beliefs. These were identified through bibliographies of included articles and prior searches on the topic.

### *Types of Studies*

Types of studies included in the review were primary research articles. These included articles with one of the following study designs: cross-sectional questionnaires and interviews, quasi-experimental pre-, posttest design, and case-control studies.

### *Inclusion Criteria*

- Paper must be about ASD
- Region where study was performed must be identifiable
- At least one of the family members must be assessed
- The assessment must be through one of the specified quality of life measures discussed below

### *Exclusion Criteria*

- Papers that are not primary research articles
- Unidentifiable region of research project
- Lacking any of the specified measures listed below
- Not written in English
- Measurement only of outcomes of the individual with ASD and no measures of family members
- Focused on a topic outside the scope of this research question

### *Article Extraction*

Within the three aforementioned databases, five nearly identical search strands were used in order to identify appropriate articles. When a Mesh term or the like was available, it was utilized. Listed in Table 1 are the five search strands used.

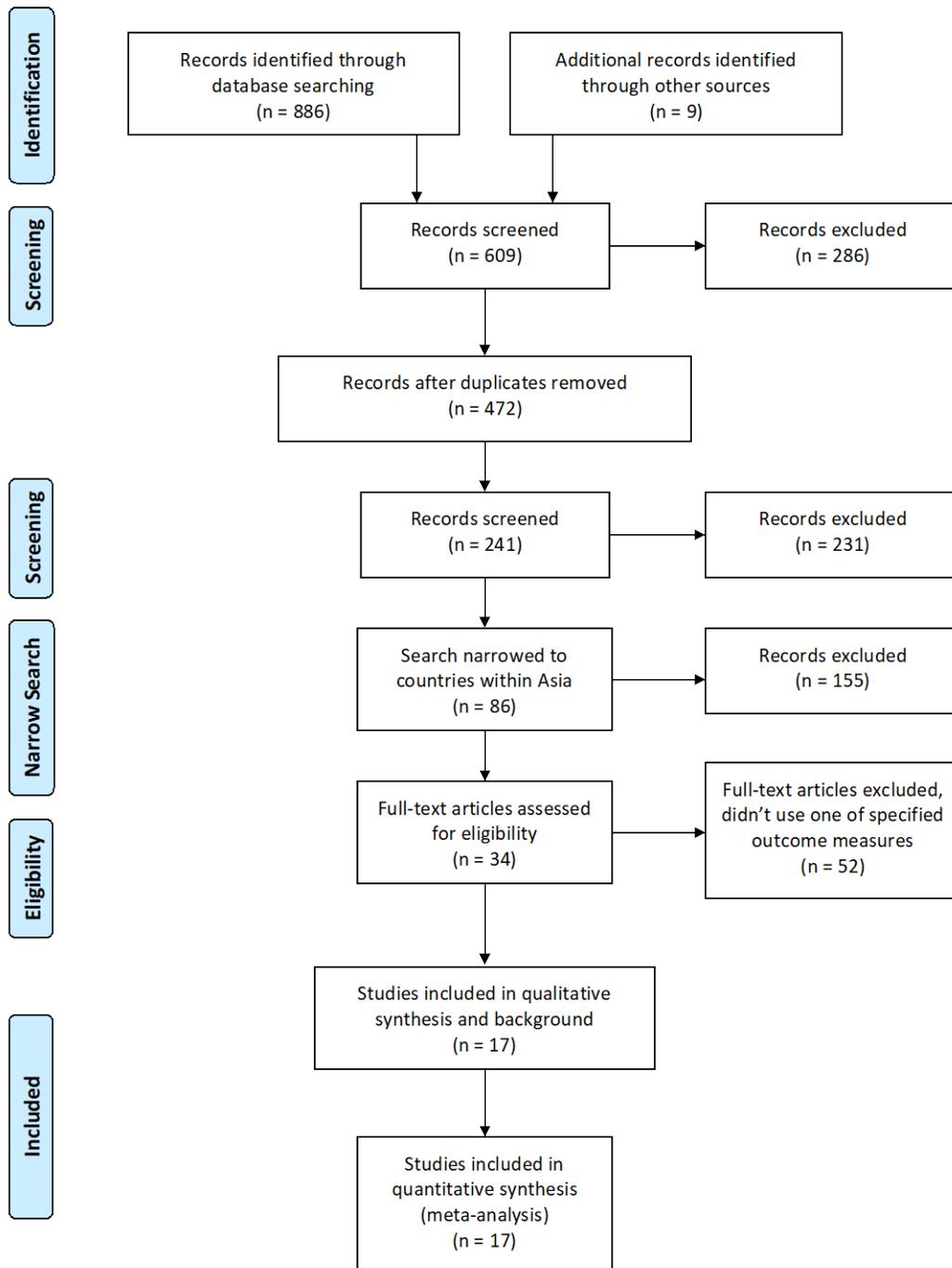
These five search strands were run in each of the three databases. Once this search took place, the articles retrieved went through a preliminary screening process. In this screening, articles that were quite obviously outside the scope of this research question or made readily available the fact that they took place in the United States were excluded. Following this preliminary screen, duplicates were eliminated. After this point, articles were further assessed across the following fields: topic, primary research, control group, country, and measurement tools used. The measurements tools field noted which instruments a study used to measure one of the five outcomes of interest: overall QOL, stress, relationships and family functioning, coping styles, and general health. Outcome measures included any quantitative measure of one or more of these five outcomes. Articles were eliminated based on the inclusion/exclusion criteria listed above, all of which were assessed through access to the full article. After this point, the decision was made to narrow the articles for consideration based on location; this decision was made in order to draw a more meaningful conclusion about the specific situation surrounding QOL for family members of children with ASD. Only research that took place in countries within Asia was considered. After this point, the available studies were assessed based on which specific measures were used for a given outcome. Each outcome was further narrowed, based on how many articles utilized a given instrument to measure that outcome. For each of the 5 outcomes, one to two of the most commonly used instruments for measurement were selected as the measurement of choice. All articles that did not use one of the tools listed below in Table 2 were excluded from the analysis. Refer to Flow Diagram 1 for the article retrieval and inclusion process.

Search	Strand
A	"Quality of Life"[Mesh] AND "Autistic Disorder"[Mesh] AND parents of disabled children
B	"Autistic Disorder"[Mesh] NOT United States[PL] AND parental stress
C	"Autistic Disorder"[Mesh] NOT United States [PL] AND family functioning
D	"Autistic Disorder"[Mesh] NOT United States [PL] AND coping strategies
E	"Autistic Disorder"[Mesh] NOT United States [PL] AND parental health

Table 1: Search Strands Utilized

Outcome	Measurement Tool
Overall QOL	WHOQOL-BREF: World Health Organization Quality of Life Scale-Brief
	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
	SoC: Sense of Coherence
Health	GHQ-12 or -28: General Health Questionnaire
	SF-36: Health-Related Quality of Life Short Form-36

Table 2: Outcome Measure



Flow Diagram 1. Adapted from PRISMA: 2009 Flow Diagram

While discussion of every outcome is included in the discussion section, the following measures had enough available data for analysis: WHOQOL-BREF, PSI-SF, SF-36, GHQ-28. As such, these tools will be explained in more depth. Each instrument discussed is available and validated in several languages.

#### *WHOQOL-BREF*

The World Health Organization Quality of Life Scale-Brief is an abbreviated version of the WHOQOL-100, and it aims to measure overall QOL. The original version contains 100 questions, while the brief version contains only 26. The questions are grouped into four domains: physical, psychological, social relationships, and environment. The WHOQOL-BREF contains questions from each of the four domains, along with two items regarding overall QOL/general health, totaling 26 questions. A higher score denotes a higher quality of life.<sup>2,13</sup>

#### *PSI-SF*

The Parenting Stress Index-Short Form (PSI-SF) derives from the original Parenting Stress Index (PSI). Both are questionnaires assessing parenting stress. The PSI contains 120 questions (19 are optional), while the PSI-SF contains 36 questions. The item rating scale ranges from 1 (strongly disagree) to 5 (strongly agree).<sup>3,27</sup> The Short Form tool contains three subscales: Parenting Distress (PD), Parent-Child Dysfunction Interaction (PCDI), and Difficult Child (DC).<sup>14,19,25</sup> Scoring of the PSI-SF mirrors that of the PSI, in which higher scores indicate higher levels of stress.

#### *SF-36*

The SF-36 is a tool used to measure health-related quality of life (HRQOL). It has 8 subscales, which can be organized into two larger categories, the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The PCS scale includes: physical functioning, role limitations due to physical problems, bodily pain, and general health. The MCS scale includes: vitality, social functioning, role limitations due to emotional problems and mental health. Each subscale receives a score from 0 (worst possible) to 100 (best possible). Therefore, higher score indicates higher QOL.<sup>15</sup>

## *GHQ-28*

The General Health Questionnaire-28 is a tool used to assess psychiatric morbidity and emotional well-being. This is derived from the GHQ-60. It contains 28 items, with four subscales: somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.<sup>36</sup> A higher score on this scale is indicative of poorer well-being.<sup>31, 24</sup>

## *Data Extraction*

If an article used one of the measurement tools described above and sufficient data was available, it was included in the quantitative analysis. If insufficient data was available for analysis, a qualitative analysis of the study was performed and included in the results section. A number of articles compared mothers and fathers within the same study. As such, within-group comparison of mothers and fathers was additionally considered and analyzed based on the data made available. The analyses performed are discussed below. Regarding the WHOQOL-BREF, 2 meta-analyses were conducting. The first (figure 1) compared intervention to control group from Rayan et al's 5-week Mindfulness Based Intervention in Jordan [30] and Shu et al's 10-week support group in Taiwan [32]. The second (figure 2) compared mothers to fathers in Jordan from Dardas et al [13] and Dardas et al [14]. Using the data from Siah et al [33], a bar graph (figure 3) was constructed with outcomes from a cross-sectional survey of parents in Malaysia separated into two groups: high sense of coherence and low sense of coherence. Another bar graph (figure 4) was constructed using data from both Wisessathorn et al's cross-sectional survey of caregivers in Thailand [37] and Kousha et al's cross-sectional survey of mothers in Iran [22] to compare groups from different studies across the same outcomes (WHOQOL-BREF).

Regarding the PSI-SF, a meta-analysis (figure 5) was performed to compare PSI-SF scores of mothers and fathers using data from the cross-sectional surveys of Samadi et al's study of parents in Iran [31], Dardas et al's study of parents in Jordan [14], and Daley et al's study of families in India [9]. Additionally, a bar graph with cross-sectional data on parents from Huang

et al in Taiwan [19], Lai et al in Singapore [23], Dardas et al in Jordan [12] and Mori et al in Japan [25] was constructed (figure 6) to compare PSI-SF scores across various studies.

Using the SF-36 measure, three bar graphs were constructed. First, a bar graph was constructed from Ji et al's study of a Multidisciplinary Parent Education intervention for parents in China [20] comparing pre- and post-intervention outcome data (figure 7). Second, data from Yamada et al's cross-sectional data from parents in Japan [38] was used to construct a bar graph comparing mothers to fathers across the individual components of this outcome (figure 8). Last, outcome data from Suzumara et al's cross-sectional study of mothers in Japan [35] was used to compare family members of children with ASD to family members of TD children, the "No ASD" group (figure 9).

GHQ-28 data from McConkey et al's seven session training course offering information and mutual support [24] were utilized to construct a bar graph (figure 10). This study had an intervention, and both pre- and two post-test measures were taken. This bar graph looks at pre- (1 point) vs. post-test (2 points) data. These data were measured overall as well as results separated into two groups based on the contact parents maintained with one another after the intervention had ended.

### *Statistical Analysis*

Our primary outcome for the systematic review was the pooled Cohen's D and 95% confidence interval to ascertain the effect of intervention on the WHOQOL-BREF. Furthermore, pooled Cohen's D and 95% confidence intervals were calculated to ascertain the effect of parental status on the WHOQOL-BREF. As a secondary analysis, the two-sample t-test and the Kruskal-Wallis test was used to compare differences in the WHOQOL-BREF for two sample comparisons and comparisons with three or more groups, respectively. Multiple comparisons were adjusted for by the Bonferroni correction, otherwise  $p < 0.05$  was considered statistically significant. All data analyses were conducted using STATA version 14 (College Station, TX).

## Results

The search strategy employed identified 25 studies. An additional nine studies were identified outside of the described search methods for building background and context, as mentioned above, and will not be discussed here. The 25 studies identified were conducted on populations in a total of eleven countries, including: Pakistan, India, Jordan, Iran, Taiwan, China, Singapore, Japan, Lebanon, Malaysia, and Thailand. Of the articles, 20 had a cross-sectional design, three had a pre, posttest design and two had a pre, posttest design with a control group. Those with the latter two designs utilized an intervention in the study. Interventions included:

Multidisciplinary Parent Education, a combination of education and mutual support, Cognitive Behavioral Therapy (CBT) for children, a Mindfulness Based Intervention program, and a support group. Seven of the articles had a control group for comparison and six did a within-group comparison. All studies investigated outcomes for family members of children with ASD. Regarding the family members assessed, 14 focused on parents, regardless of gender, including both mothers and fathers in the study; five articles only considered mothers for inclusion in the study; one article included only fathers; five articles interviewed families, which included family members outside of parents or didn't specify the exact relation of the adult to the child. The age and gender of both children with ASD and their parents varied by study. Refer to Table 3 in the Appendix for details.

The studies included in this paper used one of the eight measurement tools discussed above. The most commonly utilized tools were the: WHOQOL-BREF (nine studies), PSI-SF (ten studies), and the SF-36 (five studies). Three studies used the GHQ, but it was split between the GHQ-12 (one study) and the GHQ-28 (two studies). Nine of the studies used more than one of the eight included measurement tools. Of the 25 studies, seventeen were included in the quantitative analysis, as sufficient data was available; the remainder of the studies were qualitatively reviewed and results described in each corresponding section below. Refer to Table 4 in the Appendix for outcome data with each of these tools.

