


Disability and Illness in Families: A Dual Burden of Caregiving and Health Challenges

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Abstract

Disability and illness represent intertwined human experiences. Each can serve as both a catalyst and an outcome for the other. Physical disability often results in reduced physical activity; the intensity of disability fosters despondency, while severe injury and chronic illness may evolve into enduring disability. Nevertheless, this paper endeavors to investigate the illness trajectory stemming from disability. Utilizing primary data gathered from a dozen of fully disabled members of different households by taking their interview, this study concludes that disability not only affects the individual but also instigates illness among other family members. It is not only stressful for the particular person but also becomes a stress for the family. Frequently, individuals with disabilities endure health complications, while their caregivers experience heightened levels of stress. The intersection of illness in disabled persons and stress in their caregivers underscores that disability is not merely an individual issue but a social issue, because since the impact of disability affects the entire family unit it goes out of the personal level and becomes a social issue.

Key words: Caregiving, disability, family, health, illness, stress.

Introduction

Disability is a part of the human condition, as every individual is likely to encounter it at some point in their life (WHO & WB, 2011). It consists components both of impairment in a person, and more importantly, of barriers produced by society (Subedi, 2024). Thus, disability is taken as the total sum of impairment, activity limitation and social exclusion (WHO & WB, 2011; UN, 2006). Disability starts with impairment not only because certain individuals are only impaired, but because all human beings have unique impairments. Because of impairment, including both the disabled and non-disabled people are constrained to do all of their work better than others. But certain people are only oppressed. Therefore, disability is not more than a deliberate oppression of certain individuals in the name of impairment (UPIAS, 1976).

Disability is the most disadvantaged condition of human life because people with disability (PWD) face a wide variety of barriers like communicating to studying, playing, singing and dancing, and often interacting freely with other people in an open space due to stigma (Subedi, 2024). It has been a primary source of stress for the individual involved, as well as a contributor to family poverty. The disabling barriers consist of negative attitudes, insufficient policies, limited services, challenges in service delivery, inadequate funding, lack of accessibility, absence of consultation and involvement, and a deficiency of data and evidence related to disability. Consequently, persons with disabilities encounter numerous disadvantages, including poorer health outcomes, lower educational attainment, reduced economic participation, higher poverty rates, increased dependency, and limited social participation (WHO & WB, 2022).

Individuals with disabilities experience substantial health disparities. They are vulnerable to a range of illnesses. Disability and illness are not only mutually reinforcing phenomena, but each condition can also independently provoke or result from the other. Therefore, it is equally important to examine how disability leads to illness and how illness results in disability. This paper exclusively examines the role of disability in the onset of illness. Initially, it underscores the enduring role of disability in initiating and associating illness with the specific individual, which can be interpreted as a direct pathway from disability to illness. Secondly, it examines the worsening of illness in other family members overall, with a particular focus on key caregivers as representatives of the indirect pathway to illness. The primary objective of this study is to illuminate the role of disability in exacerbating illness within the family context, particularly with respect to the frequently overlooked caregiver. The primary research question concentrated on the duration of illness experienced by individuals, with illness specifically defined as the enduring suffering from chronic disease and the consistent use of medication for a minimum of one year.

Method

This paper is grounded in primary data collected from 8 families, which had at least one fully disabled member (FDM). FDM refers to those individuals who are unable to sustain their daily living without complete reliance on others. I determined that a sample of 8 families, each comprising one disabled member, would suffice for gathering information pertinent to the subject matter. The rationale behind selecting such families was their need to employ one caregiver responsible for the care of the FDM. To examine whether disability serves as a precursor to illness for both the disabled individual and other family members, information was gathered from both the caretaker and the caregiver. Gaining access to this information was facilitated by establishing a good rapport with these households, leading to the adoption of in-depth qualitative interviews as the most suitable data collection method. Throughout the interviewing process, both the caregiver and the caretaker were approached separately to eliminate potential influence or interference during interactions.

