Perceived Social Support Hidden Iceberg influencing Rehabilitation in families of Intellectually Disabled children

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ABSTRACT: According to Barnes and Duck, social support refers to ''everyday behaviors that, directly or indirectly, communicate to an individual that she or he is valued and cared for by others.'' Social support means having friends, identifiable people, in family, to turn to in times of need for a broader focus and positive self-image. Social support enhances quality of life and provides a buffer against stressful life events. Those who have close personal relationships cope better with various stressors, including bereavement, job loss, and illness (Salovey, 2000).
Simply Rehabilitation is defined as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment". When the rehabilitation of Intellectual Disability is concerned, the family is a great source of support for these children with disabilities in any community. Parents experience significant physical and mental stress with these children (Islam, Shanaz, &Farjana, 2013). It can be an unpleasant and challenging experience followed by frustration, sadness, and despair. Various evidence suggests that parents of children with a disability face emotional, social and economic problems that are often limited, devastating and naturally occurring (Boromand, Narimani, &Mosazadeh, 2014) as Intellectual Disability is a permanent condition unlike many other diseases. (ThiyamKiran Singh, Indla, 2008). Due to Ineffective and under-utilized pathways to rehabilitation, the parents & Siblings, suffer with HIDDEN problems in our society. Subjective description on the problems is described in this article. This study will help mental health professionals working towards rehabilitation, and parents to identify effective way of handling social support.

Keywords: Social support, Rehabilitation, Intellectual Disability, Parents & siblings problems

INTRODUCTION : Mental health can be a tough battle. Oftentimes it can take hold of your life and make you feel unworthy of social interactions or being cared for by others. However, it is important to try to persevere through these thoughts and remember that everyone is worthy of being cared for and loved. "Albrecht and Adelman define social support as verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance perceptions of personal control in one's experience.'' Social support can be offered by informational support, emotional support, tangible support. Emotional support can be particularly important during time of stress or when people are feeling lonely. Providing guidance, needed information, and mentoring are also included in social support. Social support refers to the psychological and material resources provided by a social network to help individuals cope with stress. It can include, helping a person with various daily tasks when they are ill or offering financial assistance in need. Being integrated in social relationships confers a protective benefit against maladaptive behaviors and damaging health consequences. There are several benefits of having a support system and choosing the right people to spend time with. Psychologists and other mental health professionals often talk about the importance of having strong social support network. When trying to reach our goals or deal with a crisis, experts frequently implore people to lean on their friends and family for support. Poor social support has been linked to depression and loneliness and has been shown to alter brain function and increase the risk of the following: Alcohol use, cardiovascular disease, depression, sometimes suicide.

The **family** plays a vital role in the rehabilitation process, of any type of disability, in providing emotional and physical support. Positive attitude and encouragement from the family can inspire the sufferer's commitment and progress in their rehabilitation. Additionally, the involvement from the family can ease the transition back to their home environment, especially if the family also serves as a caregiver. Intellectually disabled (ID) family on the other hand, they are the **sufferers,** & not the person with ID.

Intellectual Disability is one of the most common childhood disabilities around the world. Diagnosis of a child's disability may trigger a range of emotional responses to parents and to all family members. For some, it may be a problem that requires unusual psychological adjustment on the part of the parent and contains aspects of injury, loss and weakness. For some the birth of a disabled child may be considered a traumatic event. Parental reactions may first become a source of emotional distress as well. This may change into a period of adjustment and later a reorganization of daily family life. However, in particular, intellectual disabilities have become a universal problem in the present society (Gohel, Mukherjee, &Choudhary, 2011) and a major cause of high levels of depression faced by parents of those children (Sajjad, 2011) Moreover, in families with Intellectual disabled children, the needs and responsibilities increase exponentially. Parents need to identify the problem, get an analysis, and manage the situation in such a way that the disabled child is better prepared in the community, and use their full potential (Farheen, Dixit,&Bansal, 2013). Moreover they need to be prepared for a lower standard of living, unhealthy family functioning, and negative psychological consequences (Bazzano et al., 2015).

Rehabilitation is an important part of universal health coverage and is a key strategy for achieving Sustainable Development. Rehabilitation is not only for long-term or physical impairments. Rather, it is a core health service for any health condition which

limits functioning, and should be available for anyone who needs it. In 2017, WHO launched the **Rehabilitation 2030 initiative**, which emphasizes the need for health system strengthening, and calls for all stakeholders worldwide to work on different priority areas, including: improving leadership and governance, developing a strong multidisciplinary rehabilitation workforce, expanding finance, improving data collection and research on rehabilitation.