### *WHOQOL-BREF Results*

Four quantitative analyses were conducted with results from the WHOQOL-BREF. After conducting the meta-analysis in Figure 1 with data from a five-week Mindfulness Based Intervention in Jordan and a ten-week support group in Taiwan, an inverse relationship between interventional status and the WHOQOL-BREF scores was found, where the control group had a statistically insignificant, medium-sized effect on total scores compared to the intervention group (Cohen's D (95% CI) = -0.56 (-3.99, 2.87)). The meta-analysis in Figure 2 comparing mothers and fathers in Jordan from two studies shows that mothers had a bigger effect on total WHOQOL-BREF scores compared to the fathers; when pooling the scores, the scores were higher in mothers than in father (Cohen's D (95% CI) = 1.30 (-1.62, 4.22)). This finding was not statistically significant. Figure 3 with cross-sectional data from Malaysia separated by one's sense of coherence (SoC) shows that mean scores for each component of the WHOQOL-BREF were higher within the High SoC group compared to the Low SoC group. Each of the components showed statistically significant differences in the WHOQOL-BREF scores between groups ( $p < 0.008$  after Bonferroni Correction). In figure 4, the four WHOQOL-BREF components were stratified by article, including data from caregivers in Thailand and mothers in Iran. This shows that between the Kousha et al article in Iran [22] and Wisessathorn et al article in Thailand [37], all outcome means are statistically different ( $p < 0.008$  after Bonferroni Correction).

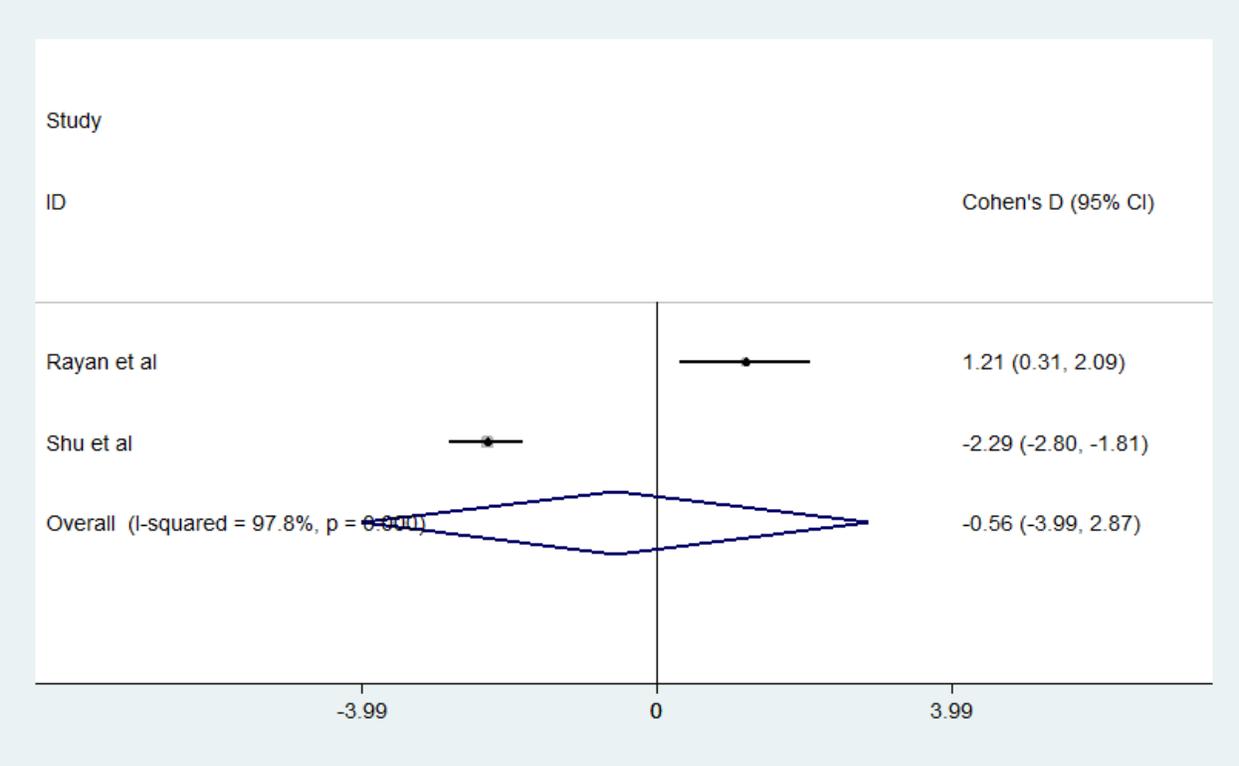


Figure 1: WHOQOL-BREF Meta-Analysis: Intervention vs. No Intervention

Pooled Cohen’s D in 95% Confidence Intervals were calculated using random effects meta-analysis

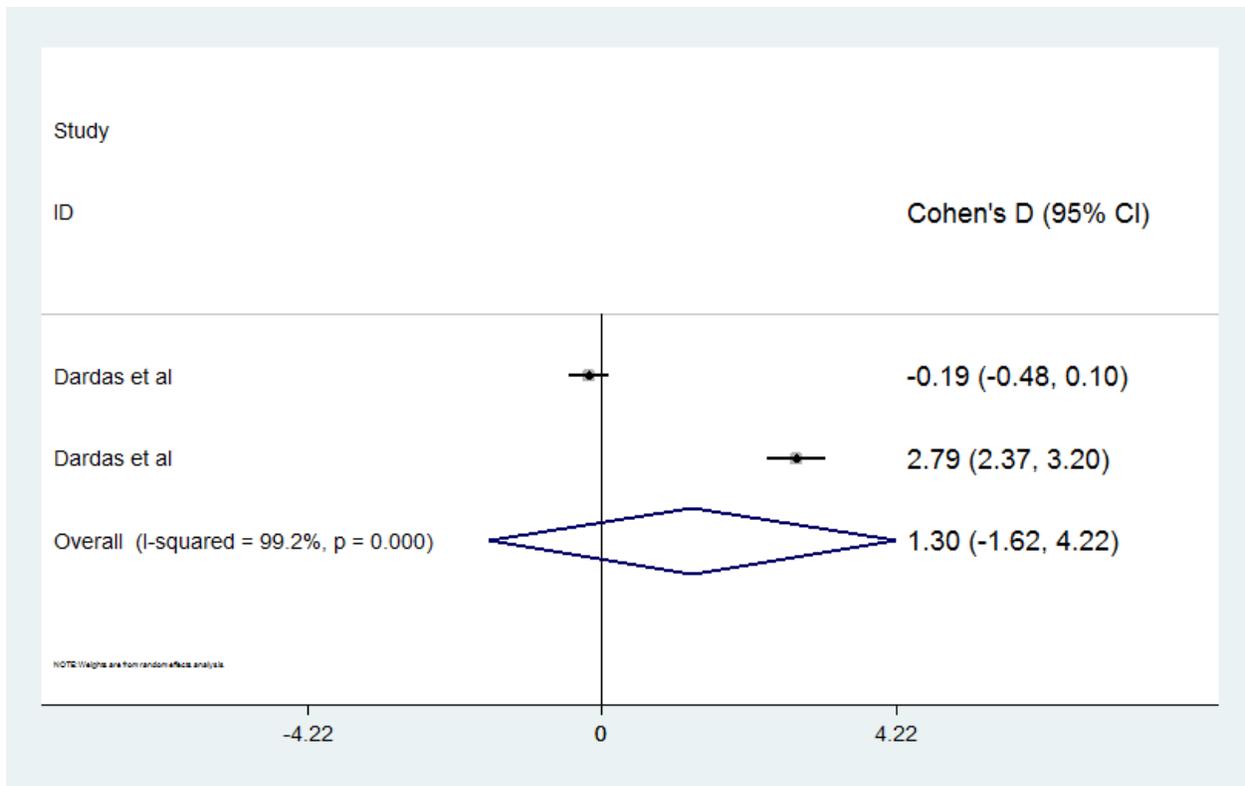


Figure 2: WHOQOL-BREF Meta-Analysis: Mothers vs. Fathers

Pooled Cohen's D in 95% Confidence Intervals were calculated using random effects meta-analysis

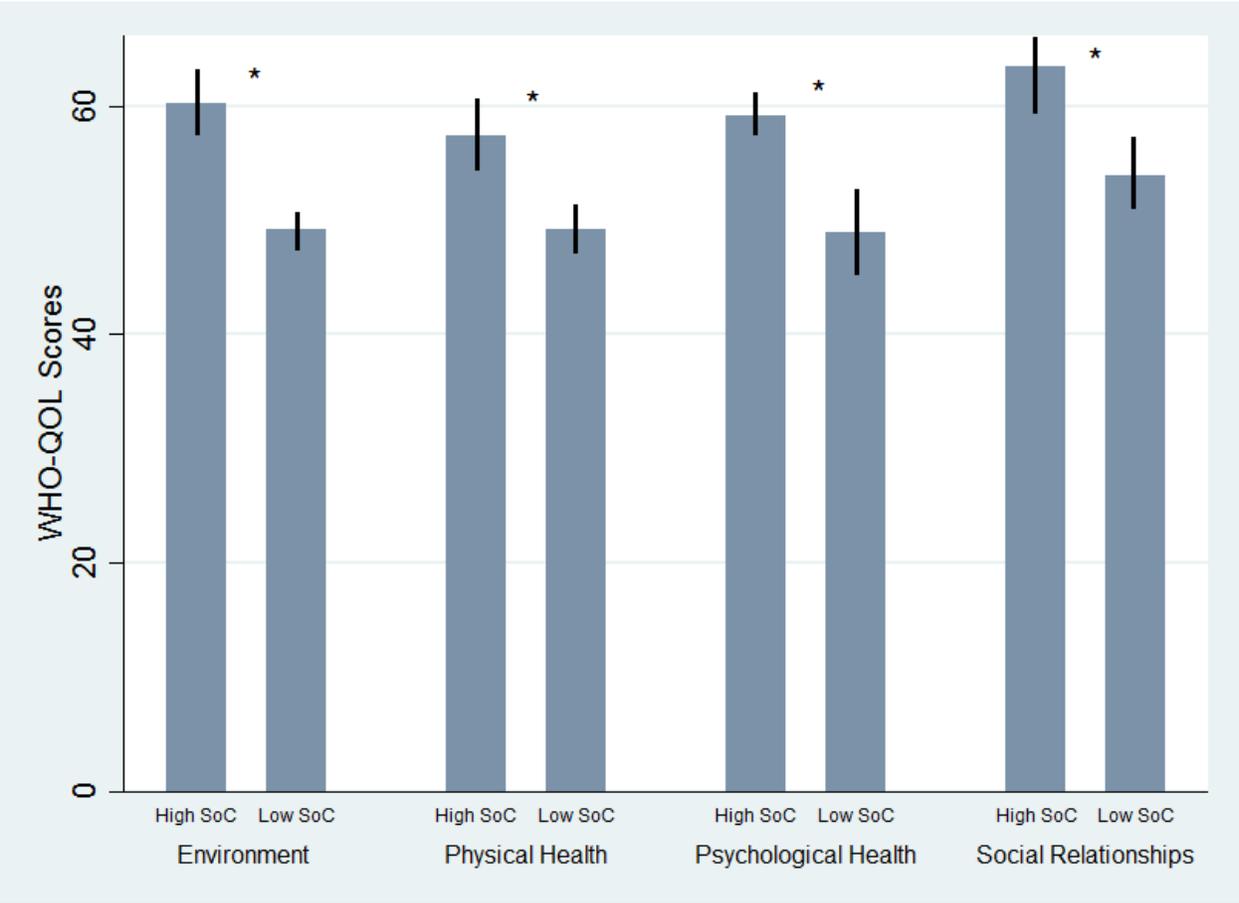


Figure 3: WHOQOL-BREF: Relation to Sense of Coherence

P values were calculated using a two-sample t-test to ascertain differences between high and low Sense of Coherence ( $p < 0.008$  after Bonferroni Correction)

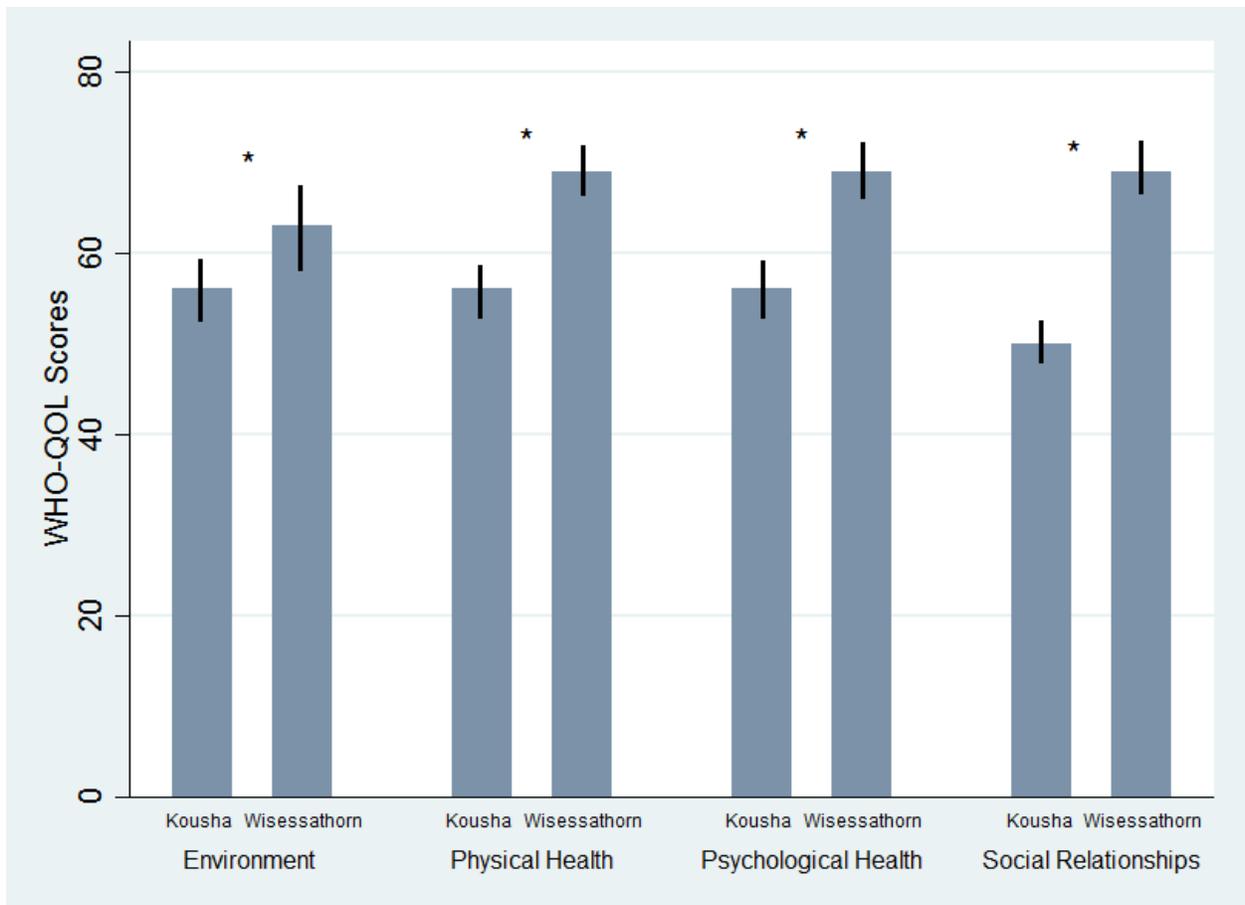


Figure 4: WHOQOL-BREF Components by Article

P values were calculated using a two-sample t-test to ascertain differences between the two studies ( $p < 0.008$  after Bonferroni Correction)

### *PSI-SF Results*

Two analyses were conducted with results from the PSI-SF. The meta-analysis in Figure 5 showed mothers in Iran, Jordan and India having a small sized effect on PSI-SF scores compared to fathers (Cohen's D (95% CI) = 0.22 (-0.21, 0.65)). Samadi et al in Iran [31] and Dardas et al in Jordan [14] showed higher PSI-SF scores among mothers compared to fathers (Samadi et al = mother =  $121 \pm 17$  vs. Father =  $110.2 \pm 17.6$ ; Dardas et al = Mother =  $118.6 \pm 22.6$  vs. Father =  $116.9 \pm 22.5$ ). This result was not statistically significant. In figure 6, the Kruskal Wallis test showed no statistically significant difference in PSI-SF scores between the four studies compared ( $p > 0.05$ ) which were conducted in Taiwan, Singapore, Jordan, and Japan. Additionally, in China Yang et al [39] found that stress across all three domains of the PSI was significantly higher in parents of children with ASD than those of TD children; this is the full-length version of the PSI-SF. Ooi et al [27] implemented a CBT intervention for children with ASD in Singapore. Parents had significantly lower levels of stress on the PSI, specifically related to the Child Domain, following this intervention. McConkey et al [24] utilized a seven-session training course in Iran, offering information about ASD as well as mutual support. This study found that parents who maintained contact with other parents upon completion of the course had lower parenting stress at three months post- and twelve months post-intervention, when compared with the overall scores in parents that did not maintain such contact, as measured by the PSI-SF.

