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Challenges in Accessing Health Care Management for People with Disability in Pakistan

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Abstract

This study examines how the lives of disabled people are challenged physically, financially and due to specialists' attitudes towards them while accessing health care management in disability centers of Rawalpindi and Islamabad. These challenges must be accommodated them in society and uphold their rights by enabling the disabled with a peaceful and productive life. Moreover, for develop firm recommendations for future policy implications and provide the researchers with a better understanding of the demographic characteristics of disabled persons in Pakistan. This qualitative, cross-sectional, descriptive study was conducted to identify the challenges confronted by physically challenged persons visiting the disability centers. A convenient sample of 100 men and women of age 15-60 years with crippling physical conditions were as sample. Data was gathered thorough questionnaire. It was concluded from the results, that they are satisfied from the disabilities centers. As the analysis showed remarkable unsatisfied results. Further the findings of the study that disabled persons are facing challenges in accessing quality health care in disability centers. Existing policies should be revised with the main focus on the accessibility of physically disabled persons in terms of building, transport, education, employment and quality affordable health services hence combating the iniquitous attitudes of agencies towards the disabled. The pre-eminent limitation is the small sample size hence not reflecting the entire disabled community of Pakistan.

Keywords: quality healthcare, accessibility, challenges, physically disabled person

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Introduction

Disability is a global issue that occurs more frequently in developing countries than it does in developed countries (WHO global disability action plan 2014-2021). The worldwide research proposes that hurdles are confronted by Persons with Disabilities (PWDS) in attaining quality health care and experience stigma, inequality and discrimination throughout their lives (Holanda, Andrade & Bezerra, 2015). Approximately 15 percent of the world's population has some kind of disability, according to statistics compiled by the World Health Organization (WHO) and almost one-half of those disabled persons are even unable to afford quality health care (Becky, 2021). Persons with disabilities are usually challenged in three aspects such as physically, financially and due to a negative attitude which greatly hinders their participation in society. These challenges must be addressed in order to enable the disabled with peaceful productive life (Krahn, Walker & Correa-De-Araujo, 2015). An estimated 14 percent of the individuals with disabilities in developed countries are employed. The rest of those with disabilities are dependent on their families for financial support (Ashok, Shetty, & Mayya, 2015).

Improving the quality of existing health care programs and services, combined with the development of new ones, is essential to ensuring better health outcomes. Inequity in health care services exacerbates health inequalities are commonly faced by disabled people which lead to worse health outcomes (Imoro, 2015). Access to health facilities is regarded as an asset of citizens whereas on the contrary lack of quality care and health facilities result in an increased risk of functional decline of a person's health which leads to an increase in work-limiting disabilities. These circumstances arise when a person wants quality care but are unable to afford it (Baptiste, 2013).

Healthcare access has been studied by researchers around the world in order to understand global health disparities and improve care. The World health organization (WHO), the international labour organization (ILO) and the United Nations educational, scientific and cultural organization (UNESCO) are the United Nations expert organizations with a resolution to endorse the objective of rehabilitation and to equalize opportunities for disabled persons. These organizations are trying to advance their participation

keeping in mind the end goal to advance multi-sectoral joint effort at the national level for disabled persons (Barnes, 2011).

Persons living with disabilities encounter frequent barriers that limit their access to basic needs and increase the likelihood of living in poverty. Unemployment, as well as the cost of medical care for persons with disabilities, cause people in this situation to be at a higher risk of becoming impoverished (Palmer, 2011). Thus, an inclusive approach is important for disabled persons to have the same rights and opportunities and to attain their full potential as sanctioned by the UN conventions on human rights and rights of people with disabilities (UNCRPD) and is signed by Pakistan (Ahmad, 2013).

Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) demands that signatory countries guarantee disabled people access to health services, including reproductive health. In addition, these countries must implement population-based public health programs with the same range and quality standards as those presented to non-disabled people. Pakistan as being the signatory country of this convention had taken several steps to aid disabled persons. In 1981, the National Council for the Rehabilitation of Disabled Persons (NCRDP) was established to carry out government policy on employment and social welfare for disabled people (Ahmed, 2021).

In 2002, Pakistan's first-ever national policy on the subject of disability has been stated. This policy of equal opportunities affirmed to provide disabled persons with equal opportunities in all spheres of life, not only by providing better health services but also by providing prosthetic limbs and supportive braces/splints to disabled persons. An effective referral system, quality health care, and barrier-free access are key to providing health services in developing countries (Arsh, 2019).

