

Uncertain Personhood: Notes on Ageing and Disability in Guwahati During COVID 19

Vaijayanti Bezbaruah^{a*}

^a*Independent Researcher. Corresponding Author- Email: vaijayanti.bezbaruah@gmail.com*

The circumstantial understanding of the ‘normal’, ushered in by the spread of COVID 19, has been the practice of ‘social distancing’. Exercising this ‘new normal’ has been a challenge in general for society. However, it is particularly important to recognize the psycho-social impact and analyse it through the lens of ageing in relation to experiences of disability. This paper therefore attempts to explore the experiences of uncertainties in the light of ageing with disabilities, pronounced during a time of crisis, leading to social distress. With the help of telephonic conversations, the paper discusses some of the stories of people living in Guwahati, in the age-group of 70 to 90, drawing on an intersectional understanding of personhood, social suffering, and symbolic disability. It is also an attempt to look into the aspect of wellbeing (physical, psychological and emotional) of the elderly amidst disabilities, while stepping into unfamiliar social boundaries of ambiguity, that further disable the elderly in terms of the sudden fading of the regular support structures and systematic foundations of the ‘social’ once known to them.

Keywords: Social Distancing, Ageing, Disability, Social Suffering, Personhood, Guwahati

Introduction

Being disabled has often been met with varied experiences of biases within the society that one lives in. Moreover, it is society that often defines whether something is ‘normal’ or a ‘pathology’ under the prescriptions of that particular local cultural system (Durkheim, 1895). In much of the contemporary anthropological literature of disability, there is a discomfort in defining and separating disability from disease (Helander, 1995:73). It comes from the biomedical view, according to which one sees ‘disability as a disease state...a temporary anomaly in an otherwise nondisabled population’ (Groce and Scheer, 1990: v). In most traditional societies, any form of disability is seen with uncertainty. Depending on the disability, the individual is often not treated as a person, as she/he is viewed as somewhere in between, ‘not quite there’. This can be described best through what the anthropologist Victor Turner (1969) terms as to be in the state of liminality¹. This situation could even be stigmatized, and be described as something incomplete or deficient of, and placed in any other social categories of ambiguity (Murphy, 1987:131). As a consequence, the person with a disability is seen to be lacking the potential to fit into the normal structure of the social order and may experience

being 'out of place' (Douglas, 1966). This particular prejudice based on the idea of potential and ability, is problematic as it also directs in the issues of accessibility towards a respectful existence. A similar debate of 'normal versus pathological' lies within the discourse of ageing experiences in most societies (Woods, 2011).

This paper adopts an anthropological approach and explores the domain of the 'uncertain' within the experiences of ageing with disabilities in an Indian society, in particular an Assamese society, during the times of COVID. While doing so, the paper tries to emphasize the cultural norms of *jotno* (care) and *daityo* (duty) in this particular cultural milieu. It tries to engage with these cultural nuances and capture the changes that these undergo and the psychosocial impact on elderly persons with disabilities.

In general, the experiences of ageing and disability have been met with similar circumstances of an uncertain future all over the world. These experiences of isolation, confusion and the feelings of being socially and physically stranded, for elderly disabled persons, can definitely are not exclusive to the social conditions caused by COVID alone, however, it surely intensifies these feelings of uncertainty. Moreover, it is important to recognize that within the Assamese urban society especially Guwahati (where the participants in the study live), it has been found (Bezbaruah, 2018) that there lies a silent prejudice against disabled elderly people. Therefore, there is a dominant belief to 'not age too soon', as there is an association of dependency and disability, drawn along with old age. In order to remain relevant, one tries to be active- socially, mentally and physically. Although there is a presence of dominant support structures among middle-class ageing people of Guwahati for respectful endurance. This is in the form of 'social structures of assistance' and 'cultures of servitude' (Ray and Seemin, 2009) in everyday lives, to receive care, whether or not they are physically disabled (Bezbaruah, 2018). Additionally, this particular belief system of an ageless mind and body with a disability free of old age, have a strong undertone of class specific views and choices of lifestyle, with global influences of active ageing, as opposed to the traditional Indian belief that old age may be accompanied by disability, and that disengagement is a normal part of ageing in India (Lamb, 2000, 2014).

Yet, it is important to note that the process of ageing with disability, may present a multiplicity of experiences, despite presenting a reliable pattern, as no one experience of old age is exactly the same as another (Davidson, 2011). This is because of an essential element called personhood, which distinguishes one person from the other, depending upon the cultural context, what Bourdieu described as 'habitus' (1977, 1990, 1984) that they are associated with. As a traditional society, the city of Guwahati was undergoing a rapid change in the belief system and was encouraging the middle-class elderly to embrace the successful ageing movement. The community in general encourages their elderly to be more independent, and weaken attachments. This idea of active ageing is especially popular among those who have come to be primarily growing older alone. It helps to establish a belief of self-reliance when their adult children often choose to live in a more advanced city as opposed to the past, when the idea of

