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10.4103/jehp.jehp_914_23

Voices unheard, insights into the lives of people with disabilities: A needs assessment study

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Abstract:

BACKGROUND: The phenomenon of disability in society is as ancient as human history itself. Approximately one billion people worldwide experience some form of disability, with a fifth of these individuals facing significant disabilities. Disability affects various life dimensions, including access to health services. This study aimed to identify the needs and challenges encountered by people with disabilities and to propose solutions for these issues.

MATERIALS AND METHODS: This qualitative content analysis research was conducted at Isfahan University of Medical Sciences in 2019. Participants included faculty members from the rehabilitation school, senior students, therapists, disabled individuals, and their families (23 interviews in total). These participants were chosen for their extensive knowledge of the challenges faced by people with disabilities. Semi-structured interviews were conducted, with informed consent obtained before each interview. The interviews were analyzed using the Graneheim and Lundman content analysis method and MAXQDA software. To ensure data accuracy, the criteria of conformability, credibility, dependability, and transferability were applied.

RESULTS: The analysis of the interviews yielded two main categories and 10 subcategories. In the category of disability-related problems, family problems, therapeutic problems, psychological problems, academic problems, and social problems were identified as the most significant. As for solutions, educational solutions, therapeutic solutions, social solutions, research solutions, and solutions for reintegrating patients into normal life were proposed to address the problems faced by disabled individuals.

CONCLUSION: People with disabilities are an integral part of any country's society. To adequately address their therapeutic needs, it is essential to equip our health workers with the knowledge and skills tailored to the specific needs and challenges of disabled individuals.

Keywords:

Curriculum, disability, needs assessment, rehabilitation

Introduction

A significant number of individuals worldwide live with disabilities.^[1] The phenomenon of disability in society is as ancient as human history, often exacerbated by factors such as war, natural disasters, industrial accidents, and other events, particularly in developing countries.^[2] A disabled person is defined as an individual with impairments in body function or

structure, or with mental impairments that substantially and adversely affect their ability to perform normal day-to-day activities for a duration expected to last at least 12 months.^[3,4] Approximately one billion people globally experience some form of disability, with a fifth facing significant disabilities. The prevalence of disabilities is notably higher in developing countries.^[5] According to 2018 statistics from Iran's Ministry of Welfare, around 1,350,000 people with disabilities are registered, 42% of whom have physical disabilities.^[6]

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How to cite this article: Sargazi S, Yamani N, Najimi A. Voices unheard, insights into the lives of people with disabilities: A needs assessment study. *J Edu Health Promot* 2024;13:157.

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Received: 27-06-2023

Accepted: 04-01-2024

Published: 29-04-2024

Disability influences various life aspects, including physical, psychological, social, interpersonal, independence, and family relationships.^[7] People with disabilities often face negative attitudes, isolation, and depression due to discrimination.^[6] They are frequently deprived of opportunities to participate in social activities, impacting their basic human rights and overall health and well-being.^[8] In addition, they encounter more challenges in accessing medical services compared to healthy individuals, such as treatment costs, long-term rehabilitation, transportation difficulties, and extended waiting times for services.^[9] Families with disabled members also struggle with issues like lack of information, financial burdens, and long-term care.^[10] Therefore, supporting people with disabilities and their families can foster positive self-concepts and enhance their confidence to participate in society. Studies suggest that adequate support can help people recover up to 30% of their lost life satisfaction within three years of becoming severely disabled.^[11]

Part of this support involves training therapists who understand and effectively address the needs of disabled individuals. Research indicates that some students may harbor negative attitudes toward disabled persons,^[12] highlighting the need for rehabilitation faculties to educate students based on their needs, mutual understanding, and respect for people with disabilities. In addition, addressing environmental and social barriers to increase the societal participation of disabled individuals is crucial, beginning with understanding their needs and challenges.^[4]

This study aims to identify the needs, problems, and potential solutions for people with disabilities from the perspectives of disabled individuals, their families, therapists, faculties, and students in Isfahan. Subsequently, we developed an extra curriculum for rehabilitation students to enhance their knowledge, attitudes, and performance regarding disability. This curriculum aims to improve their interactions with disabled individuals and increase overall satisfaction. Details of this curriculum will be published at a later date.

