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Challenges in Providing Rehabilitation Services for People with Disabilities in Iran: A Qualitative Study

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Authors' contributions

This paper was carried out in collaboration between all authors. Authors KA, HRK and MA designed the study, wrote the methodology. Author KA wrote the first draft of the manuscript. Authors MK, AR and FKF managed the literature searches. Author HS edited the manuscript. Authors KA and HRK did the manuscript review. All authors read and approved the final manuscript.

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ABSTRACT

Introduction: World Health Organization (WHO) recognizes disability as a global public health issue and a development priority, but unfortunately, the evidence shows that people with disabilities (PWD) often have lower levels of health than the general population.This study targeted to identify challenges in providing rehabilitation services for People with Disabilities.

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Materials and Methods: This article was undertaken on a qualitative content analysis. Twenty one participants were selected through purposeful sampling. Data were collected through semi-structured in-depth interviews from June 2014 to July 2015. Interviews continued until data saturation. Data analysis was performed by MAXQDA version 10.
Results: Challenges to providing of rehabilitation services were the most important for PWD that needed to receive medical rehabilitation services. These challenges were grouped into six categories of poor knowledge, negative attitude to disability, insufficient support of PWD, individual problems of providers, problems of accessibility and cost.
Conclusions: A proper rehabilitation plan requires common understanding of the challenges in providing of rehabilitation services for PWD. Understanding these challenges will help policy makers, providers, and PWD and their families consider rehabilitation as an effective component of service provision in health system. Based on findings of this study, further research is recommended to elucidate the challenges affecting provision of rehabilitation services for PWD.

Keywords: Challenges; rehabilitation services; people with disabilities; Iran.

1. INTRODUCTION

WHO recognizes disability as a global public health issue, a human rights issue and a development priority [1]. According to report published by the WHO around 785 million (15.6%) of the population of the world has a disability [2]. Like most countries, Iran struggles with the challenge of defining disabilities that trigger eligibility for rights and benefits [3]. One of the problems in rehabilitation is the lack of demographic statistics, regarding to the PWD in Iran [4]. Therefore, preserving the health and wellness of individuals with disabilities is an important public health concern [5]. Data gathered from 51 countries revealed that the PWD were more than twice as likely to report finding health care provider skills are inadequate to meet their needs. Four times more likely to be treated badly and nearly three times more likely to be denied their needs in health care [6]. Data on rehabilitation services, type and quality and estimates of needs and unmet needs are not readily available [7]. Also studies targeting health care have shown that the PWD experience barriers in the health care system [8-10]. The Articles 20 (Access) and 26 (Rehabilitation) of the Convention on the Rights of Persons with Disabilities (CRPD have addressed that Member States should ensure that persons with disabilities must have an access to a justified health service [11]. Hence, PWD often use the health care system more frequently and challenges associated with preventive health care needs for this population have not been adequately addressed [12]. But unfortunately, the studies show that PWD often have lower levels of health than the general population [13-15]. Of course, undesirable health of PWD is not necessarily a direct result of their disability, but it can be associated with problems of access to the services and programs [16]. The previous studies indicated that PWD face challenges in accessing health services [17-19].

Based on literature reviews by the first researcher the health dimensions of the PWD are often overlooked [13-15]. As a result, they are often isolated from their community`s health promotion capacities. In this study, the policy makers, managers, providers, the PWD and their families need to identify the challenges of rehabilitation service provision and try to implement their essential bustles, in order to voice-out their needs. It is understandable that the rehabilitation of the PWD depends on wide varieties of factors that the health sectors and policy makers alone cannot bear the entire load. Thus, this study was performed with the aim of exploring the challenges in providing rehabilitation services" Physiotherapy, Occupational therapy, Speech therapy and Orthosis and Prothesis" for PWD in Iran.

2. MATERIALS AND METHODS

2.1 Study Design

A qualitative approach using content analysis was employed in this study. In this method, required data is gathered directly from participants. We derived codes and categories by an inductive process, and then concepts were ordered in terms of their properties and dimensions [20].

2.2 Setting and Sampling

The study was conducted in Tehran, Iran (one of the most populated cities in the world). The

participants were selected using a purposeful sampling with a diversity sampling base on firsthand experience, expertise and also their willingness to participate in research. Data gathering was continued until researcher found not any new data from the participants. Participants included; were 7 providers of rehabilitation services and 4 PWD, 4 families with PWD, 2 people of non- government organizations (NGO) and 4 policy makers that had scientific expertise in the rehabilitation system of Iran.

