

Raising a Child with Intellectual Disability: Parental Stress and Coping

Neha Sunil P¹, Dr. Lizy P. J², Dr. Sunitha Srinivas C³

Abstract

The disability of a child is a triadic experience involving three-way interactions between the child experiencing the dysfunction, the family affected by the dysfunction, and the outer environment where the disability is manifested (Falik, 1995). Parenting is a hard job, so having a disabled child will make things more difficult. Given that children with disabilities have impaired physical-psycho-social development, parents can find their roles very stressful when dealing with developmental issues that result in social, economic/financial problems, as well as physical and psychological problems (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010). Children's disabilities may burden their family members, especially their parents, who are their long-term caregivers. Though many studies describe and document concerns, problems, or worries that disabled children face, there were no published studies that were carried out for parents with a child with a severe intellectual disability. In India, especially in Kerala, hardly any studies are done in the area of parents of children who have a severe intellectual disability. This paper has developed from a study conducted by the author with the prime purpose of identifying the level of stress experienced by parents of children with Severe Intellectual Disabilities in Special schools in Calicut district, the coping strategies adopted by them to deal with stress, and the effect of gender and the level of education of parents on their stress levels and coping. A total of 60 parents, both fathers and mothers, were included in the study (30 fathers and 30 mothers). The statistical test employed was a two-way ANOVA to find out the significant difference between gender and educational level on the level of stress and coping. The results obtained from the analysis showed that the relationship between parental stress and coping was negative and highly significant.

Keywords: Severe Intellectual Disability, Children, Parents, Mother, Father, Stress, Coping, Quantitative design.

Introduction

Intellectual disability is defined as a developmental disability that initially appears in children under the age of 18. It is a level of intellectual functioning that is below average and results in significant issues in the person's daily living skills. It is a condition that is present from birth or childhood; the effects of ID range from mild to profound (AAMR 2002). ID in a person is defined as an IQ score below 70–75. Children who suffer from ID have difficulties with language creation and comprehension, knowledge of societal and

¹ Research Scholar, Rajagiri College of Social Sciences (Autonomous), Cochin

² Research Supervisor, Rajagiri College of Social Sciences (Autonomous), Kochi

³ Professor of English, PG Dept. of English & Centre for Research, Govt. College Mokeri, Kerala, India.

community resources, personal care and social skills, self-direction, functional academic skills, and job-related skills.

Intellectual disability varies in severity (Munro, D.J., 2006). The more severe the level of intellectual disability of the child, the more stress and severe effects are observed on the parents' stress levels and well-being (Majumdar et al., 2005). This very statement on the dependence of stress on the level of disability highlights why the Respondents chosen in this study are Parents of Children with Severe ID. There is abundant evidence that parents of severely intellectually disabled children go through more than the average amount of stress compared to children with mild/moderate. There is no universal parental reaction to the added psychological stress of raising an intellectually disabled child.

The stress of Parents raising a child with an Intellectual disability is very high, because of the extra tasks that are done, and while taking care of the child, parents feel overworked, stressed out, and unhappy. Farber (2010) found that initial stress in parents appears to be sex-linked, which shifted with time. Heller and Rowtiz, in their study on parents of children with Intellectual Disability, conducted in 2007, identified that, in comparison with fathers of intellectually disabled children, it was mothers who spent more time providing care and support and perceived more caregiving burden and stress.

Several studies have also shown that there are differences in the levels of stress and coping of parents depending on their gender and the severity of the child's disability. Mothers parenting a child with ID undergo more stressful experiences than mothers of normal children. Their marriage suffers, particularly if the mother and father take different approaches to raising the child or if one parent looks after the child all the time. This study focuses on this aspect of the effect of gender on the stress and coping of the parents who raise a child with Severe Intellectual Disability. The mother of a child with ID is often the primary carer and is acutely aware of her child's disabilities (Azar & Badr, 2006; Heller, Hsieh, & Rowitz, 2007). Therefore, many studies highlighted that the behaviour and health of the children had a more significant effect on maternal parents than on fathers and may experience tremendous stress and anxiety than fathers.

Peshawaria (2008) found the effect of gender in facilitating and inhibiting factors that affect coping in parents of children with intellectual disabilities in India, and mothers were under more pressure to balance childcare needs. To them, physical support was a relief. It also found that stress and coping are interrelated, and some parents, even though they undergo more stress, cope well and get adjusted to their situation. Goldberg, Gupta, and Kaur (2010) pointed out that one main worry for parents of Intellectually Disabled children is about the future of their child and how their children will be taken care of when they die. They feel that no one else can take care of their child with the same love, care, and attention that they do, and this makes parents, especially mothers, scared about how their child will manage to survive in her absence.