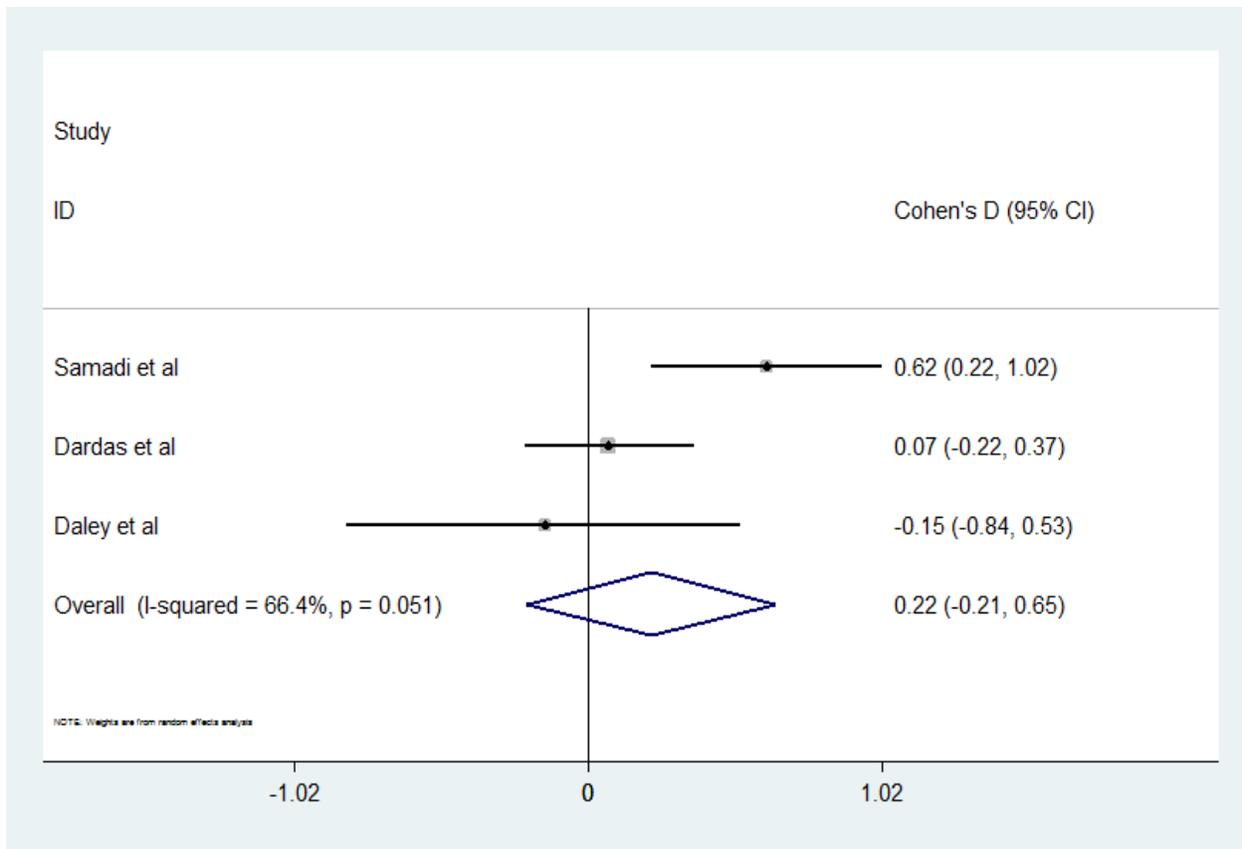


Figure 5: PSI-SF Meta-Analysis: Mothers vs. Fathers

Pooled Cohen's D in 95% Confidence Intervals were calculated using random effects meta-analysis

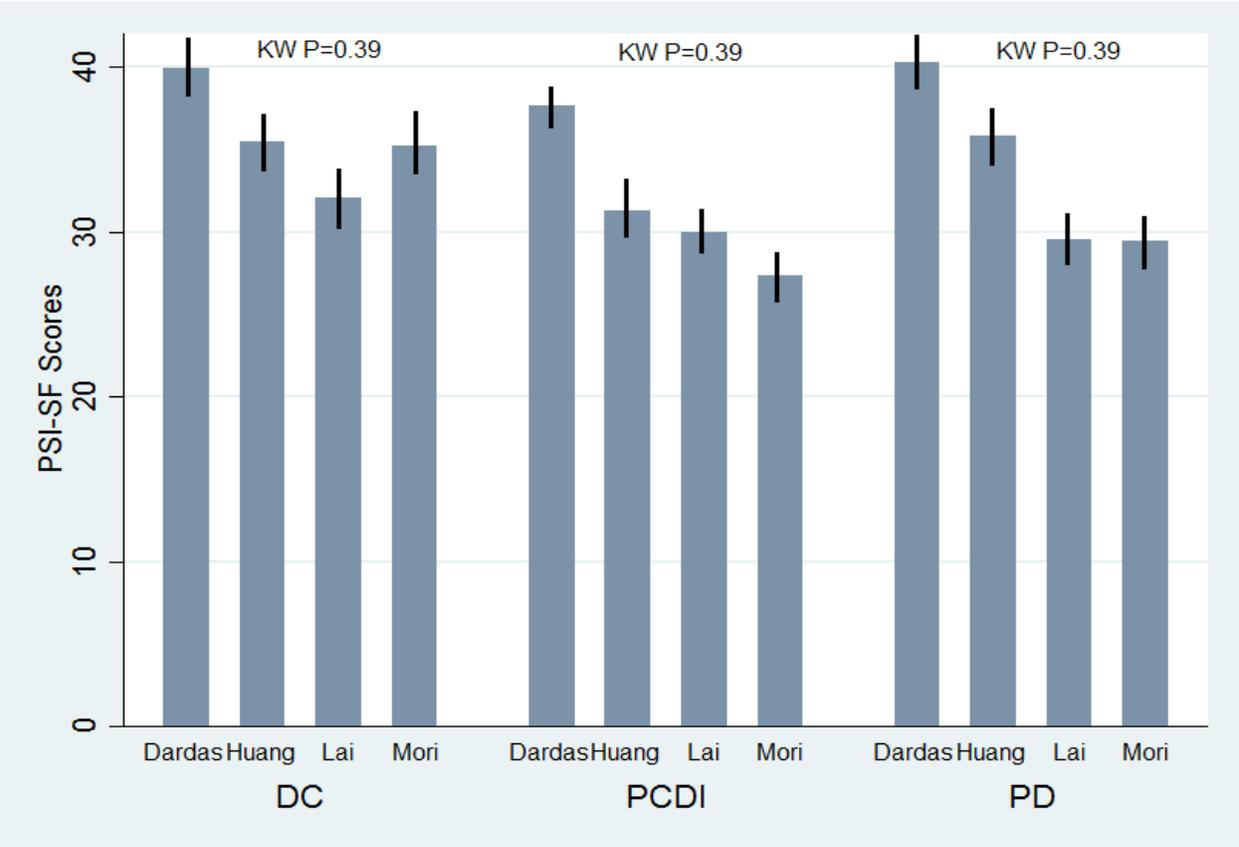


Figure 6: PSI-SF Components by Article

P values were calculated using the Kruskal-Wallis test to ascertain differences between the articles

### *SF-36 Results:*

Three analyses were conducted with results from the SF-36. There were no statistically significant differences in MCS and PCS scores between the intervention and no intervention group shown in figure 7 (intervention PCS:  $68.48 \pm 15.38$ , MCS:  $59.95 \pm 9.12$  vs. no intervention PCS:  $66.65 \pm 8.92$ , MCS:  $54.09 \pm 13.96$ ). These outcomes were measured before and after a Multidisciplinary Parent Education program in China. Even though there was an increase in scores longitudinally, the increase was not statistically significant ( $p > 0.05$ ). In figure 8, Yamada et al [38] found mean scores for each component of the SF-36 were higher within fathers compared to mothers in Japan. The following components showed statistically significant differences in the scores between groups: bodily pain, mental health, role emotional, role physical, social, vitality, and MCS ( $p < 0.008$  after Bonferroni Correction). In figure 9, Suzumara et al [35] found mean scores for each component of the SF-36 were higher within the No ASD group (family members of TD children) compared to the ASD group in Japan. The following components showed statistically significant differences in the SF-36 scores between groups: general health, role physical, social, vitality, and MCS ( $p < 0.008$  after Bonferroni Correction).

### *GHQ-28 Results:*

One analysis was conducted with results from the GHQ-28 with data from McConkey et al [24]. Following a seven-session training course in Iran offering information and mutual support, GHQ-28 scores were higher within the no-contact group compared to the contact group. These differences were statistically significant ( $p < 0.016$  after Bonferroni correction). (No contact means: pretest: 14.2, posttest-1: 6.9, posttest-2: 11.25 vs. contact means: pretest: 9.5, posttest-1: 3, posttest-2: 4.5). Parents who maintained contact with other parents upon completion of the course had significantly better well-being at three months post- and twelve months post-intervention, when compared with the overall scores in parents that did not maintain such contact. Additionally, Obeid et al [26] found that parents of children with ASD in Lebanon had lower levels of well-being than parents of typically developing children, as measured by the GHQ-12. Samadi et al [31] found that mothers in Iran had poorer well-being than fathers, as measured by the GHQ-28.

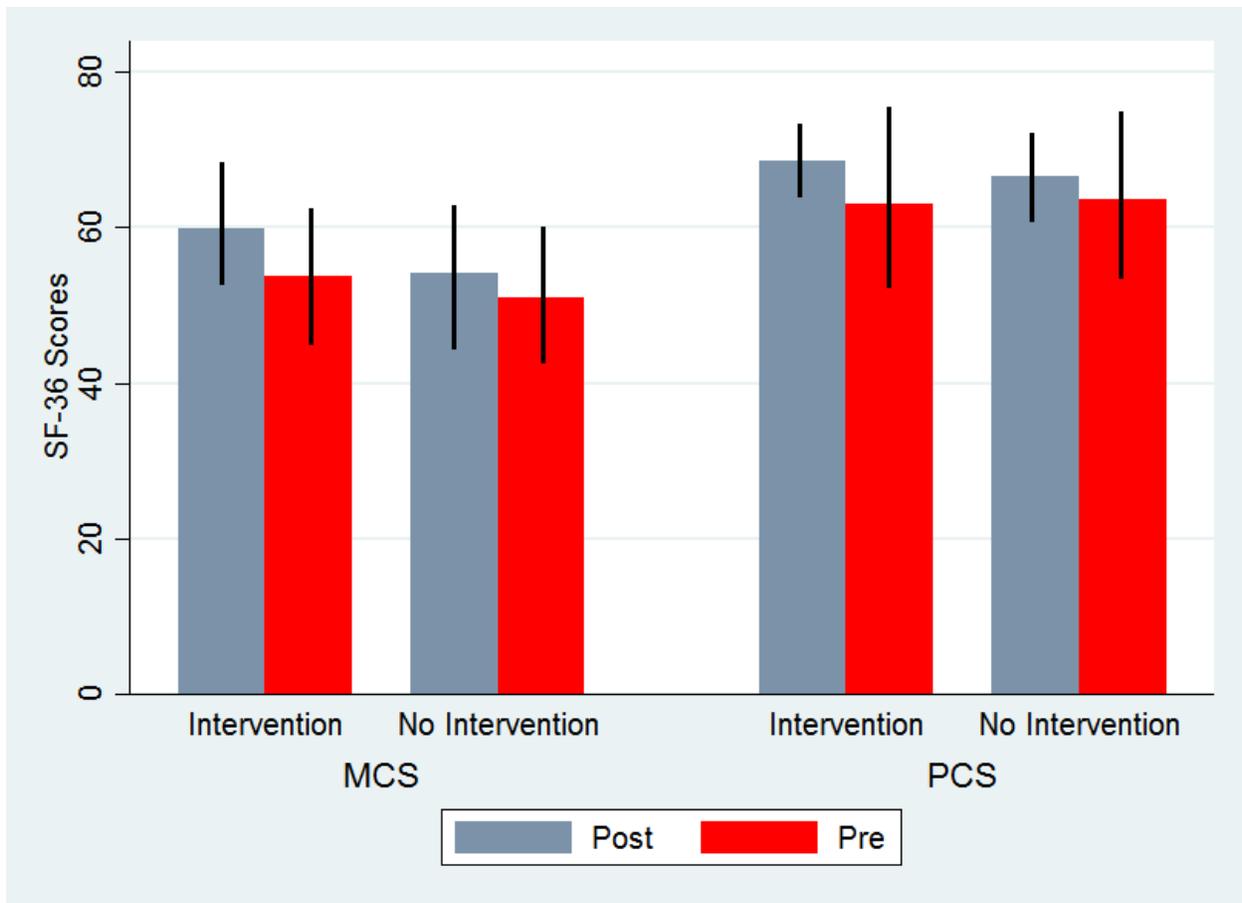


Figure 7: SF-36: Intervention vs. No Intervention

P values were calculated using the paired t-test to ascertain differences between the pre- and post- stratified by intervention status. All comparisons were statistically not significant ( $p > 0.05$ ).

