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Making Sense of the Occurrence of Impairments among Women with Locomotor Disabilities in Assam

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ABSTRACT

This paper elaborates on how women with locomotor disabilities and their family members make sense of the occurrence of their impairments in the specific contexts of their lives. The paper argues that the binary distinction between impairment and disability as espoused by the social model is irrelevant in the context of persons with disabilities in the majority world. The study was conducted among 18 women with different locomotor disabilities who had acquired their impairments early in life in the district of Kamrup Metropolitan in Assam. Using intersectionality as an analytical framework, this paper helps in understanding how the interplay of a multitude of factors such as nature of impairment, social class, social capital, access to healthcare, parents' knowledge about child health and, place of residence work simultaneously to co-construct the experience of impairment, which in turn helps to go beyond the refrains that people usually use to make sense of their impairments.

Keywords: Intersectionality; Disability; Impairment; Majority World; Assam

Introduction

In disability studies, the lived experiences of persons with disabilities are described by using different models (Ghai, 2003). These models represent socio-cultural assumptions about disability and persons with disabilities in various periods of human development, along with the ways they have been subjected to different forms of stigmatization and discrimination (Ghosh, 2012). These models were developed in the minority world, where persons with disabilities took the lead in demanding equal rights (*ibid*). Mike Oliver is credited as one of the pioneers on the discussion of models of disability. He conceptualized these models as the binary distinction between, what he termed as, 'individual' and 'social' models of disability (Oliver, 1990). The two fundamental tenets of the individual models are: firstly, the 'problem' of disability is located within the individual, and secondly, the causes of this problem originate from the functional or psychological limitations which are assumed to arise from disability (Oliver, 1990). Oliver considers medicalization as a significant component of this model (*ibid*). This is because disability is often looked at as a medical deficit, and medical professionals frequently dominate over the lives of persons with disabilities (Ghosh, 2012). The medical model explains physical, sensory or cognitive disabilities in terms of a medical etiology and emphasizes on the causal relationship between the origins and outcomes of various types of disabilities (Ghosh, 2012). Cure and overcoming the disability are the central features of this model, which are to be sought by the individual who is afflicted by it (Ghai, 2003). The medical model has been criticized for giving undue emphasis on clinical diagnosis, which in turn provides a partial and inhibiting view of the individual (Brisenden, 1986). It is argued that the problem with this model is that it not only determines the kind of treatment that is suitable for persons with disabilities, but also the type of life that they are supposed to lead (*ibid*).

In contrast, the social model of disability is a rejection of all the tenets listed above, and instead locates the problem of disability within the society (Oliver, 1990). The important tenets of this model are: firstly, it does not refute the importance of appropriate medical and rehabilitative interventions in relation to disability. Instead, it demonstrates the drawbacks of this approach in the cause of empowerment of persons with disabilities. Secondly, the model makes a conscious effort to shift the attention away from the functional limitations, physiological and cognitive impairments of the individuals, to the ability of the society to systematically oppress and discriminate them (Lang, 2001; Barnes, 2003; Barnes, 2012). This model has played a critical role in the emergence of groups of persons with disabilities and the growth of a positive disabled identity (Shakespeare & Watson, 1996).

In spite of the positive role played by the social model, from the 1990s onwards, an increasing number of disability scholars, informed by the feminist and post-modernist debates, have raised the internal critique about leaving out the body from the experience of disablement (Crow, 1996; Morris, 1998; Shakespeare & Watson, 2002). Some have argued that this model works well on a grand scale to challenge discriminatory social structures and shows the requirement for civil rights legislation to protect the rights of persons with disabilities. However, it lets them down at a personal level (Crow, 1996). The binary distinction is a product of the fear of articulating any negative feelings about the bodies of persons with disabilities, as it may result in passing a wrong message that their lives are not worth living. However, Morris (2001) considers it foolish to deny the distressing experiences of the body as impairment can a be salient element for many persons with disabilities (Shakespeare & Watson, 2002). Few disability scholars have also tried to reconcile the differences between disability and impairment in their versions of the social model of disability (Crow, 1996; Swain & French, 2000), while others have rejected the social model completely and have urged for the adoption of newer theories to comprehensively understand the experience of disability and impairment (Shakespeare & Watson, 2002).

