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Psychological and emotional state of parents having intellectually and developmentally disabled children

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Abstract

Background: A family is a functional unit that comprises of a set of individuals that provide each other with a sense of belonging, identity and a secure environment for its members, allowing them to support each other emotionally, financially and socially. A disability in the family has the potential to disrupt the proper functioning of a family.

Objectives: The main objective of this study is to know the mental and emotional condition of parents of children with intellectual and developmental disability (IDD) and to show the common view of parents towards the condition in their children.

Methods: The study was conducted based on two levels. The first level involves one to one interviews with parents of 53 children attending a special school in the Coimbatore district of Tamil Nadu state in India and was followed by a second level of the study which involved group discussions.

Results: Among all the IDDs only Down syndrome can be recognized at the birth. Parents of a mentally disabled daughter have their fears further compounded. Due to such fears, parents have reported covering their daughter's identity in public and have thought about the removal of their daughter's reproductive organs.

Conclusion: To avoid mismanagement of the child's condition, basic medical training of the parents becomes imperative and they should be educated on the reproductive rights of daughters. Hence a holistic approach involving addressing the psychological, medical and financial issues facing affected families is necessary to bring about the healthy development of the IDD child.

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Introduction

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 [1, 2]. 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. [3]. 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 [4]. 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 [3–5].

A family is a functional unit that comprises a set of individuals that provide each other with a sense of belonging and identity. It creates a secure environment for its members, allowing them to support each other emotionally, financially and socially [6]. A disability in the family has the potential to disrupt the proper functioning of a family [7].

For most families, birth is a time for happiness and celebration. However, families with children suffering from IDD often experience mixed emotions. Raising a child with IDD is a physically and mentally challenging task which often interferes with normal family routines [8]. The primary reaction of the parents upon learning of their child's mental retardation diagnosis at birth is despair and shock [9, 10]. Nothing prepares parents and other family members for the arrival of a mentally retarded child, and it is perceived as heralding a time of physical and emotional stress [11]. A change in family dynamics is observed; family members experience a range of emotions including denial, shock, anger, grief, guilt,

embarrassment, depression, withdrawal, ambivalence, disillusionment and fear [12]. The presence of a child with IDD in the family can have a negative effect on the parent's marital relationship as well. Another area of concern centers on the reactions of the sibling(s) of an affected child. As the parents tend to devote more time to the mentally retarded child, a negative impact on siblings might be observed. Further, the responsibilities of the normal sibling increases, which may result in jealousy and resentment towards the disabled child [13].

Objectives

The main objective of this study was to know the mental and emotional condition of parents of IDD children and to bring out the common view of parents towards the condition of their children. This study was conducted to know the importance of IDD children to their parents and the other purpose of this interview is also to know the parents emotional, mental condition and fear with regard their effected child at home.

Methods

The study on mental and emotional condition of parents was conducted based on two levels. The first was a one to one interview with parents of 53 children's attending a special school at the Coimbatore district of Tamil Nadu state in India and was followed by second level of study which was group discussion. The children in the special school were divided into various categories such as mild IDD, moderate IDD, severe IDD, Down syndrome with IDD and autism with IDD on the bases of IQ levels. The interview with each set of parents lasted for 15–30 min and during the interview the following details were ascertained

- Parents details (age, education, nature of work, relation of parents with effected child).

- Effected child's details (age, natal and neonatal history and family history).

Ethical issues

The study began having obtained human ethical approval from intuitional Ethical Committee, VIT University, Vellore. Informed consent was taken from the parents before involving them in this study and the parents were informed about the importance of the study.

