

Elucidating Self Efficacy & Parental Bonding on Mental Health in Families of Intellectually Disabled Children

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Abstract

An intellectual disability is one of the most disabling childhood problems around the world & it is not an easy task to be a parent for such a child. The family is a great source of support for children with disabilities in any community. The psychological stress associated with child disability puts parents, in difficult situations. Many literature highlights, the impact of child disability on parents has mostly negative effects on their health. Thus, we can understand that parents & siblings of Intellectual disability are in need of professional programme, to handle stress. Albert Bandura identified Self Efficacy as central to understanding an individual's transaction with their environment. That is, Self efficacy expectations are linked to perceived skills of individual, knowledge of appropriate behaviours and it is also linked to success or failure of task in the past. Bandura further explains, a strong inter relation among vicarious experience, social persuasion and emotional arousal in influencing self-efficacy. In this study, TOPSE, devised by Kendall S, et al. [1] is used to assess parental self efficacy. Its reliability & validity are proved by the authors. This study was conducted on 85 (female and male) siblings of Intellectually Disabled individuals in Cuddalore district of Tamilnadu. Using Parental bonding instrument, a valid tool, developed by Gordon Parker, Hilary Tupling and L.B. Brown present study aimed to correlate between self efficacy & parental bonding with mental health in adult life of parents, normal siblings in presence of intellectually disabled child in family.

Keywords: Intellectual Disability; Parental Self Efficacy; TOPSE; Vicarious Experience; Socialpersuasion; Emotional Arousal

Abbreviations: ID: Intellectual Disability; TOPSE: Tool to Measure Parenting Self Efficacy; PBI: Parental Bonding Instrument.

Introduction

One of the most prevalent forms of childhood disability is Intellectual Disability (ID). It is possible for the parents to possess tough and unpleasant experience, with frustration,

grief, and hopelessness throughout their life. This is due to the fact that ID & mental illness is a permanent condition, in contrast to many other diseases. A great number of parents accept a poorer level of living, unhealthy family functioning, and adverse psychological repercussions. Although the misbehaviour of a child is frequently associated with parental stress, the experience of depression is also dependent on how the parents perceive their situation and whether or not they employ coping strategies.

Review of Literature

The Parents of the Intellectually Disabled Children Experience Higher Stress in Comparison to the Parents of Normal Children

Shyam, Kavitha, & Govil designed a study to assess mothers of children with disabilities and mothers of children without disabilities, from three Haryana districts, India. Multi-group design that included five groups of mothers was adopted. They were mothers of children with intellectual disabilities, mothers of children with intellectual and physical disabilities, mothers of deaf and dumb children and mothers of children without disabilities. An indicator of parental stress and family burden rating was administered to 125 mothers of children with and without disabilities (25 mothers in each group). For statistical analysis, a t-test, a simple variance analysis and a Duncan post hoc test were used. Findings by Shyam, et al. showed that mothers of children with intellectual disabilities experienced significantly higher levels of parental stress and family burden compared to other mothers of children with physical disabilities, mothers of deaf and mute children, and mothers of children without disabilities.

Boromand, et al. compared the aspects of mental health between parents of mentally disabled children and those of normal children. They found significant differences between parents of normal children and those of children with intellectual disabilities in terms of mental health issues (good relationships with others, environmental governance, self-acceptance, independence, purpose in life, and personal development). Among parents of mentally disabled children, due to a lack of communication links, relationships with friends and a lack of relationships in voluntary organizations, a lack of social cohesion and a bad mood, there was a reduced amount of mental well-being.

Walsh, Mulder, & Tudor studied a sample of children with autism spectrum disorder & Intellectual disability to obtain predictions of parental stress. This study examined pain and behavioral problems as predictors of depression in parents of autistic children. They also explored the style of child rearing in ID families to deal with pain and behavioral problems and ultimately contribute to parental stress. The results showed that there was a significant correlation between Parenting styles of child rearing & stress. Another interesting finding is that fatigue also contributes to stress. The study was conducted on fatigue, stress and health issues for mothers with children of autism spectrum disorder. They have found that raising a child with autism spectrum disorder can be exhausting. Research investigated the impact of maternal fatigue on 65 mothers of young children (2-5 years old) with ASD. The conclusion of the study was that it was the maternal fatigue that linked the relationship between problematic

behavior and maternal depression. These findings suggest that the difficulties caused by a child's behavior gradually contribute to parental fatigue. They also increase stress. Therefore, an important area to consider in families with children with autism spectrum disorder was the importance of fatigue, parenting style of child rearing in the maternal health.

