

Parental Attitude towards Intellectual Disability and its Impact on Family Relationships among Parents of Children with Intellectual Disability

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Abstract

The birth of a child is happy news but, if it is born with some developmental delays, then it leads to burden for family in taking care of such child. However, the diagnosis of a child with Intellectual disability can trigger a range of emotional responses in parents and across the whole family. Parenting a child with intellectual disability is a difficult task, which causes lots of emotions, and hopelessness among parents and family members. Thus, it is important to understand the parent's attitude and its impact on family relationships to provide appropriate nursing intervention to promote psychological well-being of the parents. In this descriptive cross-sectional study of 75 participants attending IPD and OPD, department of psychiatry, Christian Medical College, Vellore the sample consisted of mothers of children with intellectual disability attending Child and Adolescent Psychiatry. Consecutive sampling technique was used. The data was collected using demographic profile of the parents, clinical profile of the child, parental attitude towards mentally retarded children. Majority of the parents (84%) had negative impact on family relationship and a negative correlation between parental attitude and negative impact on family relationship. It was found that there was a significant positive correlation between parental attitude and positive impact on the family relationship. The study identified higher negative impact among parents of children with intellectual disability. Therefore, specific nursing intervention could be done to change the negative attitude to positive.

Key words: Intellectual disability, parental attitude, impact on family relationship

Intellectual disability (ID) contributes to 10.8 percent of the burden of mental disorders, measured by disability-adjusted life-years, in India. In narrative reviews, ID is prevalent in 1.0 - 3.2 percent of the population in India depending on the definition of prevalence, study population, study design, and measures used to identify ID. Among individual studies, the prevalence of ID in the country varied from 0.28 to 20 percent (Russell et al, 2022). About 3 percent of the worldwide population is diagnosed with mental retardation. In India, about 20 million people are mildly retarded; 4 million people are moderately and severely retarded. Among these, boys are more affected than girls. The incidence of mortality is high in severe and profound retardation due to the associated physical condition (Fay J. Hosking, et al).

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Parental attitude influences the way parents treat their children, which influences their children's attitude toward them and the way they behave. Fundamentally, therefore, the parent-child relationship is dependent on the parents' attitudes. The attitude of the children depends on the parents attitudes and relationship with them. If the attitude of mothers is negative, psychological intervention for their children may be less effective (Sribas, 2013). Studies reveal that very often the parents as well as relatives have a negative attitude towards their children with disabilities (Niranjan, 2013). No parent would like his or her child to have any deficits in their intellectual, developmental, physical, or psychological domains, but often, some children have a temporary or permanent disability or disorder, which may have a profound impact on the family (Kumar & Singh, 2012).

To a parent, every child is special in his or her way. However, some children have special needs that challenge parents to find ways to best prepare these children for the future and to handle any problems that may occur. Aim of this study was to understand

the level of impact on the parents and their family relationship of the children with intellectual disability.

Need for the study

Intellectual disability is one of the major aspects of the bio-psychosocial problem among children. The children's behavioural reactions are the by product of several interacting forces and therefore, a disabled child or the discovery of such a disability can have a profound effect on the family (Niranjan, 2013).

Each child and family is unique. Many factors can influence the well-being of a family. One of them is certainly the emotional and physical health of the parents. Parents are the ones who deal with the issues associated with their child's disability and they are required to maintain the household (Niranjan, 2013). The prospects of people in caring for disabled children has shown a negative trend and sometimes, even the parents show negligence and want to abandon their children (Subhash et al, 2014).

The presence of a child with a developmental disability in the family calls for a lot of adjustment on the parents and other family members (Malhotra, Khan, & S Bhatia, 2012). Mohanty (2011), in his study on "Disability Impact and Family Efficiency in Parents of ID Children" found that attitude plays a major role in behaviour. It is essential to know the attitudes of parents towards ID. Subhash et al (2014), reported that attitude and needs are interconnected; extra concerns and needs are expected when the parents express a positive parental attitude.

