



Prevalence Of Psychosocial Health Issues Among The Parents Of Children With Special Needs: An Exploratory Study From Assam

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ABSTRACT

Child with special needs is one of the most vulnerable sections of the society. Many studies already have discussed the issues encountered by parents of special child around the world; however, there is scanty of research in the field from psychological perspective in Assam, the northeastern state of India. Therefore, the present study has been conducted in order to fill this gap. The objectives of this study is to identify the challenges encountered by parents of special child in their day to day life as well as during the situation of death toll created by COVID 19 outbreak and to understand the need for counseling service and special education program for the specially-abled children as perceived by their parents. The study is based on primary data collected from 28 participants who are parents of a special child belonging to Darrang district of Assam. In order to gather the data, convenience sampling technique, semi structured interview method, focus group discussion etc. have been used. The study has found that parents of children with special needs encounter different psychosocial problems such as physical exhaustion, financial issues, emotional trauma, social stigma, time constraints, worrying about future etc.

Keywords: Children with special needs, Psychosocial health issue, Counseling, Special Education

INTRODUCTION

Children with special needs are those who have risk for chronic physical, developmental, emotional, and behavioral condition and require special health related care services more than the typical children of their age require. After giving birth to a special child, parents start a journey of life filled with strong emotions as well as difficult choices (Kalek, 2008). Both parents, especially the mother has to go through various challenges, traumas, taboos, prejudices and other negative experiences in upbringing of the child while in some financially stable family parents can overcome the challenges quite easily and make necessary arrangements.

Being one of the most vulnerable sections of the society, children with special needs are often exploited, neglected, and discriminated against. The United Nations Convention on the Rights of the Children and the United Nations Convention on Persons with Disabilities are trying to uphold the need and importance of education to all children with special needs. India's Right of Children to Free and Compulsory Education Act, 2009 also ensures the right to free and compulsory education to all children between ages six to fourteen. The concept of inclusive education is another praiseworthy step in the field of education for special child.

In Assam, however, most parents are not much aware of the schemes, programs, policies and provisions made by government and other non-governmental agencies for special child. UNO also announced 1981 as the international year of disabled person to disseminate the awareness and information among the masses.

The parents of special child usually have to face a range emotions, challenges and trauma over the years. All these children need close monitoring by their parents. So, the particular family knows the grief, sadness, worries and difficulties associated with it. In addition, the outbreak of the COVID 19 has brought another threat to the parents of children with special needs. Although there found different studies already done on challenges encountered by parents of special child, but is still dearth of research in Assam from psychological perspective. Special education has become popular all over the world, but most parents of Assam are not much aware and seem to overlook this. Henceforth, the present study will be a guiding light for future in-depth experimental as well as non- experimental research.

REVIEW OF LITERATURE

Nimbalkar et al (2014) conducted a study to understand the psychosocial problems among parents of children with cerebral palsy. The researchers found that the mothers of children with cerebral palsy experienced some common issues such as disturbed social relationships, health issues, financial difficulties, worries about the future of the child in their absence, need for more support services than they have and so on. Jambekar et al (2018) found that children's dependency on their parents for their regular activities, lack of proper communication between parents and the child, financial constraints, stress and worry for the future of their child, reduced social life are the common problems among the parents of special child. They also found that acceptance of the special child by their sibling is less than that of their parents. Moreover, the research also indicates that there is a need for counseling services though parents hardly approached a counselor for their child. Taderera et al (2017) in Namibia found that there is a lack of awareness of the availability of programs, services and policies to benefit the children. The single, unemployed parents seem to have access to less support services and resources. Mourya et al (2016) found that specially abled child's activity limitation is significantly positively correlated with stigma and restriction of social life of the parents. Shetty and Menezes (2013) found that uneducated parents are not much aware of the mental retardation. The families with special child encounter greater financial stress, frequent disruption of family routine and leisure. Having a special child has poor social interaction and ill effects on the physical and mental health of the parents. Moreover, often parents feel about their special child as burden irrespective of their financial status, though they are not also ready to abandon their child.

OBJECTIVES

- To find out the psychosocial health issues among the parents of children with special needs in Assam
- To figure out the different issues faced by parent of children with special needs during COVID 19
- To understand the perceived need for counselling service and special education programs for children with special needs.