According to Karasav v, et al. the stress of parents was due to their inability to adjust to their child's daily needs. With the passing of time and the pessimistic outlook, parents felt incapable of controlling the situation and they were suffering so much stress. Participating in day-to-day care activities also required more physical strength from parents. The quality of life of the couple, the pressure of parenthood and the lack of support from the community based on the severity of the disability added the stress.

Stress and Coping were assessed using the Parental Stress Scale and Interview Techniques. In this study, they concluded that the birth of an abnormal child exacerbates the problem, which is caused by an unexpected, painful event beyond the control of the parents. For parents of a child with Intellectual Disability & autism, these feelings were heightened by the fact that the baby was born not healthy.

In India, spiritual growth has been proven to be one of the most effective ways of coping with the situation Singh, Famine & Famine as people have more spirituality in their view, compared to Western culture. Coping strategies utilized by the parents of the intellectually disabled children. Community has a role to play in helping families of ID to cope. Families of children with intellectual disabilities face a wide range of variability and inconsistencies. The problematic child is inseparable from the problems facing families. Hence, it is clear that planned services are really needed to adapt well and deal with the situation with confidence and a minimal amount of stress. To achieve these goals, professionals from many fields, governmental and non-governmental organizations and the general public must work together. In a school setting, a strong parent-teacher alliance is associated with a reduction in parental pressure. Research has shown that school resources can help reduce stress.

Many already published studies supports the concept that lack of parental bonding in earlier days leads to depression symptoms in adult period. The following is one such study. "Low level of parental bonding might be a risk factor among women with prolonged depression" A preliminary investigation, Hiroko Handa, Akinori Ito, Hitoshi Tsuda, Isao Ohsawa, and Toyoaki Ogawa, Department of Psychopathology and Psychotherapy Graduate School of Medicine, Nagoya University, Nisshin, Japan.

Tool to measure Parenting Self efficacy (TOPSE) is based on theory given by Bandura, in his original theory, describes, any domain of behaviour will be developed by performance mastery & vicarious experience. It has to be learnt through role modeling. Research studies from 1990 to 2001, mentions that there was a rise in the number of children referred for child guidance in Japan. As reported by 'National Institute of Population and Social Security Research', 2003, there is increase in number of children seeking professional help from 1000 to 23,000 cases as reported by Fujiwara et al., United Kingdom government. TOPSE is a multidimensional assessment, containing eight subscales. Each subscale has six statements. Totally, 48 statements, using a 5-point Likert scale where 1 represents completely disagree and 10 represents completely agree. Dimension of parenting like emotion and affection, play and enjoyment, empathy and understanding, control discipline and pressures, self-acceptance, learning and knowledge are represented. The items are rated on the scale containing positive and negatively worded items and the responses are summed to create a total score; the lower score, indicates lower level of parenting self-efficacy.

Kendall S, et al. [1] studied the relationship between parenting stress and their self efficacy. Parenting self-efficacy has been identified as a major determinant of parenting behaviour. Parenting programmes provide opportunities for parents to develop self-efficacy, through learning and by experiencing success & through encouragement from other parents [1].

Parent Training Interventions

Wade, Llewellyn, & Matthews reviewed parental training interventions for parents with intellectual disabilities. They aimed to provide the use of some home-controlled behavioral interventions for parents. Ashum G, et al. [2] suggests that when a child is diagnosed with a serious disability, parents may have similar cognitive processes similar to those of people who have experienced a traumatic event. 'Special ability' was largely ignored. They argued that mothers could work to make changes in the name of their children. The family's response to this type of stress also contributed to the perception of siblings. If parents respond favorably to their child's special needs, then the siblings' relationship is usually better.

Through these reviews, we understand, having a child with a disability is a source of chronic stress for family members and can affect them in many ways. The presence of such children causes many negative effects on the mental health of the family, and deeply influences the means of communication between family members. It is important for professionals, to use effective methods to deal with the problem.

Reasons for Absence of Parental Support

- Normal siblings may receive less attention from parents than disabled child as some parents are helpless; they try many treatments to bring the disabled into near normal stream of life.
- Some parents are always occupied with the struggle to face daily requirements of the disabled.
- In most families, depending on age of child, parents has to go for hospital visits with disabled child and the normal child finds it difficult to get along with parents. Sharing small joy with parents, it self, is difficult for them.

Need for the Study

Due to above mentioned reasons, the parents unknowingly contribute to ill mental health of siblings in their childhood period. Hence this study was devised to know whether such neglect existed in my study population, influence of parental neglect on mental health of siblings. In the study group selected, for duration of three months to six months through self efficacy training parents could master way of handling stress.