While a lot has been written about the social model, its applicability to the majority world has not been questioned until very recently. Even to this day, minority world disability scholars are divided in their opinion about the relevance of this model in the majority world. Some like Stone (2001) and Sheldon (2005) have opined that the social model is as much relevant in the majority world as it is in the minority world; others like Grech (2009) have considered using the social model in the majority world to be problematic. Grech (2009) acknowledges that the social model has been inspirational for persons with disabilities, but argues that the exportation of this model to the majority world has very many problems: The first major problem of this model, in his opinion, is that *"it is grounded in and highlights the concerns of western, white, urban, educated disabled academics in industrial settings"*(Grech, 2009: 775). According to him, while attempting to understand disablement in a particular society, it is imperative to understand the broader socio-cultural, economic and political environment. All these factors, however, are easily forgotten when life is viewed from the lens of the industrialist, welfarist and individualistic viewpoint of the West. According to him, in a context of high levels of deprivation, the emancipatory paradigm becomes a highly dubious endeavor (*ibid*). His second criticism of the social model is that *"it promotes a 'universal discourse', which, […] runs the pervasive risk of being contextually and culturally inappropriate"* (Grech, 2009: 775). He argues that the sharp distinction between impairment and disability negates the importance of *"the phenomenological aspects of functional limitations and pain and [completely abandons] the theorization of impairment"* (Grech, 2009: 776). These issues, however, have rarely been discussed across cultures. He argues that in the countries of the majority world, impairment remains a fundamental concern because poor livelihoods and ultimately their survival depend on hard physical labor that makes a healthy body an imperative. This becomes even more risky where health and social protection systems are either absent or segmented. He argues that since the subject of impairment is directly related to medical issues,

> [s]oftening the issue of medical needs, even if for the purpose of politicizing disability, can become extremely dangerous in developing countries agonizing over the most basic health care and where functional abilities influence life activities and often survival
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> (Grech, 2009: 776-777).

Grech's (2009) final criticism of the social model is that it makes a homogenizing assertion that all persons with disabilities are oppressed and excluded. Grech (2009) argued that different studies have shown that persons with disabilities experience both positive as well as negative attitudes along a continuum, even within countries. Moreover, persons with disabilities are not a homogeneous group and due to this their experiences are shaped by a myriad of factors such as the type of impairment, gender, religion, tribe, roles and rights and finally depends upon what is culturally, socially and ideologically valued. He cautions us that representing a person to be belonging to an oppressed group, when they do not consider themselves to be one, may only serve to marginalize and stigmatize that person (*ibid*).

Taking the above critique of the social model into consideration, this paper uses intersectionality as an analytical framework, to understand how women with disabilities and their family members, make sense of the occurrence of their impairments, in the specific context of their lives in the Kamrup Metropolitan District of Assam. The paper elaborates on the broader socio-cultural, economic and political environment surrounding their impairments, in order to understand how the research participants make sense of it. Such an understanding is important in order to critique the widely held understanding prevalent in disability studies, that negates the importance of impairment and usually point out the barriers present in the environment. As an analytical strategy, intersectionality helps us in understanding that human lives are multi-dimensional and their lived realities are shaped by diverse social factors and power dynamics that though are interlinked can change over time and space. Nonetheless, the importance of any category or structure in the study of social problems cannot be predetermined and must be discovered during the process of investigation (Hankivsky, 2014). Intersectionality also alerts us that at the micro level people can experience privilege and oppression simultaneously, and a multi-level analysis that links individual experiences to broader social structures and systems are crucial for revealing how power relations are shaped and experienced (*ibid*). In the last few years, the popularity of intersectionality has increased manifold, and is now considered to be a scholarly buzzword and a leading feminist paradigm with expansive interdisciplinary reach (Davis, 2008). Intersectionality has been adopted to examine the co-construction of race, gender and class in determining individual, collective and structural conditions (Naples, Mauldin & Dillaway, 2019). In spite of the analytical power of this framework to integrate analysis of varied forms of power and inequality, unfortunately disability does not find much space in intersectional scholarship (*ibid*). This drawback has now been rectified by critical disability studies, which views disability both as a lived experience as well as a social and political definition on power relations prevalent in the society, and also examines the intersection of disability with other markers of identity such as gender, class, race and sexuality to understand how these influence wider relations of power and personal experiences (Reaume, 2014; Owens, 2015).

Method

Setting of the Study

This paper is a part of the author's doctoral research on the lived experiences of women ageing with locomotor disabilities who had acquired their impairments earlier in their lives (prior to the age of 20 years). The fieldwork for the study was conducted in the district of Kamrup Metropolitan in Assam, India, between April 2015 and December 2016. The state of Assam is located in the northeastern part of India which, after partition of the country in 1947, is connected with the rest of the country via a narrow stretch of land known as the Siliguri corridor. Assam shares its border with West Bengal, six other northeastern states and the neighboring countries of Bhutan and Bangladesh. Assam comprises of people belonging to different national, ethnic, religious, linguistic and tribal groups who have been living together for centuries (Srikanth, 2000). Since independence from British rule, Assam has been severely plagued by insurgency, economic underdevelopment, continuous ethnic movements, resurgent sub-national movements and unchecked foreign infiltrations, as a result of which it has been one the most underdeveloped and destabilized states in the country (Das, 2005) until very recently.

Kamrup Metropolitan is one of the 33 districts in Assam. It was carved out in 2003 out of the erstwhile Kamrup district. In the predominantly rural state of Assam, this district is an exception as out of the total population of 1.2 million, an overwhelming majority of

1 million individuals reside in the urban areas of the district. Available statistics shows that out of the total population of persons with disabilities in the country, a vast majority reside in the rural areas under extremely poor conditions with little access to the services meant for them (Klasing, 2007). It was felt that the rural-urban differentials for the district would give a unique picture of the experience of disablement of women with disabilities. In addition to this, the presence of several established disability organizations made it easier to recruit the participants for the study.