Whereas in 2003 Pakistan's government policy reserved a 2% quota for persons with disabilities (PWDS) in Zakat. Lately, many amendments were made in National Policy (2015) to further strengthen the constitutional rights of disabled persons in Pakistan but they are still deprived of their rights in Pakistan. Present laws and government regulations should be improved since the main law for the prosperity of disabled persons was last ratified in 1981.

Though, in response to significant data gaps, worldwide researchers have been tracking changes in information sources for disabled persons over the past decade. There is a Lack of peer-reviewed literature regarding attaining quality health care by persons living with disabilities, especially in developing countries. Efforts are required to bridge the gap between developed policies for the disabled and new effective policies and laws should be created to normalize such laws. Importance should be given to work on literature covering all the aspects of the challenges faced by disabled persons. This research article is primarily focused on physically disabled persons who have crippling conditions with an aim to evaluate the quality of health care management in disability centers in Pakistan.

Literature Review

According to Krahn (2015), almost 60 definitions of disability have been presented by disability researchers globally. Generally, the word "disability" has been used in various contexts but the Global Burden of Disease (GBD) refers to "A methodological framework for quantifying the impact of diseases on people's health based in part on their ability to function. They regard disability as the loss of health, using a measurement scale to look at functioning in five key areas: mobility, cognition, hearing, vision, and self-care."

Concept of Disability

Disability is an ancient concept and is existed for as long as mankind has existed. Even though disability has been remained unchanged but our opinion regarding the concept of disability has changed over time for the better. According to the WHO disability report (2021), the developmental history of disability had many stages but mainly it is divided into main three stages depicting the gradual change in the views of people towards disability. The below table shows the stages of the evolutionary history of disability.

Table 1
Stages of History of Disability

Stage 1	*Stage 2*	*Stage 3*
Medieval Era	*1800's Era*	*Modern Era*
• The oldest time where disability was considered as an act of evil or deeds of the past (Karma). • Disability was considered as an inability and disabled persons were considered as a burden on their families and to the community as a whole. • No views of disability as a medical condition.	• In this era, disability began to be considered as a condition that had personal, public, social and policy consequences. • Disability was considered as a medical condition arising because of disease, trauma, or health issue. • No disability model has been introduced.	• Disability has been considered as a limitation in the ability of the persons due to environmental or societal factors that restrict their ability to participate in their societies or families or to access the services they required. Thus, disability is viewed as a result of an inaccessible environment.

Fellinghauer and colleagues (2012) defined Physical Disability, as "Difficulty in one or more areas of functioning, including both activities and participation."

Theoretical Framework

The theoretical framework provides a solid base for confirming the researcher's empirical observations and helps the researcher to expand on those observations. Disability models are governmental and societal tools designed to help people with disabilities. Although there are many ways to conceptualize disability, there is a lot of disagreement about which model to use. These models give an overview of ableist attitudes and the resulting limitations placed on disabled people.

Medical Model of Disability

Historically, the only model used regarding health and disease was the medical model, which attributed an individual's illness to disease, and treatment was solely medical. In more recent times, Modern thinkers have

adopted a more functional model. The medical model of disability focuses on three factors:

i. Disease and impairment, which defines disability as a matter of a health disorder
ii. Injury or trauma to a person's body or mind
iii. Prevention or treatment of the Health status

Social Model of Disability

The Social Model of Disability states that disability is created by barriers in society, such as inaccessible buildings and negative attitudes. By identifying these barriers and taking steps to remove them, we can eliminate the disability. This dynamic model has outlined the challenges and suggests the solution to overcome those challenges. It states that impairment is a social construct and that therefore the only rational solution is to change the way how society views disability and to socially include disabled persons.

Amponsah-Bediako (2013) describes the social model of disability postulates that society is organized in such a way that people with disabilities are marginalized as a result of stigma and discrimination. Therefore, the removal of these barriers would not only improve the lives of disabled people but give them equal opportunities as non-disabled people. By following this, there would be no obstacles faced by disabled persons in the community. He describes that problem lies in the environment and society, not in PWDs and mentioned in his study about following challenges/obstacles in society:

i. Inadequate Health Care Services
ii. Transport inaccesibility
iii. Environment inaccessibility
iv. Dependency
v. Poverty And Economic Dependency
vi. Isolation, Segregation
vii. Un-Employment
viii. Illiteracy
ix. In-Equity
x. Stigma

The social model takes a proactive approach to disability. This model doesn't see disabled persons as passive and believes that there is a

need to change society rather than disabled persons. Furthermore, this model suggests that it's the responsibility of society to provide support so that disabled persons can be on an equal footing as everyone else. While the Medical Model focuses on a person's impairment and assumes that disabled persons have identical needs, the Social Model focuses on a person's abilities and strengths.

