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Improving Parental Stress and Child Autism Spectrum Disorder Severity Through the Japanese Parent Mentorship Program: A Research Protocol

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Abstract

Introduction: Autism spectrum disorder (ASD) is a neurodevelopmental condition which often begins in early childhood and can involve a spectrum of persistent challenges with social communication, restricted interests, and repetitive behaviours. Literature in western and non-western countries has demonstrated that parents of children with ASD experience elevated stress relative to parents of neurotypical children. Despite the health-related burdens presented by raising children with ASD, little clinical and research emphasis is placed on reducing parental stress. Furthermore, much of the limited work on parent-centered interventions been conducted in the U.S., and few similar interventions have been developed for the Japanese population.

Methods: The Japanese Parent Mentorship Program (JPM) seeks to modify a pre-existing social support intervention (the Colorado Parent Mentorship Program developed for parents of ASD children in the U.S.) to Japanese parents by incorporating dialogue about the culturally relevant stressors, social acceptability, maternal burden, saving the face, and parent-child attachment. To test the efficacy of the JPM at reducing parental stress, a randomized control trial will be conducted with mothers of ASD children who were born and are living in Japan for a minimum of five years.

Results: Enrolment into the JPM will be associated with decreased parental stress post-intervention. The social support provided in the JPM will also be a protective moderator on the relationship between parental stress and ASD severity by weakening the overall association between parental stress and ASD severity**.**

Discussion: The JPM can improve health outcomes for parents and their children with ASD by decreasing parental stress and consequently, ASD severity, leading to numerous indirect and positive implications on their physical, emotional, and social well-being. As prompted by the JPM, cultural competence in ASD management, is associated with positive outcomes such as increased likelihood of treatment continuation, increased strength of perceived therapeutic alliance and increased perceived treatment benefit.

Conclusion: This research contributes to a major gap in the cross-cultural literature about parental stress and ASD. This work can be used to inform intervention strategies in Japan and researchers can emulate this design towards a global shift of providing culturally competent interventions for all.

Keywords: autism spectrum disorder; parental stress; social support; cultural competence

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition which often begins in early childhood and involves a spectrum of persistent challenges with social communication, restricted interests, and repetitive behaviors [1]. Various pharmaceutical [2,3,4] and behavioural [5,6] intervention strategies have been developed, permitting individuals with ASD to lead high-functioning lives. Much of the current research on ASD intervention focuses on the individual with autism; however, ASD can begin in childhood [1], and thus, parents and caregivers may bear a significant burden of ASD and play critical roles in symptom management. Furthermore, research by Eshraghi et al., [7] indicates that parental stress experienced by parents of children with ASD can "spill over" to children, exacerbating ASD symptom severity, behavioural challenges, and decreased mental well-being of the child [7]. Despite the critical role of parents and caregivers in ASD management, comparatively little clinical and research emphasis is placed on mitigating parental stress amongst parents of children with ASD (relative to the individual with ASD). Moreover, much of the limited work with parent-centered interventions (i.e., interventions primarily interested in the health outcomes of

parents of children with ASD) has been conducted in the U.S., despite the global prevalence of ASD [8]. These interventions should not be universalized without prior investigation of their cultural competence, specifically, an understanding of how parents of children with ASD in a particular country, experience parental stress and support as such an approach would neglect cultural complexities to ASD management and care. This paper seeks to critically investigate literature about parental stress experienced by parents of children with ASD in Japan, in order modify an existing parent-centered intervention strategy in the United States (U.S.), the Colorado Parent Mentorship Program (CPM) [9], to more appropriately serve the Japanese population. If successful, this new intervention, the Japanese Parent Mentorship Program (JPM), will provide more culturally competent parent-centered care to the Japanese community, improving clinical outcomes for both parents and their children with ASD.

Spill-Over Hypothesis

The spill-over hypothesis was proposed by Eshraghi et al., during the COVID-19 pandemic [7]. They proposed that increased stress experienced by parents of children with ASD during COVID-19 due to interruptions with in-person services and increased child-care demand can "spill-over" to children with ASD, lead to a worsening in ASD severity, increased behavioural challenges and decreased mental well-being of children [7]. Although not formally evaluated given ethical limitations, this hypothesis is supported by robust literature, indicating a strong positive correlation between parental stress and poor mental health of children [10-12] and between poor child mental health and worsened ASD severity,[13,14] respectively. Due to the adverse spill-over effects of parental stress on children with ASD, it is important to develop parent-centered intervention strategies to improve health outcomes for both parents and their children with ASD.

