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Unseen Struggles of Individuals with Muscular Dystrophy: An Ethnographic Study of EHSAS Welfare Trust, Rawalpindi

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Abstract

Muscular Dystrophy has many aspects that are physically, emotionally, and socially challenging for a patient and their caregivers in case of severe forms of the disease. Still, unfortunately, these aspects are not well documented. The present research aims to identify the problems of Muscular Dystrophy patients and their caregivers in the context of EHSAS Welfare Trust based in Rawalpindi, Pakistan. The objective of this ethnography are to describe the patients' and caregivers' experiences, identify the gaps in existing support systems, and analyzing the role of family involvement on patient's adjustment. Using qualitative methods, including participant observation and in-depth interviews, the research demonstrates that family networks are helpful to patients and contribute to creation of considerable practical and emotional stress on the caregivers. The findings highlight the necessity of culturally appropriate interventions to help Muscular Dystrophy patients and their caregivers. Ultimately, the study concludes that greater access to medical care, better rehabilitation, and, most importantly, extended community outreach programs and publicity are essential to ease the burden of Muscular Dystrophy patients and improve the quality of life for those affected. The findings of this study may help the policy makers to coordinate with trained professionals and advanced rehabilitation services to provide comprehensive care for muscular dystrophy patients.

Keywords: Muscular Dystrophy, support systems, challenges, healthcare, rehabilitation, community outreach, mobility

Introduction

Muscular Dystrophy refers to many closely related genetic disorders that lead to progressive muscle degeneration and weakened tissues due to genes abnormality (Mercuri & Muntoni, 2013). The severity of Muscular Dystrophy, as well as when symptoms start to appear and how quickly they progress, are distinct for each kind. Symptoms differ in severity and age of onset across Muscular Dystrophy types, even if they all belong to the same category, the most severe form of Muscular Dystrophy is Duchenne Muscular Dystrophy (DMD) due to the X-linked inheritance pattern affecting only young males. Muscular Dystrophy affects a patient's life physically, socially, and emotionally. As the disease progresses, patients face increased problems with mobility. Many patients use wheelchairs or other mobility aids and require ventilatory support for respiratory conditions. Muscular Dystrophy also disrupts family life and puts much pressure on caregivers, specifically females (Young, 2021). This includes tasks such as assisting with personal hygiene, walking, carrying out medical treatments, and providing psychological support. In many cultures, women are expected to be caregivers, associating them with self-sacrifice and nurturing, that could further limit their personal and professional pursuits. This gender expectation impacts the nature of support received and often leaves systematic gaps where there is a lack of structural systems to support it.

The relevance of studying Muscular Dystrophy falls perfectly under the umbrella of medical anthropology because it provides valuable ethnographic data regarding health and illness in a specific cultural and social context that are crucial for comprehending the lived experiences of Muscular Dystrophy patients and their caregivers. By situating Muscular Dystrophy within this framework, it will be possible to explore how cultural beliefs, social roles, and healthcare systems shape perceptions of disease and caring roles. Caring for Muscular Dystrophy patients within the Pakistani cultural setting, for example, is heavily influenced by family caregiving, religious beliefs, and cultural practices regarding disability. In this context, caring takes another form of family responsibility, an extension of the collectivist approach where family members, especially females, are expected to be the caregivers (Sufi, 2022).

However, when it comes to the caregiving role, medical anthropology goes beyond studying caregiving roles to show how health inequalities and social factors, including socio-economic status, rural or urban dwelling, and health facility access, influence both Muscular Dystrophy patients and their caregivers. For example, in Pakistan, a lack of better professional care defines many cases in which families rely on regular practitioners who do not know about Muscular Dystrophy (Baciu et al., 2017). This frequently leads to late diagnosis and poor treatment and further stresses the caregiving responsibility.