2.3 Data Collection

Semi-structured in-depth interviews were utilized to gather data. Data gathering was conducted by the first researcher through separate interviews Persian language from June of 2014 to July 2015. Before the interviews, the aim of the study was explained and the researcher obtained informed and written consent of the participants. The interviews lasted for 45 to 90 minutes and were tape recorded and transcribed verbatim.

2.4 Data Analysis

Qualitative content analysis was used to analyze the data. Study process was continued and concurrent analysis was undertaken: First, recorded interviews were transcribed verbatim. Second, before coding, the transcribed text was read several times for familiarization. Codes and categories were extracted by an inductive process with an open coding through reading of the text and dedicating related codes to them. Then, categories were obtained through systematic comparison. After completion of coding and assuring precision of coding, concepts were identified. Data analysis was performed by MAXQDA version 10.

2.5 Trustworthiness of Data

In the current study we used the strategies suggested by Lincoln and Cuba and there were four criteria, i.e., creditability, dependency, conformability, and transferability that were essential for trustworthiness [21]. To boost the data creditability, researchers prolonged the data collection and participants involvements' for 12 months [22]. In addition, dependency was assessed by the peer-check and member check strategies [23]. The background and the first researchers' interest on the subject, along with the preservation of documents of research were used in order to enhance the conformability of the data [21].

2.6 Ethical Considerations

The verbal and written informed consent was obtained via clarifying the purpose and the process of the inquiry. This study was adapted from the first author's doctor of philosophy (PhD) thesis and was approved by the ethical committee of Tehran University of Medical Sciences (TUMS) in Tehran, Iran.

3. RESULTS

The results of this study from the experiences and perceptions of 21 people who participated in the study: (Table 1).

The study provided a new perspective on the important problems of the rehabilitation services process. Furthermore, the findings identified six categories of barriers in rehabilitation for access to health services. These main categories and their subcategories are mentioned: (Table 2).

3.1 Poor Knowledge of Rehabilitation

Findings showed poor knowledge is a barrier common among providers, PWD and their families. Experiences of the participants indicated that system of rehabilitation faces with this obstacle in provision of service.

3.1.1 Poor knowledge of PWD and their families

The poor of knowledge of PWD and their families was one of participants' barriers. This obstacle can cause delayed refer and follow up for receiving of rehabilitation services. One of the participants explained the issue as:

> "Someone did not tell me; even my doctor did not give me this information that you get sclerosis disease after a period of sitting in a wheelchair" (PWD).

3.1.2 Poor Knowledge of providers

The poor of knowledge of providers was one of the concerns of participants .This challenge disrupt services and cause mistrust between

PWD and their families with providers. Also, change of therapist from provider to another provider for receiving of rehabilitation services. A participant noted the issue as:

> *"…Then, information should be updated, rehabilitation science should be updated. If I graduated this year, my licenses should be evaluated every year" (Family of PWD).*

3.2 Negative Attitude to Disability

The findings showed this challenge has a prominent role in providing rehabilitation services to individuals with disability. This barrier stated in several-level was identified including, negative attitude of PWD and their families, provider and society. Inattention to this barrier has PWD and their families and societal consequences.

Table 1. Sectors represented by study participants

Sector	Type of participant	Sex		Experience (year)	Number
		Male	Female		
PWD	Physical	*		15	
	Physical		*	20	4
	Physical		*	27	
	Physical		*	19	
Provider	Physiotherapist	*		20	
	Occupational therapist	*		17	
	Orthosist	*		15	
	Speech therapist	*		10	7
	Speech therapist		*	25	
	Occupational therapist	*		15	
	Speech therapist		*	26	
Policy maker	Deputy of Welfare Organization	*		30	
	Director General of Welfare Organization	*		20	
	Director General of Red Crescent	*		18	4
	Director General of Welfare Organization	*		19	
N.G.O	Director of NGO	*		15	
	Director of NGO	*		20	2
Family of PWD	Physical Disability	*		9	
	Mental retardation	*		20	4
	Down syndrome		*	18	
	Cerebral palsy	*		11	
Total		**15**	**6**		**21**

Table 2. Overview of the identified challenges and their subcategories

Categories and subcategories	
1. Poor knowledge of rehabilitation	**4. Accessibility problems to rehabilitation**
1.1 Poor knowledge of PWD and their families	4.1 Problem of environmental accessibility
1.2 Poor knowledge of providers	4.2 Problem of access to centers of rehabilitation services
2. Negative attitude to disability	4.3 Problem of transportation
2.1 Negative attitude of society	**5. Individual problems of providers**
2.2 Negative attitude of PWD and their families	5.1 Lack of communication ability
2.3 Negative attitude of providers	5.2 Problems of professional ethics
3. Insufficient support of PWD	5.3 Lack of interest and motivation
3.1 Shortage of admission and Insufficient support for PWD	**6. Cost problems in rehabilitation**
3.2 Releasing and ignoring of PWD	6.1 High cost of rehabilitation
	6.2 Lack of insurance coverage
	6.3 Emphasize of therapists on financial issues

