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People with Disabilities in Pokhara: Socio-Economic and Political Perspectives on Inequality

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Abstract

People with disability have been increasing nowadays with changing patterns of migration, urbanization and development. There is a dearth of research knowledge on the discovery of disability and its reactions, especially in Nepal. Therefore, this paper focuses on the discovery of acquired and inborn disability in people with disability and their reactions over the time of life trajectory. This study follows a qualitative research approach, collecting field data in 25 people with disability aged 23 years and above in Pokhara Metropolitan City using face-to-face in-depth interviews during the period August–December 2019. There are both acquired and inborn disabilities in the study area. Working long hours with hard duty, winding roads, poor treatment, poor economic condition, unavailability of the hospital, and weak political system are all associated with being disabled in the life of people with disability. This study shows that gained disability is more distressful than inborn disability.

Keywords: Disability, discovery, Pokhara city, political perspectives, reactions

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Introduction

Using different measurement instruments, the older age structure, as well as the larger capacity to observe and diagnose various kinds of disabilities in developed countries, are likely factors in the higher rates of disability (United Nations, 2015a). In 1981, the first estimates by the World Health Organization were that 10 percent of any population was disabled (World Health Organization, 2011). Estimates depend on what counts as a disability, on how severe impairment must be before they considered it disabling, and how categories are implemented in actually gathering data. It is hard to compare disability data between various countries, as there are differences in data collection designs, definitions, concepts, and methods (Elwan, 1999). Currently, around one billion people, 15 percent of the total population, experience some form of disability (United Nations, 2018). Among them, one-fifth of the global people with disability experience significant disabilities. Among the total people with some form of disability, 80 percent of the people with disability live in developing countries. Thus, disability prevalence is remarkably higher for developing countries (United Nations, 2018).

The number of people with disabilities is growing. This is because populations are ageing – older people have a higher risk of disability and because of the global increase in chronic health conditions associated with disability, such as diabetes, cardiovascular diseases, and mental illness (United Nations, 2015b; Molton & Orday, 2019). Patterns of disability in a particular country are influenced by trends in health conditions and trends in environmental and other factors – such as road traffic crashes, natural disasters, and conflict (Thompson, 2017).

Various sources of disability studies show various figures of people with disability in Nepal. The 2011 census reported 513,321 people with disability (1.94 percent of the total population in the respective census). Likewise, the 2011 National Living Standards Survey Report estimated that 3.6 percent of the total population was people with disability (Holmes et al., 2018). There was around 15 percent of people with disability in the total population in the country (Eide et al., 2016). Explorations on disability in Nepal were scant until 1980 although the basic information on disability was included for the first time in the census report of 1971. The ‘Report on the Sample Survey of Disabled Individuals in Nepal’ conducted in 1981 was the first study on disability in the country (Valley Research Group, 1996). Therefore, research on disability has a fairly brief history in Nepal.

Study on disability is a neglected subject not only in development policies and planning but also in literature. This is true not only in Nepal but also in the wider South Asian region (Sonpal & Kumar, 2012). Nepal, including several developing countries, has already committed to addressing the issues of Persons with Disabilities (PWD) by signing the United Nations Convention on the Rights of Persons with Disabilities 2006 (Chand, 2017). Political theorists need to learn more about people with disability. Political theorists Arneil and Hirschmann mention people with disability in this way:

The introduction of the social model of disability pushes disability squarely into the arena of politics, both in relation to the broader notion of power relations in society but also the degree to which states provide the accommodations necessary to remove barriers to the full inclusion and participation of disabled persons [people with a disability]. Ultimately, as the definition has evolved to the current understanding of disability as the interaction between the particular physical

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conditions of individuals and the environment they must navigate in their daily lives, it only underlines the fact that political theorists have much to learn about and contribute to these new debates. (Arneil & Hirschmann, 2016, p. 5)

In the given context, this paper explains individual processes of the discovery of disability, and initial reactions of participants concerning physical disability, and vision and hearing impairments along with socio-economic and political perspectives.

