Disability in Aging People: Functioning Difficulties and Infrastructural Barriers

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Abstract

Disability is the physical, mental and psychological condition that prevents an individual to perform common type of day-to-day activities, and creates significant barrier in social participation. It includes health loss, status loss, and social loss. Disability snatches individual's functioning capacities. Structural barriers restrict people with disabilities from full and effective participation in society. Disability is not a personal problem; it is shaped by the larger socio-cultural, geo-political and economic context of a nation. Also, there are perfect parallels between disability and aging. As people age, they experience multiple chronic illnesses. Thus, both the disability and aging require prompt service and extra care. Owing to the unfavorable socio-cultural environment, aging and disable people tend to keep their stories within without sharing them to others. Disabled people do not consider them as weak and inept, rather the negative perceptions of disability relegate people with disability to the background. Also, the contribution of currently-aging population in their past working-age deserves to be marked. Since aging crosscuts disability, it becomes fundamental to analyze the functioning condition of aging and disabled people, and their access to physical infrastructure. This paper concludes that the problems faced by aging and disabled people could be lessened if a friendly infrastructure is built.

Keywords: aging, barriers, disability, environment, health.

Introduction

Disability, often defined as physical, intellectual and spiritual conditions, limits a person to perform any kind of activities (Subedi, 2012, p. 1). The Global Burden of Disease (GDB, 2004) uses the term disability to refer to loss of health, where health is conceptualized in terms of functioning capacity such as mobility, cognition, hearing, and vision. Disability has association with person's ill-health condition, inability to perform necessary activities, and exclusion from social activities. Disability is difficult to define; it is highly contextual, and there is no single criterion of defining someone as disabled.

World Health Organization (2011) has recognized three dimensions of disability-impairment, activity limitation and participation restriction. It is roughly that the 16 percent of world population has some kind of disabilities. The population of disabled people rises if people are known about what disability is. The relationship of aging with health and disability is complicated. Disability is strongly interlinked with health condition of a person and of course the aging, which is actually the main, though not one, but several conditions related to health factors cause for disability (WHO, 2011). Infectious diseases and injury in general and chronic illness in particular is strongly associated with old age disability prevalence (WHO, 2004). Infectious diseases like HIV/AIDS, tuberculosis, lymphatic

filariasis, leprosy, etc. in adult and aging, and mumps, poliomyelitis, polio, measles, etc. in children are prime cause of disabilities. Besides, noncommunicable diseases such as cardiovascular diseases, mental disorder, cancer, diabetes, hypertensions, respiratory diseases, etc., maximize the number of disability prevalence among the aging people. Other factors causing high disability are traffic injury, occupational injury, natural calamities, wars and conflicts.

Violence and crimes are other contributing factors for disability in today's contexts. In this context, this paper presents the situation of disability and its prevalence in aging people. This paper is prepared on the basis of a primary data collected from the cross-sectional studies in two different areas of Kathmandu and Gorkha. It especially measures the situation of disability in real sense.

Sociology of disability offers a point of view of the key stakeholders concerned. It contrasts the notions that whether disability is a personal tragedy or a form of social oppression (Finkelstein, 2001a, p. 2). Finkelstein believes that though the people with disabilities have more capability to contribute to the society, they have been paralyzed, because of irrational social and cultural surroundings. Thomas (2004) supports Finkelstein as:

'... Finkelstein recounts that he and others, as disabled people, were faced with a stark choice: 'you see disability fundamentally as a personal tragedy or you see it as a form of social oppression.' ... disability has to be interpreted ... 'it is society that disables us and disabled people are on oppressed social group. ... this perspective arose ... to reflect theoretically upon the nature of the social treatment of disabled people in the 1970s ... residential care, minimal benefits, exclusion from employment and the educational mainstream, and blocks on access to the built environment.' (p. 571).

The statement above reveals how society is unequal to the people with disabilities. Social model of disability is clearly important for disabled people's political struggle to change the societal view towards them- for them it was the emancipatory strategy to 'wining control over their own lives', and releasing themselves from the paws of normal people. The erstwhile medical model of disability fails to believe the functioning ability of disabled, who are disadvantaged and cannot fulfill their expected roles in society. The medical model's perspective on aging is similar to its perspective on disability, because impairment is the key criterion of medical model for differentiating a person as capable or disabled.