3.2.1 Negative attitude of society

The Negative attitude of society was one of problems in providing of rehabilitation. Existences of this challenge can intensify disability and limits PWD and their families to participation and attendance in society. A participant said:

> *"….when I am walking in the street, I realize that everybody stops, it is like that they have seen a human from other planet. I am not saying a special group; roughly 90% of our people are like that" (NGO).*

3.2.2 Negative attitude of PWD and their families

The Negative attitude of PWD and their families has mentioned by majority of participants. Lack of effort and motivation PWD and their families is consequence of this problem for receiving rehabilitation services. Existences of this challenge can intensification of disability and limitation of PWD and their families to participation and attendance in society. A participant explained:

> *"I have faced with people with fractured hand and try to hide such dilemma. What about people who have more severe disabilities which have hindered severity their quality of life and need to assistance with couches for walk?" (PWD).*

3.2.3 Negative attitude of providers

The Negative attitude of providers is one of PWD and their families complain in providing of rehabilitation services that cause lack of ability in treatment and withdraw process of rehabilitation. One of the participants mentioned:

> *"….His/her (disabled kid) primary right is that a doctor visits him/her. When a doctor sees your child and realizes that he/she is blind, says:" this kid is blind, let it be", do not you have another kid? This kid does not become a kid for you…. Hence we have a lot to do in this regard. This attitude is in the health domain" (Family of PWD).*

3.3 Insufficient Support for PWD

The participants stated the importance of support for PWD and also believed that rehabilitation services are required after disability.

3.3.1 Shortage of admission and insufficient support for PWD

Time and how families admit PWD was one of the concerns of participants that it plays a prominent role in follow up and receiving rehabilitation services. One of the participants stated:

> *"… Some person's physical disability will be deformities that he has physical that the family would not have others see" (Family of PWD).*

3.3.2 Releasing and ignoring of PWD

Releasing and ignoring of PWD is one of the barriers that stated by participants. A participant said:

> *"Many people do not care, they say, leave him now, it spontaneously improves. Goes to first grade of primary school and will improve" (Family of PWD).*

3.4 Accessibility Problems to Rehabilitation

The majority of participants have challenged with accessibility as one of the consequences of disability. Multi-level accessibility challenges were identified including environment accessibility barriers and lack of transportation. In many cases, accessibility problems led to deprive of receiving of rehabilitation services.

3.4.1 Problem of environmental accessibility

The participants mentioned the importance of environmental accessibility and also believed that it requires receiving rehabilitation services after disability. One of the participants described it as:

> *"Accessibility to centers is a calamity for PWD. For example, there is not accessibility in small towns and deprived areas; accessibility in different types, not only physical" (Policy maker).*

3.4.2 Problem of access to centers of rehabilitation services

Problem of access to centers of rehabilitation services was one of the main issues for PWD and their families. A participant noted it:

"There are good and very specialized clinics now that are created, but few people can really go there" (PWD).

3.4.3 Problem of transportation

Problem of transportation includes lack of transport cost and lack of vehicles as well as rehabilitation devices. A participant mentioned the issue:

"Transportation is one of the biggest problems; *handling of PWD, he wants to go to work, go to university, high school, go to the doctor, and go to the park, and he wants to go to home of one of kinfolk at least once per month" (PWD).*

3.5 Individual Problems of Providers

The findings showed that individual problems of therapists is one of the obstacle in providing rehabilitation services when face with PWD and their families, therefore, existence of this challenge can disrupt in the provision of services and will have consequences for provider and client.

3.5.1 Lack of communication ability

The lack of ability to communicate with providers was one of the participants' challenges. This barrier often causes mistrust between PWD and their families with providers, and also makes them change their therapist. A participant mentioned the issue:

"When we sat down and talk about disabled, but when we do not let ourselves a client comes to us and easily communicate while are claimed, we are custodians of the rehabilitation of the country. It is clear that's only claim" (Policy maker).

3.5.2 Problems of professional ethics

Problems of professional ethics are one of the key factors in process of treatment and it causes lack of commitment as well as can withdraw rehabilitation services. A participant stated the issue:

"Professional ethics means not to betray my colleagues; if somewhere bad services are provided, I should not highlight it on the patient's mind. Highlighting that problem may question the work that I do" (Provider).

