

“A Study to Assess the Emotional Impact of Child with Developmental Disabilities Among Their Parents Attending Aathichudy Special School Puducherry”

MRS. K. DEEPALAKSHMI¹, DR. G. MUTHAMILSELVI², ILLAKIA. G³,
JAMUNA⁴, JAYAGANESH. D⁵, JAYASURIYA. J⁶, JAYASURIYA. A⁷

¹Assistant Professor, Department of Child Health Nursing, SMVNC, Puducherry,

²Principal, SMVNC, Puducherry,

³⁻⁷B.Sc. Nursing IV-Year, Sri Manakula Vinayagar Nursing College, Puducherry-605 107.

ABSTRACT

Intellectual and developmental disability (IDD) is a neurodevelopment disability that results in impairment of intellectual functioning along with poor social, communication and interpersonal skills. It affects 1%–3% of the population with the age of onset being before 18 years, The etiology of IDD is multi factorial. The majority of the cases arise because of environmental and psychosocial factors, such as, malnutrition, certain viral infections during pregnancy, etc. Approximately 25% of the cases result from a chromosomal or metabolic abnormality. The disorder presents either as a single entity or occurring in association with other disorders like fragile X and Rett syndrome . IDD is often represented by an IQ of 70 or less; it can be sub classified as moderate, i.e. IQ of 50–70, and severe, i.e. IQ below 50.

(Keywords: Developmental Disabilities, Emotional Impact, Parental Stress, Caregiver Burden, Special School, Puducherry)

I. INTRODUCTION:

Childhood is a vital stage of growth involving physical, cognitive, and psychosocial development. According to World Health Organization, developmental disabilities are long-term conditions affecting a child's functioning in multiple domains. Intellectual and Developmental Disability (IDD) is characterized by limitations in intellectual ability and adaptive behavior, usually with an IQ below 70. Children with developmental disabilities require continuous care and support, placing significant emotional and psychological burden on parents. Parents often experience stress, anxiety, and social challenges while managing the child's condition. Hence, this study aims to assess the emotional impact among parents of children with developmental disabilities attending Aathichudy Special School, Puducherry.

NEED FOR STUDY

Worldwide, about 52.9 million (8.4%) children under five years are affected by developmental disabilities, with nearly 95% living in low- and middle-income countries. In India, 2.21% of the population (26.8 million) lives with disabilities, with 69% residing in rural areas. In Tamil Nadu, around 1.17 million individuals are affected, indicating a significant regional burden, including areas like Puducherry. Children with developmental disabilities require long-term care, placing a substantial emotional and psychological burden on parents, which is often overlooked. Hence, this study is needed to assess the emotional impact among parents and to identify the need for supportive interventions.

STATEMENT OF THE PROBLEM:

A study to assess the emotional impact of a child with developmental disabilities among their parents attending Aathichudy Special School, Puducherry.

OBJECTIVES:

- To assess the emotional impact among parents having children with developmental disabilities.
- To associate the level of emotional impact and quality of life among parents having children with developmental disabilities with their selected demographic variables.

II. RESEARCH METHODOLOGY:

RESEARCH APPROACH:

The present study adopted a quantitative research approach using a descriptive design to assess the emotional impact among parents of children with developmental disabilities.

RESEARCH DESIGN:

A descriptive design was used for this study.

SETTING OF THE STUDY

The study was conducted at Aathichudy Special School, Puducherry, which provides care and education for children with various developmental disabilities.

POPULATION

The target population included parents (specifically mothers) of children diagnosed with developmental disabilities and enrolled in Aathichudy Special School.

SAMPLE

The sample consisted of 100 mothers of children with developmental disabilities attending Aathichudy Special School, Puducherry.

SAMPLE SIZE

The sample consisted of 100 mothers.

SAMPLING TECHNIQUE

A convenient sampling technique was used in this study.

DESCRIPTION OF RESEARCH TOOL TECHNIQUE

Section: A - Demographic Variables

Demographic variables of children Age, weight, APGAR score, mode of delivery, gestational age, any congenital anomalies, birth order, passing of stool and urine after birth, type of feeding.

Section : B – Standardized questionnaire

This section consists of rating scales for quality of life among children which includes self care(feeding, dressing, grooming, toileting), mobility (crawling, walking, climbing, transfers), social function (communication, play, problem solving, interaction). Based on the observation the score will be selected from rating scale.

SCORING INTERPRETATION:

S.No	STAGES	SCORE
1.	High difficulties	0-8
2.	Moderate difficulties	9-16
3.	Low difficulties	17-24

Section: C – Self developed questionnaire

Yes or no type questionnaires given to assess the parental distress among mothers have children with disabilities in rural population in Puducherry.