Research Method

This study follows a qualitative research approach to capture the lived experiences of people with disabilities, as it involves an interpretive approach to an event with socio-cultural settings of participants (Taylor & Bogdan, 1998; Thomas, 2006). It helps us to gain insights into the lived experiences of people with disabilities and assist with analysis through the provision of greater details and rich descriptions, getting data from the interviewees in the field (Silverman 2004; Smith 2003). We intended to select people with disability in Pokhara Metropolitan City. In Nepal, significant numbers of people, irrespective of age and sex, have been making their destinations into cities for the last few decades, leaving their place of origin. Even with people with disability, it is also expected that they are influxes into cities as development activities in terms of shelter, care and services are mostly oriented into cities. With the context, the Pokhara Metropolitan City is one of the major cities in Nepal. There are care homes for people with disability who have been either from the Metropolitan city or from other parts of Nepal. This Metropolitan city was also presumed to be better in gaining technological advancement for urban amenities so that the people with disability could make their life more comfortable, especially in comparison to rural and remote areas of Nepal.

In this study, thematic analysis, the meaning-making approach has been chosen for analyzing field data since it seeks to understand and describe how people (people with disability in this study) feel, think and behave within a particular socio-cultural context (Braun & Clarke, 2006; Guest, MacQueen, & Namey, 2012). Themes have been derived from the field data relative to a specific research objective and semi-structured research interviews set in this study (Wengraf, 2001; Gillham, 2000; Ritchie & Lewis, 2003). The semi-structured interviews would also be of interest to interviewees because it would allow them an opportunity to make deeper understandings of their own lived experiences in a very literal language (Gillham, 2000; Ritchie & Lewis, 2003). We went through the criteria of disability cardholders and classified their characteristics into three categories: profound disability, severe disability, and mild disability. The colour of the card belongs to red, blue and yellow respectively as per the above three categories. In this study, there were altogether 25 research participants including heterogeneous groups of people: unmarried, currently married and remarried, widower, and separated from home. Looking at the people with disability by gender and marital status, there were 18 males and 7 females in this study.

Turning into the contents of disability, the discovery of physical disability, and visual and hearing impairments, is a critical event in the lives of people with disability. They can be classified into two groups- being disabled by birth, and being disabled later in the course of daily activities of life. They are called inborn disability and acquired disability respectively. The earlier group of people being disabled by birth has a long journey of their lives. The latter group of people being disabled later has their lives different experiences. It divides their life into two parts: life before disability and life after being disabled in the case of

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acquired disability. This discovery of disability changes the lives of the people economically, socially and culturally depending on access to resources, such as their economic resources, human capital, access to treatment based on place of residence, and knowledge on disability.

Findings of the study

More than two-thirds of the total research participants were in-migrants from outside the Kaski district. Most migrants were economically deprived at their place of origin. They did not have any emotional attachment in the society and even in the family after being disabled in their life and migrated to Pokhara city. As explained above in the background of this study, this paper aims to describe processes of disability concerning profound, severe and mild disability based on their given cards of disability, especially for being people with disability in the course of their life journey.

Physical Disability

There are nearly half of the total research participants being disabled due to physical disability. Among the people with a physical disability, an overwhelming majority of them were physically disabled due to spinal cord injury, hand and leg loss, and paralysis not moving body under the waist even losing their sensation that happened later in the course of their working life. Most of them have got physical disabilities at their working ages whereas few numbers of the people have got disability by birth or at childhood ages, below age five years. There were a few numbers of research participants who met terrible bus accidents inside and outside Nepal and became disabled in their working ages. Indeed, Nepal's hilly and mountainous landscape, rough gravel roads, poor management of driving license, and lack of traffic police inspection on the speed of vehicles together with heavy loads of passengers on the bus occur the accidents and many people are injured physically and mentally. Consequently, they become disabled in the course of travelling from one place to another. Few research participants who have been disabled due to falling from a big tree and rolling down big stones from the steep hills and hitting the research participant at the time of work. Likewise, the polio vaccine has made people disabled as its bad effect.