The explanatory Model of Illness, worked out by Arthur Kleinman, offers the interpretative lens, which would help understand how illness is culturally constructed. This model stresses that cultural beliefs, values, and social environments shape individuals' perceptions of the causes, symptoms, and management of illness. People use illness narratives, have subjective explanations of disease with biomedical, social, psychological, and supernatural origins, and seek biomedicine, traditional medicines, or spiritual interventions accordingly (Kleinman, 1986). Specifically, when employed in Muscular Dystrophy context, the explanatory model framework is beneficial for addressing both the patient and their caregivers. To a certain extent, caregivers especially in collectivistic such as Pakistani culture, consider caregiving a family duty shaped by culture. The study also reveals that gender-constructed responsibilities for caregiving arrangements have women directly providing care and men facilitating male-benefit care activities alongside undertaking other physically straining tasks. The extended family helps share the burden of caregiving, yet the caregivers are physically and emotionally challenged. Analyzing the existing knowledge about Muscular Dystrophy,as well as its associations with beliefs about Muscular Dystrophy, allows interventionists to effectively dispel the myths arising from caregivers and provide relevant information to empower their decision-making. To patients, culture plays a part in how the patient and relatives view the illness, affecting patient compliance. Society plays a massive role in reducing patient's dependency on family because, in some societies, individuals who require care would not want to seek help from other sources. Many individuals avoid seeking caregiving help outside their families due to cultural norms that emphasize family responsibility, fear of stigma and judgment, and emotional dependence on loved ones. Additional factors include distrust of external caregivers, financial constraints, and limited awareness or accessibility of caregiving services. These barriers often make individuals reliant on family support instead of seeking external assistance (Lee, 2024).

The explanatory model framework sheds light on the cultural beliefs and values that impact individuals with Muscular Dystrophy and their caregivers, particularly in the Pakistani context. Caregivers, particularly female members, consider caregiving as a cultural obligation because it is a responsibility naturally inherited within the family members. On one hand, caregiving builds strength and a sense of responsibility, but on the other hand, it can cause stress and exhaustion. Caregivers, especially in certain cultures, may hesitate to seek outside help because of the social stigma attached to it. A family-centered care approach for Muscular Dystrophy patients can bring security however, it might also trigger guilt feelings or dependence because the patients are aware of the burden of the caretakers. For many patients, they consider their disease as a genetic or spiritual test that can prevent them from seeking help from outside. The patient, as well as the caretaker, often feels lonely. People face societal stigma, thereby completely depending on the family's support with no social interaction in society.

The explanatory model assists caregivers to understand the perspectives, allowing for further cultural interventions. For example, family inclusive support may organize caregiving functions or patient support organizations to eradicate loneliness and empower the clients. Such support groups should be formed based on neighborhoods where caregivers can discuss their problems, face difficulties, seek information, and get emotional comfort. These groups can also provide updates on Muscular Dystrophy and give care tips. As most caregivers and patients consider their condition a divine trial, faith-based organizations may solve the problem by providing support and acceptance. It seems that if a community event is dedicated to discussing the everyday problems of caregivers, then men and women will be encouraged to find the help they need without worrying that there will be a stain on their reputation. And also educational, and teaching programs for caregivers is useful professionally for their preparedness in caregiving roles, methods of physically handling patients safely for mobilization, proper usage of medical equipment, as well as dealing with psychological issues (Reinhard et al., 2008).

Literature Review

This research investigates the unique challenges faced by Muscular Dystrophy patients and along with their caregivers, the coping mechanisms that caregivers adopt and the role of culture in shaping patients' caregiving responsibilities. By employing the method of anthropology, the research aims to reveal the hidden efforts and personal losses that caregivers face without adequate encouragement and help (Khoury et al., 2024). It reflects a concern with understanding of unpaid work, the input that informal caregivers provide, and the need for recognition and enhancement of better policies for enhancing caregivers. Several strategies identified in the literature show how Muscular Dystrophy patients’ caregivers can be acknowledged and encouraged. For instance, Harris et al. (2024) argue that the public should address and reward the act of caring. Also, Reinhard et al. (2023) state that caregiver support groups help share experiences and build a community. Actuality measures such as paid family leave and caregiver tax credits have been recently introduced in countries such as the U.S. which is an example of how this issue can be addressed by multiple stakeholders.