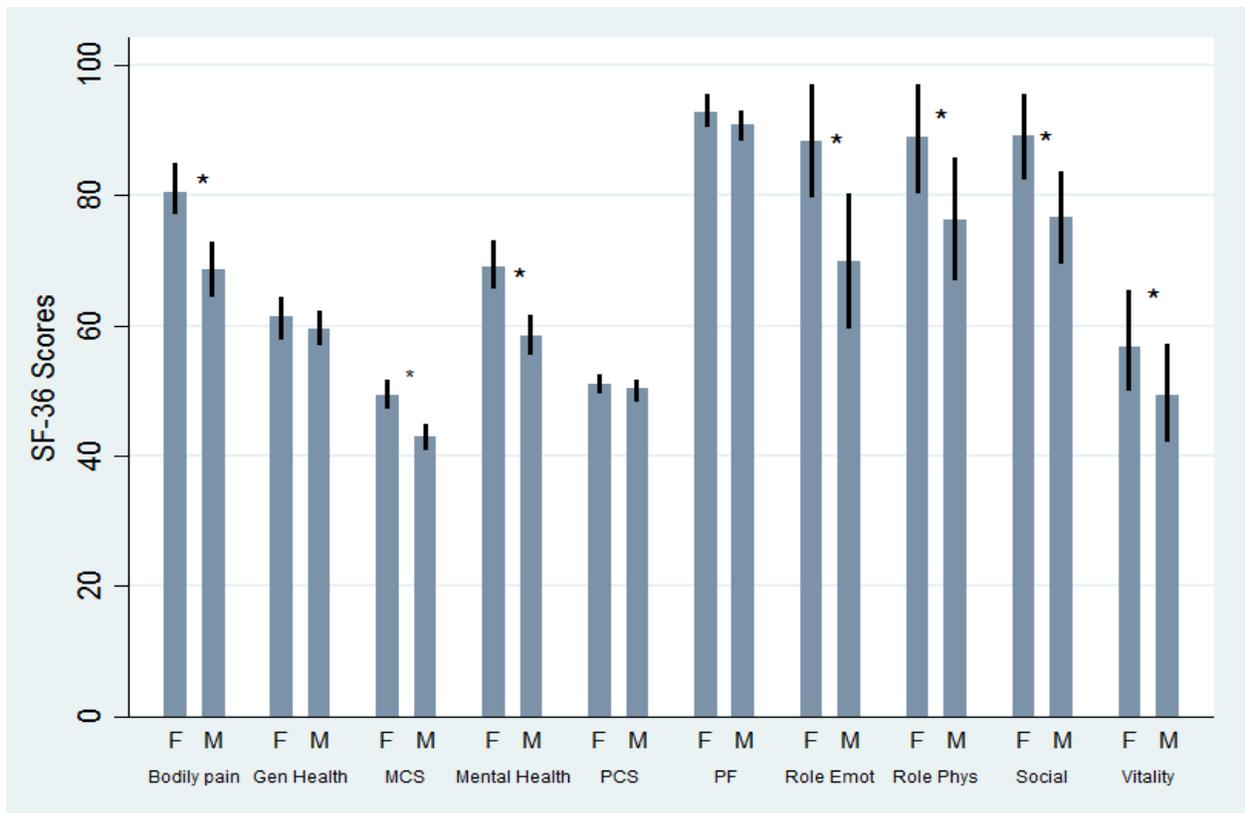


Figure 8: SF-36: Mothers vs. Fathers

P values were calculated using a two-sample t-test to ascertain differences between males and females. Statistically significant differences between groups: bodily pain, mental health, role emotional, role physical, social, vitality, and MCS ( $p < 0.005$  after Bonferroni correction)

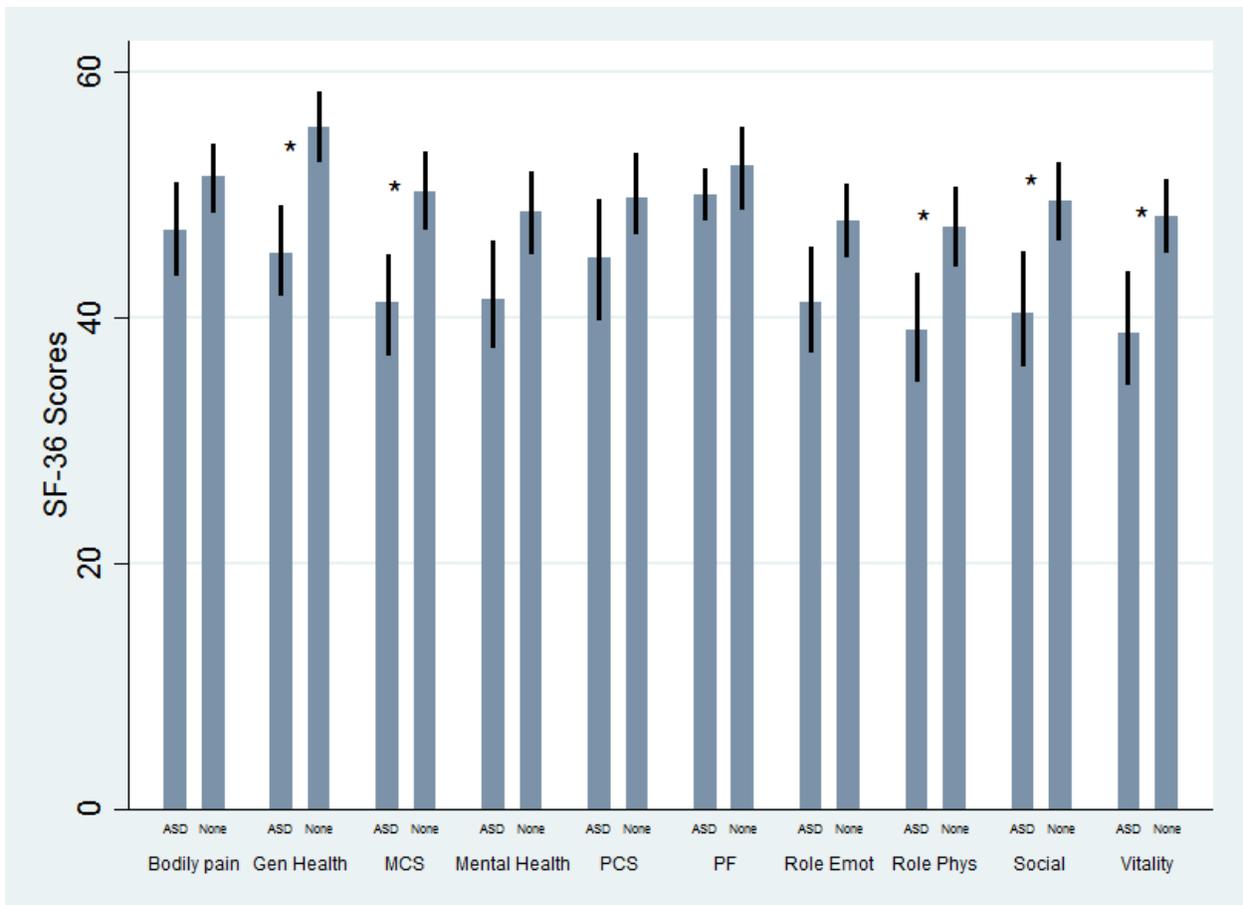


Figure 9: SF-36: No ASD (TD) vs. ASD

P values were calculated using a two-sample t-test to ascertain differences between ASD and no ASD. Statistically significant differences between groups: general health, role physical, social, vitality, and MCS ( $p < 0.005$  after Bonferroni correction)

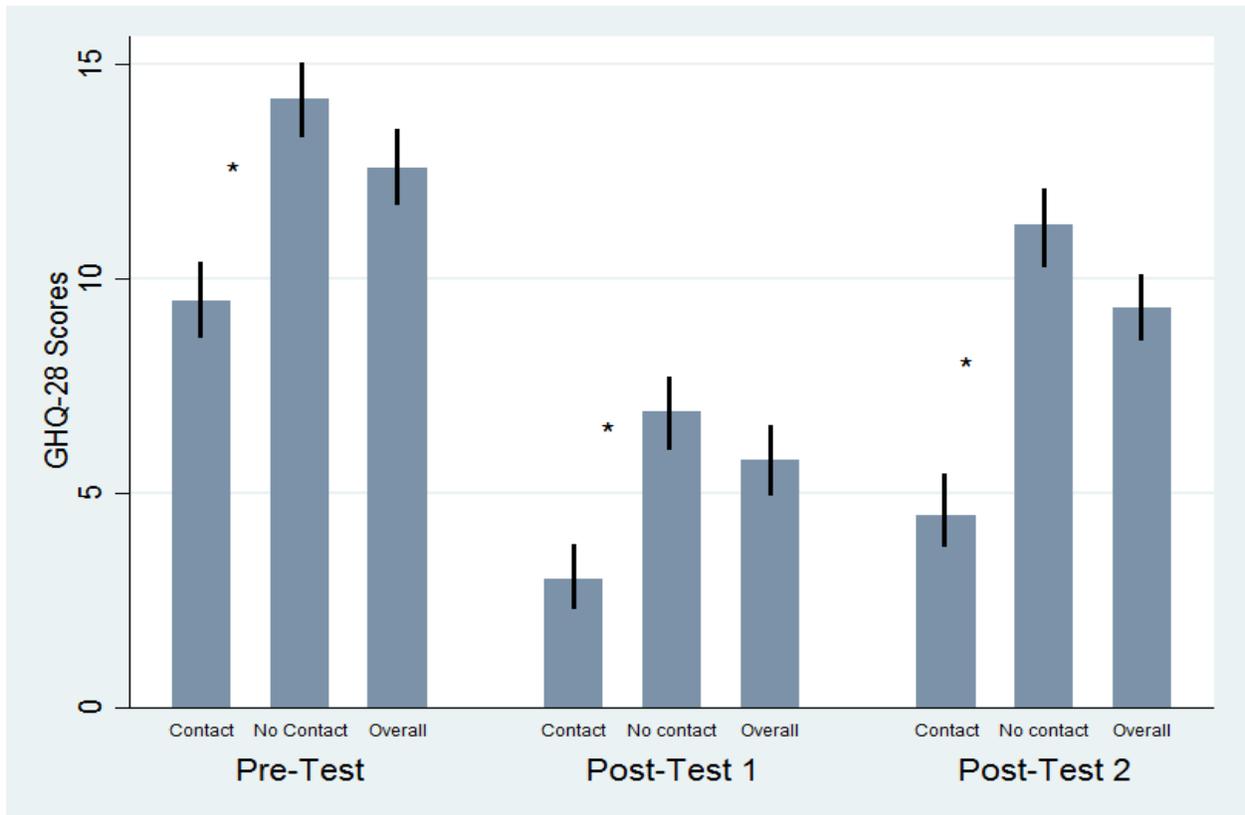


Figure 10: GHQ-28: Maintained vs. No Maintained Parental Contact

P values were calculated using the two-sample t-test to ascertain differences between contact and no contact, stratified by pre-test, post-test 1 and post-test 2 ( $p < 0.016$  after Bonferroni correction)

### *Sense of Coherence and Coping*

A number of studies discussed the impact of Sense of Coherence (SoC) on QOL. Siah et al [33] found in a cross-sectional survey in Malaysia that parents with a high sense of coherence have a statistically significant higher quality of life when compared with similar parents who have low sense of coherence, based on the WHOQOL. Three predictors of higher SoC, as measured by the SoC tool, were also noted: male, aged 45 years or above, and child with ASD aged above 7 years. Batool et al [4] found an inverse relationship between parental stress and Sense of Coherence (SoC), as measured by the Sense of Coherence tool for parents in Pakistan.

Dardas et al found in three articles [10], [11], and [12] that parents in Jordan are most likely to use positive reappraisal to cope (create positive meaning through religious aspects and a focus on personal growth), as measured by the Revised Ways of Coping Checklist (WCC-R). Two articles found that parents are least likely to use distancing (cognitive detachment and minimization of the significance of the problem), while one found that accepting responsibility (recognizing one's contribution to the problem and the solution) is least utilized.

### *Caregiver Burden and Family Functioning*

Ji et al [20] implemented a Multidisciplinary Parent Education program in China and examined multiple outcomes. A significant difference was found between mean score of family functioning before the intervention and after, as assessed by the McMaster Family Assessment Device (FAD); the same intervention did not significantly impact caregiver burden when compared with the control group, as measured via the Caregiver Burden Index (CBI). McConkey et al [24] utilized a seven-session training course in Iran, offering information about ASD as well as mutual support. This study found that parents who maintained contact with other parents upon completion of the course had better family functioning at three months post- and twelve months post-intervention, when compared with the overall scores in parents that did not maintain such contact, measured as a derivation from the FAD.

## Discussion

This systematic review sought to evaluate quality of life for family members of children with ASD in Asia. This study elucidated information on efficacy of interventions, differences between mothers and fathers in terms of quality of life, predictors of QOL, and new QOL outcome targets for intervention. These studies took place across eleven countries in Asia. Four primary outcome measures were used for analysis: WHOQOL-BREF, PSI-SF, SF-36, and GHQ-28. The following outcome measures lacked sufficient data, requiring a qualitative review and evaluation: CBI, PSI, FAD, WCC-R, and SoC.

