Original Article

Concerns and Challenges Faced by Parents of Children with Hearing Impairment: An Exploratory Analysis

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ABSTRACT

Background: Persons with Disabilities can become an integral part of society, as well as help generate higher economic growth that will benefit the Country. It is also noted that having child with disabilities affects not only parents, but also siblings and the relationship among family members. People with disabilities have the same health needs as non-disabled people for immunization, cancer screening, and screening against other communicable and non-communicable diseases. They also may experience a narrower margin of health, both because of poverty and social exclusion. *Objectives:* The present paper was carried out to investigate the concerns and challenges faced by parents of hearing impaired children. *Sample:* The sample included 15 parents of children with hearing impairment. *Design:* The research design that is used for the subject is exploratory by using purposive sampling method *Tools:* Semi-Structured Interview Schedule was administered to 15 parents of children with hearing impairment. *Results:* Significant positive concerns and challenges were noticed by parents of hearing impaired children. *Conclusion:* The parents were found to be happy with the education provided to their children with hearing impairment. They got to know about some institution through neighborhood or colleagues and their only concern being, the future of the kid in terms of employability, marriage and health.

Keywords: Concerns, challenges, parents & children with hearing impairment

Disability is not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society, in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. People with disabilities have the same health needs as non-disabled people for immunization, cancer screening, and screening against other communicable and non-communicable diseases. They also may experience a narrower margin of health, both because of poverty and social exclusion. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings.

This paper will emphasize more upon the problems and concerns of the children with hearing impairment and their parents. “Hearing impairment," means loss of sixty decibels or more in the better ear in the conversational range of' frequencies . Deafness is defined as a degree of impairment such that a person is unable to understand speech even in the presence of amplification. In profound deafness, even the loudest sounds produced by an audiometer (an instrument used to measure hearing by producing pure tone sounds through a range of frequencies) may not be detected. In total deafness, no sounds are heard at all, regardless of amplification or method of production.

Disability is the condition of being unable to perform as a consequence of physical or mental unfitness; the state of having a physical or mental condition which means that part of your body or brain does not work correctly. In health, any loss or abnormality of physiological, psychological, or anatomical structure or function, whether permanent or temporary leads to impairment. Identifying impairments that contribute to a functional problem for a patient is a key factor for a health professional to determine appropriate treatment. People with disability are unable to contribute much to the society economically as well as socially. They do not get easy employment and if they get one, it is not highly

paying. They face problems in fulfilling their social roles and behaving according to the societal norms. Although the disabled are about as likely to have been married as are persons in the general population, their marriages particularly those of disabled men, more often have been postponed to a later age. There are various challenges faced by the hearing-impaired children like lack of social interaction, language and communication problems, educational and behavioral problems and even mental health problems. The families of hearing impaired children go through challenges like social acceptance, emotional and psychological turmoil, communication problems, financial strain and social isolation. Chabassol & McNeil (1984) found in exploratory study on the decree of involvement of parents in the programs related to the hearing impaired children. Findings suggests that majority of the mothers and fathers were found to be in agreement that the father was much more open to change their work plans and schedules to meet the requirements of the hearing impaired children.

Relevance to the Study

Parent involvement in a child's development phase is very important and at the same time it is important to know the degree of involvement. Keeping this in mind the research is completely based on a parent's point of view, about their differently abled child. The research study bears a stark resemblance to the need for research to understand the implications of involving parents in the intervention plans and how they can be more effective and efficient as change agents for the befit of their differently-abled child.

Objectives

The present study was conducted to understand the concerns and challenges faced by parents of children with hearing impairment. The objectives of the study are as follows:

1. Understanding the challenges faced by the parents of children with hearing impairment.
2. Methods of coping up with the various problems the children and the parents face.
3. Perception of parents regarding the efficacy of services provided.

Method

Sample:

For this study, 15 parents of children with hearing impairment were interviewed / included in the study using purposive sampling method.

Design:

The research study was based on the parents of hearing impaired children. The research design that was used for the subject is exploratory.

Tools:

The tool of data collection that was used is a semi structured interview which is used to interview the parents. The data of the report was analyzed qualitatively. Where ever possible, quantitative data was also used .

Procedure:

The data was collected with the consent of parents of the hearing impaired children. Once the consent was given, the investigator selected the sample purposively. Semi structured interview was conducted to interview the parents to understand the concerns and challenges faced by parents of children with hearing impairment. Data gathered in field and observation at the field was analyzed. The research problem that seeks to understand the concerns of the parents of hearing impaired children and has to explore the socialization patterns to know the way in which the parents and children are coping. The data was collected by conducting home visits.