Muscular Dystrophy is a disability that affects a patient socially due to the physical challenge that they experience more when in school and may need assistance that is not easily provided. This is because they are also likely to miss some classes through frequent doctor checkups. Muscular Dystrophy has impacts on employment situations of adults where the physically disabled lay off their jobs or are challenged to secure one based on employers' discrimination (Bever et al., 2024). The cost implications demand medical care, assistance, and other continued support, which, in turn, contribute to instability and poor quality of life for the patient and the family. They also point to financial pressure as a cause of caregiver burnout.

In the context of females, a research by Withers & Hill et al. (2023) posited that in the west, female caregivers who are working while providing care are granted the paid family leave as well as flexibility at work. Bauman et al., (2021) noted that communities around countries such as the U.S. and the U.K. offer caregivers reprieve with care services, thus minimizing caregiver stress.

In Pakistan, gender roles are also seen to influence who is a caregiver. Many cultures make caregiving a woman's responsibility, meaning there is added pressure on women who cook, clean, and work while men only have to provide money. This expectation can result in fatigue and basic mental health complications (Sharma et al., 2016). It is crucial to identify such gender dynamics to develop support specifics concerning the needs of the caregivers. Culture plays a significant role in the determination of caregiving. In many Asian cultures like the one in Pakistan, for example, families feel the obligation to take care of their sick members. Although relatives can sometimes help, this support is often irregular, and cultural standards do not allow caregivers to seek outside help. In Pakistan and similar Asian cultures, families feel obligated to provide care for their sick family members due to cultural, religious, and social values. This reluctance to seek outside help stems from concerns about maintaining family honor, fulfilling religious duties, avoiding social judgment, and respecting privacy. Gender roles often place the caregiving burden on women, while limited awareness, financial barriers, and mistrust of external care also play a role. Emotional attachment and the perception of caregiving as a virtuous sacrifice further discourage families from seeking professional assistance. This research aims to understand better how caregivers manage their responsibilities in Pakistan's social context.

Several Western countries have policies that embrace the health, education, employment, and social rights of Muscular Dystrophy. For example, in the United States, there is the Americans with Disabilities Act (ADA), which demands that public places provide accessibility for disabled people. The United Kingdom plans to enhance research and utilization of specialized care for rare diseases. In Pakistan, the Protection of Rights of Persons with Disabilities Act of 2020 has given some solutions to disability rights, but there are still challenges in the healthcare system (Hayes & Bulat, 2017).

In Pakistan, the Protection of Rights of Persons with Disabilities Act of 2020 contains essential solutions such as accessibility to education, employment, and public places for people with disabilities, aid through assistive devices, and anti-discrimination laws. However, some challenges exist, connected mostly with healthcare, such as a deficit of specialized medical centers and equipment, a shortage of qualified personnel, and expensive assistive devices. These gaps are important for muscular dystrophy patients because extensive care systems further intensify their physical and psychological troubles. That is why the implementation of the Act has to respond to these challenges by creating specific centers, increasing support for caregivers, and providing equal access to health care (Ayub, 2022).

To manage Muscular Dystrophy, patients need various medical treatments, including physical therapy. Families often face the challenge of providing constant care at home. Home care workers can help by assisting with daily tasks, preparing meals, and offering emotional support. They can also support low-impact exercises and help with medications while being mindful of potential complications. Medical treatment, physiotherapy, occupational therapy, and steroids are essential in controlling symptoms of Muscular Dystrophy. However, the family has to care for their relatives at home 24 hours a day. They can help in low-impact aerobic exercise, instruct and assist on use of assistive devices, prompt the patient to take his medicines, track side effects, and provide emotional support (Brando, 2023). They need to know about interference which might be impacting patients and also obtain expert advice when there is a complex query.

Methodology

The methodology of this research is based on qualitative methods, as these methods prioritize the quality of data over quantity. An ethnographic study has examined the factors that influence the experiences of Muscular Dystrophy patients and their caregivers. Having a personal connection to the topic through my sister's condition, I focused on capturing the challenges and coping mechanisms associated with Muscular Dystrophy, particularly in Pakistan, where awareness and support structures are limited. My research began with a literature review, which revealed a significant gap in studies on Muscular Dystrophy in Pakistan. Misconceptions were common, with many mistaking Muscular Dystrophy for polio.