Parents of children with ID have to put in a lot of effort, both physical and mental, to rear the child, mainly as these children may not be able to take care of themselves or understand what they are being directed by their parents (K. A. Friedrich and Greenberg M T, 2012). Having a disabled child is a crisis event, and the well-being of parents depends on many factors, like their ability to deal with stress, coping skills, family and social support, financial and educational status, and the influence of religion and spirituality in the family. (Emerson, 2003 & Fazil, Wallace & Singh, 2004). The goal of the coping strategy is to help one come out of their problem and use their life and resources more productively to achieve a sense of fulfilment and balance in life. Strategies directly aimed at coping may include problem-solving, emotion-focused, or even support-focused (Bailey & Smith, 2000).

Besides, Pritzlaff (2001) conducted a study to examine the coping strategies adopted by parents with an intellectually disabled child and found that the most frequently utilized two coping strategies were adopting social support and reframing. Relying on spiritual support was the least used, but these findings do not correspond with Ayrault (2001) who stated

that some parents tend to avoid their relatives and friends and stay away from social circles, fearing that they may not understand their children's needs, and they spend much of their time caring for their children, taking them for assessment, therapy, or medical treatment. The coping strategies widely used by fathers were found to be problem-solving and acceptance, and for mothers, it was problem-solving, religion-faith, and denial-blame.

Farheen, Dixit, Bansal & Yesikar in 2008 tried to explore how families with an intellectually disabled child cope and the factors that mediate better or worse coping. A total of 100 families were randomly selected and interviewed (100 mothers & 98 fathers), and it was identified that male parents used problem-focused coping more often and mothers relied on emotion-focused coping more often. The effect of higher educational level, higher income, and higher family status was also found to be essential factors predicting higher levels of stress and coping. Previous studies have generated results that indicate that the education level of parents has an indispensable role in determining how they handle their disabled child and, in turn, how it affects their mental health.

Scope of the Study

Even though families with an Intellectually disabled child have received research attention, limited studies have been done to assess the stress and coping level of parents of children with Severe Intellectual Disability. In India, especially in Kerala, researchers hardly found studies that were done in the area of parents of children who have a severe intellectual disability. After a detailed search of the literature, the researcher did not find any study that properly related the stress and coping of parents of children with severe intellectual disability. It is essential to assess stress and the coping of parents and to identify the effect of socio-demographic variables on them so that more targeted research and intervention plans can be developed to promote the well-being of parents, which will ultimately lead to the well-being of the disabled child as well.

This study is undertaken with a prime focus on identifying the intensity of parental stress levels and coping, the strategies they usually adopt, and determining if there is a future requirement to develop target-based interventions.

Objectives

In this study, the following aspects were explored:

- 1) The level of stress and coping of parents of children with Severe Intellectual Disability.
- 2) The coping strategies adopted by parents of children with Severe Intellectual Disability.
- 3) The effect of gender and level of education on parental stress and coping.

Hypotheses

Null hypothesis

H₀= There will be no significant relationship between gender and level of education on parental stress and coping.

Alternate hypothesis

H₁: There will be a significant relationship between gender and level of education on parental stress and coping.

Research Design and Sample

This study has used a quantitative design. Sixty parents, including fathers and mothers of children with Severe Intellectual Disability (30 fathers and 30 mothers), are included in the study. The schools had a list of the level of Intellectual disability of their students, which was based on an IQ test. The samples (children with severe ID, IQ 20–35) were taken from this list. There was no age bar for the respondents in the study. Only parents of children

with Severe ID and who had children in schools for differently abled children in Calicut were included. The list of students who fall in the 13–18 age category and have severe ID was obtained from 5 schools, and from them, respondents (6 parents from each school, both father and mother) were randomly chosen.

Tools Used

A demographic profile was used to get information about the education, sex, age, and other details of the Respondents. To measure the level of stress, the perceived stress scale, a widely used psychological instrument for measuring the perception of stress developed by Cohen et al., was used. The tool, while created in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress. It measures the degree to which situations in one's life are perceived as stressful. Moreover, the questions are general and, hence, relatively free of content specific to any sub-population group. The items in the Perceived stress scale were about the Respondent's feelings and thoughts during the last month.

To assess the coping level and the strategies adopted, the COPE Inventory scale developed by Carver in 1997 was used. It is a multidimensional coping inventory to evaluate the different ways in which people respond to stress.

Data collected for the study were analysed using two-way ANOVA and SPSS software.