Results

15 home visits were conducted in order to interview the parents of the hearing impaired children in different areas. They were interviewed and the analysis of the data collected is as follows:

Perceived reasons for child's hearing impairment: The mothers reported that there was lack in the antenatal and postnatal care during their pregnancy. The mothers did

not take proper nutritional diet during their pregnancy and therefore the child was born weak/underweight. Three cases out of 15 were those of injury, which might have caused the impairment in the child. One of the child fell from the bed and got a head injury, another girl got this impairment because some stranger had put some seeds in her ear (that's mother's belief) and the other child again got a head injury while he was too young.

Reactions of parents when they got to know that the child is hearing impaired: The parents had different reactions towards their hearing- impaired children. Out of 15 parents, more than 7 parents said that when they realized that their child is not "normal", they blamed it on their destiny and fate.

Steps taken to improve the child's condition: It was not very surprising to know that parents had taken every possible step to improve their child's condition. Despite the financial constraints, the parents had visited numerous hospitals and doctors for getting their child cured. Some of the children were even taken for speech therapies. The parents had even gone to various temples and the local priests to get a cure for their child's condition. Some of the parents had even tried various kinds of 'totkas'(megico-religious cure) for mending the child's condition.

Difficulty in accepting the fact that child is differently abled: 12 out of 15 families said that it was very difficult for them to accept the fact that their own child could not hear and speak. The whole family went through a very difficult phase of first accepting the disability, then the child. It was even more difficult for them to make the other siblings understand about the disability of the child. As the child grew, the relatives often used to label the child as "deaf and dumb" (goonga behra) which hurt the parents' sentiments.

Physical problems faced by the parents: The physical problems majorly faced by the parents were related to the health of the child. There was no special observation except that the children used to fall sick with fever, jaundice, pneumonia etc. Another problem, which the parents faced, was related to the financial strain. The parents were working in semi-skilled or low skilled jobs as carpenters, painters or gardeners and there by earned a meager amount. Mothers of hearing impaired girls face major problems when they reached puberty. It became difficult for them to make their girls understand about the bodily changes and the menstruation cycle.

Social problems faced by the parents: The social problem faced by the parents was that of stigmatization and labeling of the hearing impaired children. The relatives and neighbors of these families used labels to denote the children with hearing and speech impairment as "goonga behra" and sometimes even as a mad child. Sometimes the women in the neighborhood often passed sarcastic comments on these children. As a result, some families had to face social isolation because of less interaction with the neighbors.

Communication problem faced by the child: It was observed that the mothers in most households understood what their child wanted to communicate. The children face too much problem in communicating. They had to be dependent on others. It was learnt that the children could not go to the shop to get stuff until they had a written list of the items they had to purchase. Similarly they faced problems if they have to commute by public transport. There were times when the parents did not at all understand what the child expresseed. This led to frustration in the child as well the parents, especially the mother.

Behavioral Problems and Coping: The behavioral problem in the children with hearing and speech impairment stems from the communication and the social problems. The major problems faced by the parents related to the child's behavior were aggression and frustration. This is because they could not express what they actually felt and even if they did, it was not sure if others understood them and reciprocated in the expected manner. Sometimes the anger was so intense that the child became violent and started throwing things. The coping mechanism that most parents used was that of expressing love and affection to their child when he/she was angry. The mothers said that they would either hug and cuddle the child or even make the child's favorite dish for dinner. Other coping

mechanisms used were scolding, ignoring or sometimes taking help from the school teacher to make the child understand. The parents were mostly supportive and cordial with their child.

Problems faced by child in academics: The parents were mostly satisfied with the kind of education that was being provided by the school. They were happy the way their child was improving in terms of using the sign language and being able to communicate. Most of the children would not sit down to study at home. They had to be threatened to study else, the parents would complain to the teacher.

Changes in child after admission in school: All parents stated that there was a positive change in their child. Six families out of 15 said that they had admitted the child to school between the ages of 5-7 years. Despite joining school at a late age, the child had learnt a great deal. It was noted that the children had a lot of aggression and frustration initially, some of them were very mischievous. However, after getting into the school, the anger and frustration level decreased. The children had inferiority complex initially but when admitted to school, this problem behavior also reduced.