In dealing with rehabilitation of ID children, parental stress related to various aspects needs to be answered by professionals. Parental stress is associated with child's misbehavior, the experience of depression also depends on how the parents perceive their situation and whether coping strategies or Stress management (Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008) is used. Prominent theories of depression and stress, in recent times, for parents of children with intellectual disabilities, focus on quantifying stress by psychological testing. This also contributes to their adaptation to the difficulties presented by children (Hassall, Rose, & McDonald, 2005). So coping with success depends on how well the parents are able to constantly change their efforts to understand, to meet the demands and responsibilities of them, with their children. (Thakuri, 2014)

According to **India Disability Statistics Report** 2017, which was updated from the 2011 census data, there are 1.5 million people with a mental disability and 0.7 million people with stressful lifestyle and the number is growing each year. In this case it is essential for every professional to play their part in reducing the burden on these parents. Therefore, the researcher of this study seeks to analyse stress & address parents of intellectually disabled children in all areas.

STRESS: When a child is born with a disability, the unexpected and permanent nature of such a disability, generally increases a parent's vulnerability to stress. There is considerable evidence to suggest that parents of children with intellectual disabilities experience greater stress than parents of children without disabilities (Hastings & Johnson, 2001). Research on disabled children shows high levels of stress in 70% of mothers and 40% of fathers of severely disabled children (Jones & Passey, 2004). The research findings alarms, increased parental stress can lead to poor parental health and well-being & it can negatively affect well-being of children. This may be associated with greater financial and care-giving demands, a sense of loneliness and isolation (Sullivan-Bolyai, Sadler & Knafl, 2003; Oruche, Gerkensmeyer, Stephan, Wheeler & Hanna, 2012 & Thwala, Ntinda & Hlanze, 2015). Over the past two decades, researchers have opened up a 'black box', considering ways that may explain the relationship between handling intellectual disabled children, and parental stress. The findings of the study were that those parents with intellectual disabled and behaviour problem children were having higher levels of stress. A number of studies found that behavioral problems predict future parental depression, and this may resolve the relationship between child behavioral problems and family dysfunction. Baker et al., found that behavioral problems in children with Fragile X syndrome had a negative impact on family unity and marital satisfaction in the form of maternal symptoms. However, the relationship between child behavioral problems and parental depression is often considered to be artificial. When these children are perceived as depressive, the tendency towards parental depression and family dysfunction as a reaction to stress may be unavoidable.

Families of children with intellectual disabilities face diverse needs of the account of the disability in their children. Some of the prominent needs reported by the parents are related to personal care needs (Plant & Sanders, 2007), management of adaptive behaviors (McCarthy, Cuskelly, Van Kraayenoord & Cohen, 2006), medical (Neely-Barnes & Marcenko, 2004), technical, financial and social needs (Verma & Kishore, 2009). While these needs are common in the context of other disabilities and non disabilities, the intensity of the above is usually very high and unique in intellectual disabilities (Peshawaria, 1995; Verma & Kishore, 2009; James & Ashwill, 2007 & Peters & Jackson, 2009).

If the parents are not supported in meeting their needs, it may further interfere with the development of a child, which in turn will create stressful situations for the family (Azar & Badr, 2006). In this context, it must be understood that parents' needs (Azar & Badr, 2010; Kermanshahi et al., 2008; Verma and Kishore, 2009) appear to depend on personal resources of the parents, family variables and the characteristics of children, and more importantly the socio-cultural setting to which the families belong. In general, parental age, marital status, and number of siblings with intellectually disabled children in the family affected the outcome (Grant & Whittell, 2000). Thus it is understood that there is no set pattern of needs except that they fall into multiple domains and multiple determinants. Within the context of parenting, the predominant view is that intellectual disabilities create stress and burden for the caregivers (Sethi, Bhargava, & Dhiman, 2007). Additionally, parents may experience the impact of financial burden, restricted social interactions, and mental worries and so on (Alexander & Walendzik, 2016).

A 2012 study by Bloomfield L, Kendall S, demonstrated a correlation between parenting self-efficacy and parenting stress. Higher parenting stress was related to lower TOPSE scores, while increased TOPSE scores correlated with lower parenting stress. Further research included an adaptation of TOPSE for parents with learning disabilities.

Social Support : Two main models have been proposed to describe the link between high social support and low stress. Buffering hypothesis and Direct effects hypothesis are the models. The buffering hypothesis after research, in terms of whether social support systems lengthen a person's longevity, health, and wellness finds a positive correlation between a strong social support system and the ability to fight cancer, avoid Alzheimer's disease. Further, a strong social support system can be a buffer against depression, anxiety, post-traumatic stress disorder, and other mental illnesses. It describes human beings as a social creature, makes sense that a strong social support system would have a positive impact on mental and physical health.