METHODOLOGY

Method

A mixed method using both quantitative and qualitative study has been adopted for the present study. For the empirical part of the research, a semi-structured interview schedule comprising 10 questions was formulated by the researcher itself. For the qualitative part, two focus group discussions (FGD) were conducted in Darrang district of Assam in order to extract in-depth information. The researcher in the present study played the role of moderator during the FGDs and started the discussion through rapport formation with an introduction of the research objectives. The researcher used an FGD guide comprising 8 questions for the discussions.

Sample

For the empirical portion of the study, 13 male and 15 female were chosen who have specially-abled child. For the qualitative part of the research, a total of 14 participants were chosen for the FGDs.

Sampling method and technique

For the current study, non-probability sampling method is used where convenience sampling technique is chosen by the researcher. The participants belong to economically weaker sections of Darrang district of Assam.

Tools

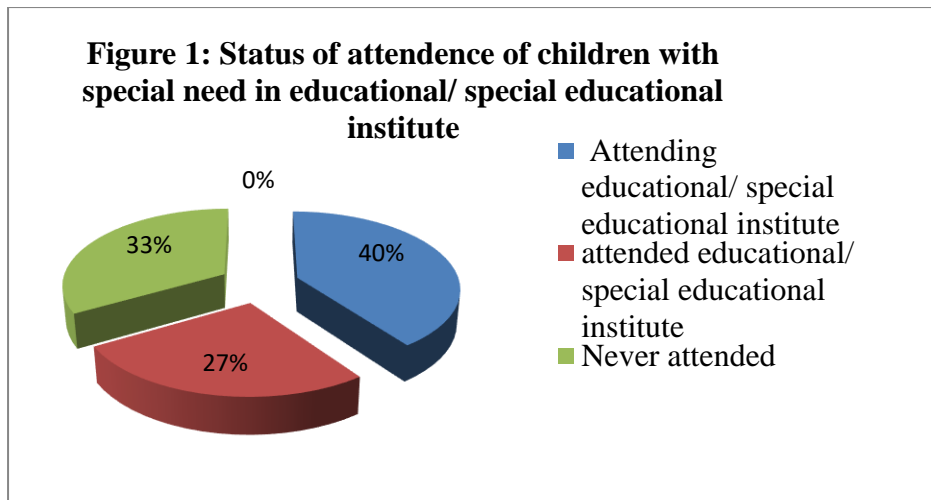
The researcher uses an audiotape recorder to record the verbatim of the participants during the FGD to transcribe it later on.

Procedure

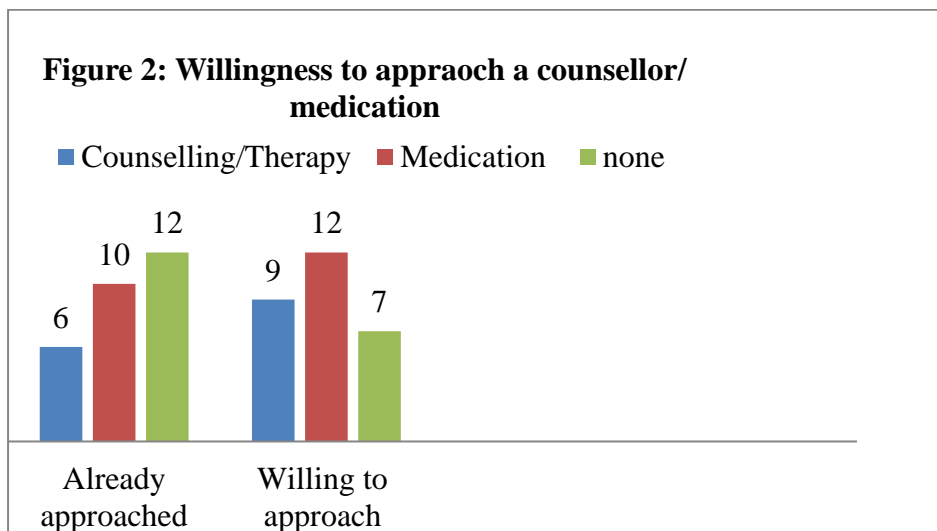
After deciding the sample, tools, and method of data collection for the study, the researcher meets the participants to form a rapport by introducing the main topic and debriefs the objectives to them. The researcher tells the participants that their participation is entirely voluntary, and their withdrawal from the research is allowed if they do not feel comfortable with it. Finally, data are extracted with the help of a semi-structured interview and FGD, and translated into English by the researcher who is well-versed in both English and Assamese.