Results

Figure 1 shows that in the mild IDD category 15.09% of effected children are in the age group of 11–15 years, in moderate IDD category 9.43% effected children are in the 16–20 year age group, in the severe IDD category 3.77% are in both age groups, 11–15 and 16–20, in the Down syndrome IDD category 9.43% are in the 11–15 year age group, in the autism IDD category 5.66% of effected children are in both the 6–10 and the 11–15 year age group. Figure 2 shows that among all categories of IDD only Down syndrome can be recognized at the birth and Down syndrome also can be recognized within 10 months of birth. In the case of autism most of the effected children are recognized before or after 40 months' of age and in a few cases only before 10 months of age. Figure 3 Represents various parameters present in natal and neonatal history of IDD children such as the place of delivery. Most of the effected children were born in hospital, in the case of pregnancy term 3.85% were premature, in case of Down syndrome with IDD and 1.92% were premature in moderate IDD and also 1.92% are post mature in mild and moderate (post mature=babies that have not been born after 42 weeks of gestation), 7.69% of effected children

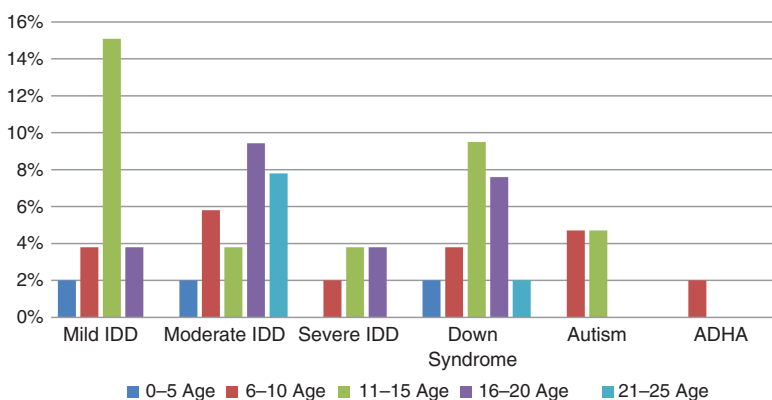


Figure 1: Distribution of intellectual and developmental disability children according to age group.

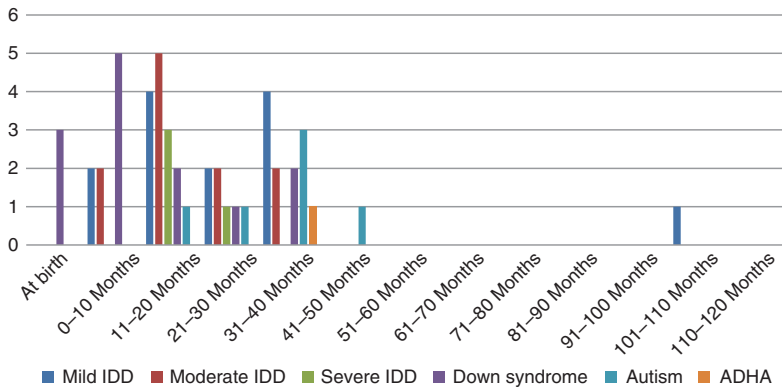


Figure 2: Age when disorder was recognized.

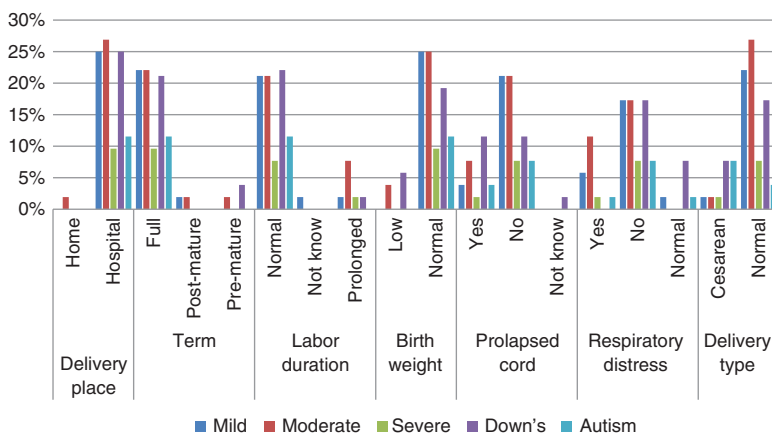


Figure 3: Natal and neonatal history of intellectual and developmental disability children's.