The primary reason is that social support lessens an individual's stress level. A heightened stress level creates cortisol in the body, which can suppress the digestive, reproductive, and immune systems. When the immune system is suppressed, there is an increased risk for getting sick.

 Many studies are done with Parents of children with Autism, to find out parenting stress and sense of coherence (SOC). It describes, powerful SOC parents perceive their role of parenting, caregiving duties as manageable. They admit their caregiving situations and children's autism-related problems through meaning making child acceptance. The reason might be that SOC helps to minimize stress, perceive life stressors & health by facilitating numerous resources within the individuals. High SOC is associated with predictive positive health outcomes (Erikson & Lindstrom,2005)

Perceived social support : Cassel hypothesized in 1974 that, under stressful conditions, the lack of social support will lead to a higher risk of becoming ill. Research has shown that supportive interactions among people are protective against the health consequences of life stressors. It appears that social support can protect people in crises from a wide variety of pathological states. Basic Social support can be divided into three types, namely perceived support, enacted support & social integration. They are weakly related to each other.

Perceived support is also known as functional support (Wills & Filer, 2001) It is the subjective judgment that family and friends would provide quality assistance with future stressors. People with high perceived-support believe that they can count on their family and friends to provide quality assistance during times of trouble. This assistance may include listening to the stressed person talk about troubles, expressing warmth and affection, offering advice , providing specific assistance such as looking after the children, or simply spending time with the stressed person.

Problems Faced by Parents of Intellectual Disability Children : In spite of child's specific needs, whether it is simple or complex, parents definitely show psychological reactions. Parents with special children experience emotional and physical trauma throughout their lives. There are various problems, parents of special children face.

Acceptance : When parents are informed by a Physician, Paediatrician, Occupational Therapist, psychologist, about reality of the child, it is very painful for many parents to accept that their child will possess some setbacks in all areas of life. They live in a state of denial and try to find a solution to this incurable problem by visiting many doctors, to hear that the disability is temporary. Their dreams and aspirations for their child vanish when they know there is nothing, they can do but accept that their child is a special child.

Self-Criticism: Most parents feel guilty and sometimes begin to wonder if their child has made a mistake. They wonder if God is punishing them for their past sins. At times, they may even feel depressed because they think that their sins are the cause of their child's suffering.

Social Discrimination: Many parents do not go to any social gatherings or even family gatherings for fear that a neighbour, relative, or others might say unkind things to make them feel inferior.

Moral Problems

Special children usually possess behaviour problems, they are stubborn and parents of such children find it difficult to manage such problems. They can be a source of frustration for parents, especially mothers, who have to manage both the home and the outside world.

Physical Fatigue and Depression : Physical tiredness can be a source of frustration for parents. The child may need a direct monitoring nearby, to avoid indirect harm such as falling off. Sometimes careful monitoring is needed for bathing, feeding, moving around or changing diapers and clothing not only at childhood age, but also at grown up age. These extra responsibilities may hurt the parent, leading to burnout. This can be a source of frustration for parents.

Socio – Economic : The socio-economic problems that parent face such as social discrimination, lack of resources to compensate disability, low financial status to avail multi therapy(PT, OT, Speech, Special Education, Yoga), all makes them unhappy. Raising an ID Child can be hence, very expensive than raising a normal child.

Family Problems

Having a child with a mental disability puts a lot of pressure on the family. Because marital relationships can be strained if the parents have different ways of dealing with the child or if the single parent has to take care of the child on a regular basis. At times, mothers may feel that they do not get enough support from their husbands in caring for the baby, and fathers may feel that their wives are unduly anxious and very protective, insisting many therapy programs for child. Parental helplessness arises from both lack of help from each partners, and the other demanding siblings in the family.

Anxiety about the future

One of the biggest concerns for parents of children with a mental disability is how their child will be cared for when they die. They feel that no one else could care for their child with the same loving care and attention, after their death.

Parents face many **emotional problems** such as depression, fear of caring for their children after their death, fear of the people who make these children victims of sexual or physical abuse. If other family members like normal siblings, grandparents, and friends are available, the burden can be lessened. The disadvantages also stem from lack of psycho education.

Expectations of parents

In many cases, parents of handicapped child are not satisfied with the slow learning of essential daily living activities. They try to push the child to **learn faster** and try to keep up with other children. When parents expect the impossible from their child, it can lead to disappointment not only for them but also for the child. Attitude towards disability, expressed by certain parents are protective. They will somehow manage all problems of their child, work for rehabilitating child to fullest possible extent. If neglect attitude is present, the child cannot be placed along with family. It has to be left out at institutions, for life time.