To encourage participation, I carried out fieldwork at the EHSAS Welfare Trust, Rawalpindi, a non-profit organization in Pakistan dealing with Muscular Dystrophy. This setting enabled me to talk with the Muscular Dystrophy patients and their caregivers. Furthermore, I conducted home visits which make the participants more comfortable sharing their personal details concerning some related issues. Hence, I got a glimpse of the dynamics of caregiving situations. Developing a rapport with the respondents was essential, especially when creating trust, which helped in gathering honest and detailed response. All the caregivers and other family members initially hesitated to share information about their issues. Still, the respondents became more expressive about their struggles and emotions as the days passed. This process was hard as it focuses the need for awareness and patience when working with vulnerable populations.

I developed an interview guide and conducted in-depth interviews and observations. This approach helped me get a diverse picture of caregiving roles and their feelings and struggles they go through during this phase. Some of the main emotions mentioned by caregivers included frustration and helplessness, and they said they usually lacked the resources to support the patients adequately. On the other hand, patients said they craved independence and described how their normal life disintegrated as the illness advanced.

For this research, I ensured that I got people from both the age groups 20-35 and 35-50, which enabled me to capture the life experiences of people going through different phases of their lives as well as those with caregiving responsibilities. Hence, these ranged settings enabled a much broader perspective on Muscular Dystrophy's effects on different life cycle phases and societal positions. Also, I ensured that my participants were selected from diverse socio-economic and educational backgrounds to give depth to my results and see the effects that social factors had to offer in caregiving.

I used purposive sampling to select participants, which involves choosing respondents based on their relevance to the research objective (Stewart, 2024). To ensure I had enough subject matter to work through in analysis, I conducted interviews until I identified data saturation, where no new themes emerged. I engaged 17 patients and 17 caregivers, balancing the ratio of males and females in both the patient and caregiver groups. The interviews were mainly about daily caregiving experiences, perceived challenges to medical care, and available coping strategies. For my research, I focused on ethical practices, such as informed consent, and confidentiality and cultural values. Informed consent was obtained from all participants, and pseudonyms were used to protect their identities.

This data supports my research arguments and demonstrates the need for a better support system for patients and their caregivers of Muscular Dystrophy in Pakistan. The current study goes a long way in providing information on the difficulties faced by this community and contributing to constructing the kind of policies required to tackle problems associated with accessibility and healthcare services. My research examines these issues to help raise the public's awareness for them and encourage the policy reforms necessary to improve the lives of Pakistani individuals affected by Muscular Dystrophy.

Discussion and Analysis

Muscular Dystrophy (MD) remains a heavy social and physical burden in families and even society in terms of patients as well as caregivers. This progressive disease that affects muscles and slowly slows down movement can greatly reduce the quality of life or lead to complete dependence, isolation, and mental complications (Domaradzki & Walkowiak, 2024). The support systems for patients having Muscular Dystrophy and their caregivers in Pakistan are very limited, with a lack of healthcare, limited assistive devices, and a general absence of public awareness. This analysis examines different sides of these challenges, highlighting physical, emotional, and socio-economic impacts while focusing on critical support gaps.

a. Physical and Emotional Challenges of Patients and Caregivers

Muscular Dystrophy features progressive and severe muscle degeneration, which massively impacts mobility and the ability to live independently. Basic tasks involving moving, picking up an object, and gradually even inhaling or swallowing become difficult or impossible without tools for mobility or total dependency on others. During my research, majority of respondents pointed out that they experienced numerous physical difficulties at home performing simple tasks like changing clothes, eating, or even bathing. It also worsens to the state where talking becomes difficult for the patient. Muscular dystrophy (MD) patients face significant physical challenges, especially in public spaces and transportation systems that are not accessible to disabled persons. One of my respondents, Saad, whose age was 25, highlighted his struggles using public transport. According to him,

"Using public transport poses many difficulties because there is no place to put a wheelchair, which makes it very difficult for me. Since the introduction of metro buses, things have become somewhat easier because they are equipped with ramps and other facilities. On the other hand, when I go to the private sector, ramps are not commonly built. While they are common in big cities, there is little awareness about them in smaller towns."