There were very few people who were categorized with profound disabilities based on their fragile health conditions. They belonged to red card holders categorized by Nepal Government. They need high levels of support from others with most aspects of daily living: help to eat, to wash, to dress, to use the toilet, to move around and to participate in any aspect of everyday life. In this context, Bal, who has been categorized as a profound disability based on a red card holder, shares his experiences on disability. He left home for a job in India at the age of 11 years and continued his job of a cook till 18 years over there. In one of his home visits, he met a bus accident while visiting his maternal uncle's home. He shares his experiences on his disability in this way:

While I was going to my mother's parents' home to say goodbye before going to a foreign country, I met with a bus accident. This accident occurred badly. We were altogether 10 people on the bus. I did not get any big wound on the external part of the body, but injury had occurred on the internal part. I could not move at all after this accident. The bus got a break fail which created an accident. I have been facing disability for my lifetime. Bal, Male

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Likewise, Hem, one of the male research participants, who has been categorized as a profound disability based on his red card holder, shares his experiences like this way:

I have had a spinal cord injury, level 2. It happened to me in 2072 BS Bhadra 16 [September 2, 2015]. When I was working at stone ore, a stone fell onto me and spinal cord injury happened. It had happened in my village of Baglung [District].
Hem, Male.

There are a few numbers of people who have been categorized with severe disabilities. They are blue cardholders. They had a physical disability because of a vehicle accident, stones rolling while working, falling down from a big tree while cutting grass on the tree as well as inborn disability. Under this severe disability, people can perform their work activities. However, they find difficulties while working because of losing their body part either hand or leg or any other part of their body. In this context, one of the male research participants, who has lost his hand due to an accident while going to India for work shares his own experiences in this way:

I was 33 years old. I was heading to a foreign country for employment. During that time, I was in India. I got an accident while riding a vehicle. I got help from passengers for treatment. They took me to the hospital and admitted me to the hospital. I had treatment for many days. I stayed around 25 days at the hospital. I spent six months on the treatment even after being discharged from the hospital.
Lok, Male

Many innocent children in Nepal have been disabled due to over speed of vehicles. Such accidents are of common occurrence in Nepal and have taken the lives of many children. Children are seriously injured while staying and playing nearby the main highway. Sushma, who became disabled by losing her one leg at the age of four years when the bus hit her playing around highway road, shares her own experiences in this way:

The bus accident had happened after some years of my birth. I became physically disabled. We had our house near to the road on the main highway. While playing on the road, the bus hit me and such an accident occurred. This accident happened to me 20 years ago. Sushma, Female

There is also a case of being disabled after injecting polio vaccine in the child at the age of two years. The effect of polio has made the person paralyzed for a lifetime. This study investigated that the polio vaccine has also an adverse effect on children's health in some cases. In this study, one of the male research participants found himself paralyzed after he was given a polio vaccine in this way:

When I was given the polio vaccine at the age of two years, I became disabled physically. My body cannot function under the waist. I came to understand my disability when I could understand it by myself. My leg does not move at all. Bharat, Male

There is another group of under mild disability with a yellow cardholder. In Nepal, drivers and their passengers have become physically disabled or lost their lives from accidents while heading to different places. There are several reasons behind accidents, either being

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overloaded passengers in the bus or fewer experiences of driving or narrow roads in the steep hills or, above all mentioned reasons. In this context, Bharat, one of the male research participants shares his experiences of getting bus accident and lost one leg in the course of his treatment in this way:

I became disabled in 2052 BS [1995 AD] at the age of 32 years. I was a driver. I was going to Gursinge, Chanauta. The steering and brake of the bus failed resulting a serious accident. I got an accident and from that time I was physically disabled. One person died at the moment and other passengers got minor injuries. I became insensitive for one and half months. A serious head injury had occurred to me.
Bharat, Male

Vision and Hearing Impairment

Around half of the total research, participants fall under this vision and hearing category with severe and mild disability in this study. There are both cases of inborn and acquired disability. People with disability who have lost hearing capacity have also lost their vision later as eyes and ears are interconnected with each other in the human body. Most of the research participants have had acquired disabilities under vision and hearing impairment. In this section, we have attempted to explain the acquired disability and inborn disability respectively.