As studies elsewhere have shown, it was found that parents of children with ASD in Asia have lower QOL than parents of TD children. The following QOL outcomes were lower in parents of children with ASD than those of TD children in Asia: general health, role physical, social, vitality, mental health, stress, and overall well-being. Parents of children with ASD face unique and distinct challenges that are layered with cultural context. Each of these outcomes should be viewed as a focus for intervention to help parents face and overcome the hurdles before them. Clarifying the mediating factors behind these QOL outcomes can be challenging. Studies discussed in this review have shown that Sense of Coherence (SoC) has a strong influence on a parent's quality of life and stress, with certain variables predicting one's SoC.<sup>33</sup> These inflexible variables (male gender, parent age > 45, child age > 7) coupled with other factors that increase SoC cultivate strength and increase the meaning one draws from life experience; all of these factors may breed confidence on a parent's journey. As a parent and their child age, they begin to grow in their own comfort with and control over the situation at hand. This study suggests that mothers have a lower SoC and therefore lower QOL than fathers. Similarly, data from India, Jordan and Iran support the idea that mothers experience higher levels of stress, mothers in Japan were found to have lower health-related QOL, and mothers in Iran had poorer overall well-being than fathers.<sup>9, 14, 31, 38</sup> Each of these studies suggest that mothers may carry a heavier burden than fathers in caring for their child with ASD. Conversely, when mothers and fathers in Jordan were compared, mothers had higher QOL than fathers.<sup>13, 14</sup> This demonstrates that the burden of care may not land solely on the shoulders of one parent. It is important to recognize

the cultural differences, duties and responsibilities within a given context and how that may impact caregiver QOL. Importantly, the bulk of negative outcomes fall on mothers in the studies included here and mothers should be the focus for impacting outcomes. Certain coping strategies were also identified as those most commonly used by parents of children with ASD, including using religion and a focus on positive growth to create meaning.<sup>10, 11, 12</sup> As part of the human experience, all people seek to create meaning, and these studies underline the importance of meaning-making when dealing with the challenges of raising a child with ASD. This review emphasizes the importance of determining and influencing predictors of QOL. For example, if one targets stress, this may improve sense of coherence; in turn, this could significantly impact QOL. Overall, parents of children with ASD in Asia have lower QOL than parents of TD children, with mothers experiencing the most significant negative impact. Further study is necessary to solidify which factors impact and predict QOL and how these can be targeted. How parents cope with their life situation also has a significant impact on QOL and may be a focus for intervention.

Outcomes for QOL were not consistently improved with every intervention implemented. For example, a Mindfulness Based Intervention in Jordan [30] was correlated with positive QOL outcomes, while a support group intervention in Taiwan [32] was correlated with negative outcomes. These outcomes challenge the idea that “anything is better than nothing.” In particular, it is important to measure outcomes for each intervention implemented to evaluate its efficacy in a given setting and population, and assumptions about outcomes following an intervention should be avoided. This systematic review found that in Asia, a Multidisciplinary Parent Education program significantly impacted family functioning while having no significant impact on health-related QOL or caregiver burden, and a CBT intervention for children with ASD decreased parental stress. An intervention may be particularly powerful in impacting one outcome while having no impact on another outcome. This highlights the importance of knowing the QOL outcome variables with the greatest need and pairing these with the interventions that most effectively impact that outcome. Upon implementation, it is of the utmost importance to scientifically measure the impact of such interventions on QOL, despite the challenges of measuring QOL. Additionally, parents having and maintaining contact with

parents in a similar situation can help improve well-being, parenting stress and family functioning. This is a feasible and tangible aid for many parents, regardless of context or availability of structured interventions.

The motivation in approaching this question focused on Asia as a whole was to reveal areas of QOL deficits that span multiple countries throughout the region. While this information may speak broadly to potential foci of future research and interventions, it also grossly oversimplifies the unique cultural differences and barriers across and within countries. Some outcomes can vary significantly based on the country of focus.<sup>22, 37</sup> Conversely, certain data may show no significant difference in outcomes across multiple countries.<sup>12, 19, 23, 25</sup> This brings into focus two important points. While similar QOL outcomes may be seen across countries in a similar region, each country has its own unique challenges and cultural context. On the other hand, across four studies in four different countries, similar outcome data was found in regards to parental stress. As such, outcomes with such homogenous and far-reaching impacts are high-influence outcomes to focus on for intervention in Asia. The strongest statements to be made about these topics are those focused on one country or one specific region within a country. Such focused research is not available in large volumes, and as such, this study took a broad approach. With more attention and research efforts, this more focused approach would provide increasingly specific and appropriate information about target outcomes and interventions.

### *Limitations*

As mentioned above, one of the limitations of this study is the lack of sufficient data among the following specific outcome measures: CBI, PSI, FAD, WCC-R, and SoC. As such, these were not included in the quantitative data analysis. While each had some data available, it was not adequate for analysis. However, these limited outcomes were discussed alongside the quantitative analyses conducted. A more comprehensive search strategy utilizing more databases may also be able to broaden the data available in future similar systematic reviews.

Another limitation of this study was the number of cross-sectional studies included and the difficulty in comparing results from these. Some contained meaningful within-group comparisons, which were used in the analysis. However, many that lacked a control group could not be appropriately compared to other studies. Similarly, some studies that use the same measurement instrument offered different raw data. A number of these tools and scales have various ways of calculating numbers and as such, comparing the results can be difficult without the users manual providing instructions for calculation to accompany each tool. While some articles used a specified tool, raw data of the results from this tool may not have been supplied if they conducted a linear regression analysis.

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## Appendix

Article	Population	Country	Study Design	Intervention	Control
Batool et al [4]	Parents total, n = 100 Mothers, n = 50 Fathers, n = 50	Pakistan	Cross-sectional field survey study		
Daley et al [9]	Families, n = 52 Adults with ASD, n = 54 Female, n = 10 Male, n = 44 Age: M 25.1, SD 6.2, range 18-44	India	Mixed-method, cross-sectional, interview and questionnaire		
Dardas et al [10]	Parents total, n = 184 Mothers, n = 114 Fathers, n = 70 Age: M 37, SD 7.6, range 21-69 Children Girl, n = 29 Boy, n = 155 Age: M 6.3, SD 3, range 2-12	Jordan	Cross-sectional, questionnaire		Comparison: Mothers vs. fathers
Dardas et al [11]	Fathers, n = 101 Age: M 39.3, SD 6.9, range 25-69 Children Age: M 5.9, SD 3.2, range 2-13 Girl, n = 16 Boy, n = 85	Jordan	Cross-sectional, questionnaire		
Dardas et al [12]	Parents total, n = 184 Mothers, n = 114 Fathers, n = 70 Age: M 37, SD 7.6 Children Girl, n = 29 Boy, n = 155 Age: M 6.3, SD 3, range 2-12	Jordan	Cross-sectional, questionnaire		
Dardas et al [13]	Parents, n = 184 Age: M 37, SD 7.6 Mothers, n = 114 Age: M 35.4, SD 7.03, range 21-57 Fathers, n = 70 Age: M 39.9, SD 7.6, range 25-69	Jordan	Cross-sectional, questionnaires		Comparison: Mothers vs. fathers

Dardas et al [14]	Parents Mothers, n = 114 Fathers, n = 70 Children Girl, n = 29 Boy, n = 155 Age: M 6.3, SD 3, range 2-12	Jordan	Cross-sectional, questionnaires		Comparison: Mothers vs. Fathers
Forouzanfar et al [15]	Mothers, n = 203 Age: M 36.01, SD 6.92, range 23-59 Children Girl, n = 72 Boy, n = 131 Age: M 7.89, SD 3.39	Iran	Cross-sectional, questionnaire		
Huang et al [19]	Parents total, n = 52 Mothers, n = 45 Fathers, n = 7 Age: M 39.24, SD 5.9 Children Girl, n = 3 Boy, n = 49 Age: M 6.33, SD 2.3, range 3-12	Taiwan	Cross-sectional, questionnaire		
Ji et al [20]	Parent total, n = 42 Mothers, n = 38 Fathers, n = 4 Average age = 34.17 Child Girl, n = 7 Boy, n = 35	China	Pre-, posttest design	Multidisciplinary parent education	Intervention, n = 22 vs. wait-list control, n = 20
Ji et al [21]	Caregiver total, n = 273 Female, n = 230 Male, n = 43 Age, M 35.22, SD 9.59 Relationship Mother, n = 199 Father, n = 30 Grandparents or aunts, n = 44 Child Age: M 4.81, SD 2.01, range 0-14 Girl, n = 52 Boy, n = 221	China	Cross-sectional study		

Kousha et al [22]	Mothers, n = 127 Age: M 33.23, SD 6.4, range 20-57 ASD Girls, n = 31 Boys, n = 96 Age: M 6.26, SD 2.92, range 2-16	Iran	Descriptive, cross-sectional		
Lai et al [23]	Parents of children with ASD, n = 73 Parents of TD children, n = 63 Parents total, n = 136 Mother, n = 110 Father, n = 26 Age: M 43.68, SD 6.36 Children Girl, n = 59 Boy, n = 77 Age: M 12.35, SD 3.67	Singapore	Cross-sectional, questionnaire		TD children
McConkey et al [24]	Parents total, n = 28 Mothers, n = 17 Age: majority 30-39 Fathers, n = 11 Age: majority over 40 Children Girl, n = 7 Boy, n = 21 Age: range 3-17	Iran	Combined methods, longitudinal analysis Home-based interviews at 3 time points: 1. Prior to training 2. Three months after course 3. Twelve months later Semi-structured interviews	Seven-session training course (10 hours total): 2 successive parent groups over a 2-month period Information about ASD and encouragement of mutual support	Pre- vs. post-test Maintained contact at 1-year follow-up, n = 8 vs. No contact with other parents at 1-year, n = 20
Mori et al [25]	Families total, n = 193 Mothers, n = 193 Age: M 38.24, SD 5.25 Fathers, n = 181 Age: M 41.05, SD 6.20 Children Age: M 7.39, SD 2.77 Girl, n = 30 Boy, n = 163	Japan	Cross-sectional, questionnaire		

Obeid et al [26]	<p>Mothers total, n = 163  Mothers of children with ASD, n = 65  Age: M 40.15, SD 6.79  Married, n = 60  Other, n = 5</p> <p>Mothers of TD children, n = 98  Age: M 38.94, SD 7.18  Married, n = 93  Other, n = 5</p> <p>Children  ASD:  Girl, n = 12  Boy, n = 51  TD: not given</p>	Lebanon	Cross-sectional, questionnaire		Mothers of TD children
Ooi et al [27]	<p>Children, n = 6  Age: M 11.50, SD 0.84, range 9-13</p>	Singapore	Pre-, post-test design	<p>16, 90-minute sessions: CBT program  Sessions with small group of children, n = 3</p>	Pre- vs. post-test
Rayan et al [30]	<p>Parents total, n = 104  Intervention group:  Mothers, n = 37  Fathers, n = 15</p> <p>Control group:  Mothers, n = 36  Fathers, n = 16  Age: M 34.10, SD 6.40</p> <p>Children  Girl, n = 23  Boy, n = 81</p>	Jordan	Quasi-experimental with non-equivalent control group	5-week Mindfulness Based Intervention program	Did not attend MBI program
Samadi et al [31]	<p>Parents total, n = 103  Mothers, n = 58  Fathers, n = 45  Families total, n = 74  Couples, n = 29  Mothers only, n = 29  Fathers only, n = 16</p> <p>Children, n = 74  Age: range 3-19, M 7.4  Girl, n = 15  Boy, n = 59</p>	Iran	Cross-sectional questionnaires and conversational interview		Comparison: Mothers vs. fathers

Shu et al [32]	Mothers, n = 27 Age: M 41, range 30-51	Taiwan	Quasi-experimental pre-, post-test control group design 3 data collection points: pre-test, post-test, and follow-up after 1 month	10-week support group program, 90-minute session each week	Mothers who refused to attend but agreed to serve as the control group, n = 19 Experimental, n = 8 Control, n = 19
Siah et al [33]	Parents total, n = 96 Mothers, n = 72 Fathers, n = 24 Age: ≤30, n = 5, 31-45, n = 69, >45, n = 40 Children Age: <7, n = 54 7-14, n = 19 >14, n = 23 Girl, n = 20 Boy, n = 69	Malaysia	Cross-sectional, questionnaire		High SoC vs. Low SoC groups
Suzumura et al [35]	Mothers total, n = 60 Mothers of children with HFPDD, n = 30 Control mothers, n = 30 Age HFPDD mothers: M 37.7, range 28-47 Control mothers: M 36.5, range 28-46 Number of children HFPDD mothers: M 1.7, SD 0.6 Control mothers: M 2.0, SD 0.9 Children Age: range 3-6 HFPDD: M 5.0 Control: M 5.0 Gender: HFPDD: Girl, n = 5 Boy, n = 35 Control: Girl, n = 5 Boy, n = 35	Japan	Cross-sectional, questionnaires		Developmentally average, matched age and sex TD children

Wisessathorn et al [37]	Caregivers total, n = 303 Mothers, n = 216 Fathers, n = 28 Grandparents, n = 44 Others, n = 15 Parents Age: M 43.17, SD 9.73, range 19-70 Children Female, n = 71 Male, n = 232 Age: M 7.83, SD 3.46, range 2-17	Thailand	Cross-sectional, questionnaire		
Yamada et al [38]	Parents Mothers, n = 147 Age: M 38.3, SD 4.6 Fathers, n = 122 Age: M 41.0, SD 5.7 Children with PDD, n = 158 Girl, n = 29 Boy, n = 129 Age: M 9.083, SD 2.5 range 6-15	Japan	Cross-sectional, questionnaire		
Yang et al [39]	Case Children with ASD, n = 361 Age: M 5.74, SD 2.78 Parents of children with ASD, n = 722 Father's age: M 36.65, SD 5.75 Mother's age: M 33.98, SD 4.64 Control TD children, n = 345 Age: M 6.14, SD 3.05 Parents of TD children, n = 690 Father's age: M 37.31, SD 5.09 Mother's age: M 34.42, SD 4.08	China	Case-control study, questionnaire		Parents of TD children

Table 3: Articles and Interventions

Article	Outcome: General QOL	Outcome: Stress	Outcome: Relationships	Outcome: Coping	Outcome: Health
Batool et al [4]				SoC-SF Mothers: M 54.56, SD 12.83 Fathers: M 60.02, SD 11.25	
Daley et al [9]		PSI-SF Mothers: M 100.7, SD 20.9 Fathers: M 104.1, SD 22.2			
Dardas et al [10]	WHOQOL-BREF Total: M 80, SD 16	PSI-SF Total: M 118, SD 23		WCC-R Positive reappraisal: M 74.30, SD 12.97 Distancing: M 55.19, SD 13.56	
Dardas et al [11]	WHOQOL-BREF Total: M 74.17	PSI-SF Total: M 94.35, SD 19.28		WCC-R Positive reappraisal: M 20.13, SD 3.29 Confrontive coping: M 12.96, SD 3.07 Planful problem solving: M 15.95, SD 3.48 Seeking social support: M 16.34, SD 3.88 Distancing: M 13.85, SD 3.17 Self-control: M 17.56, SD 3.40 Escape avoidance: M 17.74, SD 4.76 Accepting responsibility: M 9.04, SD 2.57	
Dardas et al [12]	WHOQOL-BREF Total: M 80, SD 16	PSI-SF PD: M 40.29, SD 10.47 PCDI: M 37.70, SD 8.73 DC: M 39.95, SD 7.86		WCC-R Positive reappraisal: M 74.30, SD 12.97 Distancing: M 55.19, SD 13.56,	