Accessibility problems are evident, with some urban public services offering accommodations, while private and rural areas often lack these facilities, exacerbating challenges and creating disparities based on geographic location.. Using public transport can be extremely difficult due to the unavailability of public transport accommodations for wheelchairs. But, with the introduction of metro buses, some provisions such as ramps have been introduced, though not readily available in private transport and rural towns (Mwaka et al., 2023). These revelations bring out the issue of mobility within people with disability, pointing to the fact that there should be greater public awareness on the part of the government as well as enforcing laws of transport for people with disability, both private and public means of transport. Addressing these challenges is crucial to fulfilling those objectives and giving people with disabilities the opportunity to become active members of society.

This analysis shows that the emotional impact of Muscular Dystrophy (MD) is as bad as the physical impairment attributed to patients. This transition from physical independence to physical dependency comes with social isolation and frustrations characterized by restricted mobility. One of my respondents, named Alisha, whose age was 23, described the emotional burden of these challenges and how loneliness takes over a person with disability. According to her,

"I had to come to terms with the fact that my life was going to change irreversibly. Losing my independence and facing social isolation are the hardest parts for me. There are also specific emotional triggers that can make any day go from good to bad, and figuring out coping mechanisms is a constant process. The fear of what the future holds is always lurking in the back of my mind."

People with disabilities feel the most common feeling of losing independence and being socially isolated. Losing one's ability to do things for themselves affects so many people's mental health and can make you feel very lonely (Emerson et al., 2020). Research shows that social isolation affects a significant number of people with disabilities, contributing to depression and anxiety, so coping with these types of emotions is important. Moreover, the worry of what the future will bring that weighs heavily on the shoulders of people with disabilities. Such emotional triggers can change a good day to a bad one, so individuals need to find ways to manage their feelings (Brandt et al., 2022). Studies indicate that people living with disabilities can improve the quality of their lives while managing anxiety so much through solid coping mechanisms. Therefore, providing support and resources is essential to help individuals face their fears and feelings of isolation while adjusting to their new reality. The responsibilities endured by caregivers are immense, involving physical support and emotional endurance. One of my respondents, Sara's mother, whose age is 48, shared her demanding daily routine, including assisting her daughter with movement and personal care. According to her,

"The daily care routine is quite demanding physically. It includes everything from personal care to managing her mobility around the house. Transferring and lifting her can be particularly challenging, and it's crucial to do so safely to avoid injury. My sleep patterns are often disrupted, as I sometimes need to assist her during the night."

Caring for a person with a disability can be physically demanding. People receiving care may require assistance with personal hygiene, toileting, and moving from one room to another, which may be demanding. Safely getting and moving patients who need help is particularly difficult, and lifting should be done steeply to avoid harm to both the patient and the caregiver. As we have seen, the literature reveals that many caregivers encounter some physical tasks, hence the need for appropriate training and assistive devices. Also, many caregivers suffer from sleep deprivation because they do some caregiving during the night. This can result in fatigue and stress, which worsens the caregiving role (Darragh et al., 2013). Research shows that factors such as social support are essential in enabling caregiver's physical and emotional well-being when it comes to managing these demanded responsibilities. Having this insight helps shape support and other valued services that can be used to help caregivers.

Most caregivers experience sorrow, fear, and, much of the time, a profound state of helplessness, observing the loved one's condition decline. Cultural expectations pressure caregivers, particularly women, to fulfill their responsibilities without expressing complaints. For instance, one of my respondents, Zain's mother, who was 50 years old, said it had taken the emotional strain, as she claimed;

"The initial diagnosis was a shock and set off a profound emotional response. There's an ongoing sense of grief and loss, knowing that Zain's condition will progressively worsen. The early stages of caregiving were particularly tough, as everything was new and overwhelming."