Procedure

Consent was obtained from special schools and Respondents after a detailed explanation of the research. The researcher informed the school authorities and respondents of the need for the study and its genuineness. The schools requested that the researcher keep the names of the Respondents as well as those of the schools confidential. With due respect for the requirement raised, the names of the five schools included in the study and the names of the respondents are kept confidential. Instructions were given to Respondents on how to fill out the questionnaires, and a time restriction was not placed.

Results and Discussion

The Stress of Respondents (Mothers and Fathers)

Shyam, Kavita & Govil, (2014) did a study on the effects of stress and burden experienced by parents of severely disabled children. A total of 100 parents having children with ID were studied, and it was found that parents having children with severe disabilities perceived significant stress in carrying out daily living activities, expressed greater financial burden, had low interaction in the family, perceived a negative impact on their physical and mental wellbeing, and had a more significant family burden compared to children without disabilities. In contrast to the findings of Shyam, Kavita & Govil, (2014), in this study, parents had low to moderate levels of stress; where the majority had low stress, only 5 percent of the respondents had extreme stress levels.

Coping of the Respondents

Some parents, even though they undergo stress, cope well and get adjusted to their situation. This study has identified that 71 percent of parents can deal with stress and are dealing with the issues, while 29 percent of parents are finding it difficult to cope.

Coping Strategies Adopted

Khan & Alam (2016) published a review article on the common trends of coping strategies used by parents of children diagnosed with various forms of developmental disabilities. Some of the conclusions of the review of papers include the impact of disability on health and well-being, which can range from physical ailments to depression; the effect of the severity of symptoms of disabilities on perceived stress; and the maladaptive coping of

parents with children with Intellectual disabilities. They tend to seek and rely on social and family support. The authors also highlight the fact that strategies widely adopted, like a realistic appraisal, optimism, religious and spiritual support, and more, make the parents feel less stressed. The results of this study are on par with the findings of Khan & Alam (2016), with the most widely adopted being religious coping and emotional support and the least adopted being humour, substance use, and behavioural disengagement.

Effect of Gender and Education level on Coping and Stress of Parents

The statistical test employed was a two-way ANOVA to find out the significant difference between gender and educational level on the level of stress and coping.

- No significant difference was observed in stress scores. [$F = 0.452, P < 0.504$] based on the gender of parents. The mean stress score of males was 111.47, and for female parents, it was 125.27, which was statistically equal.
- However, a significant difference was observed in the mean stress score of the parents who had an education level below graduation and that of those above graduation [$F = 9.095, P < 0.004$]. The mean stress score of parents who were below the graduate level of education was 131.58.
- Lastly, the effect of gender and education level was found to be non-significant, revealing that the level of stress was the same for parents with different educational levels, irrespective of their gender.
- A comparison of gender, educational levels, and coping scores gender-wise revealed that there was no significant difference in the coping scores of male and female parents [$F = 0.514, P < 0.412$]. The mean coping score of fathers was 6.84, and in the case of mothers, it was 6.73, which was statistically equal.
- A significant difference was observed in the mean coping score of the parents who had the education level of below graduation and that of above graduation [$F = 8.882, P < 0.012$]. The mean coping score of parents who had below-graduate-level education was 5.73, which is significantly lower than that of parents who had a higher level of education (mean 8.00).
- Lastly, the effect of gender and education level was not significant, revealing that the pattern of coping was the same for parents with different educational levels, irrespective of their gender, in considering the correlation between stress and coping.
- A significant and negative correlation coefficient was observed between stress and coping ($p < 0.01$), indicating that when stress scores increased, coping decreased linearly and vice-versa. In other words, stress and coping were inversely related. Few parents were able to cope with the situation of having an intellectually disabled child much better than the others, depending on their coping skills and resources.

Main findings of the present study

Stress and coping were inversely related to each other. The gender of the parents did not have an impact on the stress and coping scores; the educational level of the parents had a significant influence over stress and coping; the higher the level of education of the parents, the lesser the stress and the higher the coping. The analysis of the results showed that the relationship between stress and the coping strategies of the parents of severely intellectually disabled children was negative and highly significant.

Implications

In light of the findings that have emerged from the present inquiry and the valuable experience gained, the following implications are drawn: Although attitudes towards individuals with disabilities have improved in India in recent years, there are still some

negative perceptions towards these individuals. These attitudes affect parents, who may be more sensitive and emotional than parents who do not have a child with ID. When mothers are conscious of the stigma of a child with intellectual disabilities or they feel that other people are judging or have pity on their child, they may feel more stress than fathers. From the experience gained during this study, in the field of special education, there is still room to grow.