Literature Review

Aging is a globally enriched phenomenon in the twenty first century, especially it renews itself from the socio-cultural aspects of individual and society (Khanal, 2020, p. 1). It is the fastest growing segment of human population at an unprecedented rate in all countries of the world. High-rate growth of aging people have accumulated the risk for the growth of disability rates too. The prevalence of disability in aging people of Nepal is much higher, though accurate data is unavailable.

As a result of increasing birth and death rates, dramatic improvement in public health, and the

melodramatic growth in life expectancy at birth, the number of aging people has been growing rapidly in the world. During the last six decades, the life expectancy at birth in Nepal has been doubled (Khanal, 2020, p. 2). If we link this to the global scale data, people's life expectancy at birth has increased from 50 years in 1900 to 66 years in 2019 (Suzman and Beard, 2011, p. 6). People's longevity of life has been growing in global scale as people are coping over external and environmental situations of life with the help of growing knowledge, technology and invention.

Aging is the complex process, which poses the prevailing risks for devitalizing and life-threatening conditions, risks of chronic diseases, cardiovascular diseases, diabetes, cancer and neurodegeneration-Alzheimer's and Parkinson's diseases. Many individual, environmental and behavioral factors like occupation, level of income, pollution, use of tobacco and liquors, lack of accessible infrastructure, physical inactivity, lack of exercise; and such habits and behaviors pose risks of disease and disabilities in aging (UN, 2015, p. 91).

There is dichotomous relationship between aging, disability and capitalistic medical and social system, which focuses on profit; profit over health and illness as well as, medical facilities that run with the motive of profit, do not pay much interest on health services on the verge of monetary loss (Cockerham, 2005, p. 10; Khanal, 2020, p. 4). The prevalence of disability increases in aging, as a result of other destabilizing factors, especially in the developing countries, where we lack adequate physical, social, economic and social security-based infrastructure that the aging people strongly demanded; and lack of caring staffs in family as a result of urbanization, modernization and globalization. We have also discovered that due to the lack of adequate physical and social environment, people with disabilities in aging are forced to remain within the four walls at home. Today, as a result of increased chronic diseases in developing countries we can see the rising prevalence of disability in the aging people.

Measuring disability

There have been numerous complexities in defining and measuring disability, which create troubles while counting the disabled and collect data on it. World Health Organization [WHO] (1976), has operationalized three different terms- impairment, disability and handicap in defining psychological, phytological and physiological structure in a person. But many people with disabilities do not accept them as disabled but feel that they are made disabled. According to them, the non-disabled people coined the term disability to oppress the disabled people.

As we reconnect the history of collecting data on disability, it was started in early 1980s under guidance of the UN agencies. There was roughly one-tenth of world population estimated as the population of people with disabilities, but it has still been difficult to find the exact figure. Subedi (2012) observes,

The proportion of disabled people per national population varies between less than 1% in Kenya and 21% in Austria ... regional comparisons can be very misleading if the methodological differences are not taken into account. The use of different measurement instruments, the older age structure, as well as the larger capacity to observe and diagnose

various kinds of disabilities in developed countries ... WHO estimated that an average of 10% of all national population were disabled. However, in 1992, this estimation was modified to 4% for developing countries and 7% for industrialized countries. There is no consensus as to which figures to use. Reported disability prevalence rates from around the world very dramatically (p. 6-7).

There exists marked difference regarding the number of disabled people in underdeveloped and industrialized countries. Causes vary, but it is either because of the inserting of inapplicable tool or the setting of differential criteria for measuring disability. The most interesting however is to look at the prevalence of disability rate higher in industrialized countries and less in least-developed or underdeveloped countries (Subedi, 2012, p. 7). It may be because disability was stigmatized and disability allowance was insufficient. Many people even today hesitate to expose their disability to the public. The government could play a more effective role to settle this issue, but disability failed to be the priority agenda.

Disability has been a complex condition, which is not easy to measure in right way. It is verified by the minimal, only 1.94 percent of the total population of Nepal, size of disabled people in Nepal (Khanal, 2014, p. 356). Besides, the estimating of population of aging people is more challenging. Aging people associate their functioning difficulties only with their age and not with disability. They are very unwilling to be defined as disabled despite living with a clear prevalence of disability. They often consider disability is a kind of sin. Therefore, the lack of factful data on disability and its analysis makes less satisfactory analysis.