Acquired Disability

Most people with disability have had their vision impairment in the later life after birth either in the childhood ages or in their working ages. Mina, one of the unmarried female research participants, became ill of a severe headache for over six months; her parents could not follow treatment at the hospital in time because of poor economic conditions. Consequently, she lost both eyes, one after another, during the period of May-December. She has her own terrible experiences on how she lost her eyes in this way:

I was 12 years old. I had a severe headache from Jeshtha to Mangsir (May to December). I did not see it at all in Mangsir. I lost my left eye. I also lost my right eye after three days. When I lost vision of my left eye, my father took me to the hospital at Geta of Dhangadhi. The doctor said to us, "we do not have a proper machine. Go to Kathmandu immediately, as there is also the possibility of losing next eye vision." We had a problem with economic hardship at home. My father was collecting money requesting with other people for the time being. In the meantime, I lost my vision of the next eye as well. Neighbors suggested that we go to India instead of going to Kathmandu. Then, my father took me to Patyal eye hospital in Panjab, India. Veins of eyes were very dry from the X-ray report. The doctor said to me, "My eyes do not turn into a normal position. The doctor said to us, the eyes do not work even if you spend a lot of money". Then, my father took me back home.
Mina, Female.

Likewise, Umesh, one of the participants, had suffered from diarrhoea and typhoid along with an overflow of tears from his eyes. Treatment could not be done immediately for him due to economic hardship and the traditional way of doing treatment through a herbal doctor was followed. He shares his own experiences on how he got visual impairment in this ward.

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I had diarrhoea and typhoid. Tears also came from the eye continuously. There was a place called Lahan. My parents took me there; treatment was not done soon. Gradually typhoid was cured but I became blind. Umesh, Male

Lokesh, one of the male participants, has similar experiences like the above participants of Mina and Umesh in this way:

I think some problems had been arising since childhood. When I was 14/15 years it was quite difficult for me to see clearly. At the age of 16 years, I was blind. I was having a cataract. Due to lack of awareness and illiteracy, my family did not know about my disease and I became blind. It was because of poor economic family background too. Otherwise, I did not have to become blind totally. If I had had the treatment since the recognition of the disease, I did not have had to face this condition. Some normal treatment was done; a minor operation of the eyes was also being carried out. Medicine was too costly and the family did not show much concern about my disease. That's why such a problem aroused. The cost was 700 Indian rupees at that time per 1 month. It was a very huge amount for us as per our economic condition. My father died when I was small. My mother also died after my blindness as she was a patient of cancer. Lokesh, Male

Similarly, Man, who lost his eyes at age of three due to lack of treatment in time, expresses his own experiences like this way:

I was blind at the age of three years. I have had glaucoma. I did not get the treatment on time. As our places do not have so much facility even today. At that time, I could not get the checkup and medicine. I lost my eyes due to the poor economic condition and illiteracy of my family. Man, Male

A few numbers of people with disability have had their vision impairment due to their overloaded physical job inside and outside the country. They did a very hard physical job even not sleeping in the night and found the eye vision lost anonymously. In this context, one of the male research participants who worked outside Nepal shares his own experiences on how he lost his eye vision in this way:

This had happened in Qatar. I was a security guard. My job was very hard. I didn't use to have time to sleep at night too. As soon as I got my salary, I used to remit money to my home. All of a sudden, I had difficulty recharging my phone, looking at the small numbers. I felt my eyes being weak slowly and slowly. Then I called the owners of the company. They took me to the hospital. The doctor did not find my disease immediately and advised me to check pressure, sugar and other tests. Because of the expensive medical expenses, my friends told me it was not possible for all medical checks there. So they did the processing of my return to Nepal. Then, I completely become blind in 2071 BS [2017 AD]. Suka, Male

Inborn Disability

In this study, a few numbers of interviewees were inborn disabilities and were identified later in the course of playing, studying and working life. Some of the interviewees expressed that they were fully aware of being different from others at the time of entry into their working life whereas some interviewees found themselves different from others while playing and studying at schools. In this regard, one of the female research participants, who

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got disability because of her only one workable hand by birth, shared her experiences concerning her disability in this way:

I was disabled by birth. When I used to be with my friends till school life, I felt nothing about my disability. After SLC, different people from various institutions came to take data, but no one realized that I was physically disabled. I have a problem with my hand. My friend circle was very supportive of me; they took me to participate in different activities. So, I didn't even realize up to my college period. After that, when I started engaging in an institution, I realized I am also disabled.
Rekha, Female

Single disability pushes people towards multiple disabilities, as organs of the body are intrinsically interconnected with each other, especially in the cases of ears and eyes. There are a few cases of people who had an inborn disability of hearing loss, followed by the loss of vision. Asha, one of the female participants, who was deaf by birth, also lost her eye vision in this way: "I was deaf by birth. Later, my seeing capacity slowed down, and I became both deaf and blind. I am now vision and hearing impairment". Likewise, Khom, one of the male participants with an inborn disability shares his own experiences about the interconnection of disability of one eye and another eye in this way: "By birth, I could not see one eye and slowly and gradually another eye was impaired at the age of 10 years".

Most research participants came to know their condition of disability only after the beginning of working ages. In the study, people with disability with the impairment of both vision and hearing were found with the belief that the people without disabilities are like them. In this respect, Bishwamitra, one of the male research participants, shares their own experiences of identifying his disability in this way:

I had a hearing impairment by birth. It was so difficult to convey my information to my family. I could not convey my information to others when needed. I could not convey anything to other people by myself. I came to know that I am deaf. It was around when I was 16-17 years old. Bishwamitra, Male.

Likewise, Jaman Singh shares his own experiences of identifying the disability of deafness – "I was deaf by birth. I came to know my deafness when I was 19 years old".

Reactions

After being a visual impairment, people with disability think that their life is extremely filled with hardship: economically and socially. They do not see any alternatives for gaining vision again and they have to suffer a lot through the dark because of vision loss. Furthermore, young people are a little bit hopeful for the future to be secure economically and socially till father and mother are alive. They cannot figure out what would be after their parents' death. Parents are more likely to care for children with a disability because of blood relations. It would be wonderful if the government could be responsible for helpless people like them. In this context, Mina, one of the young females, who has lost both eyes, shares her own experiences in this way:

I lost both eyes. I thought my life goes ahead through the dark. I got worried about how I could go ahead in my life. Next thing, my life would go fine till my parents are alive. I thought about what would be my life after their death. I again thought that

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my life would be better if the government could support me. Life is not like thinking. People with disability have to face a lot of hurdles in life. Mina, Female.

People with disability compare themselves before and after disabilities in their life. They find that their life is much painful compared to before disability as they have already experienced how easy while being people without disability. In this study, Som, one of the male research participants, shares his reactions after being disabled in his life at the age of 9 years due to vision impairment in this way:

When I realized that I become vision impaired, I felt very pain for my situation. I saw the beauty of the world for 9 years but now I have to take the support of my family members, even for a small task. I have to suffer a lot. Hence, the situation is very painful for me to adjust to. In the initial phase, I felt very sad. I could not see people and understand people. I should take help from others. I cannot see the world also so I feel a very miserable life. I think I have become a burden for the family. The way how society perceives me is also different. I cannot move around. So I feel like instead of this life, I could have died earlier. Som, Male.