Economic Model of Disability

Economic models of disability assess the degree to which disability affects an individual's ability to contribute productively to a workforce and the costs, such as health care expenses, that result from that disability. Such costs, in turn, affect both workplace productivity and the profitability of companies and can influence government funding for health care among other things (Forrester, 2017). This economic model emphasizes that to eradicate poverty and reduce the financial burden on PWDs and their families, policies should be revised to balance the rights of the disabled with others in society.

Bio-Psychosocial Model

The Biopsychosocial Model of disability was developed with the goal of integrating the medical model and social model into a more comprehensive understanding of disability. According to a model known as the biopsychosocial model, to understand a person's medical condition, all factors--biological, psychological, and social must be considered. The bio-psychosocial model of disability is a more holistic approach to understanding disability than medical and social models. Disability researchers felt the medical model was oversimplified whereas the social model of disability took the disabled person's point of view into account (Shakespeare, Cooper & Poland, 2018).

Challenges Confronted by Physically Disabled Persons

In the context of disability, many challenges have been faced by Pwds due to social inequity which can evoke different feelings from different people. Several cultures around the world view disability as a spiritual curse. Even though there are medical explanations for the existence of a disability, these explanations are less common and more prone to being misunderstood.

In the West, disability is typically viewed through the lens of medical theories such as those surrounding the polio outbreak. In the East, however, disability is not seen as a natural phenomenon and is explained differently. Such different perceptions from people, therefore, involve government differently depending on the country.

In Pakistan, disabled persons have confronted many diverse challenges, including structural issues such as workplace design, emotional issues such as stigma, and economic barriers such as inaccessible workplaces. This is largely due to the fact that society lacks awareness and equity. It is also because government policies fail to protect the constitutional rights of disabled persons. The ultimate goal of the disability movement in Pakistan is to remove hurdles that restrict disabled persons from living a full, active life (Rathore et al., 2011).

Physical Challenges

Physical challenges refer to physical limitations that make it hard or impossible to do activities like a normal person, or to access buildings and public transportation. There are several challenges faced by people with disabilities, regardless of the nature of their disability. In most cases, disabled persons have a hard time moving about in public places and offices. This is not because they cannot move but simply because of the inaccessible environment. The unavailability of wheelchairs and artificial limbs for some disabled people results in them crawling or being carried on the backs of others (Fiorati & Elui, 2015).

Healthcare Accessibility

Accessibility is generally referred to as the ease of access to a location, service or device. In other words, accessibility is the ability to access and get benefits from something. To make things accessible to all people (regardless of their disability), it's best to make them universally designed. In the case of disabled persons, assistive devices can help achieve accessibility via indirect means such as assistive devices or infrastructure such as the availability of ramps and rails (Gudlavalleti, 2018). Physically disabled persons face various types of accessibility challenges. A few of them are:

Access to Healthcare Buildings

Disabled persons encounter physical barriers when maneuvering through buildings, which are in violation of the law regarding access for people with disabilities. This is because building codes have not been updated to accommodate disabled persons. However, there are some efforts to change typical infrastructure practices so that new buildings incorporate basic accessibility features such as adequate ramps and door widths (Gudlavalleti, 2018).

Access to Healthcare Services

Many people assume building accessibility only means wheelchair ramps, but actually, a much more important issue is ensuring that all people, including those with other disabilities, have access to all environments without having restrictions. A true understanding of accessibility means considering how people with different disabilities could be affected by your organization. This should not only include physical space but also communication and attitude of specialists or health care providers towards disabled persons. By changing the attitude or the way specialists communicate with disabled persons, we can increase accessibility (Vergunst, Swartz & Hem, 2017).

Access to Transport

In the context of transportation, accessibility is that all disabled persons can easily reach any destination. If you have more accessibility, you'll be able to reach many other activities or destinations quicker. As the majority of the population are persons without disabilities, public transport does not cater for disabled people or those with mobility problems. This makes Public transportation inaccessible to disabled persons (Bascom & Christensen, 2017).

