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Original Research Article

Family perceptions and barriers towards rehabilitation of visually disabled people: A qualitative survey from Western Uttar Pradesh

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ABSTRACT

Background: Looking at the number of visually disabled people population of Uttar Pradesh, there has been a paucity of evidence available on their perception and rehabilitation. This study was conducted to explore the perceptions and possible barriers to the uptake of visual rehabilitation services among visually disabled patients and their families in western Uttar Pradesh.

Materials and Methods: A qualitative investigation using one-to-one interviews with the convenience sampling method in the subjects severely visually disabled (Blind) participants, and their family members. The unstructured interviews were conducted by an independent interviewer. All the interviews were conducted in Hindi. The anonymous quotes of transcripts were translated into English for reporting purposes.

Results: A total of 32 interviews were conducted. 16 Participants were between 12 to 52 years of age. Parents of participants who were less than 18 years of age were present during the interview. For the rest 16 patients below 10 years of age, interviews were conducted with their parents. The discussion of each interview was transcribed. The interviews ranged in length from 12 to 30 minutes. From content analysis, four main themes were identified. They are; 1) the denial phase of parents, 2) over protective families, 3) social stigma, and 4) awareness of rehabilitation services, training centers, and government policies in communities. While the majority (95%) were aware of railway discounts many participants had not been aware of other welfare schemes run by the state government. Only 15% had heard of rehabilitation services in the state and vocational training facilities.

Conclusions: This study highlights three major challenges in the rehabilitation of visually disabled people in western Uttar Pradesh: 1) The availability of rehabilitation services in the study area, 2) The awareness of visually disabled people about these services, and, 3) The robust strategy for creating awareness about these services at the community level.

1. Introduction

"Rehabilitation" means the action of restoring someone to health or normal life through training and therapy after imprisonment, addiction, or illness. Children with congenital blindness or who developed blindness at a very young stage need special education and training. Those who receive training from an early stage of life become more adjusted to doing their routine tasks. The strategies for the rehabilitation of the visually disabled are institution-based, outreach, and community-based.[1–3] In India, the Ministry of Social Justice and Empowerment, and Ministry

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of Health and Family Welfare, and the Department of Rehabilitation initiated many training programs for the visually challenged for life skills and mobility training. They also introduced many need-based vocational pieces of training to help visually disabled people earn a living and lead an independent life. The awareness of these services among visually impaired people and their family members has been the key to having an impact on improving the quality of life of these patients.

The world health organization estimated that 10% of the world's population has some form of disability.[4] Disability is a public health concern in developing countries. In India, 2.21% of the total population is disabled.[5]The percentage of disabled people in the total population increased from 2.13% in 2001 to 2.21% in 2011.[5] Of them, 69% are from rural areas while the remaining 31% reside in urban areas.[5] The highest number (15.5%) of disabled persons in India is from the state of Uttar Pradesh.[5] Uttar Pradesh has the highest number of disabled people under various categories of disability like seeing, hearing, movement, mental retardation, mental illness, and multiple disabilities. 19% of total disabled people are visually disabled.[5] Looking at this number this study has been planned. This qualitative survey was conducted to assess the awareness of these services among visually impaired people and their family members living in western Uttar Pradesh.

2. Materials and Methods

The study was approved by CL Gupta Eye Institute Ethics Committee (ECR/1310/Inst/UP/2019) and conducted in compliance with the tenets of the Declaration of Helsinki. A sample of 50 persons was drawn out of registered severely visually impairedpatients having visual acuity <3/60 to NPL, legally blind patients according to WHO, at the low-vision department of CL Gupta eye institute, Moradabad (India). The WHO criteria for visually impaired people have been adopted to identify people with visual impairment.[6] The study duration was Jun-2018 to Dec-2018. All participants were invited to attend an individual interview, with a convenience sampling method. Individual interviews were conducted to maintain participant confidentiality and to foster a comfortable environment for in-depth responses. All participants gave their consent before the interview. All the interviews were unstructured with the main theme being an assessment of their awareness and willingness to uptake of rehabilitation services and were conducted in Hindi. Transcripts for the interviews which lasted between 12 and 45 minutes were combined and organized alongside additional notes taken during the interview. The investigator read and re-read each transcript for coding.

Qualitative content analysis was done.[7] The approach is interpretive in that; the research team documented and used these personal accounts to understand participants' experiences. The aim was to use individual interviews with visually impaired participants or their family members to understand their challenges in daily life and their knowledge about the rehabilitation framework of Uttar Pradesh (India).