Parental Stress

Parental stress is defined as the discrepancy between resources required for a parental role and their perceived ability to cope with them [15]. Cross-culturally, studies have shown that parents of children with ASD experience increased parental stress compared to parents of neurotypical children [16,17,18]. Additionally, studies have investigated the relationship between ASD symptom severity and parental stress in western (specifically, U.S., Canada, Western Europe, New Zealand, Australia) and non-western countries, but evidence surrounding this relationship remains inconsistent [17,19-21]. In western countries, studies have demonstrated a linear and positive relationship between parental stress and ASD severity [19,20]. In contrast, this positive relationship has not been consistently found in non-western countries [17,21]. Notably, Asano et al., [21] found that Japanese mothers of children with high-functioning autism experienced greater stress than Japanese mothers of children with low-functioning autism. The authors hypothesized that Japanese mothers may experience greater shame and stress when ASD severity is low/well managed (i.e., children exhibit high functioning autism) because other individuals may view the child's behaviour as poor-parenting or lack of discipline [21]. A similar finding, increased parental stress when children exhibit low ASD severity, was noted by Chung & colleagues (2013) in Korea, however, the authors also found that Korean mothers underreported ASD severity, likely due to cultural emphasis on "saving the face", or the downplaying of one's symptoms around others [22]. Additionally, Japanese mothers of children with ASD also experience greater stress than western mothers due to cultural emphasis on increased maternal burden in child-rearing [17]. Furthermore, the belief that children should be close to mothers is emphasized in Japanese culture [23]. Children with ASD tend to display less secure attachments to parents [24] and Japanese mothers may view this less secure attachment as threatening, resulting in elevated stress [23]. Finally, Porter et al., [17] investigated the relationship between ASD severity and parental stress in Japan and the U.S. and found that mothers of children with ASD in Japan exhibited higher stress when child ASD severity was low [17]. These findings are consistent with Asano et al., [21] and Porter et al., [17] hypothesized that increased emphasis on social acceptability in Japanese culture may explain the findings. Collectively, these findings will inform dialogue concerning culture-specific stressors such as social acceptability [17], maternal burden [17], saving the face [22], and parent-child attachment [23] in the proposed culturally competent intervention strategy.

Social Support

A significant relationship between perceived social support and parental stress, such that increased perceived social support was associated with decreased parental stress amongst parents of children with ASD, has been identified in western [18] and non-western countries [25,23]. Social support can be classified into "informal" support from family and friends and "formal" support from health-care providers, therapists, and professionals [26]. As predicted by the collectivist values in Japan [27], increased informal social support significantly predicts decreased caregiver burden among parents of children with ASD, however, a similar relationship is not observed between formal social support and parental stress [26]. Interestingly, informal social support is also preferred by parents of children with ASD in western and individualist countries such as New Zealand [28] and the U.S. [29]. These findings suggest that informal social support may be a cross-cultural intervention strategy to mitigate parental stress.

Current Study

In light of the growing cross-cultural emphasis on the importance of parent-centered interventions to reduce

parental stress among parents of children with ASD (and consequently, decrease ASD severity among children with ASD), researchers in the U.S. have begun investigating informal social support interventions for parents of children with ASD (Moody et al., 2019). However, few similar informal intervention strategies have been adapted to the Japanese population. This study seeks to adapt the Colorado Parent Mentorship Program (CPM), an informal social support intervention developed by Moody et al., [9] for parents of children with ASD in the U.S. to the Japanese population, developing a new, culturally competent Japanese Parent Mentorship Program (JPM) for parents of children with ASD in Japan. The research question is: does enrollment into the JPM decrease parental stress and ASD severity, and does social support moderate the relationship between parental stress and ASD severity among Japanese mothers of children with ASD? The researchers hypothesize that enrollment into the JPM will be associated with decreased parental stress and ASD severity. Within the treatment group, social support is predicted to moderate the relationship between parental stress and ASD severity, such that increased social support will weaken the association between parental stress and ASD severity.