Review of Literature on Disability and Illness

Literature pertaining to disability can be broadly categorized into two distinct frameworks: the medical model and the social model. The medical model, rooted in traditional ideology, characterizes disability as a condition of impairment and posits that the disadvantages experienced by an individual stem from biomedical failures. As this is perceived as a personal tragedy, the individual is held accountable for the circumstances he or she encounters due to such misfortune. This perspective regards impairment

merely as a physical condition, primarily as a deficiency, and constitutes the 'medically classified condition' (Barnes 1991). In other words, the medical model diminishes the significance of the social, cultural, and political contexts within which disability is contextualized or defined.

In contrast, the social model perceives disability as a social disadvantage, encompassing forms of stigma, oppression, and exclusion. It asserts that the challenges faced by PWD are not attributable to their impairments but rather to the roles played by social, political, and cultural structures. This perspective seldom endorses the belief that the difficulties encountered by PWDs result from their incapacities; instead, it emphasizes the influence of societal constraints. Consequently, the social model regards disability as a condition of social limitation imposed upon individuals. A clear distinction is thus made between impairment and disability, with the former relegated to the medical model and the latter to the social model. It is believed that impairment may or may not correlate with disease, genetics, or injuries but invariably relates to the mind, body, and senses of individuals. Disability, on the other hand, is understood as the disadvantaged circumstance engendered by the social, economic, political, and cultural environment of a given society, which is largely indifferent to whether individuals have impairments.

Moreover, Crow (2007) articulated clearly how disability aligns with the social model: "It wasn't my body that was responsible for all my difficulties; it was external factors. I was being Dis-abled my capabilities and opportunities were being restricted by poor social organization. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary!" (Crow 1992:2)

Two distinct yet polar perspectives regarding disability emerge. The medical model, by emphasizing an individual's physical and mental infirmities, asserts that disability has a clear connection to impairment; thus, it contends that an individual's physical or mental condition should serve as the initial point of discussion. Conversely, the social model posits that individuals living with various infirmities hold society accountable for favoring some specifically, the non-disabled while neglecting others the disabled. If a society possesses the capacity to be unfriendly, it simultaneously holds the potential to be friendly. Therefore, social construction ought to be the foundational element of any identity particularly regarding the disability discourse, as concluded by the social model of disability.

At one time, theoretical frameworks of disability engaged in contentious discourse, with the World Health Organization (WHO) and the World Bank (WB) endeavoring to mitigate the divide between medical and social models by characterizing impairment as an individual shortcoming and stigma, oppression, and exclusion as societal deficiencies. The conceptualization of disability as the aggregate of three distinct yet interrelated conditions namely, impairment as issues in bodily function or modifications in bodily structure, such as paralysis or blindness; activity limitations as challenges in executing activities like walking, working, eating, or dancing; and participation restrictions as difficulties in engaging in various aspects of life, such as experiencing discrimination in employment or transportation (WHO and WB 2011) has emerged as a mediating framework.

Despite this, existing literature corroborates the role of disability in the onset of illness. Physical, intellectual, or sensory impairments are regarded as primary indicators of disability, while the nature and extent of these impairments are viewed as contributing factors to disability and illness (WHO and WB 2011; Wendell 2001). Furthermore, the involvement of individuals with disabilities in health-compromising activities has been evidenced (Heslop 2013). Additionally, the indirect influence of disability in exacerbating illness at the household level has been noted. Given that caregiving is an

arduous undertaking, it imposes additional stress on the household, with the caregiver frequently becoming the principal casualty. The distressing living conditions engendered by disability identified as an indirect pathway to illness in this paper are underscored by Traustadottir (1991), Barnes (1991), Leonard et al. (1992), Altman et al. (1999), among others.