3.5.3 Lack of interest and motivation

The interest and motivation of provider has a prominent role in providing rehabilitation services and in trying to empower the PWD.A participant described it:

"I dare to say that on the third period of occupational therapy more than seventy to eighty percent wanted to call off their therapy; that shows there is no interest and motivation to their work and learning" (PWD).

3.6 Cost Problems in Rehabilitation

Due to financial problems for transporting, rehabilitation services and other current expenditures, most of the PWD need significant assistance and Iranian PWD cannot receive desirable services. Most of the participants mentioned that they do not have ability to provide these expenditures for access to health services.

3.6.1 High cost of rehabilitation

The high cost of rehabilitation was one of the major challenges and causes of discontinuation of rehabilitation for PWD and their families. Most of the participants mentioned that existence of this barrier can disrupt receiving rehabilitation services. One of the participants explained it as:

"Because rehabilitation and treatment in our country is based on the out of pocket, this makes the continuation of treatment difficult or make them leave their treatment after several sessions of therapy. In general, this leaving is because of financial reasons" (provider).

3.6.2 Lack of insurance coverage

Lack of insurance coverage was obstacle that all the participants stated. A participant described it as:

"Insurance is not defined here; rehabilitation services are not covered by insurance that unfortunately it damages someone that needs such services" (PWD).

3.6.3 Emphasize of therapists on financial issues

Emphasize of therapists on financial issue is one of the main problems for PWD and their families in receiving rehabilitation services. A participant said:

"For years, provider wonders me around by taking my child to speech therapy and says: I want to treat your child's speech. You see that is only for money, he/she increases the number of therapy sessions. The attitude is very much materialistic" (Family of PWD).

4. DISCUSSION

The purpose of this study was to understand the challenges of providing rehabilitation services. The current study was one of the studies on rehabilitation services that have addressed challenges from viewpoints of rehabilitation stakeholders such as policy makers, providers, NGO, PWD and their families. As a detailed the main challenges in providing rehabilitation services, include poor knowledge, problems of accessibility, individual problems of providers, insufficient support for PWD, negative attitude to disability and cost problems in rehabilitation. However, our findings cannot be generalized to other countries because we used purposeful sampling. Challenges that rehabilitation service-providers, PWD and their families are faced, are very complex, variant and wide. Deep and comprehensive studies are needed to explore and explain these challenges. However; this study may serve as a starting point to investigate the issue. We tried to identify the challenges from the perspective of different stakeholders involved in the process of providing rehabilitation services. Previous studies have addressed some aspects that we found. So, these aspects are discussed below based on our findings.

4.1 Poor Knowledge of Rehabilitation

We found poor knowledge of providing rehabilitation service as one of the important challenges. This finding has been emphasized by previous studies too [24-26]. Therefore, should be considered as a key barrier to desirable services for PWD because neglecting the knowledge of rehabilitation may lead to intensify disabilities.

4.2 Negative Attitude to Disability

Our results confirmed some studies that mention "negative attitude to disability" as a barrier [25,27,28]. Some of the participants believed that disability may be partly due to negative attitudes of society, providers, families, and PWD themselves.

4.3 Insufficient Support for PWD

One of the prominent obstacles found in the current study that was in agreement with other studies [29-31] was the insufficient support for PWD. Ignoring this challenge has individual and their families' consequences that can withdraw receiving rehabilitation services and it cause disability to be handicap.

4.4 Accessibility Problems to Rehabilitation

Most of the participants from different groups referred to the "problem of accessibility to rehabilitation services", the obstacle that has been emphasized in previous studies, too [32-34]. It is a common point between the viewpoints of the participants. This challenge can disrupt follow up of treatment by PWD and their families; also it causes an intensification of disability.

4.5 Individual Problems of Providers

This problem was one of the important aspects of the providing rehabilitation services that confirmed by review of literature [24,34-38]. Also, it is one of the main concerns in receiving rehabilitation services for PWD and often the consequence of this challenge is a defect in the treatment goals. The root of this barrier goes much deeper and it returns to the lack of attitude and skills in educational courses for therapists.

4.6 Cost Problems in Rehabilitation

Financial problem was found as an important challenge in rehabilitation services that has confirmed by other evidences [25,27,32,33, 39-40]. All of the participants had faced this challenge. It can disrupt continuing rehabilitation in the long term. Lack of insurance coverage and out- of- pocket payment were common in many of PWD and their families. These findings are justifiable, when consider the facts that "rehabilitation services are long term in nature", and "PWD are common in the poorest group of population" [41].