RESULT

Types of Disabilities	N (%)
Hearing impairment	3 (20%)
Visual impairment	3 (20%)
Speech and language impairment	4 (26.67%)
Developmental delay/ Autism/ Cerebral Palsy	5 (33.33)
Total	15 (100%)



Inference: Figure 1 shows that 40% of the total children still attending educational/ special educational institutes, while 27% has attended once and 33% has never attended any institute.



Inference: Figure 2 shows that among the total of 28 participants, 6 of them have already approached a counselor for their specially-abled child, 10 of them have approached medication, and 12 of them have approached nothing. In addition, 9 of them are willing to approach a counselor in future, 12 of them are willing to approach medication and 7 of them have showed no interest in it.

Table 3: Nature of problems encountered by parents in handling children with special needs

N = 28	
Life has been turned upside down	22 (78.57%)
Losing hope and enthusiasm to live	18 (64.28%)
Had to establish unique way of communication	25 (89.28%)
Childcare expenses becoming double	18 (64.28%)

Had to understand time management	24 (85.71%)
Had to experience pity from others along with other negative comments	25 (89.29%)
Negative impact on social life	20 (71.43%)
Tendency to worry about the child's condition and his future	26 (92.86%)
Negative effect on regular sleep due to stress, and pessimistic thought	23 (82.14%)
COVID 19 has created additional burden	19 (67.85)

The parents of children with special needs are inevitably affected due to the peculiar needs of their child. It is usual for most parents to go through various physical, psychological, emotional trauma and issues. They may receive assistance from family, friends, care-givers, special educators and so on in raising the child, but maintaining balance with everything still becomes a challenge for them.

Hence, on analysis of the transcription of the verbatim, the following themes emerged as the result of problems encountered by parents of children with special needs.

(1) Physical/ health issues

The first and foremost problem encountered by the parents of children with special needs is physical problem as they have to give more time to their child as compared to typical child of his age. Physical exhaustion is the result of too much attention and effort needs to be paid for the children with special needs. Having a child who requires special treatment brings greater stress and strain to the lives of parents and other family members which take a toll on them. As the child needs close monitoring for his/ her every action such as bathing, eating, moving around, walking in order to avoid inadvertent harm, the parents have to be aware and awake all the time. Changing diaper and cloths, taking them to toilet, and other indispensable daily activities also make the parent busy with them only. So, these additional responsibilities and activities are sometimes felt by the parents as burden as reported by most of the respondents which ultimately take a physical toll and leads to burnout and exhaustion. Respondents reported that during COVID 19 lockdown, they had to spend additional time with their children in order to fulfill their special intellectual indoor as well as outdoor needs. They also had to take additional preventive measures to a great extent.

(2) Financial problems

Lack of facilities is the result of low financial status. A few of the respondents reported that they do not have any job or any permanent income source. They are not able to fulfill the minimum needs of their child as the money they get from working at other's house is not enough. Raising a child with special needs is more expensive than raising a typical child, because, expenses can arise from medical care, special equipment, therapy sessions, special education facilities, adaptive learning facilities, care giving facilities, and so on. Extra financial pressure during lockdown to fulfill their dietary needs, medication has to be borne by the parents.

(3) Emotional/psychological problems

Parents of special children face a lot of emotional turmoil. Some of the parents experience a gamut of emotions since the day they got to know about their child's special need.

i. Accepting the reality

Accepting the reality becomes a tough job at first for the new parents. Respondents reported that when they got to know that their child needs special treatment, they felt broken inside. Because having a child with special needs and raising him/her needs lots of courage. It is very painful to accept the reality for most parents as reported by the respondents. Their dreams, expectations, and aspirations get shattered once they learn about their child's special needs for which they lose hope to live sometimes. The ideas of not being able to accept the reality brings anxiety, stress and other negative effects to the life of the parents.

ii. Blaming oneself

Some parents blame themselves and their fate for giving birth to a child with special needs. They express themselves in front of others in this way that perhaps they did something bad in the previous life and hence they are being punished by God.

iii. Helplessness

Helplessness is found to be common psychological issue encountered by parents of children with special needs. Generally, helplessness is the result of lack of knowledge regarding disability, resources and facilities available for a special child. Most parents feel helpless and find it difficult to take care of their child properly as they are unaware about the help and assistance provided by government programs and policies and NGOs. Moreover, inadequate handling of the child by health professionals and other paraprofessionals is also another reason of helplessness among parents of special children.

iv. Behavioral problems

As reported by the respondents, special children are generally aggressive and are not able to concentrate like a typical child. Therefore, managing their personal life, as well as also providing adequate amount of time to their child become a tough job for the parents who work outside. The aggressive and stubborn behavior of their child makes the parents also anxious and aggressive sometimes.