Children with disabilities receive much support from their families. Some families are single-parent families, but for others, the relationship between the parents is a factor that can influence the family's well-being. When the parents' relationship is a strong and supportive one, it enriches family life for all members. One report proves that if a family has a child with a disability it will affect everyone in the family (Ravindranadan & Vidhya, 2018).

According to the researchers' experience of having interacted with parents of children with ID, it has been found that different attitudes exist and their impact on the family relationship certainly prevails. However, the impact on the family relationship varies from person to person. The studies done in India on this subject are few. Hence, this study was undertaken.

Objectives

1. To assess the parental attitude towards intellectual disability.
2. To assess the level of family relationships of parents of children with intellectual disabilities.
3. To identify the relationship between parental attitude and the level of family relationship.

4. To explore the association between parental attitudes and family relationships with selected socio-demographic (parents) and clinical variables (child).

Review of Literature

Prevalence of intellectual disability: The World Health Organization (WHO) estimates that globally over 450 million people suffer from mental disorders. Currently, mental and behavioural disorders account for 12 percent of the global burden of disease. This was likely to increase to 15 percent by 2020 (Sharma et al., 2016). In India prevalence of intellectual disability varies from 1.7- 32 per thousand population. By a rough estimate, about 2 percent of the Indian population constitutes persons with intellectual disability (Lakhan et al, 2015). Intellectual disability is about 20 per 1000 in the general population. In rural areas, the incidence of Intellectual disability is 3.1 percent, and in urban, it is 0.9 percent. The NIMH mentions that 2 percent of the general population has mentally retardation. Three-quarters of them are with mild retardation and one-fourth is with severe retardation (Velayutham, Kangusamy, & Mehendale, 2017).

Attitude of parents on intellectual disability: Attitude is defined as a mental and neural state of readiness, organised through experiences exerting a directive or dynamic influence upon the individual's response to all objects and situations to which it is related (Subhash et al, 2014). Shobana & Saravanan (2014), in their study on "Attitudes and Psychological Problems of Mothers towards their Children", have pointed out that mothers of children with intellectual disabilities were found to have the most negative attitude towards their children. Mohammad & Ahmed (2015) conducted a study to explore the attitude of parents toward their children with intellectual disabilities. Results showed that there was a parental negative attitude towards children with intellectual disabilities, and there is a positive correlation of overprotection with education and future, home management, and total attitude. The study has proved that psychological counselling is effective in modifying mothers' negative attitudes toward their children with intellectual disabilities (Coumaravelou & Karuppannan, 2012).

Impact on the family relationship: The presence of a child with an intellectual disability in the family calls for a lot of adjustment on the part of the parents and the family members (Subhash et al, 2014). An Indian study by Niranjan (2013) highlighted that the parent of an intellectual disability faces many challenges such as physical problems, emotional stress, psychological disturbances, family problems, and an additional financial burden for the family. The quality of life of parents with children with ID has shown significant impairment in physical, psychoso-

cial, social, and environmental aspects. Significantly, both the mother and father's social relationship is impaired very severely (Sumit, 2015).

Methodology

A descriptive cross-sectional study was adopted; it was conducted at department of Child and Adolescent Psychiatry, Christian Medical College, Vellore. Consecutive Sampling technique was used to obtain sample from 75 parents of children with intellectual disability. Data was collected over a period of 6 week period, i.e from 22.01.18 to 04.02.18, using parental attitude towards mentally retarded children parameters (Ranbir Bhatti, 1985) and National Institute for the Mentally Handicapped Disability Impact scale (Reeta, et al, 2000). Prior to data collection departmental permission and ethical clearance was obtained from the institutional Ethics committee. Informed written consent was taken from the subjects. Data was analysed using SPSS 16 version.

Description of the Tool: The parental attitude scale uses 56 items of Likert's method of summated rating which has high reliability and validity (Kuppusamy, 1987). It has four sub-scales namely, orientation of parents towards child rearing, knowledge of intellectual disability, attitude towards intellectual disability and attitude towards management of intellectual disability.