If disability is measured in terms of what is normal and abnormal functioning based on the context for example age-group, the rate of prevalence goes higher. World Report in Disabilities by the World Health Organization (2011) avows that survey data should be collected from institutionalized populations. It is clearly noted from this field study that people's awareness on disability is also crucial for discovering the rate of disability. It is also found that the prevalence of disability in aging people is higher in Kathmandu than Gorkha, 73.3 percent in Kathmandu and 48 percent in Gorkha. One important reason regarding the stark difference in rate of disability is that both the adult and aging people in Gorkha were not conceptually clear about disability.

Disability and aging

A recent study on disability finds a higher prevalence of disability among aging people of Nepal. The National Institute on Disability, Independent Living, and Rehabilitation Research (2018) identifies disability in 35.2 percentage of the people above 65 years of age, 48 percentage in the aging people aged over 70 years living in the countryside. But in the case of Kathmandu, valley the proportion of ageing people with disability is 7:10. This data contradicts with the data produced by the Global Burden of Disease (GBD). According to GBD, estimation and prevalence of disability in aging people was 46.1 percent, which was three times higher than those of 15-59 groups (14.9 percent) and more than 9 times higher (5.1 percent) than that of children under 14 years. This data indicates that disability prevalence increases as age increases, and age is the most powerful predictor of people

health status and the prevailing risks of morbidity, disability and mortality. The percentage of people with disabilities has been, so far, consistent over the years.

The World Health Organization (2011) admits the data on disability are inadequate, and the same is the case of aging people with disabilities. Disability prevalence in older population varies depending on the country. Nonetheless, aging has a major influence on disability trends and aging people are at higher risk of disability prevalence. Higher disability rates among older people reflect an accumulation of health risks across a lifespan of disease, injury and chronic illness.

It is widely accepted that the people's longevity of life is more likely to witness multiple illnesses and disability. The rate of disability rises along with the rise of aging population. Aging people are prone to suffer from heart disease, hypertension, diabetes, cancer, lung disease, dementia and Alzheimer, and other chronic diseases. According to WHO, the industrialized countries of Europe, America and England are suffering from this problem whereby across 50 percent of aging population have a kind of disability. According to WHO (2011) Australia is reported to have 35.2 percent of its aging population living with disability. It is estimated that by the year 2030 one in four or five citizens will be aged over sixty-five. The population above the age of 85 will be 3 percent of the total population in 2030 and 5 percent in 1980 (Zola, 1989, p. 517).

According to the population monograph of, about 25 percent people of the aging population aged 60 or above were disabled in Nepal, while the overall figure of disability is just 2 percent of the total population of Nepal. The proportion of aging women with disability was slightly higher i.e., 27.2 percent than the prevalence of 24.3 percent of aging men with disability (Khanal, 2014, p. 362). This again signifies that prevalence of disability is higher in aging women than in aging men.

Methods and Materials

This cross-sectional study was conducted in Budhanilakantha Municipality, Kathmandu in 2020. Budhanilakantha is the north-east part of the Kathmandu valley, lies in the foot of Shivapuri Mountain. A total of 45 people above 70 years of age was randomly selected as a sample. With the help of an interview check-list, a face-to-face interview of all the respondents was taken. The next area of study was Bungkot village of Gorkha district. In Bungkot a total of one hundred and eleven aging people aged 70 years and over were selected as sample and interviewed.

Results and Discussions

Respondents in Budhanilakantha were from 70 to 96 years of age. The mean age of respondents was 80.82 years with standard deviation of 7.551. Among them, 53 percent were male and 47 percent were female, representing different caste, class, culture and educational background. Of all the respondents in Kathmandu, 73.3 percent were disabled; 6 percent had multiple disability, 3 percent had hearing disability, 3 percent had visual disability, 3 percent had Parkinson's disease, and 42 percent had backpain and other bodily problems.

In Kathmandu, 73.33 respondents were found living with single or multiple disability. Prevalence

of disability was higher among female respondents as their rate was 80.95 percent while only the 66.66 percent of male respondents were identified as disabled. While in Gorkha, the age of sampled population ranged from 70 years to 100 years consisting 47 percent male and 53 percent female. In Gorkha, 52 percent of the total respondents were found living with general to complex type of disability. Multi-disability was the most frequent type of disability among the respondents as this was seen in 15 percent, while 8 percent with physical disability, 13 percent with visual disability, 5 percent with hearing disability and 3 percent with mental disability. The rate of disability was higher in women than men of the same age group.