Nguon in his study found three most significant barriers to disability-inclusive local governance and community development discrimination and negative attitudes; limited understanding of the rights and capacities of persons with disabilities, not only within the family, community, and local

authorities, but also within themselves; and limited financial, technical, and human resources to promote inclusion and improve access to appropriate services [27]. While our study, in addition of those challenges, addresses the individual problems of providers and lack of supporting for PWD but it can also interrupt the provision of rehabilitation services. A report of by WHO stated the obstacles in service delivery namely; "Poor coordination of services, inadequate staffing, and weak staff competencies can affect the quality, accessibility, and adequacy of services for persons with disabilities" [6]. While the current study has addressed challenges of recipients and providers in mainstream of providing service. Fisher showed various factors including; poor information, shortage of services, and affordability across China, the local context, such as resources and social policy implementation, affect the degree to which families obtain the support they need [24]. Jacobs et al. [33] conducted an overview of the various dimensions of barriers to access health care in less-developed countries namely; availability, affordability, geographical and acceptability access to overcoming these barriers and presented an outline of existence interventions. But in the current study other challenges such as low knowledge of providers and lack of support for PWD were reached. Dew et al. found three barriers: a) travelling to access therapy; b) waiting a long time to get therapy; and c) limited access to therapy past early childhood [42]. This study did not state those challenges but mentioned two problems of accessibility: transportation and accessibility to centers of rehabilitation services. Schutzer and Graves understood barriers of motivation to exercise in older adult includes: lack of knowledge, lack of time, physical environment and Physician advice [26]. These findings are related to challenges of providing rehabilitation services. However existing study had mentioned lack of knowledge and problems of accessibility and lack of interest and motivation. Kronfol conducted a review study in Arab countries that showed issues are related to morbidity, transportation, patient–provider relationship, cost, stigma, and organizational barriers that often impede access and compliance with the care provided or recommended [34]. Present research confirmed the barriers such as transportation, cost and individual problem of providers. Marlow et al are found financial and administrative challenges to care; structural facilitators to care; and the influence of clinicians' professional demeanor on health care access [35]. This study has stated financial and communication problems of providers in access to health care but has not considered structural facilitators. Maart mentioned the hardships in accessing services namely; insufficient finances and transport difficulties [32]. While current study explored other challenges such as knowledge, communication, and attitude in providing services and confirmed their findings. Kritzinger presented some of interdependent factors that were experienced by disabled persons including: environmental, structural, communication and delivery process barriers [43]. Although their results confirmed by our study, those barriers may not only be limited to PWD, but also includes general population. Lam and Leat have reported barriers of low-vision service (LVS) namely; misconceptions of LVS, miscommunication by eye care professionals, lack of awareness, location and transportation, the need to appear independent, negative societal views, influence of family and friends, insufficient visual impairment to warrant services, cost of LVS, and reduced perception of vision loss relative to other losses in life [29]. Often those challenges have mentioned in our study except need to appear independent and influence of family and friends that it can be due to type of disability and high dependence on others in receiving rehabilitation services.

5. CONCLUSION

According to the results of this study, identifying challenges was the most important and key role in providing rehabilitation services. The main challenges in provision of rehabilitation services, includes: poor knowledge, problems of accessibility, individual problems of providers, insufficient support of PWD, negative attitude to disability and cost problems in rehabilitation. Exploring system of effective rehabilitation for providing service needs a comprehensive management that first should be familiar with all policy makers, providers, PWD and their families and other beneficiaries. In addition, a property rehabilitation plan requires a common understanding, considering the complication in addressing challenges in the long term to quality of life of PWD.

Since currently most people and organizations of rehabilitation service provision in Iran believe that the rehabilitation is measurements should be a government service in Iran. Rehabilitation needs to reform. Base on the findings

rehabilitation should be regarded as a comprehensive process that aims to help societies of providers, PWD and their families by using their maximum representation to achievement of the highest of quality of life. Also, participants recommended changing of viewpoints about rehabilitation needs to design a comprehensive plan in varied sectors of the country. It is also necessary that policy makers consider the challenges of rehabilitation services as a main part of the health plan; especially they must change their oversight of rehabilitation programs and recommended further research.

6. LIMITATIONS

The limitations have been stated; first the results did not explore the variety between types of participants, namely PWD, providers, key informants and other participants. Secondly the current research did not compare the observed PWD with other populations. Third, it seems the results cannot be generalized with another context. In spite of these limitations, the findings are valuable implications for key informants in policy making and planning for the provision of rehabilitation services.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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