Government Schemes: Government facility they vaguely knew about was the pension scheme for the child and the disability certificate that was supposed to be made. They had no idea about the reservation in educational institutes and employment sector. There was no awareness about the scholarship that the child can get. This is because they are fully dependent on the school to guide them about any such thing. Most of the families were not availing any of the schemes except for having a disability certificate. They were not aware of Awaz project started by the government to enhance the communication skills of speechless children with Cerebral Palsy. It is a software operated device provided with a conventional touch screen as well as anywhere touch screen, which is useful for children with severe problem.

Future concerns (Education, employment, marriage and social acceptance): It was good to know that thirteen out of fifteen parents said that they would let their child study as much as the child wants. It was surprising to know that even their parents were willing to educate their girls as much as they can. Some of the mothers said that they would want their child to take up some vocational training so that he/she can attain a skill as well. As far as employment is concerned, majority of the parents said that they had not really thought about it. Some mother were concerned about how would the child manage in the future if he starts up his own business. The parents wanted their children to get jobs related to computers (hardware/software), beauty culture, electrical appliance repairing, in restaurants like KFC, coffee houses or government jobs. Marriage was not a concern for most of the parents as of now. They said they had not thought about it yet as the children were very young. Some parents were very worried for their children especially the girls. They feared if the girl would get a suitable groom or not and if the in laws would accept her or not.

There were apprehensions about the social acceptance of the children. The parents felt that when the children were facing so many problems in childhood itself, there might be more problem in the future. They are worried about their children's married and social life. The parents did not want their child to be labeled by any one and they did not want their child to be mocked at. Some of the parents felt that since their children were hearing and speech impaired, they should not lead an isolated life in future.

Discussion

Present study was conducted to understand the concerns and challenges faced by parents of children with hearing impairment. As a result there were significant positive concerns and challenges noticed by parents of hearing impaired children. Study conducted by Van et. al., (2005) in agreement with the present study suggests that quality of life of children that experience language delays is impaired. The paper concluded with findings indicating that children's social life is largely affected by the language problems that they face at the age of 3 and the results provided additional inputs on the importance of monitoring language development by

parents on external stakeholders, such as doctors, therapists etc. Mullins(1987) examined 60 books written and published by the parents of the children who are experiencing some kind of imperfection, termed as 'exceptional children'. Author found that there were mainly four themes that emerged from the inputs of the parents. These were namely: *realistic appraisal of disability, extraordinary demands on families, stress, and resolution.* Lederberg & Mobley (1990) talks about the quality of life of children based on the quality of attachment during mother toddler interaction. It was found from this paper that development of a secure attachment and maintaining a good mother-toddler relationship does not depend on normal language development during the toddler years.

Similarly White KR, (1992), addresses to identify if research really agrees to the fact that intervention plans involving parents are much more effective towards a child's development. It was found to be that there is no convincing evidence from previous researches that intervention plans that involves parents are much more effective than the ones where parents are not involved.

Conclusion

The researcher paper concludes with the understanding that the parents are gradually accepting the fact that their child is differently abled and are ready to provide them with the best resources possible. The parents got to know about their child's disability by the average age of 5-7 years and they regarded weakness at birth as a reason. Giving the blame of their child's disability to their own destiny, the parents have tried their best to provide best possible treatment to their child, soon relying on blessing and prayers as the only medicine to the problem of their kid. The parents found it very difficult to accept the condition of the child as well as the child him/herself, finding it difficult to keep the child physically fit and socially accepted. The parents were found to be happy with the education provided to their differently-abled child. They got to know about some institution through neighborhood or colleagues and their only concern being, the future of the kid in terms of employability, marriage and health.

Future Recommendations

1. Regular workshops for parents on sign language and child care.
2. Group counseling with parents - sharing of thoughts becomes easier as all the parents are in a similar situation. They can share their anxieties and get solutions from within the group itself.
3. Intervention at the individual level there is a need for intervention with the children per se. while conducting sessions and interacting with the children, it was observed that there is a need to listen to the children. The children also need to learn the basic morals of right and wrong; they should be made to understand the concept of maintaining social distance from the opposite sex. Some aspects of behavior like anger management, hyperactivity, confidence building and gender roles can be tackled through individual counseling.
4. There is a need to create awareness among parents about the genetic counseling as it was seen that parents have both the children with the same disability.
5. The community has to be sensitized and the parents should also be explained that their child has the same rights as any other child. They need not compromise on anything which is for their child's welfare.
6. Awareness generation among parents regarding government schemes and programs so that their children can benefit.

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