Need and Importance of the Study

Families caring for their children with intellectual disabilities face many challenges.Mostly, 80 per cent of all people with disabilities live in isolated rural areas in developing countries. In India, families and relatives are united, and hence, 50 percent of population affected by disability, live with parents & they arenot isolated. The challenges they face in the community, due to the lack of resources and the obstacles they face in their daily lives should be analyzed for reducing stress related to **social problems**, is discussed in this study. Most of the differently abled face social problem of LABELLING by their disability. Initially they have trouble facing people, later differently abled will be used to it. In ID children, PARENTS & SIBLINGS of these children are the people who need to realize that negative consequences of ID children action also needs to be compensated with the problems experienced in society. Hence, whatever social support is available to them, needs to be effectively used at right time.

A sample survey was conducted among parents of intellectual disability children, living under various conditions. i.e., accommodation, financial status, provides the best evidence available on what steps should be taken to overcome barriers to health

care, rehabilitation, education, employment, and create environments that will enable people with intellectual disabilities to thrive. These problems vary according to the degree of restriction, the physical disability and the associated interests, values and other external circumstances of the members. The study concludes with a concrete set of recommended measures for Government and Non-Governmental Organizations

Statement of the Problem

In India, the family has a greater responsibility to care for ID children than in developed countries. Family members, (ThiyamKiran Singh et al., 2008) along with siblings are most affected by ID condition (Ashum & Singhal, 2004).

Parents have different ways of adapting to stress-related to fulfilling needs of these children (Bonab, Motamedi, & Zare, 2017). Seeking community support and professional services, marital union, and seeking information are, known to have a positive impact on the strength of the family unit. In contrast, self-criticism, distance, and social isolation are closely linked to negativity (Santos & Pereira-Martins, 2016).Coping strategies can be flexible (i.e., leading to less stress) or maladaptive (i.e., leading to more depression) coping with stress is one of the challenges in life. Apart from the scope of reducing or eliminating sources of stress, such situations require strategies in which a person adapts to the situation (Somashekar, 2017).

Parents with children with intellectual disabilities are distracted by the additional responsibilities associated with caring for their children in normal day-to-day activities. This can create great pressure mentally, physically, and socially. It is necessary to look at issues related to how parents of intellectual disability overcome their problems in the community in which they live. In this study the researcher aims to look at issues such as the impact of stress experienced by parents. After researching the magnitude of the stress, social support used by parents to reduce stress was assessed, with the ultimate goal of using effective therapy to deal with stress.

LITERATURE REVIEW

Farideh Malekshahi, Jafar Rezaian, Mohammad Almasian (2020) studied on "Intellectually Disabled Children and Their Parents' Problems: Preliminary Evaluation and the Suggestion of Effective Strategies". Apart from the functional problems that disability creates, it has negative effects on parents as well. Thus, identifying these problems plays a decisive role in the health and rehabilitation of the family. Their study aimed to determine the psychosocial problems of parents with ID, receiving services from the Iranian State Welfare Organization in Khorramabad, during 2015. The data was collected with a questionnaire for demographic and related to psychological and social problems. Results showed, all parents suffered from psychosocial difficulties, on average, mothers had more problems due to their different roles in families. Finally, a significant relationship was found between parents' education and the gender of the Children (P < 0.05). It was concluded that impact of disability on parents depends on the severity of the disability and their coping skills. If support was available to the family, their coping development was better.

M Shamim, Ahmed Abdulla, M Osman (2015) studied on "Parental Attitudes Towards Children with ID: A cross Sectional Study from NGOs in Northern India". The three main variables of the study (severity of mental retardation, gender and age) when interact with each other affect significantly on the parental attitudes towards children with intellectual disability. They concluded that there is a parental negative attitude towards children, which is highly on home management and lowest on acceptance moreover the friends also neglected to insist that it is essential to care ID child.

Shyam, Kavitha, &Govil (2014) designed a study to assess family responsibility for mothers of children with disabilities and mothers of children without disabilities, from three counties of Haryana district, India. To this end, a multi-group design that included following group 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. An indicator of parental stress and family burden rating was administered to 125 mothers of these 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., (2014) 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.