3. Results

3.1. Sample characteristics

Fifty severely visually impaired participants (having visual acuity <3/60 to NPL) and their family members were invited to participate in the interview; 32 (64%) of them participated. Data saturation was reached after 17 (53.1%) interviews. Of all, 16 (47.1%) participants were family members of visually disabled children below 10 years of age. Individual interviews were conducted with participants above 12 years of age. Parents of participants who were less than 18 years of age were present during the interview. Seven participants of more than 18 years of age were totally dependent on their families. The interviews ranged in length from 12 to 30 min. Only one interview was more than 30 min. Four main themes were identified and represented below with anonymous quotes:

1. Denial phase of parents [Nine families whose child was below 5 years of age]: All parents were fully aware of the eye condition of their children. They were eagerly looking for new treatment possibilities for their children. Of them, 6 (66.6%) families visited four or more tertiary eye care institutes in India for seeking treatment of their children. Two (22.2%) families, who had understood the medical terminology, said that the diagnosis was the same at every eye care institute. Six (66.6%) families said that they would visit any institution; if there is a treatment option available for this condition. One parent said; "....... We have been to every hospital for the treatment of our child's eye. All of them said that at present there is no treatment for this condition." [Translated in English]
   Most of the parents (6; 66.6%) had not discussed the rehabilitation of these children. They have been more concerned about treatment. One of the parents said: ".......at present we are worried about our child's treatment. Can you suggest a good doctor or hospital?" [Translated in English] One other said: "...please tell me if any new treatment comes up for this condition. I hope that there will be a possible treatment in the future. I will be in touch" [Translated in English]. Three parents (33%) had knowledge about special education and other training. One (11.1%) parent has interested to know about the training program available for parents of children with special needs. He said "....I want to help her but sometimes I did not know how to help her. Is there any program available for parents like us?"
2. Overprotective families [16 participants above 12 years of age]**:** All visually disabled persons above

12 years of age responded that their families were overprotective. All of them believed that they are able to do their routine task like other individuals with normal vision. According to them, the over-protectiveness of their families has been a barrier to making them independent. One student, who just passed out senior secondary school examination said:

"…… Previously my family had not allowed me to go outside. One day I went to my uncle's house alone without telling anyone. Then slowly my family started believing and allowed me to go outside alone. Then I joined the school for education. Now I can go anywhere independently". [Translated in English]

3. Social stigma [Data of 32 participants]**:** Of all, 10 (31.2%) of the families said that they do not prefer to attend family functions. One mother said: "…. we rarely attend family functions. Our child has a problem with his eye, other people talk about him; we did not like this." [Translated in English] Other said: "….previously we use to attend functions and parties, but now a day's her father attends them. I prefer to stay with my child at home. I am very upset with my daughter's eye problem and do not like to attend social gatherings. My daughter is my preference. I had to take care of her" [Translated in English]. However, approximately 60% of families relayed positive accounts of their experience of attending family functions and another social gathering: "…. We attend family functions with our child. Our child likes to go outside. People are very helpful, and help us to take care of him. Attending social gathering help our child to interact with others. He recognizes people by their touch "[Translated in English]. One student said: "…… he likes going to school and spending time with his school friends as compared to sitting in a room at home"[Translated in English]. Most of the students (65%) liked listening to music and playing with their school friends. Participants of the adult age group were interested in politics.
4. Awareness of rehabilitation services, training centers, and government policies: Most of the parents [8, 88.9%] of preschool-age children had not discussed rehabilitation other than treatment options available for their children. There were 13 participants between 6 to 19 years of age. They were studying in different schools. Among the rest, one participant works at a government department, one participant is receiving a pension, and eight are totally dependent on their families.

There are many government schemes available for the visually impaired and other disabled people in India. The awareness about rehabilitation centers and other services for visually disabled people was low. Most of the people have not availed of these services. Some transcripts were: "… nobody has told us regarding this" [Translated in English]."… We have never availed any scheme" [Translated in English]."…..no body till date has discussed this with us" [Translated in English].

Of all, 95% of participants were aware of concession in state transport and railways fare. Only students had awareness about the vocational training program for visually disabled people. Few (10%) participants faced problems in getting a blind certificate, which is required for availing of different government schemes. One participant said "… I faced a problem in getting my blind certificate. I got my certificate after 4-5 visits to the authorities" [Translated in English].

All of them responded that our transport services are not friendly for visually impaired people. One participant said "…. Delhi metro is the most friendly travel option for visually impaired people. Other transport systems should follow the same standard."[Translated in English]

4. Discussion

The aim of this study was to explore the experiences of visually disabled people and their families about the challenges they face in the state of Uttar Pradesh, which has the highest number of visually disabled people in the country. Visually disabled individuals in the community face many social problems. Improving the quality of life of visually disabled people is a difficult and challenging task. They are neglected in the community because of inaccessibility to services and lack of opportunities like health services, schools, vocational education programs, and jobs. Josh et al. presented the framework of community rehabilitation of disabled people in India.[8]

In our study, the parents of preschool children were actively looking for the possible treatment of their children. They have been visiting different eye care institutes in the hope of a possible treatment for their child. Also, the families of school-going children have been looking for new treatment possibilities. These families had invested a huge amount of money and their time in search of treatment. However, few families were aware of rehabilitation services available for visually disabled people. Approximately one-third of parents who even understood that the disease was not curable had not been ready to go for rehabilitation services because they wanted to explore more treatment possibilities.