SCORING INTERPRETATION:

S.NO	STAGES	SCORE
1.	Mild parental distress	0-7
2.	Moderate parental Distress	8-14
3.	Severe parental distress	15-20

STUDY FINDINGS:

SECTION A: Description of demographic variables of mothers having disabilities children..

SECTION B: Assessment of the level of emotional impact and quality of life among mothers having disabilities children

SECTION C: Association of the level of emotional impact and quality of life among mothers having disabilities children with selected demographic variables.

SECTION A: Description of demographic variables of mothers having disabilities children

Table 1: Frequency and percentage wise distribution of demographic variables of mothers having disabilities children. N=100

The demographic profile of the parents is presented in the table. The majority of parents (40%) were aged between 26–35 years, followed by 30% each in the age groups of below 25 years and 36–45 years. All participants were female (100%), and all of them were mothers of the respective children. Regarding educational qualification, 40% of parents had secondary education, 30% had no formal education, while 10% each had primary and higher education. Concerning occupation, 40% of parents were unemployed, 30% were daily wage workers, and another 30% were private employees. In terms of monthly family income, 60% of the parents reported earning less than ₹10,000, 30% earned between ₹10,000–20,000, and 10% earned between ₹20,000–30,000. With respect to family structure, 50% of parents belonged to nuclear families, 30% to joint families, and 20% to extended families. Most parents were married (90%), whereas 10% were widowed and 5% were divorced. The majority of parents (80%) had two children, while 10% each had one or three children. Regarding the duration of illness, 40% reported less than one year, while 30% each reported 1–3 years and 4–6 years. This distribution indicates that the study population was primarily composed of married mothers from nuclear families with low educational levels and family income, a significant proportion of whom were unemployed.

Table 2: Frequency and percentage wise distribution of demographic variables of children having disabilities children. N=100

The demographic profile of the children with disabilities is summarized in Table 2. Half of the children (50%) were in the age group of 5–8 years, followed by 40% in the 9–12 years category, while only 10% were aged 13 years and above. In terms of gender distribution, 60% of the children were male, and 40% were female. With respect to the type of developmental disability, 40% of the children had intellectual disabilities, 30% had autism, 15% had limb deformities categorized under "others," 10% were diagnosed with Down syndrome, and 5% had cerebral palsy. Regarding the duration since diagnosis, 40% of the children were diagnosed within the past year, while 30% each had been diagnosed for 1–3 years and 4–6 years, respectively. In terms of severity, the majority of children (80%) had mild disabilities, while 20% had moderate disabilities. All the children (100%) were reported to be receiving therapy. Among the types of therapies received, behavioral therapy was the most common (70%), followed by physiotherapy (20%) and special education (10%). Furthermore, 80% of the children traveled to school using personal vehicles, whereas 20% reached school by walking.

Section B: Assessment of the level of emotional impact and quality of life among mothers having disabilities children.

Table 3: Frequency and distribution of the level of emotional impact among mothers having disabilities children.

S.N O	Level of emotional impact	Frequency (n)	Percentage %
1.	High	30	30
2.	Moderate	50	50
3.	Low	20	20

The above table shows that 61% of the mothers experience low levels of distress, while 37% report moderate levels of distress. Only 2% of the mothers experience high levels of distress. This indicates that most mothers experience relatively low to moderate distress, with a small proportion facing high distress related to raising children with disabilities.

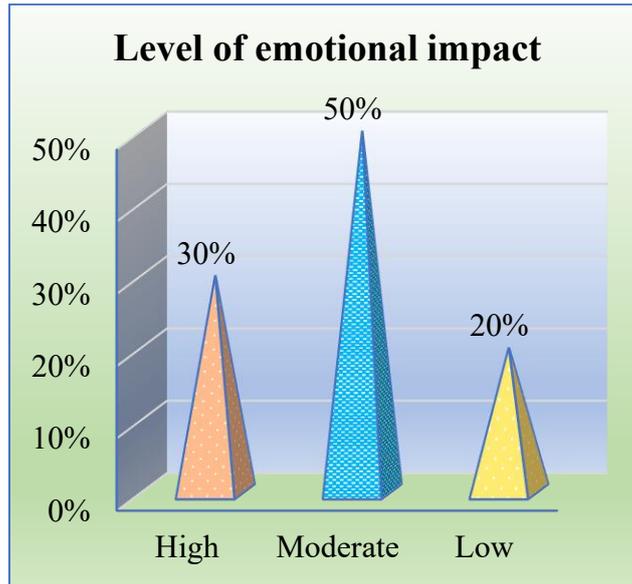


Figure 12: Percentage wise distribution of level of emotional impact among mothers having disabilities children.