had a prolonged labor duration in the case of moderate IDD, regarding birth weight 5.77% were low birth weight in the case of Down syndrome and 3.85% in the case of moderate category children. As regards the prolapsed cord complication down syndrome with IDD have 11.54% complication followed by 7.69% in moderate and 3.85% in case of mild IDD. We also found that 11.54% of the moderately IDD affected children category had respiratory distress problem with 5.77% in the mild category and 0% in Down syndrome. In the last parameter of delivery type we found that 7.69% were by cesarean sections in both the case of Down syndrome with IDD and autism with IDD. Figure 4 represents various parameters in the family history which is as follows, that is in the case of type of family 19.23% effected children have nuclear family in case of Down syndrome with IDD and 17.31% have a nuclear family in moderate IDD and 15.38% in the case of mild IDD and in case of joined family system 11.54% in moderate IDD, 9.61% in mild IDD and 5.77% in both Down syndrome and autism. Consanguinity is found in autism with IDD in 92.23% of cases, followed by 19.23%

in mild to moderated IDD and 5.77% in those with Down syndrome with IDD. There is no family history of IDD in any of the categories. Figure 5 shows the age grouping of parents in which we found that among the parents more fathers are in the age group 36–40 with many less in the age group 26–30. In the case of mothers they are more in the 26–30 year age group with many less in the 46–50 years age group. and finally this graph shows that there are very few fathers in the 51–55 year age group. Figure 6 shows the various parameters featuring the details regarding the parents such as the education of parents where we found that 41.51% of fathers are educated up to the primary level of education and 75.47% of mothers are educated to primary level, while only a few fathers among both parents are educated up to diploma or college. We also found that it was mostly mothers who spent time with the effected child. We found 26.42% of the fathers had businesses, 7.55% of fathers were in service or were daily laborers. Of mothers 84.91% of them were housewives with only a few being in business with their husband.

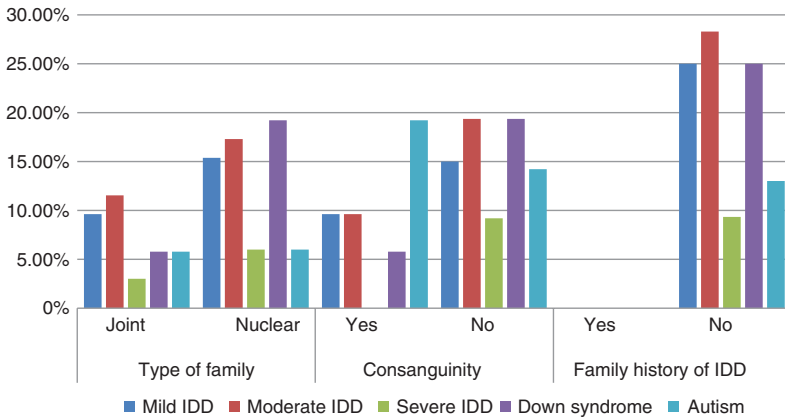


Figure 4: Family history.

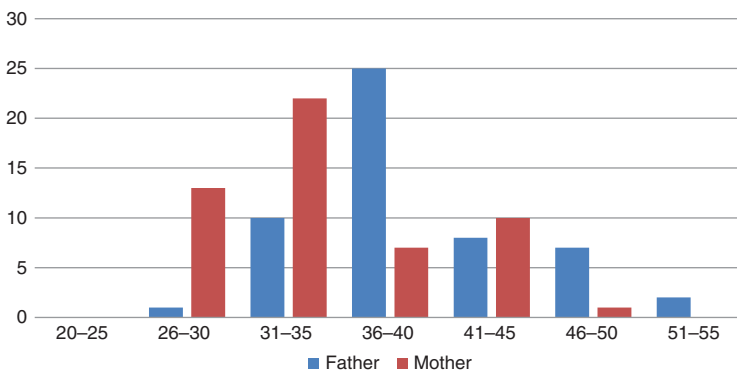


Figure 5: Age group of parents.