The Research Participants

The study was conducted among 18 women with different locomotor disabilities in the age group of 18-57 years. These women were contacted with the help of four disability organizations, out of which one was working in the rural areas of the district, while rest were working in the urban areas. The main inclusion criteria for the study include occurrence of locomotor disability below the age of 18 years, and their ability and willingness to talk about their life experiences. Since most of the disability organizations cater to poorer sections of the society, a majority of the study participants also belong to the poorer families, with a hand-to-mouth existence. One of the limitations of the study is that the sample is not representative of the total population of women with locomotor disabilities in Assam, but only of women who are associated with disability organizations and are, therefore, more privileged in terms of access to different services than others. In spite of this limitation, the study throws valuable insights on the lived experiences of the women that have been shaped by the intersection of a multitude of factors. In this paper, the focus will only be on how the women and their family members have made sense of the occurrence of their impairments.

Research Design

This research uses qualitative methods because of its ability to access several aspects of women's experiences that have been neglected by traditional social science research. Qualitative methods enable the participants to express themselves, to discuss their experiences and have their knowledge(s) legitimized, and to do so in their own terms (Ironstone-Catterall et al, 1998). The research uses life history approach as the primary tool for data collection. This approach provides a framework which allows the stories of the research participants to emerge as well as to explore these stories within the social, political, historical, cultural, familial and psychological contexts within which they are embedded (Matiss, 2005). The research participants were asked to elaborate on their experience of living a life with visible physical disabilities with a specific focus on what they thought were important events of their lives. The interviews lasted between one and a half to two hours, and the interviews were conducted either at the disability organizations or in their homes, according to their convenience. Sometimes the interviews were conducted over multiple settings, depending upon their work schedule and availability. In a few instances, the family members of the women, especially their mothers, were also interviewed for a deeper understanding of the participants' narratives. All the interviews were conducted in Assamese language. The interviews were recorded with the permission of the research participants and were later translated and transcribed into English by the author.

Data Analysis

Data collection and analysis happened simultaneously, as is characteristic in qualitative research (Hesse-Biber, 2007). Every day after coming back from the field, thoughts about the interactions with research participants were noted down. The author transcribed their interviews as soon as possible so as to not forget about the nuances of their interactions with the participants. The transcribed interviews provided rich material which was then analyzed manually using the intersectionality framework according to the themes that emerged from their narratives.

Ethical Consideration

The study has been approved by the Institutional Ethics Review Board of the university where the author was enrolled for her Ph.D. Before starting the interview, the research participants were explained about the nature of the study, the nature of participation in the study, as well as the kind of questions that they would be asked. They were told that participation in the research was voluntary and they have the right to withdraw from the study at any point. The participants were also requested to sign the informed consent form, and they were assured that confidentiality regarding their identities would be maintained.

Findings

The study participants had different types of locomotor impairments, some of which were congenital, while others were acquired due to infective causes in childhood, while still others were acquired due to traumatic causes in adolescence. Due to this reason, the women and their family members also explained the causes of their impairments in different ways. Four different themes were identified during the course of the interviews. Due to the paucity of space, this paper has clubbed the findings under three themes. Regardless of the nature of their impairments, all the research participants talked elaborately about their experience of seeking treatment for their health conditions and the impediments they faced along the way. Such experiences helped them in making sense of their impairments.

Making Sense of Congenital Anomalies

Congenital anomalies are defined as structural or functional anomalies that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy (WHO, 2016). It can contribute to long-term disability, which can significantly impact the individual, his/ her families, healthcare systems and the society in general. About 50 per cent of all congenital anomalies cannot be linked to any specific cause and very often it is difficult to identify the exact cause of the impairment (*ibid*). In this study, the causes of congenital impairments of the research participants were sporadic in nature. Due to this reason, it was found that the women and their family members think about different reasons that may have caused the impairment, as explanations from the health personnel are usually lacking. The following narrative illustrates this point.

Minakkhi, 42, was born with a congenital impairment which is clinically referred to as syndactyly[1]. Minakkhi said that she had never asked her parents about her impairment. She has, however, heard them talking to others that her hands turned out to be like this because when her mother was pregnant with her, her father had a fight with the other villagers, and to block these people from coming into their home, he had cut a log of a tree to create a barrier between their household and the other households in the village. Minakkhi elaborated that in their community (Assamese), there is a belief that one should

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[1] Syndactyly is the fusion of adjacent digits, and is the most common of all congenital hand deformities with an incidence of 1 in 2000 live births (Jordan et al, 2012). It can be both hereditary as well as sporadic in nature. Syndactyly has a large functional and aesthetic significance for those who are born with this condition. Operative management is the only definitive care for persons with this impairment (Ibid).

not cut a tree or kill an animal when there is a pregnant woman in the household. She believes that her hands turned out to be like this because of her father's actions.