There is a lack of information and resources for parents of children with disabilities, especially children with ID. Additionally, there is a lack of collaboration between the schools and parents. For example, the school rarely suggests ways for the child to improve or may not communicate about the performance of the child. By recognising that the school does not help in these areas, the additional burden will be on parents. These other responsibilities may take up more of the parents' time, contributing to their stress. The results from the current study will help professionals better understand the levels of stress experienced by parents of children with ID and develop programmes and policies to improve the support provided to parents.

Based on the findings from the current study, it can be suggested that the Ministries of Education, Health, and Social Affairs should create additional channels of communication. Websites, online groups, or community centres will increase awareness regarding children with disabilities, present effective strategies, and provide advice or answer parents' questions about their children with ID. Developing and executing early intervention programmes for children with ID, aiming at providing effective services to these children to improve their skills early in life, is also very essential. These programmes should also offer parental support to help solve issues and prevent problem-causing stress. Parent's involvement is very crucial at every level and without addressing the requirements of parents of children with ID, the well-being of a child cannot be ensured.

Parents must also receive support designed to help them as parents. This support, which may include counselling, training programmes, or other types of support, will help lower parents' levels of stress regarding their children with ID. This support will help the family better understand their child's needs and provide improved care. Sandler, Coren and Thurman in 2015 researched on families participating in training programmes for parents of children with special needs, and they found that the families participating in these training programmes showed increased knowledge of techniques for instructing their children with disabilities and had more positive attitudes towards their children.

Hastings and Beck (2004) performed a selective review of numerous studies related to intervention methods designed to reduce the stress on parents of children with disabilities. Their research review revealed that cognitive behavioural group interventions had the most potential for reducing the stress of parents, particularly mothers, of children with ID. It should also be considered that it will be beneficial to create associations or regionally located centres for parents of children with ID to meet to provide support for each other through discussion-based sessions, as this would provide a place for parents to share best practices and discuss their concerns with a group of people in a similar situation. They could exchange their experiences and difficulties and discuss potential ways to further the rights of children with ID and their parents. These groups would also benefit parents by providing socialisation and preventing feelings of isolation.

When preparing future teachers of special education, universities should reinforce the importance of parental involvement in disabled children's education. They should prepare future special education teachers by teaching them strategies to increase parental involvement in their future classrooms. The school can also provide communication development training for parents, which can help them solve the problems they have in communicating with their children. Professionally qualified counsellors should be made available to parents to discuss their concerns, and this facilitates better coping, along with building and strengthening an external support system for parents. Schools can arrange for

monthly evaluation meetings on the academic performances and behaviour of their children, ensuring the participation of all parents.

Awareness programmes will help in shaping and correcting the attitudes of society towards Intellectually Disabled children, and public awareness programmes at the local level will help reduce these social problems. The community will be aware of the issues faced by families of Intellectually Disabled children; thus, they can help in alleviating their problems. One of the main reasons for parents' stress is financial constraints. The condition of Intellectual Disability requires a lifelong commitment of time, energy, and resources by the family. They have to plan well ahead of time and anticipate the needs of the child in the future. The financial needs of these families are greater as they have to find extra money to spend on the special education, training, and treatment of this child. They should be given proper orientation towards the available financial grants from the government and help to get them.

Suggestions for further research

The present study was conducted only on parents of children with Severe Intellectual Disability. In the future, studies can be done on other levels of ID and also on the whole family (siblings, grandparents), as all the family members can be equally affected by the problems of having an Intellectually Disabled child. Also, studies should be done on primary carers, who, according to the researcher's experience in the current study, were mostly mothers; the same can be assessed in different areas, and studies can be done accordingly. A similar study may be conducted with a larger sample drawn from all special schools in the state. An investigation may be performed to compare the problems and coping of parents with children in special schools and with children not attending special schools. The quantity of support available to parents of Intellectually Disabled children can also be studied. An attempt may be made to study the role of rehabilitation programmes in the curriculum of special education as well.

Declaration

The authors have no conflicts of interest to declare.

Bibliography

JOURNALS

1. Ahmann. (2006). A comparison of coping strategies of ageing mothers of adults with Mental Illness /Intellectual Disability. *Psychology and Aging*, 64-75
2. Ayrault. 2001. Families of young children with handicaps, parental stress and family functioning. *American Journal On Intellectual Disability*, 165-171.
3. Byre & Cunningham. 2015. Stress and coping among parents of disabled children, a multidimensional approach. *American Journal Of Intellectual Disability*, 240-249.
4. Carpinello. 2005. Maternal expressed emotion, attributions and depression and entry into therapy for children with behaviour problems. *British Journal of Clinical Psychology*, 213 -216.
5. Drortar, D., 2011. Relating parent and families to the psychological adjustment of children with chronic health conditions. *Journal of Pediatric Psychology*, 149-165.
6. Faber. 2010. Families of young children with handicaps, parental stress and family functioning. *American Journal on Intellectual Disability*, 623-629.
7. Goldberg, Gupta & Kaur. 2010. Marital adjustment in families of young children with disabilities. *American Journal on Intellectual Disability*, 1-14.
8. Gupte. 1998. Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal*, 22-35.

