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Parents' attitudes towards children and adolescents with intellectual developmental disorder

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Abstract

The study attempted to explore the attitude of parents towards their mentally retarded children. The sample consisted of 66 parents of childrenwith intellectual developmental disorder (IDD) receiving mental health services from two daycare centers. An attitude questionnaire was completed by parents involved in the care and rehabilitation of the child. The questionnaire comprised of fifty statements of a Likert-type scale and served as the measuring instrument. Questions were designed to provide information on parents' behavior, perceptions, reactions, values, and feelings. Important themes that emerged from the questionnaire were analyzed using descriptive statistics. The results indicated that the parents, although having love and acceptance towards their children, were also frustrated, disappointed, and highly overprotective. This was a significant deterrent factor in the child's adaptive functioning and development of his/her independent living skills.

Keywords : Intellectual disability, Caregivers, Gender

Introduction

Every child is special to a parent. Some children have special needs and others do not, and this determines the level of parental care and treatment services in the developmental stages of life (Ravindranadan & Raju, 2007). 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 a disorder, which may have a profound impact on the family (Kumar & Singh, 2012).

Intellectual disability (ID) is considered to be a bio-psycho-social problem. Genetic, biochemical, biological, social, psychological, and various interacting forces like attitude and family dynamics, peers, and society in which the child lives, play an important role in the adaptive and normal functioning of a child. There are millions of intellectually challenged children in the world who have been considered to be dangerous, incurably insane, and incapable of learning even the simplest task. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), intellectual developmental disorder (IDD) "is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (American Psychiatric Association, 2013). The intellectual functioning of persons with IDD is below average and their intelligence quotient (IQ) is 70 or less (Sarason & Sarason, 2005). The origin of the disability is before one reaches the age of 18 years (Luckasson, Borthwick-Duffy, Buntinx, Coulter, Craig & Reeve, et al, 2002). Children and adults with IDD never gain respect from society at large as they are not given full benefits, rights, and privileges, like other individuals with no deficits. Review suggests that, prior to the development of institutional care for the retarded, they were treated with the most rudimentary manner focusing only on their physical needs and disregarding psychological, emotional, or social needs. Very often their parents and society have had a negative attitude towards children with disabilities. Social marginalisation and community rejection are common and they are often demeaned and ridiculed. The attitudes of parents are an important component of the "handicapping" environment (Nevid, Rathus, & Greene, 2000; Hahn, 1982; Yuker, 1988). As stress among parents rise due to the increased demands for energy, time, and financial resources, it may affect their treatment towards the child. Additionally, the social stigma and ridicule attached to any form of disability leads to social isolation. If negative emotions among parents and caregivers are high, it may lead to family disharmony which may have a negative impact in the development and rehabilitation of these children.

(Bowlby, 1988), the father of attachment theory, had rightly mentioned that the greatest loss and negative consequences of an intellectually challenged child is lack of adequate nurturing relationships with adult caregivers. Therefore, the way that parents' react to a child with special needs, partly depends on how they perceive it, and the practical implications that the disability or illness has on them (Chaturvedi & Malhotra, 1984). This in turn determines their attitude towards the same, and if disability is present, then stress and negative emotions increase (McConachie, 1986). (Kagan & Havemann, 1980) defined attitude as an organized and enduring set of beliefs and feelings which predisposes one to behave in a certain way. Hence, the emotional component within the attitude distinguishes it from beliefs. The attitude of people towards these individuals are often accompanied by negative feelings of hostility, shame (Rangaswamy, 1989), denial, guilt, grief, projection of blame, withdrawal, rejection (Drew, Logan, & Hardman, 1984), as well as feelings of helplessness, inadequacy, anger, and shock, while some others have disbelief, depression, and self-blame (Chandramuki, Shastry, & Vranda, 2012). Findings from studies focusing on family dynamics have reported high levels of stress and negative emotions. Family crisis may result from the presence of a special needs child. The health of the parents determines the family's wellbeing; but "guilt, ambivalence, disappointment, frustration, anger, shame, and sorrow" are often exhibited by parents (Schild, 1971). Thus, the attitude of parents may cause hindrance in the process as well as the outcome of adaptive functioning in the children with IDD because the environment in which a child is born and brought up has a huge impact on a child's psychological and physical wellbeing. Individuals with disabilities are often viewed as incapable of doing anything in life and taking care of their basic needs, but a study by (Hazarika, Talukdar, Choudhury & Das, 2014) to assess the outcome of daycare center services on learning skills of the children, found that they can learn a great deal after training in various self-help and social skills. Hence, individuals with intellectual disabilities are trainable and educable, although severe to profound levels of disability need regular custodial services due to their very limited learning capacity. However, in India, disability is viewed in terms of a “tragedy” with a “better dead than disabled” approach and therefore disabled people are isolated and shunned from entertainment and enjoying a healthy life (Girimaji & Srinath, 2010). In India, the prevalence of ID varies from 1/1000 to 32/1000 (Thengal, 2013). While the majority of persons with IDD have traditionally been cared for by their families, there are institutionalized care centers run by non-governmental organizations (NGOs). The Acharya Ramamurthy Committee has reiterated the role of special schools to serve as resource centers for the assimilation and integration of these children into normal schools, and thereby improve their level of education. In Assam, although integrated education facilities are present in few schools, they are inadequate. Hence, the majority of parents send their children with IDD to special schools and rehabilitation centers. Two such daycare centers were selected from greater Guwahati for this study population. Parents who were involved in the care and management of their child, were the focus of this study which explored the attitudes of these parents, who had accepted the status of their child as deficient, and may have realized the need of special care and rehabilitation for the growth and adaptation of their child in society. The need to include children with IDD in general schools though, is highly felt, but the education scenario in this perspective is very grim, therefore these children are not receiving adequate responses from their parents, family members, and their teachers. In essence, research on IDD is almost negligible in Assam. Therefore, the purpose of this study was to explore the attitudes of parents towards their children with IDD.