A few months later her mother was interviewed at their home, which is about 45 km from Guwahati. She said that many people in the village feel that Minakkhi's hands are like this because her father had a pet tortoise which he had left in their family pond with the help of a plastic net. Her mother said that she was *unsure* if her daughter's condition is because of this reason, or she has been like this since her birth. She, however, believed that it is because of her *beyakormo*(bad deeds) and *bhagyor dux* (faults in her destiny) that this has happened to her daughter. She explained said that in her youth she might have made fun of persons with disabilities in the streets, and her daughter's disability could be a punishment for that sin.

From Minakkhi and her mother's narratives, it can be seen that both of them have internalized the *traditional animistic beliefs* about the cause of disability, that it is a cause of punishment for bad deeds (karma) (Stone-MacDonald &Butera, 2014). Stone-MacDonald &Butera (2014) in their review of literature on cultural beliefs and attitudes about disability in East Africa, have noted that among the Nandi of Kenya, it is considered a taboo to kill animals without good reason, during a wife's pregnancy (Ogechi&Ruto, 2002, as cited in Stone-MacDonald &Butera, 2014). The review also found that laughing at persons with disabilities can cause an individual to have a child with disabilities, cause an accident that would harm that individual or cause the future generations of the family to be cursed (Stone-MacDonald &Butera, 2014). Minakkhi and her mother seem to hold similar beliefs about her impairment. Minakkhi's mother also seems to have internalized the widely prevalent notion in India and other parts of Asia, that the disability in the child is due to the faults of the mother (Ghai, 2003; Koydemir&Tosun, 2009; Crabtree, 2007).

While Minakkhi and her family held traditional beliefs about the cause of her impairment, it was found that such beliefs did not hinder her parents from seeking treatment for her condition. Her mother said that when Minakkhi was about three-four years old, she and her husband, at the advice of some relatives, took her for a consultation to a tertiary hospital in Guwahati. In the hospital, the doctor told them that they would be able to cure her impairment by surgically separating her fingers. However, considering her young age, the doctor asked them to come back a few years later. When she was eight years old, Minakkhi's *Aita* (paternal grandmother) accompanied her to the hospital for the surgery. Her parents were not able to accompany because of their busy work schedules at home and in the agricultural field. Minakkhi's mother said that at the hospital, the doctor was able to separate only two of her fingers in both her hands and he asked her to return back a few weeks later to complete the procedure. Unfortunately, at that time her *Aita* fell sick and passed away, because of which Minakkhi was not able to return back to the hospital and her surgery remained incomplete. According to both Minakkhi and her mother, her fingers joined back as a result of abruptly stopping her treatment.

From the interview it was clear that her mother considered herself responsible for their inability to continue Minakkhi's treatment. Her mother's guilt was further accentuated by a recent interaction with a *Gonok* (a sub-group of Brahmins who are in the hereditary occupation of astrology), whom she had consulted to know if and when Minakkhi would get married. The *Gonok* told Minakkhi's mother that when she was pregnant, a bad spirit had entered her body because of which her daughter was born with this impairment. Hearing this, Minakkhi's *Bou* (elder brother's wife), who was nearby, started laughing and said, *"They are from the older days. They believe in such things"*. Minakkhi's mother, however, did not care what her daughter-in-law thought about her beliefs. Her *Bou* further said that at that time the healthcare facilities were not very adequate and it is due to this reason that Minakkhi's hands remained like this. She argued that a child with the same condition from the current generation would have been cured because of the advancement of medical facilities and the availability of healthcare facilities nearby. Minakkhi's mother interrupted her and said that Minakkhi could have been cured even at that time, but it was because of their mistake that they were not able to continue her treatment. She feels that if they had taken Minakkhi to the hospital at the age of 12-13 years, probably her fingers would have been separated. But unfortunately, this thought did not occur in their minds at that time because they had to look after so many things. It is important to note here that the road connectivity and transportation facilities from their village to Guwahati was very poor at that time, which could also be one of the factors that hindered her parents to take her back to the hospital later.

The above narrative suggests that traditional beliefs about impairment often coexist with the faith in the healing powers of biomedicine. In order to understand why this is so, one must also keep in mind the situation of Assam in the 1980s and 1990s which was marred by ethnic and political strife, insurgency and underdevelopment, making it increasingly difficult for people residing in rural areas to seek treatment from healthcare facilities located far away in the city. Although Minakkhi's mother did not mention the political context of the state directly, this aspect cannot be overlooked while analyzing Minakkhi's barriers to seek treatment for her condition. In effect Minakkhi's mother's guilt at not being able to cure her daughter shows in part her sorrow at not being able to change her daughter's *kopaal* (fate) despite a cure being available for her condition. On the other hand, it can be seen that being more educated than her unlettered mother-in-law, and not bearing witness to the lifelong struggles that Minakkhi has had to endure, her *Bou* considered Minakkhi's impairment to be a result of inadequate healthcare facilities and not a result of an intersection of a number of factors including the nature of her impairment, her rural residence, her parents' poor financial condition and the political context of the time when she was growing up. Her comment also shows that there has been a definitive shift regarding impairment among the younger generation, wherein they do not ponder much about the cause of the impairment. Rather, they emphasize more on the 'cure' of the impairment.