In general, people think of themselves off as being poor, economically and socially as they could not be responsible economically and socially in the family and society after being disabled. The prime responsibility of males is often taken as being the economic backbone for the family. Most male members wonder how their family would survive after being disabled. In this condition, tears from eyes roll down continuously. In this study, Lok, one of the male research participants shares his own experiences of being disabled in this way:

Being disabled was a very miserable condition. However, I saw other people with disability in worse conditions than myself. I thought of myself and my family on how to survive ahead when I was in the hospital. This incident happened to me in India. When people living in India used to see me in the hospital bed, my eyes got wet and tears fell continuously. Relatives also cried looking at my situation. I also used to tell them not to cry about my situation. I said to them, "My heart breaks down if you cry". Days went like that way. Lok, Male

Socio-economic and Political Perspectives

This paper deals with disability, primarily on how the discovery of disability turns into reactions and leads to bad impressions in people with disability. There is not enough social security provision for their livelihood, though the Nepal government has introduced this provision in recent years. People with profound disabilities cannot work being economically independent, especially in the context of lack of medical and technological advancement like as in Nepal. This means that people with disability have to depend on other people without disabilities, particularly with parents, relatives, and well-wishers. How long their parents, relatives and societal people support them bears significance to the lives of people with disability because people without disabilities think of reciprocity that they are less likely to get anything back from them. Therefore, people with disability have deep-rooted feelings of economic crisis as one of the reactions. Furthermore, people with disability presume that they are being stigmatized and discriminated against in family and society from socio-cultural contexts. Many people have a blind belief that people with disability must have done some bad *karma* in the present or the past life. The difficulties and hardships are considered as inevitable misfortune against sin and as the punishment of God.

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These situations of the presumed stigma and discrimination further aggravate their quality of life after discovering disability whether inborn or acquired after birth due to accidents or heavy overtime works as discussed in the section of findings of this study.

In the meantime, after the discovery of disability, irrespective of the nature of disability either inborn or acquired, people with disability attempt brainstorming for their prospects so that they can help themselves in the course of their remaining life. They find parents as foremost supporters in their life. Again, people with a disability consider that the support from the parents would end along with the death of the parents, therefore, they keep on thinking about other sustainable means. Their mind keeps moving around seeking supports from their parents, other immediate family members, relatives, societal people, and supports from the government. Thus, disability brings reactions in people with disability in various ways and they attempt to make their life run smooth even after disability as much as possible.

Going through this research, it is necessary to address issues of people with disability at both macro and micro levels. Political leaders have to play important roles to encourage the people with disability, making the political system appropriate so that people, irrespective of disability status, find a conducive environment to uplift themselves by working on income generation. If it is so, people should not be the victim of not receiving hospital treatment and vision loss because of poor economic status. Nepal's government has brought a health insurance scheme, but most of the poor people are far from the information on the one hand and implementation on this scheme seems poor across the country. Furthermore, superstitious beliefs, as mentioned above, are still in Nepali societies that can be reduced gradually by giving awareness programs from people to people at the micro-level.

Conclusion

People often follow herbal health medicine before going to the allopathic hospital for their treatment, especially in rural Nepal. This practice causes late to reach the patient at the hospital. Consequently, sick people are taken to the hospital when they become sick seriously. There are research participants who faced multiple health problems of childhood age, which has led them to blindness. In this study, people with acquired disabilities perceive more difficulties in comparison to those people with inborn disabilities. The reason behind this is more likely to be that people with disability after birth have already spent their life with ease and comfort before their disability as they compare themselves before and after their disability, irrespective of the nature of the disability. Likewise, the people with disability who have become disabled in childhood ages have already normalized their way of life to a greater extent than those people with disability who became disabled in the later stages of their working life. However, the nature and type of disability are equally important in making a comparison with different groups of people with disability.

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