Objectives

The study attempted to explore the attitudes of parents towards their children with intellectual developmental disorder (IDD)

Methods

Study Design

This was a cross-sectional descriptive study carried out in two rehabilitation centers in Assam, India. Participants were selected through convenient sampling. Study criteria included: a) parents of children with IDD; b) parents involved in providing care to the intellectually disabled; c) able to read and write English, so that they can comprehend the self-administered scale; and d) those who were willing to participate and had provided written consent. A sample of 66 were eligible to participate in the study. This study was conducted as part of a workshop arranged to provide psycho-education to the parents of intellectually disabled children. This set of parents had not participated before in any kind of psycho-education or workshop related to IDD.

Measures

1. Demographic data survey instrument

The demographic form consists of items to elicit information regarding age, gender, education, and presence of the intellectually disabled at home.

2. Attitude scale of parents towards their mentally retarded children

The questionnaire comprised of fifty statements of a likert-type scale which served as the measuring instrument for this study. The researcher asked questions using a rating scale to obtain information that a yes/no answer would not divulge. It has been established that a likert type scale questionnaire provides questions which are standard and comparable among individuals. Less articulate respondents are not considered as a disadvantage and the respondents report about sensitive issues when using such questions. Answers generated by these questions are found to be easier to code and analyze (Bailey, 1987; Behr, 1988; Neuman, 2000).

This questionnaire was developed using

statements from the Parental Attitude Research Instrument – PARI (Schaefer & Bell, 1958), the Thurston Sentence Completion Test (Thurston, 1959; Parekh, 1988). Questions were designed to provide information on parental behavior, perceptions, reactions, values, feelings, etc. Respondents had to indicate to which degree they agree (or not) with each statement, by encircling the number corresponding to one of five response categories varying from 'strongly agree' to 'strongly disagree'. The questionnaire was used in a dissertation for the degree of Master of Arts (Walsh, 1968; Govender, 2002), is extensively used in various research, and continues to be the best available instrument as it is highly reliable and valid for obtaining information. The scale taps five themes, which are randomly spread across the table, apart from knowledge. The important themes assessed are Love and Acceptance, Embarrassment, Frustration, Disappointment, and Overprotection.

Procedure

Data was collected before the workshop started. On introduction, the first author explained briefly about the aims and methods of the study to all the participants. Parents who were willing to participate were asked to complete the questionnaires. The time taken to complete the questionnaire was 45-60 min. The participants were assured that their answers would remain strictly confidential and that their anonymity would be protected. Subjects were informed that this data would not be released to other persons without their permission.

Ethical considerations

Permission was obtained from the administrators of the rehabilitation centers where the study was conducted. Participants were introduced to the aims and procedures of the study to decide if they would like to participate. After obtaining written consent from them, the tool was administered. Participants were given freedom to withdraw from the study at any part of the procedure without attributing any reasons. Ethical clearance was not required as it was a questionnaire-based observational study with no intervention.

