PSYCHOSOCIAL INTERVENTION FOR MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER – A RANDOMIZED CONTROLLED TRIAL

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CHAPTER 7

Summary and Conclusion

This chapter provides a summary of the study, including the key findings. The chapter discusses the implications of the findings, the limitations of the study, and recommendations for future research. It concludes with a reflection on the study's contributions to enhancing the well-being of mothers and children with ASD.

Summary

The present study was undertaken to understand the impact of a psychosocial intervention for mothers of children with ASD. The primary focus was on evaluating how the intervention helped in building and strengthening the mothers' support networks, enhancing their use of effective coping strategies, and overall reducing the stress levels they experience. These mothers, who are predominantly the primary caregivers, often face significant challenges in raising children with ASD. By providing targeted psychosocial support, the study aimed to improve their well-being and ability to manage the unique demands associated with caring for a child with autism.

Aim

To examine the effects of Psychosocial Intervention for mothers of children with autism spectrum disorder (ASD) on their overall quality of life.

Objectives

1. To understand the needs of mothers of children with ASD and develop a psychosocial intervention module.
2. To assess the parental stress on mothers of children with ASD before and after psychosocial intervention.
3. To examine the perceived support on mothers of children with ASD before and after psychosocial intervention.
4. To identify the coping of mothers of children with ASD before and after psychosocial intervention.

Methodology Summary

This study employed a mixed-methods research design, integrating both qualitative and quantitative methodologies. The study was conducted in two phases:

Phase 1 Needs Assessment and Module Development.

Data Collection. Extensive literature review and in-depth interviews with mothers of children with ASD.

Purpose. To understand the personal experiences of the mothers and to develop a tailored psychosocial intervention module based on the qualitative findings.

Participants. Purposive sampling method was used to recruit mothers of children with ASD from identified centres in the Kamrup Metropolitan District of Assam, who met the study criteria and consented to participate.

Tools used. Tools used in the study included a semi-structured interview approach with open-ended questions based on extensive literature reviews.

Data Analysis. Thematic analysis, deemed most suitable for Phase 1 of this study, involved transcribing data, coding, categorizing, and deriving themes.

Phase 2: Main Study.

Design. Phase 2 utilized a classical experimental design, implementing a before-and-after test with a control group.

Sampling. Simple random sampling was used to assign 41 consenting mothers into control and experimental groups.

Tools used.

Socio-Demographic Profile Sheet: Developed by the researcher to collect background information such as age, gender, education, marital status, occupation, income, and family structure.

Kuppuswamy Socioeconomic Status Scale (2022): A tool to classify urban households in India based on education, occupation, and monthly income, placing households into one of five socioeconomic classes.

Parental Stress Scale: An 18-item scale measuring parental stress levels through various stress indicators like perceived stress, work/family stress, loneliness, and social support. Scores range from 1 (strongly disagree) to 5 (strongly agree).

Multidimensional Scale of Perceived Social Support (MSPSS): A 12-item scale assessing support from family, friends, and significant others. Scores indicate low, moderate, or high support.

Brief COPE: A 28-item scale assessing coping strategies, divided into three factors:

- **Problem-Focused Coping:** Active coping, planning, and positive reframing.
- **Emotion-Focused Coping:** Emotional support, humor, acceptance, and self-blame.
- **Avoidant Coping:** Self-distraction, denial, and behavioral disengagement.

Data Collection. Pre-assessment was conducted, followed by the introduction of the intervention to the experimental group. The first post-assessment was done immediately after the intervention, followed by another assessment one month later, and a follow-up assessment three months later, using standardized tools to measure stress, coping strategies, and perceived support.

Intervention. The psychosocial intervention module included sessions on enhancing knowledge about ASD, addressing stigma, building and strengthening support systems, using effective coping responses, managing emotional distress, and handling the child's challenging behaviors.

Analysis.

Socio-Demographic Data: Analyzed using mean, standard deviation, frequency, and percentage.

Main Variables: Analyzed using t- tests and repeated measures ANOVA to assess changes over time in stress, coping, and support.