Methodology

DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. Reported that while it takes time for mothers to accept their children, they feel pressure from society, particularly when their children exhibit unpredictable misbehaviour in public, such as beating others, throwing temper tantrums. As a result, they restrict their social networks. Barentt, et al. who state that having a diverse set of strategies is more beneficial than having only one or two.

Aim of the Study

To assess parental bonding components, correlate it to train Self Efficacy coping for family members of Intellectually Disabled children at Cuddalore district of Tamilnadu.

Study Design

The study was done at Cuddalore district, by selecting normal sibling of intellectual disability, either male or female available in family. Approaching each family with their consent for the study was met along with NGO's of Cuddalore district. Assessment with Parental bonding instrument and TOPSE was done with 85 parents & siblings. The following graphs present the various demographic details of the study Figures 1-3.

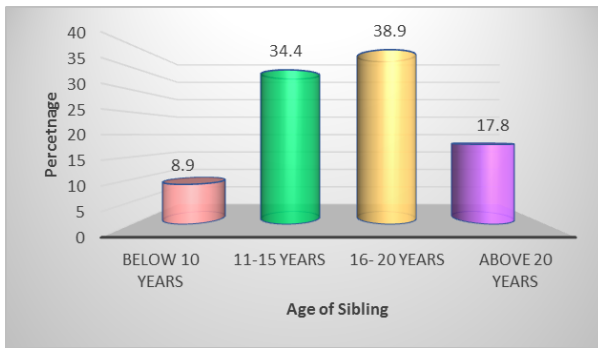


Figure 1: Frequency and percentage distribution of age of Sibling.

It is inferred that most of the sibling (38.9%) are in the age group of 16 to 20 years old, followed by 34.4 percent of the sibling are 11 to 15 years, 17.8 percent of the sibling are above 20 years and 8.9 percent sibling are in the age group of below 10 years.

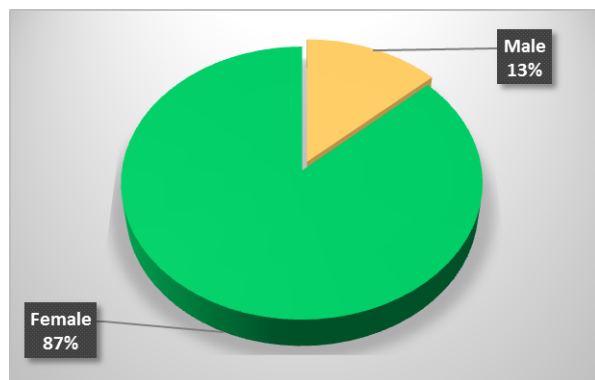


Figure 2: Percentage Distribution of Gender of Sibling.

Regarding gender of sibling, most of the respondents (87%) are female and 13 percent of them are male.

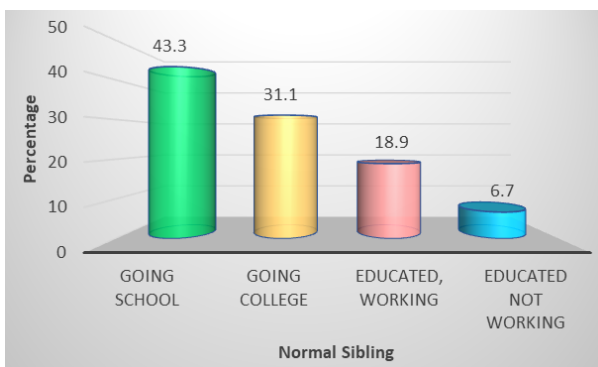


Figure 3: Percentage Distribution of Position Sibling.

Regarding position of sibling, among the respondents (43.3%) are going to school, followed by 31.1 percent of them are going to college, 18.9 percent of the respondents are educated and working people and 6.7 percent of the respondents are educated people but not working.

Services Required for Intellectual Disability

Most of the respondents (41.6%) are in need of daily Occupational therapy, 31.9 percent of them are taking any programme in special education, 16.3 percent of the respondents are taking vocational training, 6 percent of them attending yoga classes and only 4 percent need nursing care to look after them. Hence we can understand the essential travel, absence in their work place, leaving normal sibling at home & attending to ID children activities of parents.