Statistical analysis

The data was analyzed, and results were presented in narratives and tables. The table with percentages was used to determine the distribution between genders. The data was analyzed in terms of percentage.

Results

Characteristics of the participants and their children according to gender

The total number of children with IDD (IQ < 70) was 66 and out of this, 65% were males and 35% were females. Fifty eight percent were mothers and 42% were fathers, among the caregivers who were involved in the treatment and rehabilitation services of the child (Table 1). There was a high proportion of female caregivers in this study.

Table 1: Gender of children and caregivers

	Male, n (%)	Female, n (%)
Gender of the children	43 (65)	23 (35)
Gender of the caregivers	28 (42)	38 (58)

Analyses of the themes of favorable and unfavorable attitudes

1. Love and Acceptance

Statements to elicit the theme of "love and acceptance" were the following:

1. When I think of my mentally retarded child, I think how lucky I am; God gave him so much more than lots of other kids .
7. One of the bad things about raising mentally retarded children is that you are not free enough of the time to do just as you like
13. I have accepted the fact that my child is mentally retarded
14. I would love my child more if he/she were not mentally retarded
30. I would rather be caring for my mentally retarded child than doing some other kind of work.
35. In his /her way, my mentally retarded child brings so much pleasure to our family, the same as the other members.
44. It makes me feel good to know that I can take care of my mentally retarded child.
47. I don't mind when people look at my mentally retarded child

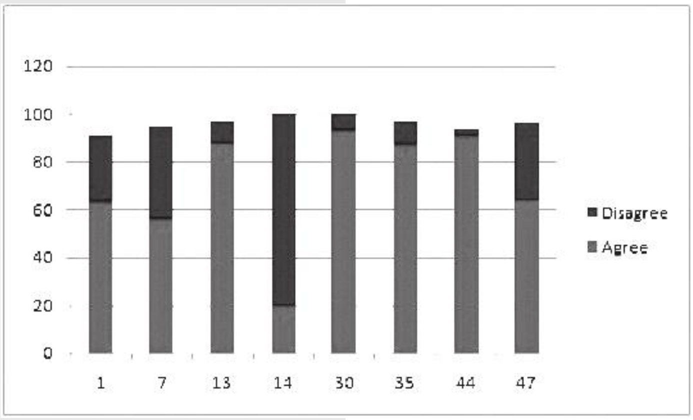

Figure 1: Love and acceptance

The parents of children with IDD had feelings of love and affection towards their child as 88% had accepted their child's status, 90% agreed that they would rather care for their child than do some other kind of work,87% felt pleasure in having their child at home, 91% felt good to know that they could take care of their child by themselves and 63% parents felt lucky to have a child with IDD (items 1, 13,30,35,44) and were thankful to God for the same. Eighty percent denied that they would love their child more if he or she did not have IDD (Figure 1).

2. Embarrassment

Statements to elicit the theme of "embarrassment" were the following:

18. I feel embarrassed taking my mentally retarded child with me to functions

43. Sometimes I feel ashamed because of my mentally retarded child

50. I am not embarrassed when people question me about my mentally retarded child

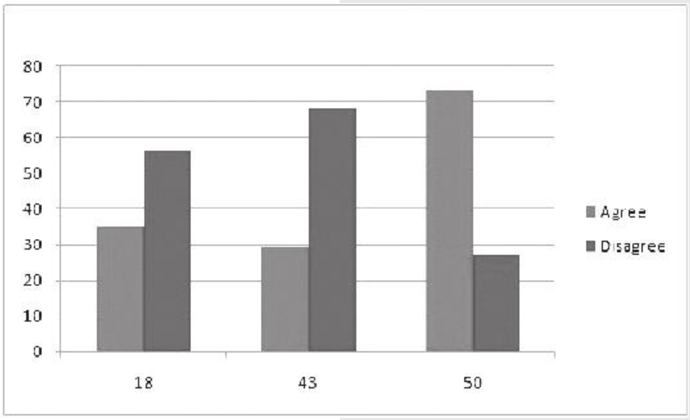

Figure 2: Embarrassment

In the theme of 'embarrassment' the findings denote that 73% did not feel embarrassed when people questioned them about their child's intellectual status, and a small percentage of the population felt ashamed about their child's status and taking them to functions and other social occasions (Figure 2).