Importance of medical explanation about disability

The study found that medical explanation from healthcare providers about the cause of impairment helped the women and their family members tremendously in making sense of their impairments. It was seen that such participants did not ponder much over the cause of their impairment. They were also better adjusted in their lives and had accepted their impairments as something that was written in their *kopaal* and would have happened no matter what they had done to prevent it. In contrast, the women who had not received an adequate explanation from their healthcare providers remained confused about their medical conditions and sometimes also blamed others for their impairments. The study also found that access to appropriate healthcare and thereby access to appropriate medical explanation about impairments is determined by a number of intersecting factors such as social class, parents' awareness about child health and social capital. These points are illustrated in this section with the help of narratives of two women with the same medical condition (poliomyelitis) acquired several years apart, but who belong to different strata of the society.

Mayuri, 57, grew up in Shillong, the former capital of Assam, where her father was posted at that time. When Mayuri was one and half years old, she and her mother paid a visit to her mother's natal family in Guwahati. At that time, they had gone to visit one of her mother's cousins. Mayuri's mother believes that her daughter had contacted polio from her cousin's son who was defecating on his pot, while Mayuri was standing close to him and talking to him. She said that at that time she was not aware that polio spreads in this way and she was also not aware that the other child was infected with polio . Within a few days, her mother observed that Mayuri had very high fever, and was unable to turn on her right side. She also observed that her right upper and lower limbs would cling to her body. Mayuri's mother consulted her *Pehadeu* (father's sister's husband), who was a doctor and had received training in polio management from Bombay (now Mumbai). With one look at her, the doctor was able to identify that this was a case of polio. Thereafter, he took her blood samples and was able to confirm that this was indeed a case of polio.

Mayuri's mother said that at that time they had never heard of a disease called polio and so she asked for details from her *Pehadeu.* The doctor then explained to her in great detail about the etiology of the disease. She, for instance, was able to explain to me that polio spreads through the feces of the infected child, and due to this reason she kept herself and her daughter locked up in a room in the top floor of her mother's home in Guwahati for three months. She also said that even though she was aware that the incubation period was three weeks, she did not allow her daughter to interact with any of her brother's children for three months, out of the fear that they would also get the infection. She said that this would have made her very upset.

Mayuri's mother also remembers that the doctor massaged Mayuri's body with some special oils at night to bring back the strength of her body. The doctor started living at the mother's home and took it upon himself to massage his patient. Mayuri's mother feels that it is because of the dedicated care from her *Pehadeu* that Mayuri recovered from her illness within one and half months. She said that her happiness knew no bounds when she saw Mayuri move her hands after her illness. She also said that some people had advised her husband to take Mayuri to Bombay for treatment, but her *Pehadeu* stopped them from going anywhere and told them that he would provide the best quality care to her in Guwahati. She also feels lucky that both of them were in Guwahati at the time of onset of her illness, amidst her family members. She does not know if she would have found someone to care for her daughter in Shillong.

The above narrative shows that the perception about polio was absolutely limited at the time when Mayuriwas infected. In spite of this, her family received adequate medical explanation that enabled them to cure her condition without any severe impairment. It is apparent from the narrative that this has been possible because she is from an affluent family, which could have even afforded her treatment from outside the state, if they had wished. But they did not have to take this route because Mayuri received quality treatment at her maternal grandparents' home. Apart from this her family's affluence was also visible from the fact that her mother was not burdened with any household responsibilities during those three months when she and Mayuri remained locked inside her maternal grandparents' home. As would be visible from the following narratives, this is a luxury that was not available to the mothers of most of the other research participants. It was due to these intersecting factors that Mayuri and her mother never pondered about why this disease afflicted her. Her mother simply replied, *"It happened naturally. This was in our kopaal"*. Like in the previous section, this comment again shows that the traditional and biomedical explanations about impairment are not mutually exclusive of one another, but often coexist together as a means to help people make sense of their impairments.

In contrast to Mayuri, the other research participants who had polio or other fever induced impairments belonged to socio-economically poor households. It was found that families of these women suffered from immense difficulties while seeking healthcare for them and when they did find a healthcare provider, they did not provide the patients' families with adequate medical explanation for the condition. In such cases it is seen that the women and their families use the names of different diseases with different etiological causes interchangeably. In certain instances, they even considered their doctors to be responsible for their conditions. The following narrative gives a glimpse of this.

Nayana (30+) was about two and a half years old, when one day she had developed very high fever. At that time, her parents had only recently shifted to Guwahati from their village in the Dhubri district, and had started working as live-in domestic workers for an affluent family. During the one week when she had very high fever, Nayana's parents gave her several over-the-counter medicines to cure her. These medicines, however, had little effect on her condition. Thereafter she developed an abscess in her umbilicus, and it was only at this point that her parents rushed her to a doctor. Nayana said that this doctor was 'not able to identify her condition', and gave her medicines for 'malaria' instead. After taking these medicines, her condition deteriorated further. Later her parents took her to another doctor, but he didn't want to take any risks by treating her, as her condition was very critical. After much pleading, this doctor gave her one 'good medicine' which, according to Nayana, stabilized her condition.