The Colorado Parent Mentorship Program

Moody et al., [9] developed the CPM in Colorado, U.S. The program included three intervention steps: (1) action planning, (2) navigation training and, (3) parent-to-parent mentorship. During the action planning meeting, parents shared their concerns and goals, and the study staff delivered semi-structured action plans to meet parents needs (e.g., educational training resources). During the navigating systems training, a standard Family Voices Colorado training about navigating ASD resources was provided. Finally, the mentorship stage occurred over six months. Mentors were also parents of children with ASD (minimum two years after diagnosis) who were trained to provide effective mentorship (active listening, unbiased emotional support based on their own experiences and knowledge of resources). Mentor-mentee pairings were matched for demographics, child characteristics, socio-economic status, religion, and parenting style. The researchers found that enrollment into the CPM improved parents' emotional well-being and satisfaction with disability-related services. Unfortunately, the researchers did not investigate parental stress pre- and post-intervention. Ideally, a replication and validation study of the CPM with respect to its efficacy at decreasing parental stress in the U.S. should be conducted prior to introduction into Japan; however, due to resource constraints, improved parental well-being is assumed as a proxy for decreased parental stress, and thus the CPM will be used as a model for the JPM. This assumption, particularly the relationship between increased parental well-being and decreased parental stress, is validated in the literature [30, 31].

Methods

Participants

The inclusion criteria for mothers are: (a) A minimum 18 years of age (b) at least one child has received an ASD diagnosis from a healthcare provider and, (c) the mother was born and is living in Japan for a minimum of five years (included to avoid cultural heterogeneity). In this analysis, only mothers have been selected to avoid possible confounding with respect to single parents, marital status, satisfaction. There will be no other exclusion criteria for the age or symptom severity of the child with ASD, as the randomized control trial design should ensure that such variables will be randomly distribution between groups, and this assumption will be validated via demographic analysis using chi-squared statistics. Due to resource constraints, the participants will be recruited via volunteer-based convenience sampling through social media postings, and advertisement/ word-of-mouth at clinics, hospitals, and universities in Tokyo, Japan.

Procedure and Materials

The study will employ a randomized control trial (RCT) with an active (JPM) condition and a routine- care condition. All participants will be instructed to complete five questionnaires upon consent in the study. They are: a background questionnaire, the Multidimensional Scale of Perceived Social Support, MSPSS, which measures perceived social support from 3 sources: family, friends and significant other [32], the Perceived Stress index (PSI) which measures perceived stress level [15] and two measures of ASD symptom severity: the Social Communication Questionnaire (SCQ) ,[33] and the Social Responsiveness Scale-2 (SRS-2) [34]. The background questionnaire will be created by the researchers to gather demographic information. All other questionnaires have been validated in the Japanese population [34-38]. Upon completing the questionnaires, participants in the active condition will participate in the JPM. Attrition bias will be accounted for by comparing participants who stay in the study to those who leave with respect to demographic and outcome variables. The expected length of the program is six months, and all participants will repeat the questionnaires after the JPM has concluded. Participants in the routine-care condition will then be offered a full intervention.

The Japanese Parent Mentorship Program

The JPM will follow all structural elements of the CPM and will integrate discussion about social acceptability [17], maternal burden [17], parent-child attachment [23] and saving the face[22]. During meetings, mentors will be encouraged to initiate conversations, actively discuss, and validate these culture-specific stressors. However, critically, a mentor in the JPM will be introduced as a “friend” to participants, to further cultivate an informal support network. Finally, the Japanese speaking

researchers will work closely with autism centres, hospitals, universities, and community partners in Japan to compile action planning and navigation training resources that are relevant to Japanese individuals. All elements of the JPM will be delivered in Japanese.

Statistical Analysis

Within the JPM condition, mean differences in perceived social support (MSPSS) pre- and post-intervention will be investigated to determine if the JPM succeeded at providing informal, mentorship/friendship-based social support. Mean differences in parental stress (PSI) and ASD severity (SCQ/SRS-2) between the JPM condition and waitlist condition, at both time-points, will be computed using Analysis of Variance (ANOVA) tests. Finally, within the JPM condition, a simple regression between perceived stress (PSI) and ASD severity (SCQ/SRS-2), and a moderation analysis of perceived social support (MSPSS) will be conducted.

Results

The expected findings support the research hypothesis. Enrollment into the JPM will be associated with decreased parental stress post-intervention (aligns with findings of the CPM which promoted increased parental well-being). Similarly, and in accordance with the spill-over hypothesis, enrollment into the JPM will be associated with decreased ASD severity of children. Finally, social support provided in the JPM will be a protective moderator on the relationship between parental stress and ASD severity, by weakening the overall positive association between parental stress and ASD severity.