A study conducted by Subedi (2018) on the access of 36 individuals with disabilities to health facilities revealed that 58% of them lacked access to health services. Only 1% of their 90 siblings reported a lack of access to health services. The same study indicated that 69% of disabled participants felt they were not treated fairly by their family members, whereas none of their non-disabled siblings reported experiencing any unfair treatment from family members. It indicates that a highly inequitable relationship exists between disabled and non-disabled members in both the home and society, with disabled individuals serving as the primary victims.

A review of the literature suggests that disability has operated both directly and indirectly in the emergence and escalation of illness. Not only do persons with disabilities (PWDs) contend with or are predisposed to illness, but their family members particularly caregivers are also vulnerable to health challenges due to the taxing nature of their caregiving responsibilities.

Empirical Findings and Analysis

It was unexpectedly revealing to discover that all eight PWDs were adversely affected by illness. They experienced chronic ailments necessitating ongoing medicinal interventions. Moreover, five of them had been continuously reliant on medication for over five years. Even more surprising was the fact that none of these individuals had ceased their use of medication, nor was there any indication of amelioration. This indicates that PWDs were utilizing medications not for the purpose of curing their conditions but rather to alleviate discomfort. Furthermore, inadequate hygiene and poor sanitation were implicated in their health issues. One respondent, aged 68, articulated:

“I used to be an active worker. I was never fatigued. I turned down every request. However, after becoming disabled, I was confined to this cage. I constantly reminisce about my past life wandering freely, climbing trees, seeking adventure only to awaken to the reality of being in bed. I do not wish to take this (gesturing to the nearby medication) but feel compelled to do so. Currently, I suffer from chronic constipation, which necessitates manual assistance to evacuate my bowels. People see me merely lying in this bed, yet no one understands the extent of my internal turmoil.”

The aforementioned statement highlights the distressing living circumstances experienced by persons with disabilities (PWDs). It was further observed that the respondent exhibited a lack of expressiveness while responding, revealing his resignation to his plight. He admitted to a reluctance to continue living, and his prolonged sigh indicated an absence of joy in his existence. In his estimation, an extended life equated to an existence fraught with pain and anxiety.

One woman recounted her situation as follows:

“Awaiting death while confined to this bed has become my daily reality for years. Due to mobility issues, I have been unable to bathe for months. I have neither changed my attire, nor combed my hair, cut my nails, or washed my face. Observe, an unpleasant odor surrounds me. At times, I contemplate self-harm, but who would assist?”

The experiences delineated above were articulated by a woman who suffered from paralysis on the right side of her body. While paralysis constituted a significant health issue, it also gave rise to additional health complications. The posterior aspect of her body was marked by bruises and unsightly dirt stains. She noted that the incessant intake of medication, ostensibly aimed at alleviating paralysis, had inadvertently invited cardiovascular disease and gastritis into her life. The paralysis was progressing to other areas of her body, accompanied by swelling and discomfort.

A distinctly unique perspective was shared by another respondent

“I do not experience the same level of concern that others typically do. I receive a pension. You may observe that my residence is equipped with an accessible room, toilet, and bathroom, with ample space to accommodate a wheelchair. Most importantly, I have an exceptionally devoted wife. Were it not for her, I would not be able to lead this fulfilling life. Therefore, if misfortune were to befall her, I would have to follow suit. Previously, I was in good health, but within a year of becoming disabled, I have developed diabetes and require medication.”

The foregoing statement suggests a relatively normal existence for a wheelchair user. However, it is evident from his demeanor that the absence of a competent caregiver could precipitate a cascade of challenges. It is noteworthy that the contentment of disabled individuals often hinges on the presence of a supportive caregiver, a resource frequently unavailable to them. In addition, the onset of diabetes can be seen as an unfortunate consequence of his disability.

Moreover, the remaining seven respondents within the cohort also shared their experiences. Many echoed sentiments similar to those articulated above, acknowledging that living with a disability often equates to enduring pain, stigma, scarcity, mistreatment, or a combination thereof. Such conditions are conducive to significant stress. Furthermore, none of them refuted the notion that their disabilities contributed to the onset of other ailments. Ultimately, they admitted that their health had been deteriorating due to the complications introduced by their disabilities.