This, however, was not the end of her parents' agonies. After a few weeks, her parents started to notice that unlike earlier, Nayana did not move at all, and would lie down on the bed all the time. When one month passed like this, her parents got very worried and took her to an orthopedic for consultation. This doctor told her parents that she was infected by 'typhoid' and it could not be cured. He also told her parents to stop seeking treatment for her condition, as she could not be cured even if she was taken out of the state for her treatment. He, however, taught her parents a few exercises and asked them to continue those at home.

After her recovery from the illness, Nayana could never walk again. Through the help of his employers, her father was able to get a wheelchair for her to ease her mobility. Apart from mobility, her impairment impacted her life in other ways also. Nayana's parents tried very hard to get her admitted to government schools, but none of the schools that they had approached, was willing to give her admission citing accessibility issues. Eventually, she was admitted to a special school for children with intellectual disabilities, despite the fact that her impairment was only physical in nature. It was only at this school that Nayana heard the word 'polio' for the first time, but still used it interchangeably with 'typhoid'.

Nayana said that her father was a strong believer in God, and after she fell sick he was not able to make sense of her condition. According to her, he was very depressed for a very long time about this. However, her parents did not blame God for their sufferings. Instead, they consoled themselves by thinking that it was God's will, and would have happened no matter what was done. According to Nayana, such an understanding helped her parents in making sense of her impairment, and arguably relieved them from their guilt as well for not taking her to a doctor in the very beginning of her illness episode when she started showing symptoms. Nayana, however, blamed her father's employers for her impairment. She said that as 'non-literates from the village' who had recently migrated to the city, her simple-minded parents were not aware about what to do when a child falls sick. As domestic workers, her parents had to meet all the requirements of their employers, and this eventually left them with very little time to care for their own needs.

According to her, it is because of this exploitation that she had to suffer from the debilitating effects of 'typhoid'. She also considered the first doctor who gave her wrong medicines to be responsible for her impairment. With regards to this also, Nayana felt that her father's employers should have guided her parents better regarding what to do when a child falls sick.

The two narratives above show how the life trajectories of both the women have been different due to the intersection of factors such as social class, level of awareness of their parents regarding child health and social capital. In spite of the fact that both of them had the same condition (polio), although about three decades apart, Mayuri received much better care and much better explanation for her medical condition because of her stronger social capital. This enabled her and her family members to reconcile with her medical condition. In contrast, as a daughter of poor migrant daughter, who were dependent on the goodwill of their employers, Nayana faced a lot of vulnerabilities. It is very likely that her treatment was also interrupted by the frequent skirmishes in the state during the period of her illness. Since an interview could not be scheduled with her mother, this is only a speculation about her treatment.

Disability and Poverty

It is now widely acknowledged that disability and poverty exist simultaneously in the majority world (Meekosha, 2008). This is because of two reasons: first, the root causes of impairment in the majority world are malnutrition, lack of services and landmines, and these are likely to hit the poorest the hardest; and second, people with impairments are more likely to be poor worldwide due to the disabling barriers that prevent them from getting an education, employment, access to appropriate healthcare and other services (Stone, 1999). It has been argued by Ingstad (1990) that among poorer households, having a member with disabilities affects all other family members as the resources available to the household have to be redistributed keeping into consideration the needs and concerns of the disabled person (cited in Grut, Olenja&Ignstad, 2011). This was also found to be true in the case of the study participants. The following narratives illustrates how poverty limited the access to healthcare and rehabilitation facilities for one of the research participants (Sobiha), while for another participant (Dolly), poverty forced her to work at a hazardous workplace at a very early age, that eventually exposed her to her impairment and limited her life opportunities in the future. But over and above these two individuals, the other members of their families were also adversely affected for having a person with disabilities in the family. Both the women blamed their *kopaal* for their conditions.

Sobiha's mother, a poor Bengali Muslim woman, had married a relatively affluent Christian man, who was more than double her age. He had another wife before her, and had converted to Islam to marry Sobiha's mother. Sobiha's younger sister said that when her mother was seven months pregnant with Sobiha, she fell down from the stairs on a rainy day. After her fall, she suffered from pre-labour rapture of membranes (PROM), but was not able to go to a hospital immediately as she was all alone at home. She was taken to a hospital only after three days when her husband returned home. As a result of this fall, Sobiha, 18, was born with cerebral palsy that has affected her intellectual abilities, speech and her gait. Her doctor diagnosed her problem immediately after her birth, and due to the absence of state-run physical rehabilitation centres at that time, referred her to a disability organization for physical rehabilitation. This organization, at that time, was located very close to their home in Guwahati, which enabled Sobiha's mother to access physical rehabilitation for her daughter. However, a few months later, she was pregnant again due to which she had to discontinue her treatment. This setback to her treatment was quickly followed by the death of Sobiha's father when she was only two years old and her sister was only nine months old. After his death, there was no financial support for the three of them, as her father's pension along with his property went to his first wife. She also did not receive any financial help from her siblings because they were also very poor. As a result, the responsibility of running the family fell on the shoulders of Sobiha's mother. She soon started a small shop in a footpath. Following this, her mother had little time to spare for Sobiha's physical management. By this time, the disability organization had also moved to its permanent location in another part of the city. Sobiha's mother said that money was so scarce during this period that she spent whatever little money she had on buying milk for her children, instead of buying medicines for Sobiha or for taking her for physical rehabilitation to the disability organization. Sobiha's mother further said that no one ever told her that daughter's condition would deteriorate if her medicines were not continued. Listening to her mother narrate the story of her impairment, Sobiha reflected, "*Ma fell down, that is why I am like this. What to do now? This is my kopaal.*"