Caring for someone with a chronic or terminal illness can have a deep emotional impact on caregivers. They often deal with a mix of grief, stress, and burnout as they cope with their loved one's declining health. For example, caregivers may feel grief and loss as they watch their loved ones get worse, leading to significant emotional pain both during and after their loved one's illness (Trualta, 2024). Many caregivers experience burnout, which is a state of physical, emotional, and mental exhaustion caused by the demands of caregiving. Research shows that over 60% of caregivers report feeling burned out, making it hard to care for themselves and their loved ones. The mental health of caregivers is greatly affected by their responsibilities; those who feel more burdened tend to have worse mental health outcomes. Recognizing the signs of stress and burnout is important to prevent long-term exhaustion. Building a support network can help ease some of the emotional weight. Connecting with healthcare professionals or support groups can provide caregivers useful tools to cope during these tough times. Understanding these challenges is key to finding effective ways to manage stress and seek the right support.

Particularly, Muscular Dystrophy patients face a variety of difficulties because of their gender, depending on socially appropriate roles and positions assigned. In a research, women with Muscular Dystrophy experienced common barriers, and these included prejudices from society and healthcare providers, limited education and employment opportunities, and discriminative healthcare deliveries based on gender (Yaghmour et al., 2021). While men may struggle with shift work and related burdens or chronic physical illness affecting their ability to provide for the household, there are new concerns about failing in male provider roles and social stigmatization (Baldwin & Twigg, 2024). Despite that, both genders experience mobility issues and social isolation.

b. Existing Support System for Muscular Dystrophy

The support system for people with muscular Dystrophy in Pakistan demonstrates strengths, particularly through ongoing medical care, physical therapy, mental health counseling, and community empowerment initiatives. NGOs and charities, including the Muscular Dystrophy Association (MDA) and EHSAS Welfare Trust, play a vital role in providing medical supplies, financial aid, and emotional support, fostering respect and awareness for individuals with muscular Dystrophy. However, a more comprehensive approach is essential to enhance care and empowerment. My research respondents largely echoed these points, highlighting similar needs and experiences. One of my respondents named Saad, who was 25 years old, highlights the need for system-wide reforms in Pakistan's disability support by comparing it to higher global standards seen in countries like Japan, Germany, the US, and Britain. According to him,

"In other countries like Germany, the United States, and the United Kingdom, such patients receive better treatment. They have dedicated parking spaces and houses, and the government extensively supports their needs. Unfortunately, this is not the case in Pakistan."

Countries like Germany, the United States, and the United Kingdom offer strong support systems for individuals with disabilities, including accessible public spaces, financial assistance, and specialized health services. In Germany, social protection programs help with living expenses and employment opportunities, allowing disabled individuals to live more independently (World Bank Group, 2024). The U.S. enforces accessibility through the Americans with Disabilities Act (ADA), which requires public places and workplaces to accommodate people with disabilities, making life easier with designated parking, accessible buildings, and inclusive facilities. Similarly, the U.K. provides government-funded support for healthcare, housing, and daily needs, helping disabled individuals live more fully and independently (Oliver et al., 2022). In Pakistan, however, such extensive support is limited, and public infrastructure often lacks accessibility features, making daily life challenging for disabled individuals. Improving these services could greatly enhance their quality of life by following some of the approaches used in other countries.

One of my respondents, Yusra, underscore necessary medical and rehabilitation services, including regular physiotherapy at home. They can help decrease the extent to which muscular Dystrophy is physically debilitating. She also suggests that the system should ensure its transport, educational programs, and employment opportunities to help patients achieve independence and inclusion. According to her,

“Emotional damage is lesser if there is an attendant at home, but family members initially struggle, although they try to support over time. However, if they stop caring, it causes significant emotional damage.”