Major Findings

Table 5.1 Comparison of age among mothers in study group and control group. The mean age of mothers in both the study group (34.00±5.45) and the control group (34.25±6.30) suggests that participants are in their Middle Ages. The t-test result (t=-0.136, p=0.893) indicates no significant age difference between the two groups.

Table 5.2 Comparison of socio-economic status, education, occupation, family type and religion among mothers in study group and control group.

The socio-economic status distribution showed differences between the study and control groups, with the study group having more respondents in upper middle and upper lower categories, while the control group had a higher proportion in upper middle and lower middle categories. However, the chi-square analysis ($\chi^2 = 2.918$, $p = 0.404$) revealed no statistically significant difference in socio-economic status between the two groups, indicating that the variations were likely due to random chance.

The educational distribution showed that most respondents in the experimental group had completed graduation or higher education, while the control group had more high school graduates. The chi-square test ($\chi^2 = 10.293$, $p = 0.016$) revealed a statistically significant difference in education levels between the two groups, indicating a clear association between education and group membership.

Occupation In both groups, most respondents were homemakers, with small proportions in private jobs, business, and domestic help. The chi-square test ($\chi^2 = 3.397$, $p = 0.334$) showed no statistically significant difference in occupation between the experimental and control groups, indicating that occupation distribution is similar in both groups.

Family Type In both the experimental and control groups, the majority of respondents belonged to nuclear families, followed by joint and separated families. The chi-square test ($\chi^2 = 0.210$, $p = 0.901$) revealed no statistically significant difference in family type between the groups, indicating that family type distribution is similar across both groups.

Religion In both the experimental and control groups, the majority of mothers identified as Hindu, followed by smaller proportions identifying as Christian or Muslim. The chi-square test ($\chi^2 = 2.088$, $p = 0.352$) showed no statistically significant difference

in religion between the groups, indicating similar religious distributions across both groups.

Table 5.3 Comparison of Children's Ages between Mothers in the Study Group and Control Group. A t-test showed no significant difference in the mean age of children with ASD between the study group (8.09 years) and the control group (7.05 years), with a p-value of 0.441.

The frequency distribution analysis was conducted for the age of children with autism, and the mode was found to be 4 years old.

Table 5.5 Comparison of Children's gender between Mothers in the Study Group and Control Group. In both groups, males were more prevalent: 43.9% in the experimental group and 26.8% in the control group, compared to fewer females.

Table 5.7 Shapiro-Wilk Test for Normality of Data in Study and Control Groups. The normality of the data was assessed using the Shapiro-Wilk test, with results indicating that both the study group ($W = 0.973$, $p = 0.202$) and the control group ($W = 0.987$, $p = 0.846$) met the normality assumption.

Table 5.8 Comparison of Perceived Social Support among Mothers in the study group and control group. The experimental group showed significant improvement in perceived social support immediately after the intervention, which was maintained at one month and three months, while the control group's scores remained unchanged. The interaction effect between time and group was significant, with improvements confirmed at all post-intervention points. However, no significant differences were found between post-intervention time points.

Table 5.9 Comparison of Problem Focused Coping among Mothers in the study group and control group. The experimental group showed significant improvement in problem-focused coping, which was sustained at one month and three months post-intervention, while the control group's scores remained unchanged. Statistical analysis revealed significant changes over time, with a significant interaction effect between time and group. Pairwise comparisons confirmed improvements at all post-intervention time points, but no significant differences were observed between post-intervention time points, indicating the coping skills were maintained over time.

Table 5.10 Comparison of Emotion Focused Coping among Mothers in the study group and control group. The experimental group showed slight but sustained improvements in emotion-focused coping, while the control group's scores remained unchanged. Statistical analysis revealed significant changes over time, with a notable interaction effect between time and group. Pairwise comparisons confirmed significant improvement immediately after the intervention, with the gains maintained over time, highlighting the intervention's effectiveness.