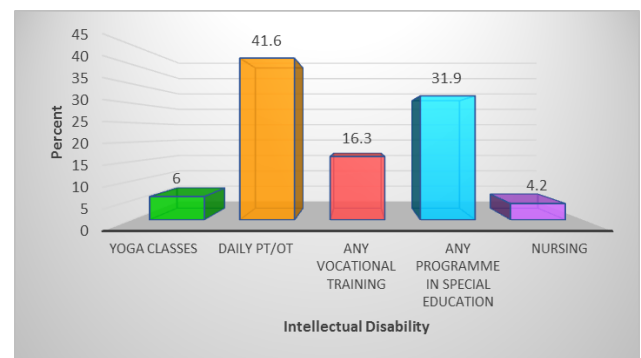


Figure 4: Services Required for Intellectual Disability.

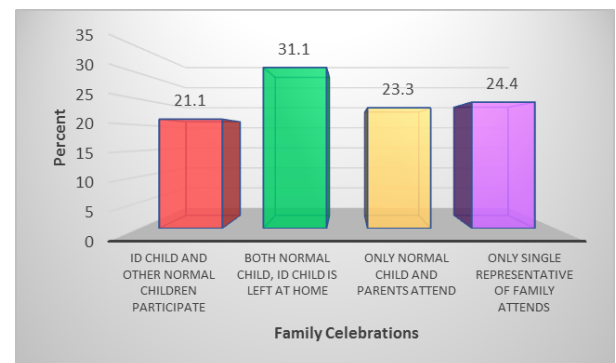


Figure 5: Percentage Distribution of Family Celebrations.

Percentage distribution of family Celebrations is given in above graph. It is inferred that most of parents (31.1%) are attending family celebrations like marriage, LEAVING both normal child, ID child at home, 24.4 percent said only single representative of family attends, 23.3 percent said only normal child and parent are attending family celebrations, and 21.1 percent of the respondents said ID child and other normal children participate celebrations. From these graphs

we could clearly understand the siblings in families.

Parental Bonding Instrument (PBI)

Using Parental Bonding Instrument, a valid tool, developed Parker, Tupling and L.B. Brown the parents were assessed on existence of different parental attitudes. PBI is a 25 item self-report measure in which attitudes are expressed through two dimensions i.e. care and over-protection reported in the original version of scale. All items are rated on 25 item questions, including 12 "care" items, 13 "over protection" items. In this scale, parents can be effectively assigned to four quadrants based on attitude scores. In qualitative terms, the parent behaviour could be thus rated. Higher the score, higher is the level of warmth, protectiveness and authoritarianism. It can either be administered for both parents or separately. High care, low overprotection is concept of Optimal bonding, low care & low overprotection implies weak bonding.

PBI reports have been found to be stable over 20 years' time Pavlovic H, et al. It is considered as the most reliable measure to test for parenting styles in both clinical and non-clinical settings. PBI evaluates parental attitudes derived from an individual's childhood experiences with parents. It is done because, for normal sibling born along with ID children, work pressure & various daily care activities for ID children of parents, leads to a neglect attitude. Such behaviour of parents leads to destructive effect on mental health & wellbeing for siblings. Moreover parental attitude is related to personality of children. If low level of care is given to sibling assuming that they can look after themselves in childhood period itself, it is proved that, such an attitude is highly associated with depressive symptoms. (Parker G Parental reports of depressives An investigation of several explanations Journal of Affective Disorders (1981) 131-140).

Discussion

- Family support is especially important for parents & siblings of children with intellectual disabilities. It appears that increasing support and learning self efficacy reduces some aspects of stress. Special parent training programmes should be provided to these parents in order to assist them in controlling their ID children behavioural difficulties.
 - The rehabilitation team members, while working for intellectual disabilities need to concentrate on self efficacy training for family & siblings. This would elicit their pain, dreams, and worries about their own future and the future of their intellectually disabled sibling.
 - Parents should cultivate and maintain realistic attitudes toward their intellectually disabled children. Parents should understand the sufferings of normal siblings also & should provide timely care to them.
- Curriculum tailored to the practical needs training after assessing abilities of these Special children should be on Maintaining hygienic look, clean habits of toileting, expressing their needs should be taught using specialised instructional techniques. More emphasis should be placed on the method of learning by doing, in the mother tongue as the medium of instruction.
 - The majority intellectual disabilities come from low-income families. Hence appropriate Occupational therapy based exercises to lower their functional limitation can lower the parental stress.

Conclusion

From my study it could be concluded that in most families here exists neglect attitude of care for siblings. Professional's rather focussing attention on intellectually disabled alone; need to concentrate on siblings also at an earlier age to avoid mental ill health at their adult life. Professional help to siblings is essential, to fulfil their own developmental level of functioning, to help the family achieve goals. Thus integrating them into mental well-being.

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