3. Frustration

Statements to elicit the theme of "frustration" were the following:

4. Mentally retarded children will get on any woman's nerves if she had to be with them all day

6. Raising mentally retarded children is a nerve-wrecking job.

25. If my mentally retarded child was more pleasant to be with, it would be easier to care for him/her

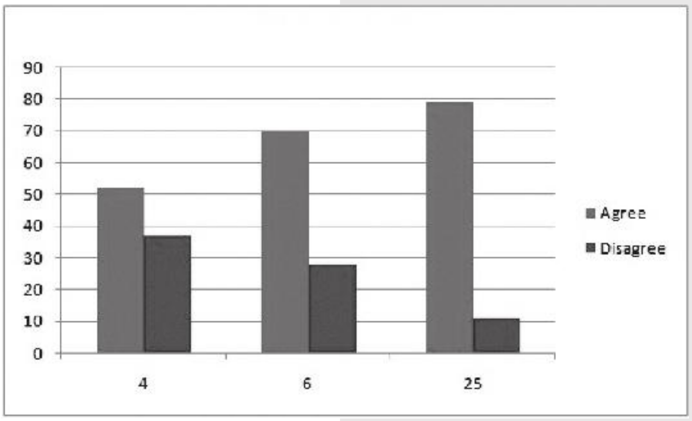

Figure 3: Frustration

Results showed that in the theme of ‘frustration’, 70% agreed that raising children with intellectual deficits was a nerve-wrecking job, while 52% agreed that these children would get on any woman’s nerves if she had to be with them all day (items 6,4). More than 75% reported (item 25) that if their child was more pleasant to be with, it would have been easier to care for him/ her (Fig 3).

4. Disappointment

Statements to elicit the theme of “disappointment” were the following:

12. I felt disappointed when I found out that my child is mentally retarded.

26. Thinking about my mentally retarded child’s future makes me sad.

46. I am disappointed that my mentally retarded child does not lead a normal life.

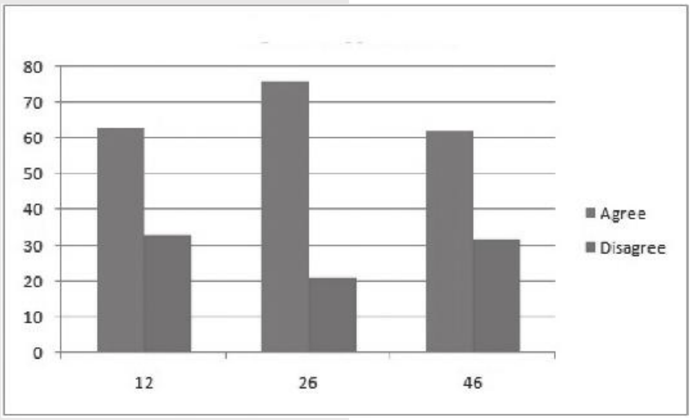

Figure 4: Disappointment

Results suggested that 68% felt disappointed when they found their child to be intellectually disabled, 62% felt disappointed that they cannot lead a normal life, and 76% felt sad thinking about their child’s future prospects (Fig 4).

5. Overprotection

Statements to elicit the theme of “overprotection” were the following:

29. My mentally retarded child feels that I am the only one who understands him/her

32. I always watch to make sure that my mentally retarded child does not do physical harm to himself/ herself

33. My mentally retarded child would be in danger if he she got out of the house or yard.

34. When others are around my mentally retarded child I cannot relax, I am always on guard

38. I am very careful about asking my mentally retarded child to do things, which might be too hard for him/ her.

42. I feel that I must protect my mentally retarded child from the remarks of other children

49. My mentally retarded child’s needs come first

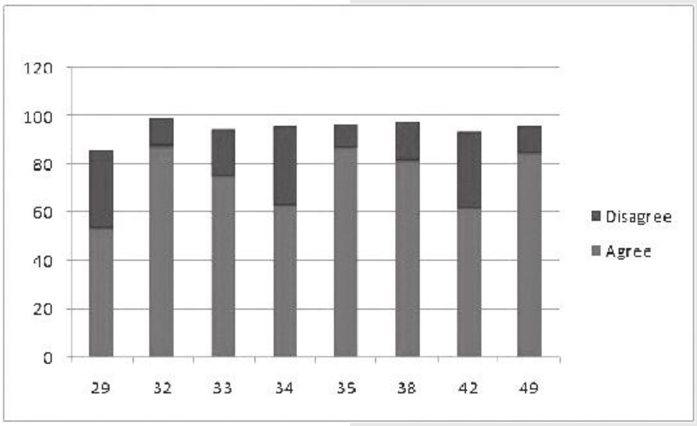

Figure 5: Overprotection

In the theme of 'overprotection', 88% reported that they always watch to make sure that their child would not do physical harm to himself/herself. Seventy five per cent of parents believed that their child would be in danger if he or she got out of the house or yard (item 33). Sixty three per cent of parents reported that they could not relax and are always on guard when others are around their child (item 34). Eighty two percent of parents felt cautious about asking the child to do things which might be too hard for him/ her (item 38). Sixty two per cent reported that they should protect their child from the remarks of other children, and more than 85% (item 49) felt strongly that their child's needs come first. (Fig 5).

Discussions

The findings of the present study showed a considerable amount of favorable attitudes of parents towards their children with IDD. As in the themes of love and acceptance, a significant proportion reported to have accepted the child's status, loved him or her, felt pleasure having him/her at home to take care of, and was also thankful to God for the same, which did not signify remorse or negativity towards them. Strong feelings of love and affection were also reported in another study done in upper Assam by (Thengal, 2013). Although findings in the theme of love and acceptance were strikingly positive, interestingly, they were frequently accompanied by feelings of frustration, disappointment and rejection, with considerable amounts of expressed emotions of over-protectiveness, which is reported by other researchers (Thengal, 2013; Zuk, 1959; Worchel & Worchel, 1961; Ryckman & Henderson, 1965; Ramgopal & Rao, 1994). The underlying dynamics of these parents who felt frustrated and disappointed, could be due to the stigma and rejection by their communities, as more than 60% reported that they were not relaxed when others were around their child, were cautious about others' remarks towards their child, and took personal responsibility to protect their child from the remarks of society. Hence, it suggests that, although Guwahati is an urban city, parents still believe their children would be discriminated against, in society. Another way of understanding this could be, as reported by (Zuk, 1959), that the parents are caught between strong feelings of love and hate for the child, and the conflict between these opposing feelings may have result in guilt ,which may have manifested in the form of frustration and disappointment.

The findings suggest overprotectiveness

of extra love, caution, and care,that could be compensatory behavior for the underlying rejection and guilt as reported by (Tredgold & Soddy, 1970), who mentioned guilt and rejection were being internalized, while love and care were extended more. (Kanner, 1941) also emphasized that rejecting attitudes may be manifested in the form of overt hostility, guilt, neglect, perfectionism, and compensatory behavior of overprotection. Our findings indicated that more than 80% of parents were overprotective in terms of being watchful almost all of the time, would get anxious when giving them any work to do, and were cautious of them getting hurt by others; so, keeping the child's needs first was their goal, which was not a healthy parenting practice. The study thus highlights the great extent of negative and unhealthy attitudes in the parents because they viewed their children differently, were overly cautious with them, and gave them more attention than was required. Interestingly, these vain attempts could in turn raise their levels of frustration and disappointment, which were also reported in the scale. It is also interesting to note that the parents' efforts to be extra-careful, could be detrimental to the growth and development of their children with IDD, as they would not get any opportunities to learn on their own, nor be independent in their living skills. However, this is a very significant finding among these parents who have been sending their children to the daycare centers, because if this attitude of over-protectiveness does not alter, then their children would remain handicapped and may not reach an adaptive level of functioning.

Strengths/weaknesses and future research

It is one of the first studies done in Assam and the first in Guwahati, an urban city, which has thrown light on the inclusion of parents in the treatment and care of children with IDD, focusing on the factors that would hinder the process of normal growth and development of these children. The present study had its own limitations, as the sample size was small and convenient, so the findings cannot be generalized. Other related aspects like age, socioeconomic condition, educational attainment and family structure, were not considered in this study. However, there was a restricted exploration of underlying issues and the respondents' subjective experiences and interpretations were ignored. Further studies are required to confirm and elaborate findings of the present study. Such studies should include qualitative methods to gain access to respondents' own understandings of their social behavior. This study has provided a basis for much needed similar research in other rural areas in Assam.

Conclusions

Parents who accept their child's status of intellectual deficits and receive help from the rehabilitation centers have unfavorable attitudes, false perceptions, feel stigmatized and discriminated against, thereby leading to frustration and disappointment with compensatory over-protectiveness. Hence, the parents of these children could be included in intervention strategies, along with the child's rehabilitation, to ensure comprehensive care towards these families with intellectually challenged children.

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