Discussion

If successful, the JPM can improve clinical health outcomes for Japanese parents and their children with ASD by (1) decreasing parental stress among parents of children with ASD and (2) indirectly decreasing ASD severity amongst children by minimizing parental stress "spill-over." Decreased parental stress is linked to numerous positive health outcomes for parents, such as decreased risk of depression and anxiety [39], increased immunity [40], and protection against auto-immune diseases [40], as well as increased quality of life [41] and family functioning [42]. Thus, enrollment into the JPM, which directly reduces parental stress, can indirectly benefit the social [42], psychological [39], and physical [40] well-being of parents of children with ASD. Furthermore, decreased ASD severity, as predicted upon parental enrollment into the JPM, is associated with numerous positive health outcomes for children, including improved physical health [44,45], mental health [13,14] and social functioning [43,46]. Ultimately, if successful, the JPM can improve health outcomes for parents and their children with ASD by decreasing parental stress and consequently, ASD severity, leading to numerous indirect and positive implications on their physical, emotional, and social well-being.

Additionally, the spill-over hypothesis [7] highlights a global need for investment in parent-centered interventions for parents of children with ASD in the aftermath of COVID-19. This need can be satisfied by implementing the CPM in Japan unmodified; however, imposing such intervention strategies as "universal" seeks to neglect the cultural complexities of treatment by homogenizing the experiences of stress and support in western and non-western cultures. A lack of cultural competence in care, as occurs if the CPM is not modified into the JPM, can isolate parents of children with ASD from seeking help by imposing western values. For example, discussion about individuality and autonomy, which are common values in western cultures [47], can isolate Japanese individuals who value social-acceptance [17] and parent-child attachment [23]. As robust literature on cultural-competent interventions has documented, Japanese parents who enroll in the CPM (prior to modification) may say, "they (intervention providers) just don't understand me" [48,49].

In contrast, cultural competence in ASD management, specifically, a willingness by intervention providers to understand a client's cultural background, as provided in the JPM, is associated with numerous positive outcomes such as; increased likelihood of treatment continuation [50,51] increased strength of perceived therapeutic alliance (between patient and intervention provider) [50,51], and increased perceived treatment benefit [50,51], resulting in improved treatment and health outcomes for Japanese parents and their children with ASD.

Limitations & Future Directions

The researchers acknowledge three limitations in the design. Primarily, due to the convenience sample of volunteers, the study population will likely be over-representative of higher socio-economic status mothers who are motivated to seek ASD support. To avoid matched-pair analysis (and subsequent analytical/theoretical considerations about single-parent, married and marital satisfaction) only mothers will be allowed to participate in the JPM. A subsequent analysis which investigates the effectiveness of the JPM at reducing parental stress among fathers of children with ASD is an important area of future research. In addition, the culture-specific stressor of "saving the face" is integrated in the JPM due to a shared phenomenon observed in the Japanese and Korean population, and an assumption of cultural homogeneity is made due to limited research in this field. Such assumptions of homogeneity pose a starting point for cultural-clinical research, however, should be validated as literature continues to build. Finally, the Japanese population was selected for this study because limited cross-cultural research about parental stress in Japan was found during the initial literature review, compared to other cultures where no analogous work was found during review. As literature about cross-cultural differences in parental stress amongst

parents of children with ASD continues to develop, replication studies in global cultures is an important future direction. In addition, the numerous positive implications of decreased parental stress and ASD severity on the physical, psychological, and social well-being of parents and children with ASD can be validated in replication studies.

Conclusions

This paper has adapted an existing parent-centered intervention, the Colorado Parent Mentorship Program (CPM), for parents of children with ASD in the U.S. [9] to the Japanese population by incorporating discussion about culturally relevant stressors such as saving the face [22], social acceptability [17], parent-child attachment [23] and maternal burden [17]. This new intervention, the Japanese Parent Mentorship Program (JPM), may improve clinical outcomes for parents and their children with ASD by minimizing parental stress and related co-morbidities, as well as decreasing the spill-over of parental stress on child ASD severity. The JPM is novel and important because it provides culturally competent care to parents of children with ASD in Japan, whereas traditional interventions have focused on the child with autism predominantly in western countries. In addition to the clinical implications of the JPM in improving health-outcomes for parents and their children with ASD, this research builds on the work of Porter et al., [17] and Moody et al., [9] to contribute to a major gap in the literature about cross-cultural differences in parental stress and ASD. This work can be used to inform future intervention strategies in Japan and researchers' can emulate this design in global cultures, towards a global shift of providing culturally competent interventions for parents and their children with ASD.

List of Abbreviations Used

ASD: Autism Spectrum Disorder
CPM: Colorado Parent Mentorship Program
JPM: Japanese Parent Mentorship Program

Conflicts of Interest

The author declare that they have no conflict of interests.

Ethics Approval and/or Participant Consent

As this study will involve human participants, Research Ethics Board (REB) will be obtained from the University of Toronto's Social Sciences, Humanities and Education REB.

Authors' Contributions

TP: independent contributor to this manuscript.

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