Economic Challenges

Viewing disability in economic terms, disabled persons require special assistance that is different from others. For instance, they may need special medicine or wheelchairs. They may also need personal caretakers. In other words, to fulfil the needs of disabled persons extra costs is required. Even with help from the government and other people, disabled

people still have a difficult time surviving in this competitive world (Palmer, 2015).

It has been concluded from the above discussion there have been very few studies regarding the challenges confronted by physically disabled persons in accessing quality healthcare in disability centres. The present study was mainly based on foreign studies. The researcher review previous studies and cited them in the study. In the view of the literature studied by a researcher, it is the first study in accessing the challenges faced by physically disabled persons in attaining quality health care at disability centers in Pakistan. This study provided basic information's to policymakers regarding the current situation of physically disabled persons in Pakistan and also laid the foundation to improve the right to justice and equal opportunity.

Objectives of the Study

During this study our primary objectives are:

i. To explore the demographic characteristics of disabled persons.
ii. To evaluate the quality of health care in disability centres.

Selection Criteria of the Study

This study includes only those participants who fulfilled the following criteria:

Inclusion Criteria Patients were included in the study if they having

i. 15-60 years of age
ii. Physical disability with crippling conditions
iii. Both Male and Female gender

Exclusion Criteria Patients were excluded from the study if they having

i. Any other type of disability (e.g. intellectual disability, learning disability).
ii. Psychological issues/ depression

Methodology

The study used a survey method to collect data, and the data were analyzed descriptively. Following procedural steps were adopted to accomplish the goal.

Sampling Techniques

Researchers used convenience (or accidental-volunteer) sampling to recruit participants from disability centres that have certain inclusion criteria. The participants were recruited who met the selection criteria as they enter the main entrances of each disability center. The researchers surveyed 100 people from four different disability centres. According to Gall et al., (1996) for smaller populations, say N=100 or fewer, it is usually not worth conducting a survey of the population as a whole. As the targeted population size of the present study was smaller, therefore small size was considered.

Instruments: For data collection, questionnaires were developed after studying the relevant literature. The factors of a social and economic model of disability were included in the study as explained above. These models pointed out different challenges encountered by PWDs such as environmental, attitudinal and economic barriers. Factors of these models are Inadequate Health Care Services, Inaccessible Transport, Inaccessible Buildings, Poverty and Economic Dependency, Isolation, Segregation, Un-Employment, Illiteracy, In-Equity and Stigma. For this research study, an instrument was developed that would focus on these factors. In part-11 of the questionnaire, five main factors were selected for this study are Health Services Accessibility, Accessibility of Specialists, Specialist Attitude, Cost Effectiveness and Overall Satisfaction. These main factors are sub-divided and a total of 28 items are studied in this research. A researcher decided on a descriptive research strategy and designed a questionnaire survey to analyze the challenges in accessing quality healthcare management in disability centres of Rawalpindi and Islamabad.

Validity and Reliability: The researcher consulted experts throughout the questionnaire development and modification of the items. After modification of the items, the reliability analysis shows that Cronbach's alpha for the questionnaire is 0.871, signifying that the questionnaire was internally consistent. The values of Alpha for each sub-indicators was:

Front Desk process (FDP), .83; Environment of Disability Centre (EDC) .89; Availability of Facilities (AF), .83; Accessibility of Specialist (AS), .87; Specialist Attitude (SA), .78; Overall Satisfaction (OS), .89. The alpha coefficient results indicated that the instrument was reliable.

Results

Demographic Characteristics of Respondents

The physically disabled persons' demographic and responses to a structured questionnaire are presented here. Information regarding demographic characteristics of respondents in terms of age, gender, family income, employment status, education, type of disability, age at which disability arose, type of mobility aid disabled persons is utilizing analyzed and presented in the following tables.

Table 2

Demographic Characteristics of the Study

Variables	*F*	*Mean (SD)*
Age		2.15(0.936)
15-25	26	
26-35	44	
36-45	19	
46-60	11	
Gender		1.56(0.498)
Male	44	
Female	56	
Education Level		3.07(1.578)
Illiterate	28	
Elementary	10	
High School	15	
College	21	
University	26	
Vocational	28	
Employment Status		1.91(1.12)
Employed	23	
Seeking employment	10	
Student	16	
Un-employed	51	
Marital Status		1.98(0.994)
Married	35	
Un-married	47	
Divorced	15	