Material and Methods

Study Design and Setting

This qualitative content analysis research was conducted at Isfahan University of Medical Sciences in 2019.

Study Participants and Sampling

The study involved faculty members from the rehabilitation school, senior students completing their internships, therapists working in rehabilitation centers, and disabled individuals and their families.

These participants were chosen for their extensive knowledge of the challenges faced by people with disabilities. Purposeful sampling was employed to select interviewees who could provide the most informative insights.

Data Collection Tool and Technique

In qualitative studies, the sample size is not predetermined but is guided by the concept of data saturation. In this study, interviews continued until no new information was revealed, resulting in a total of 23 interviews (six faculty members, five students, five therapists, and seven disabled individuals). The interviews were analyzed using the Graneheim and Lundman content analysis method and MAXQDA software.^[13] Each interview was initially read in paragraphs to grasp an overall understanding, followed by a verbatim reading to extract initial codes. These codes were then categorized based on relevance and interdependence, forming appropriate clusters. Subcategories related to each other were grouped, and suitable titles were assigned to each category to extract the main themes. The categories were revised after each interview, and data collection ceased once saturation was achieved, and no new codes or categories emerged.

Ensuring Data Accuracy

To ensure the accuracy and robustness of the qualitative data, the criteria of conformability, credibility, dependability, and transferability, as outlined by Guba and Lincoln, were applied.^[14] For conformability, the research stages were reviewed by several colleagues to confirm the accuracy of the coding method. Credibility was assessed by presenting the full text of all interviews, along with the coding and initial classes, to a qualified professor in the field for their confirmatory and supplementary opinions. Dependability was ensured by conducting all interviews within three months, focusing on the same subject in each semi-structured interview. For transferability, a clear description of the context, participant selection, data collection, and analysis processes was provided, enabling readers to judge the applicability of the findings in other contexts.

Ethical Consideration

Informed consent was obtained before conducting semi-structured interviews. The files of all interviews were collected anonymously and confidentially encrypted.

Ethical code: R.MUI.MED.1398.214

Results

The analysis of the interviews led to the identification of two primary categories and 10 subcategories. The

first category addresses the problems associated with disability, while the second focuses on potential solutions. These categories and their subcategories are detailed below.

First Category: Disability Problems

This category encompassed the needs and challenges identified by disabled individuals, their families, therapists, and academic professionals. It included five subcategories: family, therapeutic, psychological, academic, and social problems.

Family problems

In the realm of disability, family issues were a primary concern, encompassing communication, psychological, and economic challenges. Communication problems included not involving the child in community activities, diminished interactions with relatives, and familial rejection. A therapist noted, *“Parents sometimes face rejection from their own family or vice versa, leading to reduced communication.”* [Participant 4]

Psychological issues in these families ranged from feelings of guilt, unrealistic expectations, blaming others for the disability, and denial of the disability to broader psychological struggles and overall family exhaustion. One therapist shared, *“Parents often look for someone to blame, pointing fingers at doctors, society, the environment, or even their spouse, accusing them of causing the child’s disability.”* [Participant 4]

Economically, the significant cost of treatment and care was a recurring concern among families with disabled members. A faculty member explained, *“Families who rely on overnight centers often do so because they can no longer support their disabled member, either financially or due to exhaustion.”* [Participant 11]

Therapeutic problems

The second major category identified from the interviews relates to issues in therapy for disabled individuals. These problems were multifaceted, involving both therapists and the healthcare system.