According to the literature, her experiences can be linked to many people with muscular Dystrophy. Mobility limitations, respiratory dysfunction, and fatigue are well described in the literature as major contributing factors to a decreased quality of life for individuals with Muscular Dystrophy (Sirayder et al., 2022). There are also psychological implications to receiving a diagnosis, loss of independence, and social isolation, among others, outlined in these studies that highlight the necessity for psychosocial support when managing emotional distress (Reynolds et al., 2022). Studies have confirmed the significance of comprehensive healthcare, inclusive care planning, social support networks, and advocacy approaches that must be integrated in patient management to make recovery outcomes relatively favorable (Milligan et al., 2020). In addition, research also emphasizes the importance of psychosocial support and financial assistance programs in improving the quality of life for patients as well as their families.

c. Systemic and Societal Gaps in Support System

The unavailability of essential assistive devices like wheelchairs or communication aids exacerbates the challenges of living with Muscular Dystrophy. One of my respondents, Noreen, who is 33 years old, expressed frustration with the high costs and lack of maintenance for assistive devices like this;

"A major issue in Pakistan is the lack of maintenance and repair for wheelchairs, which are often imported and customized, making them costly."

Major concerns for wheelchair users in Pakistan include the shortage of maintenance and repair services available. Many wheelchairs today are either imported or made to order, making them costly and, therefore, out of the reach of many people. A study shows that due to a lack of local repair services, wheelchair users are forced to travel long distances to repair their wheelchairs, meaning they spend many hours without mobility aid (D'Innocenzo et al., 2021). This problem is compounded by the fact that few users know they have a right to these services, and the system for providing assistive technology is not well developed. Such issues can be solved by setting up repair services whereby carrying out maintenance locally through training artisans could ensure people keep their mobility devices in good condition.

Also, access to repair services within the same duration would significantly enhance the lives of the users of assistive devices. Research shows that the availability of repairs prolongs the lifespan of devices and makes the users feel independent as they are included members of the society. Organizing mobile repair stations or community workshops, especially in rural areas, can provide important services where access to such specialized centers is restricted. By concentrating on such advancements, Pakistan will also be facilitating mobility aids and providing the right support to disabled people for improved quality of life.

However, in the case of Pakistan, there are some other issues associated with the provision of the assistive devices, in addition to the issue of cost and maintenance. In cities across the country, many people lack substantial access to locally available devices compared to imported ones, which are costly. As stated by Shahzad et al., (2023), this problem is worse when we look at the situation in Pakistan, where there is very less assistive technology and very less has been done to develop inexpensive, durable, and culturally sensitive solutions for disabled people.

Further, rural areas severely lack assistive devices and services since healthcare is frequently minimally developed. Karki et al. (2024) evaluate the shortcomings of public policies that failed to require the use of such devices, notably in rural areas. There are no rehabilitation centers, and there is no training for local artisans for repairing and maintaining the devices, which further impact the disabled individuals and their families to come to urban areas for these services.

From the viewpoint of the explanatory model of illness, this case describes the overall context wedded to the infrastructure shortages and socio-economic inequalities in shaping access to healthcare. Therefore, Pakistan needs to design specific policies and localized repair services for disabled individuals and provide government-subsidized assistive technology programs to encourage disabled people to be independent, which, being part of cultural value, is also an enforceable way of implementing sustainable change.

d. Improved Care for Muscular Dystrophy

Special Talent Exchange Program (STEPS) and Armed Forced Institute of Rehabilitation Medicine (AFIRM) are some organizations in Pakistan that help individuals with muscular Dystrophy. STEPS supports other initiatives that offer vocational education to enable the target group to acquire employment skills and activities to foster independence. On the other hand, AFIRM provides medical treatment for muscular Dystrophy with physiotherapy and employment training to develop skills in personal care and by create employment opportunities for clients with muscular Dystrophy (Fujita et al., 2021).