Dardas et al [13]	<p>WHOQOL-BREF  Physical:  Fathers: M  67.67, SD 14.38  Mothers: M  64.91, SD 13.85  Psychological:  Fathers: M  63.48, SD 14.27  Mothers: M  59.68, SD 16.01  Social relations:  Fathers: M  69.05, SD 15.77  Mothers: M  64.27, SD 17.34  Environmental:  Fathers: M  55.93, SD 13.92  Mothers: M  55.79, SD 14.21  Total:  Fathers M  62.88, SD 11.98  Mothers: M  60.48, SD 12.89</p>				
Dardas et al [14]	<p>WHOQOL-BREF  Fathers: M  58.2, SD 9.2  Mothers: M  83.2, SD 8.8</p>	<p>PSI-SF  PD:  Fathers: M 39.1,  SD 10.3  Mothers: M 41.1,  SD 10.5  PCDI:  Fathers: M 38.5,  SD 8.6  Mothers: M 37.2,  SD 8.8  DC:  Fathers: M 39.3,  SD 7.8  Mothers; M 40.3,  SD 7.9  Total:  Fathers: M 116.9,  SD 22.5  Mothers: M 118.6,  SD 22.6</p>			
Forouzanfar et al [15]					<p>SF-36  Physical  functioning:  M 66.07,  SD 27.69</p>

					<p>Role physical: M 38.55, SD 40.74 Bodily pain: M 56.53, SD 30.57 General health: M 51.88, SD 25.65 Vitality: M 38.36, SD 23.04 Social functioning: M 54.99, SD 28.89 Role emotional: M 38.92, SD 42.37 Mental health: M 42.35, SD 23.47 MCS: M 43.65, SD 24.59 PCS: M 53.25, SD 25.51</p>
Huang et al [19]		<p>PSI-SF PD: M 35.81, SD 8.65 PCDI: M 31.34, SD 5.76 DC: M 35.50, SD 7.43</p>			
Ji et al [20]	<p>CBI Intervention Pre: M 54.64, SD 14.39 Post: 51.37, SD 19.09 Control Pre: M 56.85, SD 17.32 Post: M 52.43, SD 11.10</p>		<p>FAD Intervention Pre: M 2.31, SD 0.23 Post: M 2.07, SD 0.23 Control Pre: M 2.36, SD 0.26 Post: M 2.07, SD 0.21</p>		<p>SF-36 PCS Intervention Pre: M 63.11, SD 7.42 Post: M 68.48, SD 15.38 Control Pre: M 63.54, SD 9.69 Post: M 66.65, SD 8.92 MCS Intervention Pre: M 53.85, SD 9.10 Post: M 59.95, SD 9.12 Control Pre: M 51.00,</p>

					SD 15.96 Post: M 54.09, SD 13.96
Ji et al [21]	CBI M 58.09, SD 16.45		FAD M 2.36, SD 0.24		SF-36 PCS: M 58.72, SD 12.48 MCS: M 45.58, SD 16.71
Kousha et al [22]	WHOQOL-BREF Physical health: M 22.68, SD 5.59 Psychological health: M 18.6, SD 4.76 Social relationships: M 9.43, SD 2.53 Environment: M 24.92, SD 5.87				
Lai et al [23]		PSI-SF ASD Total: M 90.29, SD 23.37 PD: M 29.51, SD 9.04 PCDI: M 30.03, SD 8.95 DC: M 32.12, SD 8.43 TD Total: M 79.27, SD 18.67 PD: M 26.00, SD 7.18 PCDI: M 7.18, SD 6.94 DC: M 27.60, SD 6.51			
McConkey et al [24]		PSI-SF Total Time 1: M 110 Time 2: M 84.67 Time 3: M 103 No contact Time 1: M 112.5 Time 2: M 87.1 Time 3: M 106.05 Contact Time 1: M 105.25	FAD Derivation Total Time 1: M 27.92 Time 2: M 39.46 Time 3: M 34.17 No contact Time 1: M 29 Time 2: M		GHQ-28 Total Time 1: M 12.58 Time 2: 5.78 Time 3: 9.32 No contact Time 1: M 14.2 Time 2: M 6.9 Time 3: M 11.25

		Time 2: M 78.62 Time 3: M 98	38.85 Time 3: M 33 Contact Time 1: M 25.25 Time 2: M 41 Time 3: M 37.12		Contact Time 1: M 9.5 Time 2: M 3 Time 3: M 4.5
Mori et al [25]		PSI-SF Asperger's PD: M 30.50, SD 8.64 PCDI: 28.80, SD 7.82 DC: M 42.17, SD 9.37 Total: M 101.47, SD 21.26 Autism PD: M 29.45, SD 6.90 PCDI: M 27.40, SD 7.05 DC: M 35.23, SD 7.89 Total: M 92.09, SD 17.81			
Obeid et al [26]					GHQ-12 ASD: M 2.14, SD 0.56 TD: M 1.84, SD 0.38
Ooi et al [27]		PSI Pre (T1) Child domain: M 116.00, SD 30.00 Parent domain: M 161.40, SD 33.40 Total: M 277.0, SD 56.78 Post (T2) Child domain: M 99.00, SD 27.55 Parent domain: M 148.40, SD 31.63 Total: M 247.40, SD 55.77			
Rayan et al [30]	WHOQOL-BREF Intervention Physical: Pre: M 53.78 Post: M 55.77				

	<p>Psychological: Pre: M 48.48 Post: 57.29</p> <p>Social Relationships: Pre: M 56.41 Post: M 60.26</p> <p>Environmental: Pre: M 45.91 Post: M 46.69</p> <p>Total: Pre: M 204.58 Post: M 220.00</p> <p>Control group Physical: Pre: M 59.62 Post: M 60.65</p> <p>Psychological: Pre: M 46.63 Post: 48.56</p> <p>Social Relationships: Pre: M 54.00 Post: M 55.60</p> <p>Environmental: Pre: M 47.00 Post: M 47.77</p> <p>Total: Pre: M 207.25 Post: M 212.60</p>				
Samadi et al [31]		<p>PSI-SF Mothers: M 121, SD 17.0 Fathers: M 110.2, SD 17.6</p>	<p>FAD Derivation Mothers: M 26.2, SD 5.8 Fathers: M 27.5, SD 5.7</p>		<p>GHQ-28 Mothers: M 15.4, SD 7.7 Fathers: M 9.2, SD 5.9</p>
Shu et al [32]	<p>WHOQOL-BREF Intervention Total Pre: M 68.42, SD 2.50 Post: M 63.66, SD 2.21 1-month post: M 65.54, SD 1.82</p> <p>Physical Pre: M 18.21, SD 2.09 Post; M 17.14, SD 2.47 1-month post:</p>				

	<p>M 17.68, SD 1.65  Psychological  Pre: M 16.04, SD 2.63  Post: M 14.72, SD 2.23  1-month post: M 15.73, SD 1.21  Social relationships  Pre: M 17.50, SD 2.50  Post: M 16.09, SD 2.16  1-month post: M 16.09, SD 2.16  Environmental  Pre: M 16.67, SD 2.50  Post: M 15.71, SD 2.38  1-month post: M 16.04, SD 1.58  Control Total  Pre: M 67.74, SD 2.12  Post: M 68.34, SD 1.82  1-month post: M 66.29, SD 1.80  Physical  Pre: M 18.08, SD 2.20  Post: M 18.77, SD 1.86  1-month post: M 18.00, SD 1.21  Psychological  Pre: M 16.08, SD 2.29  Post: M 16.08, SD 1.67  1-month post: M 16.31, SD 1.81  Social relationships</p>				
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	<p>Pre: M 17.25, SD 1.94  Post: M 17.38, SD 1.90  1-month post: M 16.00, SD 2.31  Environmental  Pre: M 16.33, SD 2.02  Post: M 16.11, SD 1.85  1-month post: M 15.98, SD 1.30</p>				
Siah et al [33]	<p>WHOQOL-BREF  High SoC  Physical health: M 57.46, SD 11.61  Psychological health: M 59.13, SD 13.59  Social relationships: M 63.48, SD 11.91  Environmental factors: M 60.31, SD 14.23</p> <p>Low SoC  Physical health: M 49.19, SD 10.92  Psychological health: M 48.89, SD 12.35  Social relationships: M 53.91, SD 14.14  Environmental factors: M 49.17, SD 14.02</p>			SoC M 4.36	
Suzumura et al [35]					<p>SF-36v2  HFPDD group:  Physical functioning: M 50.0, SD 7.7  Role physical: M 39.0,</p>

					<p>SD 13.3  Bodily pain: M 47.1, SD 12.1  General health: M 45.2, SD 12.8  Vitality: M 38.8, SD 11.2  Social functioning: M 40.4, SD 14.7  Role emotion: M 41.3, SD 13.4  Mental health: M 41.5, SD 13.1</p> <p>PCS: M 44.9, SD 10.9  MCS: M 41.2, SD 11.2</p> <p>Control group:  Physical functioning: M 52.4, SD 6.0  Role physical: M 47.4, SD 8.8  Bodily pain: M 51.5, SD 10.1  General health: M 55.5, SD 9.2  Vitality: M 48.3, SD 7.9  Social functioning: M 49.5, SD 10.7  Role emotion: M 47.9, SD 9.4  Mental health: M 48.6, SD 8.4</p> <p>PCS: M 49.8, SD 8.8  MCS: M 50.3, SD 8.4</p>
Wisessathorn et al [37]	<p>WHOQOL-BREF  Physical: M 25.92, SD 3.58  Psychological: M 22.12, SD 3.51  Social: M 10.65,</p>				

	SD 1.69 Environmental: M 27.72, SD 4.48				
Yamada et al [38]					<p>SF-36 Mothers Physical functioning: M 90.8, SD 10.7 Role physical: M 76.2, SD 37.4 Bodily pain: M 68.7, SD 23.9 General health: M 59.6, SD 20.1 Vitality: M 49.4, SD 23.5 Social functioning: M 76.7, SD 24.5 Role emotional: M 69.9, SD 39.0 Mental health: M 58.5, SD 22.5</p> <p>PCS: M 50.3, SD 6.9 MCS: M 42.9, SD 11.9</p> <p>Fathers Physical functioning: M 92.9, SD 10.9 Role physical: M 88.9, SD 25.5 Bodily pain: M 80.4, SD 20.7 General health: M 61.5, SD 17.5 Vitality: M 56.8,</p>

					SD 17.6 Social functioning: M 89.1, SD 16.2 Role emotional: M 88.3, SD 25.0 Mental health: M 69.1, SD 16.9  PCS: M 51.1, SD 5.5 MCS: M 49.4, SD 8.0
Yang et al [39]		PSI Case Child domain: M 145.16, SD 20.35 Hyperactivity: M 30.76, SD 4.80 Adaptability: M 34.04, SD 6.48 Reinforces: M 15.09, SD 3.86 Demandingness: M 28.34, SD 5.08 Mood: M 14.64, SD 3.30 Acceptability: M 22.29, SD 4.29 Parent Domain: M 163.61, SD 22.28 Competence: M 40.10, SD 4.83 Isolation: M 17.88, SD 3.93 Attachment: M 18.39, SD 3.76 Health: M 16.04, SD 3.40 Role Restriction: M 23.54, SD 5.40 Depression: M 26.20, SD 5.46 Spouse relationship: M 21.45, SD 5.10 Total score: M 308.76, SD 37.38  Control Child domain:			

		<p>M 110.67, SD 18.89</p> <p>Hyperactivity: M 25.26, SD 4.87</p> <p>Adaptability: M 25.67, SD 5.11</p> <p>Reinforces: M 11.14, SD 3.42</p> <p>Demandingness: M 21.40, SD 4.47</p> <p>Mood: M 12.06, SD 3.01</p> <p>Acceptability: M 15.14, SD 4.15</p> <p>Parent Domain: M 140.21, SD 21.12</p> <p>Competence: M 34.99, SD 5.12</p> <p>Isolation: M 15.40, SD 3.41</p> <p>Attachment: M 16.01, SD 3.16</p> <p>Health: M 14.63, SD 3.00</p> <p>Role Restriction: M 18.46, SD 4.99</p> <p>Depression: M 21.85, SD 5.33</p> <p>Spouse relationship: M 18.86, SD 4.35</p> <p>Total score: M 250.88, SD 36.44</p>			
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Table 4: Outcome Data

**COMPREHENSIVE REVIEW ARTICLE**  
**MINDFULNESS BASED INTERVENTIONS FOR CHILDREN WITH AUTISM SPECTRUM DISORDER**  
**AND THEIR PARENTS: MECHANISM, EVIDENCE, AND FEASIBILITY**

## **Abstract**

Parents of children with autism spectrum disorder face significant challenges, due to the pervasive and chronic nature of their child's diagnosis. Supports for and emphasis on interventions for parents are lacking. Children with ASD are now becoming adults and also lack adequate psychological support. This article seeks to investigate mindfulness based interventions and their utility, feasibility and impacts on this population. There is a reciprocal relationship between parental mental health and child behaviors. Mindfulness may be a feasible aid in this challenge and can address this need on a global level. Mindfulness based interventions have positive effects on parents including impacts on psychological health and well-being, quality of life, and satisfaction, among others, with outcomes maintained at follow-up. Parents learn to shift their focus from problem solving to non-judgmental acceptance through positive reappraisal. This facilitates healthier parent-child interactions. Mindfulness interventions for individuals with ASD improved social responsiveness and quality of life while simultaneously decreasing rumination. Feasible interventions should be brief, flexible, culturally appropriate, and easily applicable in every day life. There is evidence that mindfulness may be culturally acceptable and practical in variably resourced countries to meet the urgent need within parental mental health.