Widow	3	
Cause of Disability		1.27(0.446)
Congenital	27	
Acquired	73	
Type of Mobility Aid		3(1.082)
Crutches	17	
Wheelchairs	8	
Artificial Limbs	35	
Orthosis (Brace/Splint)	40	
Family Income		1.38(0.582)
20,000 or below it	67	
20,000 to 50,000	28	
Above 50,000	5	

Results Based on Challenges Faced by Physically Disabled Persons

In this section, responses to challenges faced by physically disabled persons are analyzed. The researcher identifies 5 main challenges (Health Services Accessibility, Accessibility of Specialist, Specialist Attitude, Cost Effectiveness and Overall Satisfaction) and these main factors are sub-divided and a total of 28 items are studied in this section of research. This table shows a detailed, quantitative analytical framework of challenges faced by disabled persons visiting disability centres in Rawalpindi and Islamabad. The below table presents responses in the form of a percentage, standard deviation and mean. In order to simplify the description, strong agreement (SA) and agreement (A) were combined into one category. Similarly, strongly disagree (SDA) and disagree (DA) were also combined into one category.

Table 3

Disabled Persons' Response on the Challenges Confronted by Physically Disabled Persons

Responses on the Challenges Confronted by Physically Disabled Persons						
Variables	*Items*	*SA*	*N*	*SDA*		
		%	**%**	**%**	**S.D**	**Mean**
	Simplicity	37	7	56	0.96	2.54
	Speedy	31	3	66	0.9	2.7
Front Desk Process	Polite	43	4	53	0.89	2.46

	Confidentiality	32	9	59	0.56	2.86
	Waiting Time	30	2	68	0.77	2.43
Environment of Disability Centre	Room temperature	47	5	48	0.51	2.76
	Noise	44	12	44	0.6	2.45
	Cleanliness	40	7	53	0.64	3.04
	Bathroom facility	17	6	77	0.62	3.24
	Canteen facility	23	9	68	0.71	3.36
Availability of Facilities	Ramps	20	8	72	0.88	3.08
	Side rails or Grab rails	25	5	70	0.9	2.93
	Elevator/lift	18	10	72	0.96	3.01
	Adequate doorway	14	4	82	0.75	2.89
	Space for wheelchair	25	5	70	0.99	3.26
	Seating Provision	15	2	83	0.98	3.18
Accessibility of Specialists	Difficult to connect	62	9	29	0.85	2.96
	Difficult to ask questions	61	2	37	0.71	2.23
	Devotion of proper time	31	4	65	0.74	2.78
	Guidance to avoid abnormal gait	40	6	54	0.78	2.56
	Guidance of donning and doffing of appliance	64	11	25	0.86	3.01
Attitude of specialist	Helpful	38	2	60	0.74	1.86
	Polite	38	6	56	0.66	2.1

	Caring	22	3	75	0.59	1.89
	Professional	42	8	50	0.57	1.74
Overall Satisfaction	Affordability	18	10	72	0.53	1.64
	Information Provision	39	7	54	0.64	1.87
	Brace/splint or artificial limb provision	64	15	21	0.66	1.97

In the above table first column presents the significant variables. The second column of this table shows the 28 sub-items studied in this paper. The third, fourth and fifth column indicates the percentage of responses collected from respondents. The sixth and seventh column of this table indicates the standard deviation and mean of sub-items.