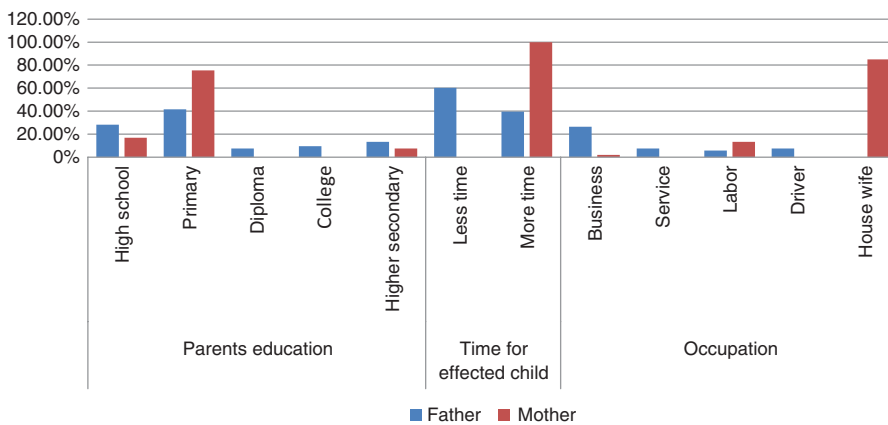


Figure 6: Education, occupation and time for effected child details of each parent.

The data that was collected after conducting the second level, where the group discussion revealed common themes of frustration and worry amongst the parents of the IDD children. The parents reported primary reactions of shock, and an inability to accept the fact that their child was disabled. They asked repeated questions

about the cause and possible medical treatments to cure their child’s condition, even after being informed that the condition in question was incurable by doctors. Parents reported fears of their child’s condition affecting their position in the society, especially because IDD is still considered a social stigma in India. The socioeconomic status

of the population surveyed was low; hence they also expressed fears regarding the additional finances that would be incurred in the course of their child's treatment/management of the disease.

The high cost and inadequacy of the available medical facilities also contributed to parental anxiety. This fact led to situations where the parents were unable to deal with medical emergencies, such as seizure attacks during night time. This situation further worsened in the case of working parents, who neither had the time nor the resources to manage their child's condition. In the absence of any alternative solution, they admitted resorting to tying their children at home and administering sedatives in case of their child being hyperactive, after leaving home for work.

In Indian society, marriage is considered to be a very important milestone; unmarried women are commonly relegated to a socially inferior status. This social stigma also affected the psyche of parents with IDD daughters who repeatedly enquired as to whether a normal marriage was a possibility for their daughters. Another female-centric issue which is particularly relevant in India is the occurrence of crimes against women. Individually, these crimes are already a major cause of concern, and for a parent with a mentally disabled daughter, fears about their daughter's safety are further compounded. Due to such fears, parents reported to covering up their daughter's identity in public and thinking about the removal of the daughter's reproductive organs.

Discussion

Families are not fully equipped to cope with the problems that arise while bringing up a child with IDD. In the initial stages following the diagnosis of their child, counseling becomes a matter of utmost importance. Only with the help of proper guidance from trained counselors and professionals, can they manage their child's condition correctly. Awareness needs to be established in the society about conditions that are still regarded as taboo such as IDD to create a safe and healthy environment for the upbringing of afflicted children. Social support also alleviates the additional stress that affected families put upon themselves [14]. It provides them with a measure of reassurance that they are not completely alone in their predicament, which ensures that they do not succumb to feelings of despair and hopelessness. To avoid mismanagement of the child's condition, basic medical training of the parents becomes imperative. Parents need to be

taught the right ways of administering the correct drug and at the required dose, and also the handling of medical crises like seizures and violent fits. The surgical removal of reproductive organs to manage issues related to contraception and menstruation in disabled young women is performed without their consent and hence is a violation of their rights [15]. Caregivers should be educated on the reproductive rights of women and the appropriate ways to handle such health matters. Hence a holistic approach involving addressing the psychological, medical and financial issues facing affected families is necessary to ensure unimpaired family dynamics and the healthy development of the mentally disabled child.

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