Interpretation: 56 items have different scoring ranging from 0 to 4. The overall minimum score is 78 and the maximum is 118. The median value from the total parental score was considered as the attitude score. In this study, scores greater than 101 is considered positive attitude and score less than 101 is considered as negative attitude.

NIMH Disability Impact scale is culturally specific, to identify the nature and degree of impact on the parents (both positive and negative) having a child with Intellectual disability. The scale measures 11 areas of the impact in the family, which include physical care, health, career, support, financial, social, embarrassment/ridicule, relationship, sibling effect, specific thoughts, and positive effect. This tool has a test-retest reliability of 0.75 and good content, construct and face validity. The inter rater reliability was found to be $r=0.849$, $p<0.001$.

Scoring: For the domain 1-10 the scoring are as follows: for the 11th domain it is reverse scoring. 0 -No difficulty and Not at all; 1-some difficulty & sometimes; 2-lot of difficulty and most of the times.

For the 11 domain, the scores are as follows: 2-lot of effect, 1-some effect, 0-no effect.

Results

Figure 1 reveals that 54.67 percent of the mothers had positive attitude whereas, 45.33 percent moth-

ers had a negative attitude. The overall parental attitude mean score was 101.05 ($SD\pm 8.571$). The mean score of selected domains of parental attitude regarding intellectual disability orientation to child rearing, knowledge of Intellectual disability, attitude towards intellectual disability, attitude towards management of intellectual disability were 68.78 ($SD\pm 7.93$), 14.17 ($SD\pm 2.65$), 9.65 ($SD\pm 2.73$) and 8.71 ($SD\pm 1.505$) respectively.

Figure 2 shows 84 percent negative impact and 16 percent positive impact on family relationship of parents of children with intellectual disability. The overall mean impact score on the family relationship of negative and positive impact was 28.47($SD\pm 18.41$) and 10.72 ($SD\pm 2.287$), respectively.

As the parental attitude score decreases; there is a decrease impact on the negative aspects of the family relationship. However, it was statistically not significant ($r=-0.15$; p value=0.19).

Figure 4 illustrates that as the parental attitude score increases; there is an increase in the positive aspects of the family relationship. However, it was statistically significant ($r=0.31$; p value=0.007).

Discussion

Socio demographic and clinical variables of parents and child: The majority (61.3%) of the parents were

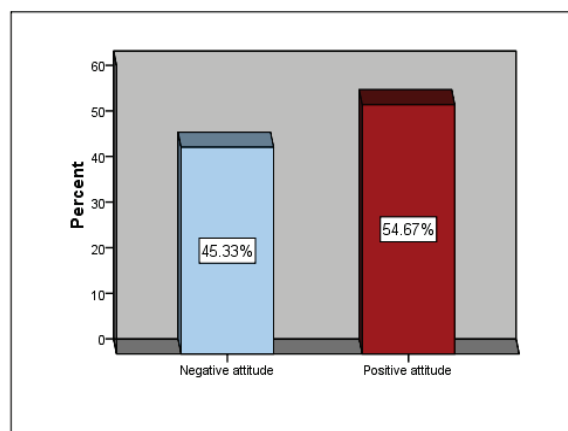


Fig 1: Distribution of subjects based on parental attitude on intellectual disability.

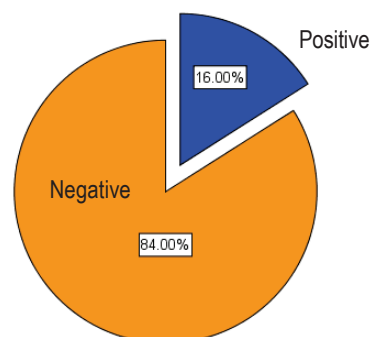


Fig 2: Impact of family relationship on children with intellectual disability.