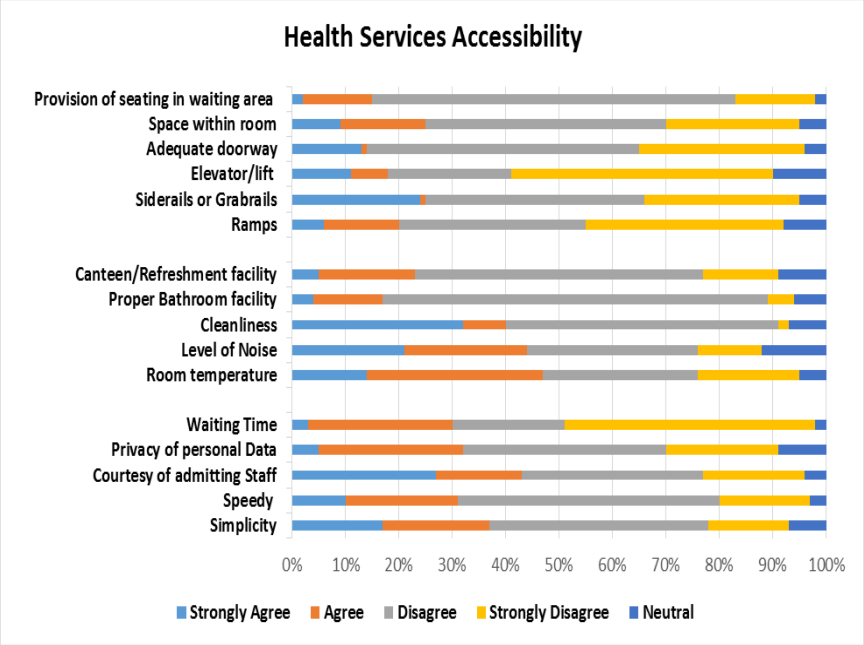

Figure 1 Graphical Representation of Disabled Persons' Response on Health Services Accessibility

As shown in the above figure, the respondents were given five choices: “Strongly Agree (SA)”, “Agree (A)”, “Neutral (N)”, “Disagree (D)”, and “Strongly Disagree (SDA)”. In order to simplify the description in the table, Strong Agree (SA) and Agree (A) were combined into one category. Similarly, Strongly Disagree (SDA) and Disagree (DA) were also combined into one category. The overall results revealed that the percentage of satisfaction about the Health Services Accessibility, Specialists Accessibility, Specialists Attitude and Overall Satisfaction from disability centres was remarkably low which showed that physically disabled persons were continuously facing challenges in attaining quality health care.

Conclusions

The results of the study revealed that physically disabled persons faced various challenges while visiting disability centres of Rawalpindi and Islamabad. Following were the major conclusions of the said study:

1. It was found that a considerable strength of respondents faced challenges in the front desk process when visiting the disability centres. All these negative experiences can lead to a feeling of isolation among disabled persons.
2. This result clearly shows disabled persons were dissatisfied with the present environmental adaptations on the four studied disability centres. Based on the findings of the present study, it is believed that there is a severe defect in the accessibility of the facility for the physically disabled.
3. Buildings have not been constructed in a way that can be used by the disabled, rather they want disabled persons to use the same way with the ‘abled’.
4. The availability of facilities in disability centres was not satisfactory and disabled persons had faced challenges in this aspect while accessing disability centres.
5. Accessibility of specialists is another major challenge faced by physically disabled persons. It is revealed that the patient's communication difficulties or lack of confidence, affected their ability to express their concerns to the specialists. But at the same time, this also included the failure of specialists to inform patients to

avoid abnormal gait patterns and devote proper time. It might be due to the overwhelming workload on specialists but the results also indicated that the number of respondents also agreed that specialists did guide them about donning and doffing of the appliance. Overall, results suggest that lack of information or understanding between specialists and respondents led them to become frightened or feel pressured to seek treatment.

6. The study found that some of the respondents felt that health professionals held negative attitudes toward disabled persons, while others felt that health professionals held a positive attitude toward disabled persons; however, all of the respondents believed that health specialists should be educated about the disabled population. According to them, specialists did not either pay attention to them or did not attend to them promptly. Research has shown that negative attitudes or perceptions regarding disabled people have led to negative outcomes in rehabilitation services.
7. It is important to note, however, that the attitudes of healthcare workers toward people with disabilities may simply reflect attitudes toward people with disabilities in Pakistani society at large. Most healthcare workers have not received training or awareness initiatives to alter broader social attitudes and perceptions.
8. The results exhibit that a majority of the respondents were not satisfied with the disability centres in terms of affordability and information provision but on the other hand, they were satisfied with the brace/splint or artificial limb provided by the disability centres.

Recommendations

The conclusions lead to the following recommendations:

1. Existing policies need to be revised with the main focus on the accessibility of physically disabled persons in terms of building, transport, education, employment and quality affordable health services hence discrimination against people with disabilities was combated.
2. The findings suggest that the disability program and authority of disability service centres provide accessible facilities, quality services with a positive attitude, and a respectful attitude toward people with disabilities through developing disability-friendly infrastructure, recruiting professionals with a disability studies background.
3. A seminar may kindly be held to address the challenges confronted by physically disabled persons.
4. The study recommended that building codes should be revised to ensure that all new buildings and renovations meet the needs of the disabled community.
5. The media should take an active role in helping to break down the barriers of prejudice and discrimination against the disabled community.
6. Raise public awareness about the different definitions of disability.
7. Authorities need to solicit the views of disabled people about their needs, the development and implementation of disability programs, to ensure better services.
8. Training sessions and workshops shall be conducted at regular intervals to train the health specialists in dealing with disabled persons.

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