Issues related to therapists included a lack of understanding of the patient’s specific needs, difficulty in accurately diagnosing the patient’s condition, cultural challenges with the patient, low self-confidence stemming from poor communication with patients, inadequate supervision of patient exercises, limited time allocated for each patient, stress due to excessive workload, and instances of patient mistreatment. One therapist expressed, *“If I’m told to see no more than five patients a day, I can dedicate myself fully to them. But when pressured to see more, I can’t give each one the time they need.”* [Participant 8]

The second aspect concerns the healthcare system, including insufficient oversight of private rehabilitation centers, a weak insurance system, treatment confined to clinic settings, neglect of therapists’ physical capabilities, overburdening therapists with too many patients and a lack of support for therapists. A therapist noted, *“In our country, rehabilitation services lack substantial government financial support and adequate insurance coverage.”* [Participant 1]

The third set of therapeutic problems pertained to the treatment process itself. Challenges here included the lengthy duration of treatment, the application of personal biases in treatment approaches, and patients discontinuing treatment due to prolonged or ineffective therapy. *“Patients often discontinue treatment when it’s prolonged or requires many sessions, especially if they don’t see any improvement”* shared a therapist. [Participant 1]

Psychological problems

This category encompassed a range of mental and emotional challenges faced by individuals with disabilities. These included being pitied by others, experiencing emotional trauma, feeling rejected by family and therapists, struggling to accept their disability, suffering from low self-esteem, depression, isolation, exclusion, boredom, anxiety, diminished attention and memory, and even having suicidal thoughts. A faculty member highlighted, *“Particularly those who were previously active and then suffered spinal cord injuries often face severe mental and psychological issues. They are at a high risk of becoming completely withdrawn, isolated, or even suicidal due to lack of adequate attention.”* [Participant 2]

Academic problems

The fourth category of disability-related issues pertained to the challenges faced by disabled individuals in university settings. Key problems identified include the absence of a supportive system for disabled students within the university, neglect of disability considerations in the university’s mission and planning, inadequate standard equipment for disabled students, poor physical design of university facilities that fail to accommodate disabilities, and insufficient communication skills among professors and university officials. A disabled student from Isfahan University shared his experience: *“Navigating through the university, I encounter numerous barriers that prevent me from reaching my destination.”* [Participant 22] This statement underscores the difficulties faced by disabled students in academic environments lacking proper accommodations and support.

Social problems

The final category of issues related to disabilities concerns social challenges. These included the segregation

of disabled children from their peers, insufficient government support for people with disabilities, societal pity towards disabled individuals, negative societal perceptions of disability, and employment difficulties faced by disabled people. A faculty member highlighted a significant issue in the educational system: *“In our country, schools segregate disabled children from non-disabled ones. Children with physical disabilities are sent to one school, while those with mental disabilities are sent to another, further distancing them from mainstream societal conditions.”* [Participant 2] This segregation reflects broader social and cultural challenges and attitudes toward disability.

Second Category: Solutions

This category encompassed the solutions suggested by the interviewees and organized into five subcategories: educational, therapeutic, social, research, and reintegrating the patient into normal life.

Educational solutions

The interviewees proposed a range of solutions divided into two sub-groups: Student-related education and Disabled person-related education.

Student-related education

This included creating a simulated clinic environment, training students based on the real-life experiences of disabled individuals, fostering connections between universities and the broader community, introducing courses on research methods in rehabilitation, and courses on communication skills for students and therapists. Other suggestions involved revising psychology and psychiatry courses, enhancing the completeness of student training, extending the duration of clinical teaching, integrating courses vertically, exposing students to a diverse range of patients, revising certain courses, and evaluating professors' teaching styles and knowledge. A faculty member suggested, *“We could have courses like ‘Speech Therapy for cerebral palsy (CP) Individuals’ or ‘Physiotherapy for Spinal Cord Injuries’ in relevant departments.”* [Participant 12]

Disabled person-related education

This involved teaching disabled individuals and their families the necessary skills and professions tailored to their abilities. A family member expressed, *“If there were skill training classes for my child with mobility issues, enabling them to work and earn, it would greatly boost their motivation for life.”* [Participant 19]

Therapeutic solutions

The interviewees suggested several therapeutic strategies, including adapting treatment guidelines to local contexts, ensuring psychiatric evaluation and necessary counseling for patients, providing tailored

exercises, and establishing dedicated rehabilitation centers for different types of disabilities. A therapist emphasized the need for cultural relevance in treatment approaches: *“We must revise our therapeutic guidelines for various disabilities to align with the current cultural and societal context of Iran.”* [Participant 1] This approach underscores the necessity of customizing therapeutic methods to effectively address the unique needs of individuals with disabilities within specific cultural settings.