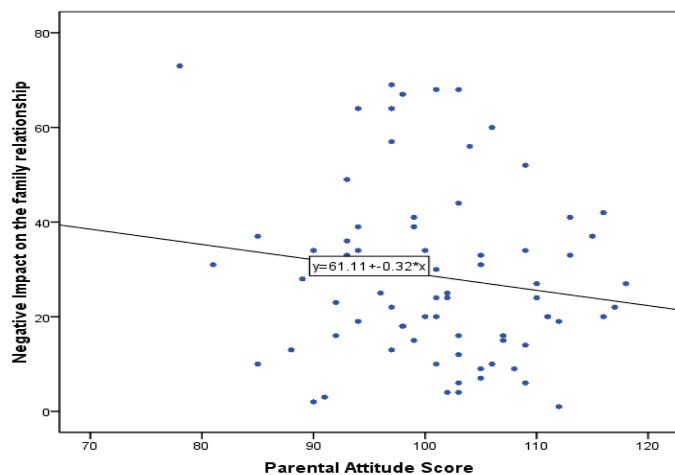


Fig 3: Correlation between parental attitude and negative impact on family relationship.

between 26-35 years, and 52 percent families have two children. Majority of the parents (62.7%) were living in nuclear families and 52 percent of families living in urban areas. Most of the parents (38.7%) had an education up to the graduate level, 49.3 percent of the mothers were homemaker. The majority of the children (45.8%) fell in the age group of 6-12 years, 80 percent of the children were male, and 64 percent were the first born in the family. 38.7 percent were diagnosed with intellectual disability disorders and 29.3 percent were unspecified. Most of the children's identification of symptoms were between 0-5 years (84%). The majority (94.7%) were undergoing treatment for a period of 0-5 years. Most of the families (93.3%) had no history of mental illness, and 92 percent had no history of intellectual disability.

The level of family relationships of parents of children with intellectual disability: The findings of the current study showed that negative impact on the family relationship is 17.36 percent, which is supported in a study done by Suchismita Pahantasingh et al, (2018) "Attitude of Parents towards Their Intel-

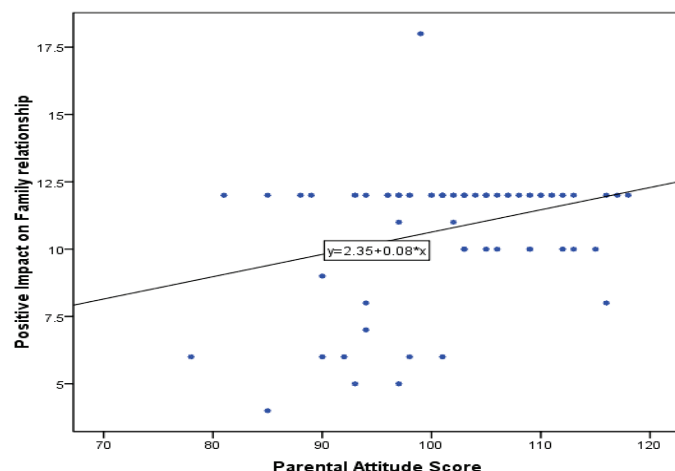


Fig 4: Correlation between parental attitude and positive impact on family relationship.

** Correlation is significant at the 0.01 level (2-tailed) (N=75).

lectually Disabled Children and its Associated Psychosocial Impact on Them" which reported 7 percent mild and severe negative psychosocial impact. It was also found in the present study that mothers were having maximum negative impact on the domains like 'finance' (31.75%) and 'embarrassment' (25.14%) areas. These findings proves that the mothers could be from a low socio-economic background or middle-class family not having enough funds to allocate in order to meet the needs and train their children. However, the least negative impact is noticed in the domains of specific thoughts (7.61%) and career activities (8.86%).