The above narrative clearly shows difficult familial circumstances (like marriage with an already married and much older man, and his death only a few years after marriage), and dire financial condition increased the vulnerability and helplessness of Sobiha's mother. This in turn hindered Sobiha's access to physical rehabilitation, despite the fact that her condition was diagnosed at birth. It can be seen that both Sobiha and her mother had resigned themselves to their *kopaal*, which according to them was responsible for all the hardships that they had to endure in their lives, including Sobiha's impairment.

Unlike Sobiha, Dolly, 34, acquired her impairment as a consequence of poverty. Her right forearm was amputated when she was about 13 or 14 years old. One year before this incident her father, who was the only working member in the family, had passed away. Dolly has three siblings, out of which her older sister and younger brother were studying at that time, while her youngest sister was only one year old. Dolly was not much interested in studies, so she voluntarily dropped out of school after class 5 to help her mother earn a livelihood. After the death of her father, Dolly's mother had received a sewing machine from the garment shop where her father had worked. With the machine she and Dolly used to sew *mekhela*[2] for their neighbors, but this fetched them only a small amount of money, and was not sufficient to run a family with five people. In order to supplement the family income, Dolly started working as a helper for a printing press. She had only worked there for a few months when a wood cutting machine, which was not working properly, fell on her right forearm, severely injuring it. After the accident, she was taken to a government hospital where the doctors said that they cannot treat her and referred her to another government hospital. At the second hospital, the doctor told her mother that they will not be able to save her forearm as it might get rotten from inside. Since she was left with no other option, her mother had to agree to amputate her daughter's right forearm. The expenses for treatment were met by the printing press.

After this incident, Dolly's life has changed tremendously. Even though the amount she earned was meager, her life transformed from being an active earning member of the family to someone who was not able to find any well-paying jobs because of her impairment. Additionally, before her accident, she was also able to help her mother in her sewing work. Perhaps what she regrets most is that her *Bhaiti* (younger brother) had to drop out of school in order to take the responsibility of the family. About five years before the interview, Dolly found a job in an organization that worked for the physical rehabilitation of persons with disabilities. Even though her job paid her a meager stipend,

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[2] The bottom portion of the traditional Assamese dress.

and she was in the lookout for better opportunities elsewhere, she was happy to have found this organization as she met many other persons with disabilities here who helped her in forgetting about her miseries. She also said that she sometimes suffers from intense pain in her amputated limb but she has been told that there is no cure for that, except painkillers. This lingering pain makes her very frustrated and sometimes she hits herself hard in her frustration. Doctors had also suggested that she might consider wearing a prosthetic limb, but the one that her second employer bought for her was of low quality and it further intensified her pain. As a result, she stopped wearing it after one or two attempts. When I asked her if she blames anyone for her accident, Dolly replied that this was written in her *kopaal*. She further said that her mother had asked her not to work, but she was adamant to continue working at the printing press due to the financial condition of her family. She also said that she strongly believes in God despite the fact that she has had to face many hardships in her life.

From the above narrative it can be seen that it was the death of her father, who was the only earning member in her family, and poverty that exposed Dolly to her impairment. Dolly blames her amputation on her *beya kopaal,* which brought misfortune not only for herself but for her entire family as they lost a productive member because of this reason. She also regrets that because of her, the entire family had to go through very rough times.