Functioning difficulties

Functional capacity is considered to be a precondition for one's daily living. This capacity is high in young age and decreases with aging. Aging is normally a stage in which a person feels health loss and impairments. As a result, there are high chances of disability in aging. According to population monograph of Nepal, about 25 percent of people over sixty years are disabled, whereas Global Burden of Disease identifies more than 46 percent people, almost the double of the Nepal's disability and aging data, of the same age group as disabled globally. With the increase of age, physical as well as mental condition of a person deteriorates. Functional disability in aging leads aging people towards poor-performance of basic activities of their daily living. When people feel that they lack capacity to lead a healthy and quality life, it means they have difficulties in functioning. And this situation prevails high among the aging people of Nepal.

Aging is often associated with difficulty in working. It results in poor performance, passive living, and rising dependency on others (Khanal, 2020, p. 17). Survey in Kathmandu shows that the 32 percent of the total respondents were living with functioning difficulties. Among the 32 percent, 2.2 percent had difficulty in eating, 11 percent had difficulty in dressing, 7 percent had difficulty in bathing and moving, and 4.4 percent had difficulty in defecation. They have extremely difficulties in conducting their basic activities without support from other family members and supporting staffs. Additionally, among aging people who had difficulties in carrying out basic activities in daily living, 25 percent had difficulties carrying out instrumental activities in daily living (IADL) for example preparing food, buying foodstuffs, paying bills, carrying pets, etc., thus living in extreme dependency-difficult to live without getting continuous assistance and support.

Capacity depends highly on person, but one cannot be fully active and consistently capable throughout his life. However, people's life demand consistent supply of means for survival. People view aging as less productive life-span in which one needs personal care and social assistance. Thus, the social security scheme becomes crucial for rescuing aging people from being vulnerable. Disability in aging is not only associated with physical limitation, but also with mental and psychological malfunctioning, which pose more risk than physical deterioration. Data from more than 58 percent of aging people reveals that the living condition of people in countryside than in Kathmandu is more vulnerable be it either while conducting basic activities for daily living or instrumental activities for daily living.

Environmental barriers

Disability matters a lot with the available environmental barrier. And, the environment in which people live largely concerns with the prevalence and rise of disability. In other words, the role of a build environment such as buildings, houses, roads, transport, interior, etc., in shaping disability is widely felt. During the study also, it was found that the proper disability-friendly build environment was lacking, in the context of Nepal. Social environment such as attitudinal, familial, and economic environment was found to be quite distant from realizing the real life of sampled aging people with disability.

The psychological, build and physiological environment is supposed to be enabling to both the aging and disabled people so that it could be less risky for them while carrying their daily life. Such an enabling environment has become the basic norm in advanced societies. But most of the private houses as well as public infrastructures and buildings either in city or in rural areas of Nepal found missing disabled-friendly. Schools, universities, hospitals, public places, buildings, roads, means of transportations are poorly managed and inappropriate to aging people and people with disability. Compared to the difficulties faced by the disabled people, aging people with disabilities have to face more challenges.

Pedestrians are totally ignored in Kathmandu. There is a lack of wide, smooth and disabled-friendly footpath. Even in the main city areas, footpaths are occupied by electricity polls, construction materials, undisposed garbage, etc. Public transportation is the worst area, which is crowded and is unfriendly to any passenger be it a normal traveler or a disabled or aging person. Nepal's topography is also challenging to the people with disability as most of the areas are covered by sloppy hills and mountains. As a result, activities of people with disabilities are limited to private spheres, and their participation in public sphere is restricted.

Conclusion

The study finds a perfect correlation between aging, disease and disability. The difficulties faced by aging people with disability were extreme be while working in-home or traveling outside. Despite the unequal gender roles, women tended to have a relatively higher life-expectancy and aging men had a higher prevalence of disability. Higher prevalence of disability in old age reflects an accumulation of health risks, injury, and chronic illnesses, but disabling social, infrastructural and topographical environment was found highly contributive to ignite the barriers to aging people with disability and their minimized functions. Enabling environment encourages all people to feel motivated and give result while working, and this environment is more important for the disabled and aging. But the lack of a supportive environment came to be the key barrier of disabled and aging people, who in absence of those barriers could contribute positively to their family and society. Finally, the enabling environment is proved to be more beneficial to society than to the wellbeing of disabled people or aging population.

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