The current study findings reveal that the positive impact on the family relationship is 59.9 percent. This finding is supported by Suchismita Pahantasingh et al (2018), which reported 90 percent. These may be because mothers verbalised that they develop an attachment and a sense of responsibility to meet the Child's need as they find joy even in small significant improvement in the child's condition.

Relationship between parental attitude and the level of family relationship: The findings of the study showed that there is a negative correlation between parental attitude and negative impact on the family relationship ($r = -0.15$; $p = 0.19$), which revealed that as the parental attitude score increases, there is a decrease in the negative impact of the family relationship. However, no related study was found between these two variables. Few mothers reported that they develop a hostile attitude towards their mentally retarded children because the failure of the child to perform as other children in the competitive society. It further increases family stress. In addition, certain factors like limited financial resources, insufficient support system, and lack of services contributed to the impact on the negative family relationship. This finding is supported by a study that assessed the 'parental attitudes towards children with Intellectual disability', which found that acceptance was found to be negatively correlates with education and future, hostility and home management. In addition, rejection was also found to be negatively correlated with permissiveness, whereas a highly negative correlation was found in the aspect of permissiveness with education and future (Shamin & Osman, 2015).

The current study also found a significant positive correlation between parental attitude and positive impact on the family relationship having children with intellectual disability ($r = 0.31$; $p = 0.007$). This implies that as the parental attitude score increases, there is an increase in the positive impact of the family relationship, which is supported by Suchismita et al (2018). Considering their child's future as important as their own self, the

parents are ready to help their children becoming independent and to be self-reliant in some areas of the life.

The association of parental attitudes, family relationship with selected socio-demographic (parents') and clinical variables (child): Significant association was found between religion ($p=0.024$), number of children in the family ($p=0.054$), early identification of symptoms ($p=0.027$) and family relationship. Mothers (39) having two children in their family had expressed their inability to focus their care on other children, which adds to their burden in caring for their child. In addition, fewer mothers had verbalised that meeting the physical needs of the affected child often tiresome and leaves them completely exhausted; however, some parents believed that having a normal second child would be of some support to the affected child at present and in future.

Recommendations

- A nurse counsellor can be appointed to explore the feelings and emotions of the parents.
- Component of health education could be incorporated into nursing education.
- A nurse can organise a campaign in the community set up to educate the parents and do IQ assessments of children at the schools.
- A nurse-led psycho-education can be planned to impart knowledge through short-term parent training programmes, professional guidance and counselling services, and pre-vocational and vocational guidance.
- Special institutions or NGOs can build an appropriate and successful rehabilitation and intervention program for management of children with mild to moderate intellectual disability.

Study Implication

Nursing education: The nurses need to involve themselves in the planning and implementation of educational activities for the parents of children with intellectual disability. Early preventive techniques during prenatal, intra-natal, and post-natal teachings can be taught to all pregnant women.

Nursing practice: Nurses must be able to identify the parents who are at the risk for physical or mental stress and psycho-educate them. They can play a major role in preventing psychological ill-health among parents by supporting them in managing their children to identify the signs of developmental delays and can support the family at the time of initial diagnosis.

Nursing research: The study findings bring the greater scope of implementing family intervention strategies among these parents thus can reduce the negative impact. Nurses can use these findings to

guide them in future research in this area of preventive psychiatry. Research can be driven towards studying the efficacy of simple therapeutic and preventive strategies that parents can be taught as an early intervention method.

Conclusion

The findings of the study showed that there is a negative correlation between parental attitude and negative impact on the family relationship and a significant positive correlation between parental attitude and positive impact on the family relationship. The study was a cross-sectional one, which assessed the level of parental attitude of children with intellectual disability and its impact on the family relationship. The study reveals that parents had both positive and negative attitude and the impact on the family is more towards the negative aspect. Although the study does not find any association between parental attitude and socio-demographic variables of parents and children and clinical variables however, there are significant associations between the impact on the family relationship with religion, number of children and early identification of an illness, and the parental attitude has a significant positive correlation with the positive impact on the family relationship.

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