Table 4: Frequency and distribution of the quality of life among mothers having disabilities children.

S.N O	Quality of life	Frequency (n)	Percentage %
1.	Mild	17	17
2.	Moderate	83	83
3.	Severe	0	0

Figure 12: Percentage wise distribution of quality of life among mothers having disabilities children.
Section C: Association of the level of emotional impact and quality of life among mothers having disabilities children with selected demographic variables.

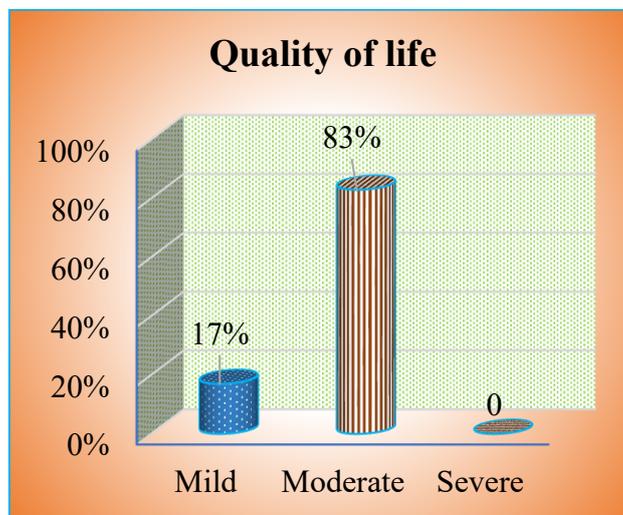


Table 5: Association of the level of emotional impact among mothers having disabilities children with selected demographic variables.

* Significant at P ≤ 0.05 level

The above table shows that there is a significance association of age of the baby and gestational age with the level of parental distress among mothers having disabilities children.

Tabel 6: Association of the quality of life among mothers having disabilities children with selected demographic variables.

*** Significant at $P \leq 0.05$ level**

The above table shows that there is a significance association of weight of the baby during birth and model of delivery with the quality of life among mothers having disabilities children.

III. CONCLUSION

The present study assessed the parental distress and quality of life among mothers of having disabilities children in the selected area. The study findings concluded that majority of the mothers experience low levels of distress and had moderate quality of life. There is a significant association between education and dietary patterns with the level of depression among cancer patients. Similarly, there is a significant association between the birth weight of the baby and the mode of delivery with the quality of life among mothers of children with disabilities.

NURSING IMPLICATIONS

- The findings of this study have implications for nursing practice, education, administration, and research in managing parental distress and improving the quality of life among mothers of children with disabilities.

NURSING EDUCATION

- Nurse educators should design and conduct educational programs to enhance understanding of the emotional and psychological challenges, particularly distress and reduced quality of life, experienced by mothers of children with disabilities.
- Educational programs should emphasize the integration of mental health support into pediatric and maternal care, promoting coping strategies to manage stress and emotional burden.
- Training should equip nurses with the skills to identify early signs of parental distress and emotional exhaustion, enabling timely intervention and support.

NURSING PRACTIC

- The study results can help nursing personnel recognize the psychological distress experienced by mothers of children with disabilities and understand the specific coping mechanisms they may adopt.
- Nurses play a crucial role in providing emotional support, guidance, and resources to mothers, ensuring that they receive appropriate psychological and social assistance.
- Incorporating regular mental health screenings and support mechanisms in pediatric and maternal care will help address distress and improve the well-being of mothers.

NURSING ADMINISTRATION

- In-service training programs should be arranged to educate nursing staff on the psychological challenges and stressors faced by mothers of children with disabilities.
- Awareness initiatives should focus on recognizing symptoms of distress, encouraging early interventions, and ensuring comprehensive maternal mental health care.
- Administrators should advocate for accessible mental health support, including counseling services, peer support groups, and stress management programs for mothers.

NURSING RESEARCH

- The findings of this study can guide the development of evidence-based interventions to reduce parental distress and enhance the quality of life of mothers caring for children with disabilities.
- Future nursing research can explore the effectiveness of various interventions (e.g., counseling, mindfulness practices, community support programs) in alleviating stress and improving coping strategies among these mothers.
- Additional studies should investigate the long-term psychological and social impact of caregiving on maternal mental health, focusing on resilience-building strategies and holistic support systems.

RECOMMENDATIONS

- A similar study could be conducted with a larger sample size across multiple healthcare settings to enhance the generalizability of the findings.
- Future research could explore the impact of different types and severity of disabilities on maternal distress and quality of life, as well as the role of family and social support systems in mitigating stress.