Social stigma toward persons with blindness is a barrier to the rehabilitation of visually disabled people. Allen et al. reported that moral disapproval, denigration, and avoidance are part of this stigma.[9] This can affect adjustment leading to decreased social and self-acceptance.[9] Kent et al. also reported that a lack of sight was almost always framed in a negative fashion.[10] Sood et al. advocated the training of visually impaired people on daily living skills like using toilets, body hygiene, use of electrical appliances and food preparation, etc.[11] These skills should be treated as survival skills for visually impaired people.[11] The social network size of visually impaired people was associated with participation in their voluntary work.[12] Most of the time family members are responsible for providing instrumental and emotional support to visually impaired people. In our study, few families had stopped going to social gatherings because of their visually impaired children. They feel that their child had not comfortable going out. There is limited research available on the adjustment process of visually impaired person's family members.[13] A greater emphasis on counseling and training of family members of visually impaired people is needed to overcome social stigma towards visually impaired people.

Overprotective families are also one of the barriers to making visually impaired people independent. Lowered expectations and overprotection of the individual with a disability can cause lowered self-esteem which can result in a lifetime of underachievement and failure to reach their full potential.[14] Overprotective families may be reluctant to enroll their visually impaired children in formal education. Parents of visually impaired children tend to overprotect their children due to safety concerns.[15] However, most of the visually impaired participants in this study felt that they can do their routine tasks independently. They would like to go outside and many times their family had not allowed them to go outside.

Hospital-based rehabilitation services have a limited impact on the community because of their limited utilization. The frameworks of rehabilitation of visually disabled people are not as per the need of the hour. Also, the awareness of available rehabilitation frameworks is limited. Visual rehabilitation should take into account spontaneous adaptation strategies and promote functional compensatory cortical plasticity by means of specific training methods.[16] Prioritization of resources like finance, manpower, and materials is one of the challenges in rehabilitation services.[17] Improvement in health-related quality of life after rehabilitation of visually impaired people had been reported in previous studies.[18–20] Life skills training programs can reduce parenting stress in mothers of visually impaired children.[21] Such a need has been felt by many parents of disabled children in our study too.

Awareness of the families plays a major role in the rehabilitation of visually impaired people. In our study, participants between 20 to 22 years of age have been fully dependent on their families for normal tasks. Education and training would have made them independent. This highlights the low awareness of rehabilitation services for the visually disabled at the local community level. One other participant of 12 years of age had not attended school because of a complete lack of awareness of his family. On the other side, one 18-year-old student has been studying in a different city far away from his hometown.

Approximately 50% of participants have been studying in schools. The majority of them belonged to the urban population of the study area. Few of them were aware of other vocational training for visually disabled people. All of them believe that there is a need for counseling centers at least at a district level for visually disabled people. So that visually disabled people living in that district would be benefitted. These centers should provide comprehensive information about education, the location of schools for the visually impaired, vocational training, the location of training centers, new technology for rehabilitation, other life skills, employment opportunities, and different government schemes available.

The awareness of different government schemes for disabled people is low at the rural community level. The concession in fares of state roadways and train fares has been the most availed scheme among study participants. However; this sample is not the true representative of visually disabled people in western Uttar Pradesh. One participant in our study benefitted through a pension scheme for visually disabled people. The majority of participants who were above 18 years of age had not benefitted from any scheme for disabled people.

The qualitative research methodology has its own limitations. However, this methodology has been adopted in this study because the data generated by this method have an enhanced level of detail. In summary, this study highlights three major challenges in the rehabilitation of visually disabled people: 1) The availability of rehabilitation services in the study area, 2) The awareness of visually disabled people about these services, and, 3) The need for a robust strategy for creating awareness about these services at the community level. The results of the present study may guide the development of future rehabilitation interventions for visually impaired people in the study area.

5. Conclusion

In conclusion, our study underscores the significance of addressing three pivotal challenges in the rehabilitation of visually disabled individuals. Firstly, the availability of rehabilitation services within the study area emerges as a critical concern, emphasizing the need for enhanced infrastructure and accessibility. A comprehensive and well-distributed network of services is fundamental to ensuring that visually impaired individuals can readily access the support they require.

Secondly, the awareness levels among visually disabled individuals regarding the available rehabilitation services represent a noteworthy obstacle. Efforts should be directed towards disseminating information and fostering a greater understanding among this demographic about the assistance and resources at their disposal. This involves not only enhancing outreach programs but also tailoring informational campaigns to be inclusive and accessible to individuals with visual impairments.

Lastly, the study highlights the imperative for a robust strategy aimed at creating awareness about rehabilitation services at the community level. A holistic approach that engages communities, families, and local stakeholders is essential to build a supportive environment for visually disabled individuals. This strategy should encompass educational initiatives, community workshops, and collaborative endeavors to cultivate an inclusive mindset within the community.

The insights gleaned from our study are invaluable for guiding the development of future interventions in the rehabilitation of visually impaired individuals in the study area. By addressing the challenges of service availability, awareness, and community-level engagement, future initiatives can aspire to create a more accessible and supportive ecosystem for the visually disabled population. In doing so, we contribute to fostering a society that recognizes and accommodates the needs of individuals with visual impairments, ultimately promoting their integration and well-being.

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None.

7. Conflict of Interest

None.

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