Social solutions

The interviewees proposed a variety of effective social solutions, including fostering collaboration between rehabilitation faculties and disability associations, organizing rehabilitation exhibitions, enhancing cooperation among different institutions, establishing relevant nongovernmental organizations (NGOs), raising public awareness, revising laws, implementing the use of elevators and ramps, improving accessibility to public transportation for disabled individuals, and promoting the cultural acceptance and normalization of disability in society.

One therapist highlighted the importance of inclusive urban design: *“We should design our cities so that disabled individuals can access schools, cinemas, parks, and other public spaces just as easily as non-disabled people.”* [Participant 1] This approach emphasizes the need for a societal shift towards greater inclusivity and accessibility for people with disabilities.

Research solutions

The interviewees recommended several research-oriented solutions, such as conducting in-depth studies in rehabilitation and disability, interviewing disabled individuals and their families, identifying their specific needs and challenges, and modifying educational curricula based on research findings. A faculty member emphasized the importance of research skills: *“Students in rehabilitation fields should be well-versed in research methods. This way, if they encounter a patient with a complex or unclear issue, they have the tools to investigate further.”* [Participant 2] This approach highlights the need for a research-driven understanding of disability, ensuring that educational and therapeutic practices are informed by real-world data and experiences.

Solutions for returning to normal life

To achieve independence and a sense of purpose, it is crucial for disabled individuals to lead a normal life. This subcategory includes solutions like fostering a sense of usefulness in disabled persons, boosting their morale, assigning them responsibilities, engaging them in various activities, enhancing their motivation levels, improving their quality of life, and increasing their involvement and

participation in the community. A disabled participant expressed their aspirations: *“As a member of society, I want to have my own job and income, be able to go to work every day like everyone else, and use public transportation.”* [Participant 21] This statement underscores the desire for normalcy, independence, and active participation in societal life among people with disabilities.

Discussion

This research focused on identifying the challenges faced by individuals with disabilities and exploring solutions to these issues, as seen through the eyes of the disabled, their families, therapists, rehabilitation faculty professors, and students in Isfahan. The study categorized disability-related problems into family, therapeutic, psychological, academic, and social issues, which are deemed the most significant. As potential remedies, it suggested educational, therapeutic, social, and research strategies, along with ways to reintegrate the disabled individual back into normal life.

Families with disabled members commonly encounter economic, social, and psychological difficulties, a trend supported by other research studies.^[15,16] These families often grapple with a range of challenges, including functional, economic, and psychological issues, highlighting the need for educational, financial, and psychological support.^[17] In 2019, Yilmaz’s study shed light on the specific needs of mothers with disabled children, such as financial, informational, and social support. These mothers tend to face higher stress levels and more severe physical and mental health problems compared to mothers without disabled children.^[10] In addition, research conducted in Greece has identified unemployment, low income, and limited education as major obstacles to accessing healthcare for individuals with disabilities.^[9]

Having a family member with a disability significantly affects the entire family and its various functions. This is due to increased costs for treatment and care, the need for special equipment, more focused attention on the disabled member at the expense of others, societal stigma, and limitations on common activities like outings and family visits. Consequently, these families require support from relevant institutions or NGOs, including financial aid and training in caregiving, stress management, problem-solving, and communication skills to improve their quality of life. Research indicates that life skills and family training greatly enhance mental health and reduce stress in these families.^[18]