9. Hastings & Beck .2004. Psychoeducational interventions for family caregivers. *Journal of Behavior Therapy*, 321-330.
10. Heaman. 2006. Mothers' and fathers' perceptions of stress and coping with children who have severe disabilities. *American Journal on Intellectual Disability*, 99- 110.
11. Heller T & Rowtiz L. 2007. Maternal and paternal caregiving of persons with Intellectual Disability. *Family Relations*, 128-132.
12. Hurwitz. 2000. Family's role in providing support to disabled persons in India's changing times. *International Journal for the Advancement of Counseling*, 1 -27.
13. Jain. 2009. Positive adaptation in parents of adults with disabilities, education and training in Intellectual Disability and Developmental Disabilities U.S council for Exceptional children. *Journal on Intellectual Disability*, 123- 130
14. KA Fredrich & Greenberg MT. 2012. Adaptation of families with Intellectual Disability. *Journal of Mental Deficiency*, 125-138.
15. Kazak, A., 2017. Families with disabled children, stress and social network in 3 samples. *Journal of Abnormal Psychology*, 137-146.
16. Khan & Alam. 2016. Parental perceptions of stress and coping, families of children with and without disabilities. *Journal of Clinical Psychology*, 143- 149.
17. Lewin, K 2004. *Frontiers of Group Dynamics: Concept, method and reality in social science, social equilibrium, and social change*". *Human Relations*, 15–41.
18. Margalit.M. 2019. A study of behaviour disorders in moderately retarded children and their relation to parental attitude. *Indian Journal of Clinical Psychology*, 27-31.
19. Marika.V. 1999. Stress and coping in parents of children with Down syndrome. *British Journal of Clinical Psychology*, 49-53.
20. Marshall. 2013. The impact of behaviour problems on caregiver stress in young people with Intellectual Disability. *Journal of Intellectual Disability*, 172–183.
21. Munro, D., 2006. Epidemiology and extent of Intellectual Disability. *Psychiatric Clinics of North America*, 591-593.
22. Nand & Shukla. 2015. Impact of Intellectually Disabled children on the family. *Journal of Clinical Psychology*, 473-478.
23. Nehring. 1994. A follow-up study of Intellectual Disability focusing on parental attitudes. *Indian Journal of Psychiatry*, 370-376.
24. Perret & Batshaw. 1992. Children with disabilities. *A Medical Primer*, 664-669.
25. Pritlaff. 2001. Social support of mothers of children with Intellectual Disability. *American Journal of Intellectual Disability*, 110-152.
26. Peshwaria. 2008. Differentiated coping strategies in families with children or adults with intellectual disabilities, 'The relation of gender, family composition and the life span. *Journal of Applied Research on Intellectual Disabilities*, 235-270.
27. Reckman, P., 1999. Comparison of mothers and fathers perception of the effect of young children with and without disabilities. *American Journals On Intellectual Disability*, 585-595.
28. Sandler, Coren & Thurman. 2015. Families of Adults with Intellectual Disability, stress level, depression and need for services. *Journal Of Intellectual and Developmental Disability*, 371-374.
29. Waisbem. 2008. Stress and coping in parents of children with Intellectual Disability. *Psychology and Aging*, 41-44
30. Wikler. 2011. Predictors of stress in parents of developmentally disabled children. *Journal of Psychology*, 133-150.

BOOKS

1. Annapurna. 2007. *Mentally disabled children and family stress*. New Delhi: Discovery publishing house.

2. Farheen, Dixit, Bansal & Yesikar. 2008. *The ways of coping*. Newyork: Consulting Psychologist Press.
3. Folkman S & Lazarus RS. 1984. *Coping and emotions*. Newyork: Columbia University Press.
4. Schafer. 2004. *Stress management for wellness*. Philadelphia: Pearson Education.
5. Sefye. 2016. *Fundamentals of nursing Intellectually Disabled, process and practice*. Philadelphia: Pearson

WEBSITE

1. AAMR. 2002, February 3. *Intellectual disability: definition, classification and system of support*. Retrieved June 27, 2019, from American Association of Intellectual Disabilities: <http://www.aiimr.org>