Table 5.11 Comparison of Avoidant Coping among Mothers in the study group and control group. In the experimental group, avoidant coping scores slightly decreased after the intervention and remained stable, while the control group's scores stayed unchanged. Statistical analysis showed no significant changes or interaction effects between time and group, and pairwise comparisons confirmed that the changes in avoidant coping scores were not statistically significant.

Table 5.12 Comparison of Parental Stress among Mothers in the study group and control group. In the experimental group, perceived stress levels decreased after the intervention but slightly increased at the three-month follow-up, though still lower than baseline. The control group's stress levels remained stable. Statistical analysis showed significant differences in stress levels over time and an interaction effect between time and group, indicating different changes for each group. Pairwise comparisons revealed significant reductions in stress immediately after the intervention and one month later, but stress levels rebounded at the three-month follow-up.

Implications of the study

The implications of this study are twofold, stemming from both the needs assessment phase and the main intervention study as a whole. These findings extend across various domains, impacting educational practices, support services, clinical interventions, policy development, community initiatives, and parental advocacy.

When it comes to educational practice, educational institutions can develop tailored support programs aimed at enhancing coping skills and resilience among mothers of children with autism. These programs should provide resources, strategies, and guidance to help mothers effectively navigate the challenges associated with autism parenting. Moreover, educators and school staff can benefit from professional development opportunities focusing on understanding the needs and experiences of these

mothers, fostering empathetic and supportive interactions. Schools can create supportive environments by offering access to support groups, counseling services, and workshops aimed at promoting well-being and coping strategies.

Additionally, incorporating parental perspectives, including insights from mothers of children with autism, into educational practices is crucial. Schools should actively involve parents in decision-making processes and seek their input on educational strategies to ensure interventions and supports are tailored to meet the unique needs of each child and family. Promoting collaboration between educators, parents, and other stakeholders is essential for fostering positive outcomes for children with autism. By implementing these implications, educational practitioners can create more inclusive, supportive, and effective learning environments for children with autism and their families.

Furthermore, healthcare professionals, including psychologists, counselors, and therapists, psychiatric social workers, can integrate the study's findings into clinical practice, offering tailored counseling and therapeutic interventions to enhance coping skills and resilience among mothers. Collaboration between mental health professionals and educational institutions can further enhance support services for families. Policymakers and advocacy organizations can utilize the study's insights to develop policies and initiatives supporting families of children with autism, advocating for increased funding for support programs and improved access to mental health services. Community organizations and support groups can design targeted services, such as peer support groups and training workshops, based on the study's findings to better meet the needs of mothers. The study empowers parents to advocate for their needs within their communities and educational settings, fostering collaboration between stakeholders. The study also suggests avenues for future research to explore coping responses and support needs among mothers of children with autism, further contributing to the body of knowledge in this field.

The practical implications of this study are substantial. The psychosocial intervention can lead to significant improvements in maternal well-being by reducing stress and enhancing coping strategies, which can, in turn, contribute to better mental health outcomes for mothers. By alleviating maternal stress and improving coping mechanisms, mothers are likely to be more effective in their parenting roles, positively

impacting the developmental and behavioral outcomes of children with autism. Additionally, the intervention can improve family dynamics by addressing maternal stress and providing strategies for managing the challenges of raising a child with autism, thereby enhancing overall family functioning and relationships. Furthermore, the developed intervention module serves as a valuable resource for healthcare providers, social workers, and mental health professionals working with families of children with autism, offering a structured approach to support these families.

The theoretical implications of this study contribute to the existing body of knowledge on interventions for parents of children with autism, highlighting the specific needs of mothers and the effectiveness of tailored psychosocial interventions. The findings offer deeper insights into the stress and coping mechanisms of mothers of children with autism, which can inform future research and theoretical models on parenting stress and coping in similar contexts. Additionally, the study provides valuable evidence on the design and implementation of effective psychosocial interventions, serving as a reference for developing similar programs for different populations.