Promotion of Illness among Family Members

Since disability constitutes a socially constructed reality, it establishes a reciprocal relationship with individuals outside of it. Within a familial context, persons with disabilities (PWDs) receive support from others while concurrently contributing to the lives of those around them. This indicates that they are not solely impacted by their circumstances but also exert influence on others. Therefore, it is prudent to investigate whether disability has repercussions on the health of the family unit. Examining the perspective of caregivers of disabled members, as discussed in the previous section, reveals that living with disability can impose significant challenges, often proving burdensome for caregivers. Some experiences articulated by caregivers during the interviews are quoted below. One caregiver remarked:

"With his (referring to the disabled member) disability, poverty descended upon this family. In the name of medical treatment, we depleted all our assets. He continues to require financial resources, yet we possess neither money nor property. Our existence now hangs in the balance. If anyone becomes gravely ill, we have no alternative but to endure or perish. Who will lend us money? We have begun to live with compromises regarding minor ailments. "

The aforementioned statement confirms that disability indirectly jeopardizes the family's welfare. Complete disability emerged as a stage necessitating specialized care and ongoing financial resources

for medical treatment. Families sought to medicate their disabled members, but there was no assurance that the latter could revert to normalcy and make contributions to the family. In such circumstances, families experienced a vicious cycle characterized by disability, illness, poverty, and stress.

Similarly, the father of a disabled youth expressed the following sentiment:

"Having a disabled member is truly burdensome in practice. Neither they nor their families find happiness. It is a grave issue, one that people typically cannot fathom. Can you envision the challenges of arranging a marriage for a daughter with a disabled sibling? Furthermore, we carry bitter experiences that we cannot share with others. It is not only the disabled individuals who face stigma, but also their siblings and the entire family. "

It was observed that the disabled members encountered more challenges than simplicities in navigating their daily routines. They faced stigma and neglect. Disability was progressively driving the family into poverty. The chronic health issues of disabled individuals, coupled with their medical expenses, their inability to engage in productive labor, and the additional burden of care required, alongside the family's social stigma, constituted significant sources of stress and trauma.

Conclusion

This paper has reached three primary conclusions. Firstly, individuals with disabilities experience frequent health issues and exhibit a heightened susceptibility to illness. Continuous medication has not facilitated their recovery from ailments. Physical inactivity has led to the emergence of additional health concerns such as diabetes, chronic pain, persistent bruises, swelling, itching, and burning sensations. Additionally, they grapple with the anxiety of remaining in a vulnerable state. In this context, their mental suffering is also evident. Thus, individuals with disabilities endure physical ailments, which in turn foster restlessness and, above all, mental stress. In conclusion, the majority of their health issues were instigated and exacerbated by their disabilities.

Secondly, being a relative of an individual with a disability necessitates consideration not only for oneself but also for the disabled person. Families play a pivotal role in navigating the challenges associated with caregiving. Moreover, caregivers often find themselves devoid of adequate time to contemplate their personal lives, develop their potential, advance their careers, pursue their professional interests, and maintain a sense of vitality. They experience escalating levels of pessimism and have commenced to accept illnesses as a part of life.

Finally, the issues faced by one family member become matters of concern for the entire family. PWDs are suffering in their own due to illness or other mental stress, and are stigmatized, misbehaved and oppressed. Since, disability has been the key source of stigma of related family as well, the family also suffers tremendously. So, disability should not be perceived as a merely individual phenomenon; rather, it is a social construct with broader implications for the family problems. It ought to be addressed not in isolation but in relation to various familial dynamics. Consequently, examining the circumstances of families leads to the conclusion that disability constitutes both an impairment and a social condition, which can precipitate health issues among other family members.

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