Farheen, Dixit, &Bansal (2013) conducted a study of Stress experienced by families with mentally disabled children enrolled in special schools in Indore. In their study, 102 mentally disabled children famillies participated. A preliminary self-administered questionnaire, "Family Discussion on Stress and Resistance to Mental Disorders" (FISC-MR), developed at NIMHANS Bangalore, was used in the study. Percentage of Pressure scores were measured on the Likert scale, in the various stages. The following areas of stress was studied. Stress for daily care, emotional stress, social stress and financial stress. Of these, 81% of households reported stress of daily care, 65% reported emotional stress, 51.5% reported social depression, and 64% of families reported financial stress. In this regard Farheen et al., 2013, concluded that greater & severe stress was reported by families in increased inclusion of care and reduced leisure time. A moderate level of stress was felt in many families in small areas and neglect of other family members.

Walsh, Mulder, & Tudor (2013) in the study to obtain predictions of parental stress, used a sample of children with autism spectrum disorder. This study examined pain and behavioral problems as predictors of depression in parents of autistic children. They also explored the style of child rearing to learn how to deal with pain and behavioral problems and ultimately contribute to parental stress. The results showed that it was problem behavior that was a factor and that there was a significant correlation between pain and stress behavior predicting depression.

Zablotsky, Bradshaw, and Stuart (2013) conducted a study on the relationship between mental health, depression, and coping strategies among mothers with autism spectrum disorders. They also emphasized that raising a child with autism spectrum disorder can be a stress-filled experience for parents. After comparing child, mother and family-level factors, they reported that mothers of children with ASD were more likely to have poor mental health, which meant they had higher levels of depression compared to mothers of children without autism spectrum disorders. This includes healthy as well as the presence of strong coping skills. Relationship studies have shown that parents stress levels are associated with their child's age, level of intelligence, authenticity of autistic symptoms, and behavioral changes.

Gupta & Mehrotra (2012) used the short version of the Parenting Stress Index and a few questions in 2009, in New Delhi and Faridabad counties to obtain a sample of sixty-six patient families through six active NGOs. Among the variables, they found that the female gender of the child was associated with greater stress. It was related to a child's inability to meet parental expectations and to satisfy parents in their role as parent. Parents who work at high-paying and respected jobs are under greater pressure. In line with this, religion was found to be a common tool in coping. Many parents say they receive little social support from their families in caring for their child.

Perceived social support in ID parents

Perceived social support views of parents were assessed by asking the following questions, developed by the researcher, as part of her research study.

- Is there any special person around you, with whom you can share "joy", "sorrow", 'enjoy' for certain period of time leaving your family responsibilities for stress relief?
- Is the second circle of family members, friends being supportive
- Will they drop out of you, saying some work needs immediate attention than listening to you, since, always the stress of yours is hidden with Intellectually Disabled child
- Is there a time, when you felt Siblings born along with your ID child needs to be trained in having good social support for rectifying their life stressors

The response made by parent participants indicated that they were unable to find a supportive person other than the professionals from whom they seek help. Moreover, the researcher also found that some coping skill training is essential for them in absence of good social support. It was also found that siblings, of these ID children were less able to TOLERATE SIMPLE insults also made by their peer group.

Suggestions

•   Non Governmental Organizations (NGO) should come forward for launching the community based training and rehabilitations programmes for parents of ID children along with Professionals who doesnot indulge in seeking advertisements for their service. This can minimize the amount of money spent on unnecessary banners etc…the real beneficiaries may be benefited with learning how to gain social support, not only on WORLD DISABILITY DAY but Permanently on all days of the year.

•   Parents should take the ID children with them to attend different social functions like marriages, religious functions and other occasions of social gathering and should also encourage them to interact with the people present in the function.

•   In Special schools established for Intellectual Disability children, as suitable to the needs and abilities of ID children, stress management programs for parents and siblings should be taught through appropriate gathering of parents. More emphasis should be laid as learning by doing method, rather by lectures.

•   Through Integrated Child Development Scheme (ICDS) nutritious diet and medical checkup to all the intellectual disability can be provided regularly.

Conclusion

Being a parent of an intellectually disabled child requires great will power. This study showed that parents of intellectually disabled children experienced more daily parenting stress. More the stress more is chances of depression. Mothers experienced greater stress as compared to fathers due to greater involvement in care giving of the intellectually disabled child and spending more time with their intellectual disabled child. Every individual has their way of dealing with a stressful situation. With the strategy differing along every stage of life, some have a positive way of dealing and some negative way of dealing with the situation. This study researcher found that parents of intellectually disabled children need early training through social contacts, better coping skills, to use THROUGHOUT life time. The findings also indicated that the parents having higher level coping strategies had lower level of perceived stress.The researcher hopes, this study will be a notable milestone in the field of using social support as an effective tool in rehabilitation.When the mental health of parents improves, there will be a positive vibration of siblings and thus will create a healthier family.

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