Majority of the respondents demanded easier and improved accessibility of transport for people with muscular Dystrophy for making them mobile. They want effective legislation regarding equal rights of these people to combat the discrimination in the context of equal access to education, employment, and other public services. Also, schools are encouraged to introduce friendly policies by incorporating special devices to help students with diverse needs, such as electric wheelchairs and mobility aids that enhance independence and accessibility for students with physical disabilities. To improve self-mobility and overall health, it is essential to provide affordable access to assistive devices, such as electric wheelchairs and communication gadgets, which support independence and enhance quality of life. One of my respondents named Arslan, who was 30 years old, illustrates that there is still a need for more funding and innovation, even in well-supported areas. According to him,

"While I'm grateful for the existing support, there are areas where further interventions could make a significant difference. I need more specialized medical care, specifically designed for muscular dystrophy patients. Advanced rehabilitation services that incorporate the latest therapies could improve our quality of life. Access to assistive devices and technology is also essential; these should be more affordable and accessible. Improved accessible transportation options are crucial for maintaining independence and social connections. Educational initiatives that cater specifically to our needs and potential employment opportunities designed to accommodate our physical limitations would be incredibly beneficial."

The essential and critical care required by muscular dystrophy patients includes specialized medical services, more complex rehabilitation services, and accessible and affordable assistive devices. It focuses on the importance of accessible transport, especially in enabling independence and social interaction, and calls for educational initiatives and job opportunities (Tariq, 2022). Approximately the control of motor function and an enhanced quality of life requires a multi-disciplinary approach to management, while the availability of affordable mobility aids is a crucial need for daily navigation. Such issues can be very useful in improving the lives of those with Muscular Dystrophy.

Many research recommendations emphasize the importance of specialized medical treatments, modern rehabilitation centers, and cheaper facilities and aids for muscular dystrophy patients in Pakistan compared to developed countries. Where the Protection of Rights of Persons with Disabilities Act (2020) appears to signify civil liberty's continued evolution, it does not cover the range of rights and services that the disabled citizen calls for. It also points to the significance of organized access to further healthcare and other rehabilitation services that should improve patient's results and, most importantly, their quality of life. Constant re-invention of services, local rehabilitative initiatives, and awareness campaigns are important for progress. Collaboration of government agencies, NGOs, and the private sector are working on finding the most effective solutions for people diagnosed with Muscular Dystrophy. Together, government agencies need to find ways to create better employment support programs that can assist people with muscular Dystrophy in living more independently. These upcoming investments will make Pakistan a just and equitable society that will uphold the rights of those who are vulnerable to muscular Dystrophy and advance their well-being.

Conclusion

This research shows that patients with muscular Dystrophy and their caregivers in Pakistan face different challenges, such as physical limitations, social isolation, and financial difficulties, affecting the independence of patients with Muscular Dystrophy. The study stresses the need for a comprehensive support system that including healthcare and mental health care for caregivers to relief from stress and burnout. Lack of access to gene therapies and other approaches is one of the reasons for upgrading health systems and focus on creation of specialized health centers, as well as to pay much attention to the increased psychosocial needs of patients. The research shows that there is a need for societal acceptance of caregivers, support from the community, and public health programs to be launched in support of caregivers to attain a compassionate society. It calls for urgent policy reforms to improve the health care facilities and caregiving services, encouraging people's worldwide collaborations to address similar issues faced by caregivers, especially in developing countries. This study not only unveils the complexity of physical-bio-cultural problems faced by Muscular Dystrophy patients and their caregivers in Pakistan. The work contributes to knowledge by highlighting the role of culturally embedded beliefs that underpin perceptions of illness in our society. Moreover, this study calls for culture-sensitive interventions, policy changes and international cooperation to combat the deficits while enhancing ethical imperatives in health anthropology.

Recommendations

Following are the recommendations based on findings of this study;

- Conduct nationwide campaigns to reduce stigma, educate the public on muscular Dystrophy, and encourage societal acceptance of patients and caregivers.
- Enforce disability-friendly policies, improve infrastructure accessibility, and ensure compliance with the Protection of Rights of Persons with Disabilities Act.
- Foster partnerships between government, NGOs, and local communities to provide resources, organize support groups, and create a collaborative care model.
- Develop centers equipped with advanced medical care, rehabilitation facilities, and trained professionals to cater specifically to muscular dystrophy patients.
- Ensure the availability of affordable and locally manufactured assistive devices, such as electric wheelchairs and communication aids, alongside repair and maintenance services.
- Implement financial support, training programs, and mental health counseling for caregivers to alleviate stress and promote their well-being.

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