Discussion and Conclusion

Taking majority world theorist Grech's (2009) criticism of the social model of disability, this paper attempted to understand how women with locomotor disabilities and their families make sense of the occurrence of their impairments. It was found that the social model distinction between impairment and disability made no sense for the study participants as they were too engrossed in their socio-cultural, economic and political circumstances. It was found that these circumstances hindered the women from accessing healthcare for their conditions that in turn aggravated their health conditions. For instance, in the case of Nayana, her treatment was hindered because of her family's socio-economic status that made them very dependent on their employer's goodwill. As a result of this there was a delay in seeking treatment, which resulted in her permanent disablement. For Sobiha, even though her condition was diagnosed at birth, her mother was not able to continue her treatment due to the difficult familial circumstances like the birth of her younger sister and death of her father soon after. This necessitated that her mother prioritize earning a livelihood for her family instead of seeking physical rehabilitation for her condition. For Minakkhi her rural residence and distance from the healthcare facility located faraway in the city, where her condition could have been corrected, hindered the cure of her condition. Arguably the political events of that period also hindered her access to healthcare. Although Dolly received proper healthcare after her accident, it was not followed up by the provisioning of a good quality prosthetic forearm which could have reduced her pain substantially. Among all the research participants only Mayuri received appropriate healthcare because of her affluent socio-economic background and strong social capital. The findings of the study corroborate what Grech (2009) had stated about the importance of studying impairment in the majority world context, because it is of fundamental concern for the people here. Additionally, it is evident from their narratives that the study participants faced a myriad of different problems which intersected to form unique experiences for each one of them. Thus, it is imperative that more emphasis is put to study the heterogeneous experiences of persons with disabilities rather than homogenizing their experiences and rendering those who are further marginalized due to factors like caste, class, religion, gender, ethnicity or place of residence, voiceless. In this regard, intersectionality is very helpful because as it makes it clear that human lives are multi-dimensional and their lived realities are shaped by a multitude of social factors. As mentioned earlier in the paper, no category or structure can be predetermined in the study of social problems and it can only be discovered during the process of investigation (Hankivsky, 2014). In this study, it can be seen that social class, nature of disability and place of residence have determined the lived experiences of the people. On the other hand, other prominent social categories like gender, ethnicity, caste, religion and linguistic identities have not emerged as important categories that have shaped their lives. Future studies on the lived of experiences of persons with disabilities in Assam must explore these categories more deeply.

In the available literature on disability models from India, it is seen that one of the predominant models is the *religious/ moral model*. According to it, disability is regarded as the divine retribution for past sins committed either by the individual or by his/ her ancestors. In this model, the concept of *karma* governs the basic assumptions about disability and persons with disabilities are considered to be suffering from the wrath of

God (Ghosh, 2012). Another related notion within this model is that God inflicts suffering on good people in order to test their resilience and inner strength. The common factor in both these explanations is that disability is God's will, which must be respected (Dalal, 2002). This model or the *karma* theory within this model is so popular in the literature on disability in India in the minority world that anybody who is not interested in emphasizing on this model is forced to reconsider (Kumar, Hiranandani & Sonpal, 2013). As a result, the focus on the *karma* theory is overarching in the existing literature. Unfortunately, much of the literature on disability in India has emerged from the metropolitan cities like Delhi, Mumbai and Kolkata. As a result, there is not much representation on how people belonging to other cultures make sense of their impairments. In this study, it has been found that the research participants use different refrains to make sense of their impairments which include *kormo* (*karma*), bhagyo (destiny), *kopaal* (fate) and God's will. How each of the participants and their family members has used these refrains, however, varies from context to context. *Kormo* (*karma*), for instance, is used to refer to the outcomes of bad deeds committed either by the individual or his/her family members in their present or previous lives. In this study, only Minakkhi's mother blames her *beyakormo* (bad deeds) and *beyabhagyo* (bad destiny) for her daughter's impairment. As shown above, the reasons for this could be that her daughter's impairment is congenital and that they were not able to seek healthcare for her condition despite the fact that cure was possible. In some cases, the participants used the refrain of *kopaal* (fate) to make sense of their impairments. This was used when the parents of the participants had done everything in their capacity to improve their child's condition, yet they could not be successful because of factors beyond their control (in the case of Mayuri, Sobiha and Dolly). *Kopaal,* therefore, was used as a refrain to reconcile themselves to their fates, instead of fighting against it. It was found that such an explanation liberates them from the feelings of sorrow and guilt and helps them in coping with their altered life circumstances. Apart from these, the study also found that some of the research participants and their parents were staunch believers in God and regardless of the severity of their impairments and the hardships that they had faced as a result of it, they do not doubt the blessings of the Supreme Being on them (Nayana and Dolly). Belief in God also gives them the strength to realize that their impairments were part of God's plan for them and would have happened, no matter what they would have done to prevent it. Thus, these refrains helped the research participants in psychologically coping with their impairments and their life situations, especially when they were aware that cure for their conditions were available but they were not able to access it due to circumstances beyond their control. As a result, the participants used both traditional and biomedical explanations to make sense of the occurrence of their impairments and this is only a reflection of their vulnerabilities and helplessness in a peripheral state with crumbling health and social infrastructure.

In conclusion, this paper attempted to understand the complex ways women with disabilities and their family members make sense of their impairments in the context of an urban district in Assam. It is evident from this paper that understanding the occurrence of impairments is of vital importance in a study on how people make sense of their impairments in the majority world with limited access to healthcare services. Intersectionality as an analytical framework helped tremendously in understanding how the interplay of a multitude of factors such as nature of impairment, social class, social capital, access to healthcare, parents' knowledge about child health and place of residence, work simultaneously to co-construct the experience of impairment. As can be seen from the paper, the use of intersectionality helps in going beyond the refrains that people usually use to make sense of their impairments.

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