Limitations of the study

The present study encounters several limitations that warrant acknowledgment. Firstly, the issue of size and diversity emerges as a concern. The participant pool is restricted in number and lacks diversity in terms of cultural and socio-demographic factors. Consequently, the findings may not be generalized to the broader population. Secondly, the reliance on self-reported data introduces a potential source of bias, as participants may be inclined to provide socially desirable responses, thereby impacting the reliability of the data. Thirdly, the requirement for mothers to recall past experiences, including early signs and symptoms and interactions with healthcare practitioners, introduces the possibility of inaccuracies or omissions in the information provided. Moreover, the study's reliance on a single time point of data collection during need assessment is a noteworthy limitation. This limitation restricts our ability to comprehend the progression and changes in parents' experiences over time.

Furthermore, the intervention study includes a follow-up period of only three months, which may limit the ability to fully assess the long-term sustainability of the intervention's effects. A longer follow-up period would provide more comprehensive insights into the enduring benefits. Additionally, the dropout rate could have impacted

the study's findings, introducing potential bias. The absence of blinding further contributes to the possibility of bias, as it may have influenced expectations and outcomes.

Future Recommendations

1. Future studies should further investigate the nuances between mothers who receive spousal support and those who do not, delving deeper into potential impacts on maternal well-being and coping strategies. Longitudinal studies tracking these differences over time would provide valuable insights into the sustained effects of spousal support.
2. Subsequent research should emphasize exploring disparities between mothers who actively participate in support groups and those who do not, shedding light on potential benefits and barriers associated with such engagement.
3. There is a need for future studies to intricately examine the influence of extrinsic factors on perceived social support among mothers, recognizing the complex interplay of various contextual elements in shaping support networks.
4. Similarly, future research should extend its focus to elucidating the diverse coping mechanisms employed by mothers of children with autism, recognizing the multifaceted nature of coping strategies and their impact on maternal resilience.
5. Future investigations should prioritize scrutinizing the quality of services rendered by special schools or centres catering to children with autism, employing comparative analyses to identify areas for enhancement and optimization.
6. Further research should devote attention to comprehensively understanding the barriers that impede certain families' access to healthcare facilities, thereby informing interventions aimed at promoting equitable healthcare access.
7. Exploring the potential influence of mothers' socio-demographic characteristics, such as education level, on their perceived support, coping strategies, and stress levels, should be a focal point for future studies.
8. Future inquiries should delve into the unique experiences and challenges faced by single mothers of children with autism, aiming to provide tailored support and interventions to address their specific needs and circumstances.

9. Future research should incorporate fidelity measures to ensure intervention consistency and reliability across different study settings. Standardized protocols and structured monitoring mechanisms can enhance the reproducibility of intervention outcomes.
10. Longitudinal studies should be prioritized in future research to assess the long-term impact of psychosocial interventions on maternal well-being, coping strategies, and perceived social support. Examining intervention effects over extended periods can provide stronger evidence for sustained benefits.

Conclusion

This study demonstrates that psychosocial interventions significantly improve the well-being of mothers of children with autism. The research highlights how these interventions can reduce maternal stress, enhance coping mechanisms, and bolster perceived social support. Immediate post-intervention improvements were evident, with reductions in stress and enhancements in coping and social support. However, maintaining these benefits over time was a central theme.

Psychosocial interventions are crucial in addressing the mental health challenges faced by mothers. By providing tailored support, these interventions help mothers manage stress more effectively and improve their overall emotional well-being. These interventions empower mothers by equipping them with practical tools and strategies to cope with the demands of raising a child with autism. This support is vital in fostering resilience and improving the quality of life for both mothers and their families. While the immediate benefits of psychosocial interventions are significant, it is essential to recognize that long-term support is necessary to sustain these improvements. Continued intervention helps mothers navigate ongoing challenges and adapt to evolving needs. Regular follow-ups and ongoing support ensure that the positive outcomes achieved through initial interventions are maintained. This continuous engagement helps prevent relapse and supports sustained emotional and psychological health. Stakeholders, including researchers, practitioners, and policymakers, must prioritize the development and implementation of long-term psychosocial support. Investing in these interventions is essential for achieving lasting improvements in the well-being of mothers and, by extension, their children.