(4) Social problems

One common problem reported by the respondents is social issues. They reported that their participation in different social gatherings such as marriage party, family get together and other social occasions has been reduced. Since they are not able to take their child everywhere to them, so they prefer to be at home with him/ her only. The daily routine of their child has become their priority rather than their own interests and expectations.

i. Social stigma

Society is still in the grasp of stereotypical thought and hence having a child with special needs is stigmatized often. A few of the respondents reported that the society thinks that the reason of disability of their child is their sin in previous life. The disability is hence often associated with stigma and discrimination. The misconception associated to child's lack of abilities, unique needs makes the parents, families and the child himself/herself prone to social stigma and discrimination.

ii. Societal perception and response

The stereotypical notion toward disabilities often makes the parents vulnerable to mental health issues and therefore, parents' self-perception starts deteriorating. Respondents reported that they are often misunderstood by the society and hence ashamed of themselves. Society is still not able to accept the disability as something physiological rather than spiritual.

(5) Others

Besides these there are some other issues encountered by parents of special children. Some of them reported by the respondents are as follows:

i. Time management

Time management for parents of children with special need is very crucial. The working mother has to sacrifice and compromise a lot in her life for fulfilling the needs of her child. As to feed them and make them sleep on time is important, both parents have to learn the art of managing time to balance the personal and professional life.

ii. Worry about future

It is common in all the parents to think of their child future. One of the main concerns of parents of special child is about how their child will take care of himself/ herself after their death.

DISCUSSION

It has been observed in the present study that the dependency of the special children for their daily activities on the parents, the communication issue, their behavioral problems are some of the problems faced by parents of special child. It reveals that financial issue is the common concern among the parents of special child. Another study found that financial problem is experienced by most parents as it is another crucial factor in the upbringing of the child (Nimbalkar et al., 2014). The respondents who are single parent as they have lost their husbands already reported that they are unable to provide their child with adequate facilities. The unemployed fathers are more negatively affected by their child's condition. Though better financial condition will not mitigate their woes of having a special child, but it definitely helps them minimize their stress levels.

The study indicates that parents of special child often get humiliated. In a similar study conducted in Mangalore, it has been found that having a special child is something to be ashamed as perceived by family members. Nimbalkar et al., (2014) found that the parents of special child have to receive many adverse comments about their child which is really very disturbing for them. Previous study also indicated that child's functional limitation or disability is significantly positively correlated with parents' social restriction (Mourya et al, 2016).

In the present study, parents reported that they develop the adjustment with their special child and try to cope up with the challenges associated with them, but their siblings find it difficult to get along with them. In a study conducted in Mumbai, it has been found that special children are accepted by parents, family members, peers, and neighbors (Jambekar et al, 2018). However, all the challenges have been increased during the COVID 19 lockdown to a great extent (Fazil et al., 2020).

SUGGESTION

- Parents should be made aware of the government programs, policies and facilities related to disability.
- Parents should also be made aware of disability and their causes.
- They should receive suggestion from physician as well as mental health professionals in a regular basis and also inform the behavioral change of the child to physician time to time.
- Help and support from friends, family members and community is required.
- Government should provide free special education program and establishment of residential and free schools for children with special children can be a praiseworthy initiative.

CONCLUSION

Our society has been changing and developing in a very faster rate. But our society sometimes seems to be sick because of its stakeholders' negative attitude and perception toward a special child. For that matter, inclusive education should be good medium and awareness program can also be organized time to time. Special schools and institutions should be involved in their education, training, therapy and adaptive learning. For providing rehabilitation, community and government also need to join hands. Therefore, through this small scale research, the present study throws light on the wide range of difficulties associated with the physical, social, financial, psychological issues encountered by the parents of children with special needs.

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