## **Autism Spectrum Disorder**

### *Parental and Family Strains*

Autism spectrum disorder (ASD) is a heterogeneous, lifelong neurodevelopmental disorder with a rising global prevalence, for which there is no cure and a paucity of evidence-based interventions.<sup>5, 7</sup> Due to its chronic nature and pervasive effects, this disorder commonly causes psychological distress for individuals with ASD as well as their family members, placing a considerable strain on family systems.<sup>5, 8</sup> The burden placed on parents rearing children with ASD can substantially impact their quality of life (QOL) and psychological wellbeing, and adequate support for these individuals is lacking.<sup>4, 6</sup> The demands and responsibilities of raising a child with ASD can result in psychological, financial and physical burdens.<sup>6</sup> Families must face the negative societal attitudes towards individuals with disabilities,<sup>6</sup> lack of support and risk of losing support,<sup>5</sup> and difficult child behaviors.<sup>7</sup> Additionally, parents often remain responsible for caring for the child well into adulthood, a time when older parents begin to face their own health issues due to aging.<sup>5</sup> The chronic strain these parents face has been found to be associated with dissatisfaction with their “position in life,”<sup>6</sup> higher stress, psychiatric problems, poorer health,<sup>2</sup> increased anxiety, depression, somatic complaints and burn-out.<sup>1</sup> High parental stress in turn predicts economic hardship, insufficient supports, and child problems, including aggression, self-injury, and social and communicative deficits.<sup>2</sup> High parental stress may result in the parents having less ability to implement interventions for the child, resulting in less developmental progress.<sup>2</sup> Reciprocally, ASD severity level is associated with more psychological distress in parents.<sup>7</sup> Parental stress predicts child outcomes and child behavior predicts parents’ mental health outcomes. This cyclical relationship highlights the importance of offering interventions both for individuals with ASD and their parents, as management of one directly impacts the outcomes of the other. The majority of current interventions are focused on the individual with ASD, possibly offering collateral benefits to parental mental health, but interventions for the sole purpose of parental psychological support are lacking.<sup>2, 6</sup>

### *Strains on Individuals with ASD*

Strains on individuals with ASD are exacerbated during transition points in life, such as the transition from childhood to adulthood.<sup>1,5</sup> At this transition point, schooling, emotional and biological changes occur; in addition, an increased importance of peer relationships and increased prevalence of anxiety and depression in individuals with ASD are also seen.<sup>1</sup> With an increasing number of adults with ASD, the importance of addressing their psychological wellbeing and commonly co-occurring conditions such as anxiety and depression has also come into focus.<sup>8</sup> These common comorbid conditions may aggravate ASD-related impairments and may present atypically, further increasing the importance of diagnosing and treating these conditions; however, the resources and evidence for these treatments are scarce.<sup>8</sup>

### *Global Perspective*

The prevalence of ASD is rising not only within the United States but also across the globe. This fact raises concern about supports and interventions available for our neighbors elsewhere. In low- and middle-income countries autism-related resources for parents are scarce, despite the requirement of life-long care for individuals with ASD and the association with parents' psychological exhaustion, stress, anxiety and depression.<sup>7</sup> One study in Jordan notes that there is little public interest in ASD in the Arab world.<sup>7</sup> In this middle-income country, there are few special services for children with ASD; educating these children is a major challenge as they must attend a special school, which provides services only to a small percentage of individuals with ASD.<sup>7</sup> They are not integrated into the regular school system, and all services are child-focused, not parent-focused.<sup>7</sup> Due to the broad impacts of this disorder for individuals with ASD, their families and society as a whole, it is important to identify practical, evidence-based treatment options. In addition, due to its global impact, it is of specific importance to determine feasible interventions that can be implemented abroad in variably resourced settings.

## **Mindfulness Based Interventions**

### *Mindfulness*

Mindfulness has recently risen to popularity as an effective method for reducing stress and improving well-being in caregivers, among other populations.<sup>5</sup> Mindfulness encompasses many ideas and has varied definitions. It has been described as “purposefully paying attention and being present in the moment,” (Lunsky, 2017) “conscious awareness that arises by focusing attention on elements in the environment as they are, in the actual moment, and without judgment,” (Sizoo, 2017) and “moment-to-moment, nonjudgmental awareness, cultivated by paying attention in a specific way; that is, in the present moment, and as non-reactively, as non-judgmentally, and as open-heartedly as possible” (Rayan, 2018, p. 12). The goal of mindfulness is changing the way individuals experience negative emotions. This occurs by teaching non-judgmental acceptance of negative sensations, as they are perceived. This is particularly effective for problems that don’t offer immediate solutions.<sup>5</sup> Through non-reactive acceptance of the current situation, one can cultivate the mindset that allows for positive reappraisal of the situation.<sup>6</sup> Mindfulness has been found to be negatively correlated with high levels of anxiety, stress and depression.<sup>7</sup> Similarly, mind-body therapies focus on the connection between mind, body and health and have been shown to improve symptoms of anxiety, depression, stress and sleep problems.<sup>3</sup> Mindfulness and mind-body therapies have the potential to improve QOL for a variety of populations by impacting perceived QOL and positive stress reappraisal in a way that is adaptable, acceptable and effective.<sup>6</sup>

### *Mindfulness Based Interventions for Parents and Caregivers*

Mindfulness based interventions have particular applications in the ASD population, both for individuals with ASD as well as their parents and caregivers. Due to ASD’s chronic and pervasive nature, it is imperative that caregivers and individuals with ASD alike, cultivate an attitude of nonjudgmental acceptance of the situation.<sup>4,6</sup> Increases in optimism, attributions of control, and self-efficacy are associated with lower psychological distress, all of which can be increased through mindfulness exercises.<sup>4</sup> Mindfulness interventions for caregivers may be focused on a number of aspects that improve wellness, including parenting skills, self-care, and parent-child

interactions. Interventions focused on mindfulness have potential to reduce psychological distress for parents of children with ASD, increase psychological acceptance, decrease depression, and improve overall self-reported health.<sup>5</sup> This increased acceptance also helps facilitate the process of parents being open and available to gaining better parenting skills.<sup>6</sup> Due to the chronic stress these parents are exposed to, these types of interventions teach parents to experience difficult situation in a different way that focuses less on solutions and more on being present in the moment.<sup>5</sup> Similarly, in regards to self-care, parents grow in their awareness of physical and emotional needs, which can ultimately help safeguard against parental exhaustion and burnout.<sup>5</sup> It can additionally teach parents to develop self-compassion, which is critically important not only with the challenges of their relationship with the child but also the challenges of coping with their child struggling with societal acceptance.<sup>1</sup> With increased mindfulness in parent-child interactions, the stress of daily, often reactive, interactions can be reduced.<sup>5</sup> Parenting training with a mindfulness focus can help parents learn to slow down their reactions and be aware of their intention to act prior to taking action.<sup>1</sup> It also has potential to increase parents' feelings of competence and satisfaction.<sup>5</sup> When a child has a difficult behavior, parents can learn to take a moment to stop, breathe and think, rather than allow this to trigger an impulsive, emotional and intense reaction, overall reducing parental reactivity.<sup>1</sup> It is of particular importance that parents of children with ASD have an air of calm about their being, as these children function best in a predictable social environment that is not overly emotionally charged or labile.<sup>1</sup> Parents can also learn to pay attention to their child in a more open, non-judgmental way, allowing them to cultivate acceptance of their child and their station in life.<sup>1</sup>

### *Mindfulness Based Interventions for Individuals with ASD*

Mindfulness based therapies also have great potential to impact QOL for individuals with ASD themselves. Young people with ASD find social situations challenging, can become overwhelmed by internal and external stimuli, and additionally often have co-occurring anxiety and depression.<sup>3, 4, 8</sup> These interventions address many of these core features. Social situations can be challenging as these individuals cannot understand the perspectives and emotions of others as well as their own; through meditation, they can increase self-awareness and empathy for others and self.<sup>4</sup> External and internal stimuli can easily become overwhelming, particularly when these individuals struggle to see the bigger picture, get lost in details or ruminate in repetitive thought patterns; mindfulness can train one to widen or narrow their lens of attention.<sup>4</sup> Executive functioning can also be a task, with individuals often finding flexibility difficult; mindfulness is positively associated with one's cognitive flexibility and offers the tangible opportunity to practice shifting one's attention, such as from breath to sound.<sup>4</sup> Broadly, mindfulness increases one's awareness of signs of stress in the body and through a brief meditation or breathing exercise, one can redirect self out of auto-pilot and into the present moment, reducing stress and widening perspective.<sup>4</sup> Individuals with ASD also commonly have concomitant anxiety and depression, often related to deficits in theory of mind, understanding of social context, and executive function.<sup>8</sup> Through a lifetime of problematic social interactions and an accumulation of negative experiences, anxiety and depression in these individuals are likely related to a "...painful awareness of [one's] handicap and differences from other people" (Sizoo, 2017). However, as mentioned above, these psychiatric conditions are often masked by or confused with the typical symptoms of ASD. They also may be manifested in an atypical manner, such as depression expressed through aggressive behavior, sleep problems, or deterioration in function.<sup>8</sup> Additionally, rumination is a common symptom in these individuals, which only further exacerbates anxiety and depressive symptoms.<sup>8</sup> All of these factors illuminate the potential value and impact of using mindfulness and mind-body therapies in improving the QOL for individuals with ASD.

### *Parallel Mindfulness Training: Parents and Individuals with ASD*

The importance of concomitant training for parents and adolescents is highlighted by the reciprocal relationships between parenting stress and child behavior problems.<sup>1</sup> Mindfulness meditation in parents has potential both to increase parental feelings of competence and satisfaction as well as decrease aggressive behaviors in the child with ASD.<sup>5</sup> Acceptance has similarly been found to mediate the relationship between child behavior problems and paternal well-being, including stress, anxiety and depression.<sup>4</sup> This reciprocal relationship elucidates the importance of finding evidence-based mindfulness therapies for individuals with ASD and their parents or caregivers for the beneficial impact on QOL for all parties.

### *Mindfulness: A Global Perspective*

Due to their potential for broad implementation, mindfulness interventions also come into the spotlight as a potential key component in management of ASD on a global level. The question remains whether such interventions would be considered acceptable, feasible and impactful in settings of various cultures and resources.

## **Outcomes and Evidence**

### *Currently Available Interventions*

As discussed, there is a paucity of research on evidence-based treatments for individuals with ASD. Applied Behavioral Analysis (ABA) is the only evidence-based treatment for ASD and other behavioral interventions have shown some promise in improving social skills and reducing anxiety symptoms in individuals with ASD.<sup>1</sup> Antipsychotics are indicated to address symptoms of severe irritability but not the core symptoms of ASD and even then, at the expense of many negative side effects. The majority of interventions are child-focused, and those for parents are generally education and support focused, rather than honing in on parental wellbeing. In recent years, various studies have confirmed the impacts of rearing a child with ASD on psychological well-being and begun considering the impact and importance of Mindfulness Based Interventions (MBI) for individuals with ASD and their parents and caregivers, some of which will be review here.

### *Mediators Between Child Behavior and Parental Psychological Distress*

Jones et al (2014) replicated the findings that psychological acceptance is a mediator of the association between child behavior problems and psychological distress in mothers of children with ASD. This study examined both child symptomology measures as well as parental wellbeing and mindfulness measures to assess the mediating role of psychological acceptance. This found that child behavior problems are a significant independent predictor of maternal anxiety, maternal and paternal depression and stress, but are not significantly associated with maternal or paternal positive gain nor paternal anxiety.<sup>4</sup> Maternal and paternal predictors and mediators varied, but overall mindful parenting and psychological acceptance were found to be predictors of the majority of outcomes. Child behavior problems remained significant predictors of maternal and paternal stress.

### *Impacts of Mindfulness Based Interventions*

Lunksy et al (2017) compared outcomes for parental interventions while awaiting child services. The two intervention arms were a Mindfulness-Based Cognitive Therapy (MBCT) and a parental education and support group, with the primary outcome being the depression anxiety stress scale measuring psychological distress. Both groups reported similar satisfaction, but only the mindfulness group reported significant reductions in psychological distress, which were maintained at 20-week follow up, over and above the non-specific effects of education and support.<sup>5</sup>

The article by Dykens et al (2014) investigated the utility of treating mothers in groups led by peer-mentors with the use of adult-oriented curricula. It compared the outcomes from two different interventions, Mindfulness-Based Stress Reduction (MBSR) and Positive Adult Development (PAD), which is anchored in teaching the tenets of positive psychology. Both interventions showed significant improvements during treatment in parent distress and dysfunctional parent-child interactions, with additional improvement in four secondary outcomes: anxiety, depression, insomnia severity and life satisfaction.<sup>2</sup> Continued improvement or maintenance of gains was found at follow up. The most significant gains at 6-month follow-up were found in anxiety and depression, followed by insomnia and personal distress. When comparing the two interventions, MBSR showed greater improvements in anxiety, depression and insomnia compared with the PAD group. However, at follow-up the outcomes were found to be equal, with the PAD group showing more improvement in depression and life satisfaction than the MBSR group.

### *Global Perspective*

Rayan et al (2018) sought to establish the relationship between mindfulness and psychological distress in Arab parents of children with ASD, expanding to consider a global view. This information will inform development of mindfulness-based interventions that could reduce psychological distress in these parents. Parents of children with ASD living in Jordan were found to have above average levels of depression, anxiety and stress, with maternal levels higher than paternal.<sup>7</sup> Severity of ASD was significantly associated with psychological distress, anxiety and

depression. A significant correlation was found between mindfulness scores and parental stress, above and beyond variance accounted for by age, gender and ASD severity level. Rayan et al (2016) additionally considered the global applications and implications of MBIs for parents. This study used a Brief MBI for parents of children with ASD in Jordan. Outcomes revealed improvements in psychological health and overall QOL in both the intervention and control groups.<sup>6</sup> However, the intervention group had additional improvements in social relationships, positive stress reappraisal and mindfulness scores.

### *Comparative and Parallel Therapies*

Sizoo et al (2017) point to the fact that many interventions have evidence to support their efficacy over and above control groups or baseline. Here they considered whether cognitive behavioral therapy (CBT) or MBSR had a greater impact reducing anxiety and depression in adults with ASD. Both groups showed significant improvement in depression and anxiety scores, positive and negative general mood scores, rumination, and autism symptom scores following treatment.<sup>8</sup> These effects were sustained at three months in both groups. Bruin et al (2015) considered the use of parallel mindfulness training both for adolescents with ASD and their families, with positive impacts for each. Adolescents reported increased QOL and decreased rumination, without impacting worrying, mindfulness or core ASD symptoms.<sup>1</sup> “One adolescent explained that his thoughts were like overcrowded subways in rush hour. In the MYmind training, he had learned to just be on the platform. Subways with many thoughts would still come to his platform, but he was now able to let them pass, to just observe them and stay calm.” (Bruin, 2015, p.911) Due to the adolescent training, parents reported their child had increased social responsiveness with no significant impact on ASD core symptoms. Parents reported outcomes following their own intervention of increased mindfulness measures, decrease in stress post-test, which lost significance at follow-up, decrease in dysfunctional parenting styles and a borderline increase in QOL.