- Further studies should examine the long-term effects of caregiving on maternal mental health, emphasizing coping mechanisms, emotional resilience.

BIBLIOGRAPHY

JOURNAL REFERENCE:

- [1]. Abbeduto L, Seltzer MM, Shattuck P, Krauss MW, Orsmond G, Murphy MM. Psychological well-being and coping in parents of children with disabilities. *Res Dev Disabil.* 2004;25(4):44-70.
- [2]. Bailey DB, Golden RN, Roberts J, Ford A. Maternal depression and developmental disability: Research recommendations. *Am J Ment Retard.* 2007;112(3):1-13.
- [3]. Baker BL, Blacher J, Olsson MB. Stress in families of children with intellectual disabilities. *J Intellect Disabil Res.* 2005;49(6):15-30.
- [4]. Dykens EM, Fisher MH, Taylor JL, Lambert W, Miodrag N. Reducing distress in mothers of children with disabilities: A randomized trial. *Pediatrics.* 2014;134(2):80-100.
- [5]. Dyson LL. Parental stress and adaptation in families of children with developmental disabilities. *J Dev Disabil.* 1997;20(3):112-135.
- [6]. Deepalakshmi.k et.al .A study to assess the psychosocial impact due to Lockdown among school going children at selected community area Puducherry, *Journal of Medical and Dental science Research Review*, Vol -11, Issue03, Indexed, IF-6.89,2024.
- [7]. Deepalakshmi.k et.al A study to assess the malnutrition level from Gomez's classification among under five children at Kalitheerthalkuppam, Puducherry. *Journal of Medical and Dental Science Research*, Volume11,Issue6,Indexed, IF-6.89.June2024
- [8]. Deepalakshmi.k et.al A study to assess the prevalence rate towards child abuse among parents of school age child at Sanniyasikuppam, Puducherry *Journal of Medical and Dental Science Research*, Volume11,Issue6,Indexed, IF-6.89.June2024
- [9]. Emerson E. Mothers of children and adolescents with intellectual disabilities. *J Dev Disabil.* 2003;34(5):78-102.
- [10]. G. Sathyavathy, "A Study to Assess The Compassion Fatigue, Moral Distress, And Work Engagement In Emergency And Intensive Care Units Among Nurses In, SVMCH, At Puducherry", *International Journal Of Novel Research And Development, IJNRD*, Volume 1, Issue 3, June, 2023, ISSN: 2456-4184.
- [11]. Gallagher S, Phillips AC, Drayson M, Carroll D. Parental stress and immune function in children with developmental disabilities. *J Dev Behav Pediatr.* 2009;30(1):56-78.
- [12]. G. Sathyavathy, Effectiveness of deep breathing exercises on reduce cancer pain and stress, *International Journal of renewable energy exchange- JTTU*, 2321-1067/Volume 10, ISSUE 6, PP 85-92.
- [13]. Hastings RP. Parental mental health and stress in families with children with disabilities. *J Appl Res Intellect Disabil.* 2002;15(5):44-60.
- [14]. Hodapp RM, Urbano RC. Quality of life in families of children with intellectual disabilities. *J Ment Retard.* 2007;45(5):25-55.
- [15]. Lai SK, Oei TPS. Factors influencing parental stress in families of children with special needs. *J Dev Behav Pediatr.* 2014;35(1):24-30.
- [16]. Lecavalier L. Behavior problems in children with developmental disabilities. *Res Dev Disabil.* 2006;27(3):56-78.
- [17]. Minnes P. Family stress associated with caring for children with developmental disabilities. *J Ment Retard.* 1988;26(5):67-92.
- [18]. Olsson MB, Hwang CP. Depression in mothers and fathers of children with intellectual disabilities. *J Intellect Disabil Res.* 2001;45(6):67-95.
- [19]. Rezendes MR, Scarpa A. Parenting stress among mothers of children with disabilities. *J Autism Dev Disord.* 2011;41(3):45-60.
- [20]. Singer GH. Meta-analysis of interventions for parents of children with disabilities. *J Ment Retard.* 2006;111(3):112-135.
- [21]. Wang M, Michaels CA, Day MS. Stresses and coping strategies in families with children with disabilities. *J Spec Educ.* 2011;45(1):35-50.

NET REFERENCE:

- [22]. <https://www.apa.org/parenting-special-needs>
- [23]. <https://www.autismspeaks.org/parenting-support>
- [24]. <https://www.cdc.gov/ncbddd/disabilityandhealth/parents.html>
- [25]. <https://www.hhs.gov/programs/parental-stress-disabilities>
- [26]. <https://www.jamanetwork.com/journals/jama/fullarticle/2787652>
- [27]. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3601272>
- [28]. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5183822>