Studies in Iran and elsewhere reveal that happiness, life expectancy, and satisfaction levels in disabled individuals are significantly lower than in non-disabled

people. These can be improved through interventions and training focused on mindfulness, psychological, social, and spiritual aspects, along with providing support, thereby enhancing their mental and physical health, happiness, life expectancy, and satisfaction.^[19] Among elderly disabled individuals, mental health issues and social needs like privacy, communication, recreation, and skill learning, as well as employment and retirement concerns, are primary factors affecting their happiness and satisfaction.^[20]

Families with a disabled member often experience lower physical, environmental, and psychosocial health compared to others. Caregivers, due to their extensive responsibilities, find little time for personal interests and social interactions. Research involving mothers of disabled individuals highlighted the effectiveness of emotional and psychosocial support in improving their and their disabled children’s quality of life. Family support plays a crucial role in maintaining the morale and life quality of disabled individuals.^[21]

Disabled individuals, their families, and caregivers need to have access to relevant information about the disability, its nature, dimensions, consequences, new treatment methods and equipment, and details about the insurance system and patient support. This knowledge is vital for the well-being of the disabled individual and their support network.^[22]

For a person with disabilities to maintain their independence and boost their self-esteem and morale, it is crucial for them to actively participate in society, pursue education, engage in leisure activities, and feel like a normal individual with the same human rights as others. Society bears a responsibility to facilitate this. This perspective aligns with findings from a study in China focusing on the needs of disabled individuals in care centers. The study found that engaging in work, social interactions, teamwork, and self-directed learning significantly enhances their self-esteem, sense of worth, and overall happiness.^[23]

In light of the educational solutions identified in this research, it is crucial for academic faculties to pay attention, especially since the quality of rehabilitation services for disabled individuals partly depends on the training of therapists in rehabilitation faculties. Rehabilitation students need to possess self-esteem and confidence, which can indeed be enhanced. One effective method to boost their confidence is through training programs tailored for rehabilitation students. For instance, Fortune and colleagues implemented motivational interviewing (MI) training for occupational therapy and physiotherapy students, which proved beneficial in enhancing their confidence.^[24] In addition,

certain interventions can improve students' performance in clinical settings. Andonian, for example, discovered a link between the emotional intelligence of occupational therapy students and their clinical performance.^[25] Therefore, by enhancing students' emotional intelligence, their effectiveness in clinical environments can be significantly improved.

A common issue identified in this study among disabled individuals was the inadequate communication skills of therapists, highlighting the need for enhanced communication training in rehabilitation education. Research by Jones and colleagues in Australia supports this, suggesting that physiotherapy student training, irrespective of cultural context, should focus more on developing communication skills during their undergraduate education.^[26] Communication skills are vital for patient satisfaction and the success of the therapeutic process. Therefore, it is advisable to implement strategies aimed at improving the communication skills of both students and practicing therapists in clinical environments.

Limitation and Recommendation

Interviewing people with severe disabilities was difficult, and it was not possible to communicate with some of them. It is recommended for similar research in the future, to use an expert who has been in contact with disabled people for a long time for interviewing.

Conclusion

Individuals with disabilities are an integral part of any society and should enjoy the same human rights as other members. They ought to be able to integrate seamlessly into society and live independently. This requires focused attention and strategic planning, particularly in developing countries like Iran. Empowering people with disabilities to utilize their skills and expertise can significantly contribute to the nation's development. Rehabilitation faculties, which train therapists to serve disabled individuals, play a crucial role in enhancing the quality of these services. It is beneficial for the curriculum for rehabilitation students to include training in communication with disabled individuals and their families, anger and stress management, time management, professional ethics, empathy, teamwork, and active listening. These skills can make the rehabilitation process more effective. Therefore, revising the educational curriculum of rehabilitation programs or incorporating these elements as additional courses is highly recommended.

Acknowledgments

The authors appreciate the DAAD (German Academic Exchange Services) for financial support and also thank

Hamburg University and Isfahan University of Medical Sciences for their cooperation.

Financial support and sponsorship

DAAD (German Academic Exchange Services) Organization.

Conflicts of interest

There are no conflicts of interest.

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