### *Review of the Literature*

Hourston et al (2017) did a systematic review to evaluate the types, outcomes and accessibility adaptations of mind-body therapies for individuals with ASD. Mind-body therapy interventions included an attentional or mindfulness component and varied broadly from MBSR to yoga and t'ai chi to acceptance and commitment therapy (ACT). This study found that seven studies administered interventions solely to parents, one to mothers only, two to parents and children, one used mindful parenting, and four interventions taught parents mindfulness protocols to deliver an intervention to their child.<sup>3</sup> Of the four randomized controlled trials, results showed adults with ASD had improvements in depression, anxiety and rumination; children with ASD showed improvements in self-control and behavior; interventions for parents showed improvements in child hyperactivity. Multiple studies showed improved mental health, thought management, and psychological distress for individuals with ASD following intervention. Yoga interventions offered improvements in aberrant behaviors based on teacher ratings and Nei Yang Gong showed improvements in neuropsychological tests of executive function.

<b>Intervention</b>	<b>Description</b>
Mindfulness	Being aware of the present moment and present thoughts in a nonjudgmental way. Often taught by a trained instructor in sessions for several weeks in conjunction with home practice.
Mindful parenting	Parents learn meditation and mindfulness skills that they can exercise when interacting with children.
Yoga	A movement-based therapy that incorporates physical poses and attention to breath. Taught by a trained instructor.
Nei Yang Gong	A movement-based therapy that uses a sequence of slow movements, mental exercises, and breathing exercises. Similar to qigong or t'ai chi, it also incorporates Chinese theory of qi.
Acceptance commitment therapy (ACT)	A type of CBT that include mindfulness aspects. It emphasizes a nonjudgmental stance when monitoring thoughts. The commitment component is an active process of identifying life values and promoting behaviors that work toward them.
Mindfulness-Based Stress Reduction (MBSR)	Incorporates mindfulness meditation, body awareness, and yoga to increase one's mindfulness, typically group sessions 8x weeks
Mindfulness-Based Cognitive Therapy (MBCT)	Incorporates components of cognitive behavioral therapy with mindfulness based stress reduction, emphasizing a new way of being and relating to one's thoughts and feelings, typically group sessions 8x weeks
MYMind training for Youngsters with ASD	Highly standardized protocol based on the Mymind protocol for children with ADHD and mindfulness training for adults with ASD, 1.5 hours each 9x sessions, training and homework based in MCBT and MBSR
Positive Adult Development (PAD)	Incorporates evidence-based interventions from positive psychology, incorporating concepts such as maximizing virtues, abilities and optimism

Table 1: Mindfulness Interventions and Descriptions <sup>1, 2, 3</sup>

## **Implementation and Feasibility**

### *Considerations of Implementation*

While evidence supporting the efficacy of interventions has merit, if said tools are not practical or possible for individuals to use, then it ultimately has little utility. It is of the utmost importance, then that we consider the evidence through the lens of feasibility of implementation. In particular, parents of children with ASD may have many common barriers to attending a class or training session, including child issues (childcare, health problems, etc.), parent problems (health issues), and transportation difficulties.<sup>5</sup> The demanding structure of some intervention programs makes compliance difficult for parents of children with ASD as finding childcare can be overwhelming, among other obstacles.<sup>6</sup> Interventions then must be made particularly accessible and meet the specific needs of this population.

### *Modifications to Increase Participation*

Several of the interventions discussed above crafted their teaching and training in a way that met these unique needs. Rayan et al (2016) used a Brief Mindfulness Based Intervention (MBI), with brevity to reduce attrition rates, which was implemented by a clinical nurse in psychiatric and mental health. It was shortened to a 5-week course, noting that the most important factors predicting positive outcomes are not the number of session attended, in-class hours, or duration and frequency of mindfulness practices.<sup>6</sup> Rather, factors such as a parental belief that the program is logical and credible, preference for the program and belief that it will be efficacious have more impact on outcome than the specifics mentioned above.<sup>6</sup> Attrition rates were found to be 13.3%, which is lower than other studies.<sup>6</sup> This also suggests that MBI may be culturally acceptable in Jordan and in general has potential to be adapted and implemented in different cultures.<sup>6</sup>

Lunksy et al (2017) used a less intensive form of mindfulness intervention than MBSR or MCBT, which included a brief audio homework from "Finding Peace in a Frantic World." Finding time for this may have been easier than protected time for other required elements. Additionally, web links were provided with optional paper-based homework and CD recordings. The full-day

silent retreat was eliminated. The most portable intervention they were taught and practiced both inside group and outside of group was the three-minute breathing space. The goal of this intervention was to weave practices into one's current life circumstances, rather than proposing a major schedule change required in the more intensive interventions. For example, part of the parents homework was the loving-kindness meditation from MBSR, which introduced parents to the idea of performing mindfulness activities with their child.<sup>5</sup> During sessions, parents were encouraged to engage with other parents during a mid-session "tea break" for debriefing as a form of self-care.

### *Sustainability and Empowerment*

Dykens et al (2014) used peer-mentors to lead group interventions, whom were well-trained mothers of children with disabilities. They had the ability to lead groups in the community setting and had the natural advantage of parent-to-parent rapport. Both the Mindfulness Based Stress Reduction (MBSR) and Positive Adult Development (PAD) arms were lead by these peer-mentors. There were daytime and evening sessions at an accessible community site with optional childcare, including care for siblings. All of these factors weigh heavily upon parents when it comes to coordinating the details of attending such a session. The mentors went through four months of training on intervention curriculum, the role of the mentor, and research ethics.<sup>2</sup> This included online training, directed readings and either regular mindfulness or positive psychology practices. They were instructed and observed by a social worker or psychologist and met weekly for supervision. In each group, parents were also encouraged to practice exercises at home. This model has multiple strengths. It empowers the parent group and rather than coming in to "fix" their problems, it teaches them how to help carry and assist one another. It also accesses the strength of the local community. It is sustainable in that a large number of peer-mentors could be trained to influence a large number of people in their own region.

### *Parallel Interventions*

Bruin et al (2015) used a nine-week mindfulness training for adolescents with ASD with a parallel mindful parenting training. The intervention for adolescents (MYmind: Mindfulness Training for Youngsters with ASD) came from the MYmind protocol for children with ADHD in combination with mindfulness training for adults with ASD.<sup>1</sup> The novel protocol added an additional session to increase the repetition for the participants. The additional session was designed for individuals with ASD and focused on coping with changes; interestingly, those in the study valued this session less than other sessions. Parent and child intervention ended with a joint session to include both together. Sessions were highly structured, and homework included practicing meditations, diary registrations and reading handouts. Parents went through Mindful Parenting training, which followed a detailed manual. Two-thirds of the training was MBSR/MCBT and one-third was related to mindfulness parenting issues. This was completed in a group format, and parents were encouraged to practice meditation at home. The instructors were mental healthcare professionals with ASD experience. This intervention showed a low drop-out rate and nearly 90% of all sessions were attended, indicating this is a feasible parallel intervention.

### *Adaptations for Individuals with ASD*

Hourston et al (2017) systematic review specifically considered modifications for accessibility. As core features of ASD may make certain mind-body interventions challenging, this review discussed studies that made adaptations to serve this specific population, however no direct comparison was made between outcomes with the modified and non-modified interventions. Two mindfulness-based interventions for individuals with ASD used less metaphorical and ambiguous language and omitted certain cognitive elements that these individuals may find challenging, such as examination of one's thoughts.<sup>3</sup> They also increased the amount of time for breathing exercises and weeks of training to account for possible slower information processing. In reference to Bruin et al (2015), Hourston et al (2017) notes key aspects and adaptations of the program: use of less abstract language as well as provision of detailed outline overview of each session to allow for anticipation of sessions and put participants at

ease. Lastly, an ACT intervention was modified for individuals, which they reported were useful and the program was overall satisfying. These modifications included smaller group size, shortening of mindfulness exercise, addition of exercises related to sensory sensitivities, modification of stress management worksheet, and limitation of use of metaphors.

### *Comparative Therapies*

Sizoo et al (20017) utilized both CBT and MBSR, both of which were designed for adults with ASD to treat their anxiety and depressive symptoms. Modifications included text clarification such as avoiding metaphors, making instructions as clear as possible, and homework planning based on the level of executive function.<sup>8</sup> They also added more repetition of exercises and overall moved at a slower pace. Participants completed exercises and homework on a daily basis. Experienced therapists who were trained in either MBSR or CBT protocols for adults with ASD implemented the protocol. Each was a 13-week program with 90-minute sessions each.

### *Implementation and Feasibility*

As discussed, parents of children with ASD face many common barriers to accessing important interventions for themselves and their child. There are many factors that can assist in increasing interest in and attendance at these interventions. External factors that can increase compliance include offering interventions at multiple times throughout the day at multiple sites that are easily accessible and providing childcare during the program.<sup>2</sup> Outside of the specifics of the program, it is important that parents believe in the power of the program and its efficacy.<sup>6</sup> Intervention factors that may increase attendance and decrease attrition rates include brevity, flexibility, and the ability to weave the practices into everyday life and practice portable interventions.<sup>5, 6</sup> Adaptations to interventions for individuals with ASD included decreasing the amount of metaphorical language used, moving at a slower pace to allow more time for processing, and offering a detailed outline of the program and what participants can expect.<sup>1,3,8</sup> Mindfulness based interventions may be culturally acceptable and feasible on a global scale as well, especially with use of peer-mentors and implementation of culturally sensitive material.<sup>6</sup>

## Summary

### *Call to Action*

Individuals with ASD and their parents face many unique challenges due to the pervasive, chronic nature of this diagnosis, impacting QOL for each in specific ways. Parents of children with ASD have above average levels of stress, depression, and anxiety, including outside of the United States.<sup>7</sup> Children with ASD are living into adulthood and typically continue to live with their parents, necessitating parents remain lifelong caregivers.<sup>2</sup> It is the responsibility of healthcare providers to assess and intervene on QOL measure for these caregivers and individuals with ASD.<sup>6</sup> Some parents may be solely focused on child support and overlook the need for self care and tending to one's own psychological needs.<sup>5, 7</sup> There are also global and cultural differences in tendency to seek care, such as Asian parents being less likely to seek psychological support and more likely to internalize their emotional experience.<sup>7</sup> Mindfulness, described as "Conscious awareness that arises by focusing attention on elements in the environment as they are, in the actual moment, and without judgment" (Sizoo, 2017) may have the power to positively impact wellbeing of individuals with ASD and their parents. Review of multiple studies found mindfulness based interventions to have positive effects on a multitude of factors for parents, including: psychological health, social relationships, overall QOL, positive stress reappraisal, mindfulness scores,<sup>1, 6</sup> distress, anxiety, depression, insomnia, life satisfaction,<sup>2, 5</sup> reactivity, parenting styles,<sup>1</sup> child behaviors, and rumination.<sup>3</sup> Mindfulness can be particularly effective in situations of ongoing difficulty that are out of one's control.<sup>5</sup> Many improvements in outcomes were maintained at follow-up.<sup>2, 3, 5, 8</sup> The shift to meeting parental needs to decrease stress and remain engaged results in greater improvements than traditional parental training.<sup>2</sup>

### *Impacts of Mindfulness Based Interventions on Parents*

Some studies found these interventions increased mindfulness scores, which have previously been found to have positive consequences on physical and psychological well-being.<sup>6, 7</sup> By exercising mindfulness, parents can shift from a problem-solving to a coping skills mindset. Consistent with many of these findings, higher post-intervention mindfulness scores were often accompanied by reports of higher QOL.<sup>6</sup> Similarly, increases in positive reappraisal are also associated with better outcomes, as parents are able to view their child and their station in life as benign, if not meaningful and beneficial.<sup>6</sup> If parents perceive their child with ASD as exceeding their resources, it results in stress, so the ability to reappraise positively is a useful coping strategy gained through the broadened attention that comes from mindfulness.<sup>6</sup> The tenets of non-judgmental acceptance allow for flourishing of the parent-child relationship; parents utilize mindful play and observation, which allows them to see and focus on their child's positive attributes and successes.<sup>6</sup> Similarly, a decrease in reactivity allows parents to observe and describe their own thoughts and emotions without getting caught up in them.<sup>7, 1</sup> They approach their child in a nonjudgmental way, offering their full attention and regulating their responses.<sup>1</sup>

### *Reciprocal Relationship and Parallel Interventions*

Severity of child ASD characteristics was found to be associated with parental distress, anxiety and depression, highlighting the need to offer interventions to both parties.<sup>1, 4, 7</sup> This reciprocal relationship means that improving parental outcomes opens the door for them to be more engaged and energized parents, in turn improving child outcomes.<sup>1</sup> There may be additional synergistic effects of offering parallel intervention programs to both parents and their child with ASD.<sup>3</sup>

### *Impacts of Mindfulness Based Interventions on Individuals with ASD*

Mindfulness interventions for individuals with ASD found improvements in: social responsiveness, QOL, rumination,<sup>1</sup> positive and negative general mood, autism symptom scores, irrational beliefs, anxiety, and autistic symptoms.<sup>8</sup> Mindfulness may help individuals with ASD look at their circumstances and thoughts from more of a distance without being caught up in them and simply be as they are.<sup>1</sup> CBT and MBSR both have significant impacts on anxiety and depression, with effects sustained at 3 months.<sup>8</sup> Individuals with ASD commonly have comorbid anxiety and depression, and clinicians should seek to employ CBT and MBSR to address these needs and reduce functional impairment, especially as there may be a bi-directional relationship between ASD symptoms and these comorbid conditions.<sup>8</sup>

### *Practical Implications and Global Perspective*

Utilization of peer mentors offered a feasible and meaningful intervention for parents of children with ASD.<sup>2</sup> Specifically, this approach meets a pressing need to improve mental health outcomes globally for parents of children with ASD.<sup>2</sup> Addressing barriers to program attendance and encouraging home practice of meditation similarly increased feasibility.<sup>5</sup> Program length and flexibility are important factors that influence program attendance and completion. Participants can still have meaningful outcomes in less rigorous and intensive programs.<sup>5</sup> Future considerations may include online training options or embedding these programs into standard child services.<sup>3, 5</sup> It is important to cater mindfulness-based interventions for individuals with ASD to meet their specific needs and address known difficulties within this population to add to their impact.<sup>1</sup> On a global scale, there is potential for mindfulness-based interventions to be culturally acceptable, feasible and impactful in a variety of countries and resources settings.

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