ageing well was bound to the structure of the family, in the primary care of one's children. In the effort to showcase old age in a positive light, though, this belief of self-reliance, has not been able to see the intimate relation between ageing and disability. It also overlooks certain challenges especially in situations when it comes to capturing the ageing experiences of a person with disability (PWD), or when certain types of disabilities (arthritis, high blood pressure, diabetes, depression, loneliness, dementia etc.) might come along with advancing age. There is then an underlying dichotomy drawn within the process of ageing by putting it into the compartments of 'abled ageing' and 'disabled ageing'. Additionally, there is an evident lack of understanding within the successful ageing movement especially in a traditional society like Assam, about the psycho-social impact and the experiences of social suffering, understood by the older disabled persons, in the attempt to be independent, during a social crisis such as COVID. Accordingly, the social world of this community, which was in the process of a transition, has not only been suddenly at a standstill due to COVID, but it has now begun to pose a challenge to certain life choices of elderly people with disabilities. It has raised certain existential questions which is why I believe, it important to understand personhood, as it is an influential factor in shaping an individual response to a social situation. The existential questions arise when the types of social assistance that come in the form of domestic help, caregivers, family, neighbours and friends are heavily compromised. These everyday support mechanisms enable them to not feel socially disabled, and enhance their belief and practice of ageing well, especially when children are absent as caregivers. It is worth a sociological enquiry as to what happens when these spaces of association and familiarity, are suddenly threatened. What then is its consequential effect on the elderly with limited access to the external world? Therefore, the following sections engage with the dynamic understanding of personhood of older person with disabilities, and the transformation that it undergoes in an event of shared social suffering. It is also an attempt in exploring the idea of symbolic disability, which is neither of the body or the mind, but of the experience of uncertainty, that the mind and the body endures as a consequence of social suffering.

Methodology

The data for this paper includes analysis of texts and ethnographic fieldwork, apart from in-depth telephone conversations. The ethnographic fieldwork was a part of my PhD, and took place in the city of Guwahati. The study generated narratives collected through telephone conversations, in the city of Guwahati, in the district of Kamrup. Some of the people who participated in these conversations were also participants who had contributed to my PhD thesis, where a chapter focused specifically on the practice of caregiving and the personal meanings of wellbeing for older persons. With COVID 19 being a characteristic element in determining the psychological, social and physical wellbeing, these contributions made by the participants added character in understanding the changing nature of the social that shaped the Assamese personhood of older person with disabilities. Through this ethnographic journey, it was possible to analyze observations and in-depth interviews to establish a dialectical

relationship with the discipline of sociology, that emerges from a set of everyday actions. However, for the purpose of this particular paper, the main technique of collecting information was through telephonic conversations, which had its own challenges which could be a limitation as to the aspect of it being less personal. Nevertheless, as a researcher I had built prior connections during my PhD fieldwork, which made it more feasible for me to establish a relationship of familiarity. The conversations were focused on COVID and how it contributed in redesigning meanings and practices of language, relationships and above all the understanding of care and ageing in light of disability within the changing family structures.

I restricted myself from visiting stories of other Indian cities, as I have an aspect of reflexivity in terms of living in the city of study during this dire situation. Also, having a shared habitus of living with elderly parents-in-law (one of whom we lost a month ago) gave me a vantage point. It was a privilege to have their children living with them at this moment of panic and ‘social distancing’, which gave rise to the need to look at the social conditions of those older persons who are living alone or only with their spouses. The situation becomes grave when either or both of them are persons with disabilities. The four case studies in the following sections, document exactly those situations that a broader question on the effects of a pandemic like COVID 19 on a traditional society like Assam.

Ageing alone: from social reciprocity to social distance

For the first time I feel very alone.... (pauses).... what if I die in my sleep...? Do you think they ...will they? (a confused pause) just let me decompose (with an additional emphasis)? Will my children be able to even see me for the last time? In that case, who performs my last rites?’

The above is a part of a telephonic conversation that had taken place with an elderly woman of 83 years. It is a significant addition in the paper, as it lets us interpret the manifold layers of meanings, attached to the very words as well as the sentiments behind it. The recent practice of social distancing during the COVID 19, has brought in a shared suffering of loneliness, uncertainty and anxiousness. The above excerpt also speaks of an indiscernible longing for one’s loved ones, in the event of living alone. Old age essentially is attached with an undertone of fear although, within the meaning of an Indian personhood, there is an idea of readiness (Lamb, 2000) towards death. This readiness towards the ultimate destination, does get compromised in the form of fear, when one imagines ageing to be accompanied with disability. Within the fabric of the Assamese society, there has been a significant transition in the family structures— from joint to nuclear and sometimes single households, in the event of children moving away to other cosmopolitan cities, or when experiencing spousal loss also created a vacuum in the lives of the older people (Bezbaruah, 2018). This emptiness is every so often, filled by the act of social reciprocity, in the form of having significant others, like friends and good neighbours, that makes one belong to something larger than their own personal space.

The casual 'Hello' (Bhaal ne) has an inherent attachment of care, and lets the person be in connection to another. The sharing of quality time and food is an eminent activity among the middle-class ageing population of Guwahati. The concept of 'abelir saah' (evening tea) has been a valuable part of the Assamese society. Moreover, the act of shared care, is an integral part of the 'social' here. While the neighbourhood is considered to be a large support system, which in return has always valued its older generation, especially when they live in the common boundaries of comfort. Therefore, it was found that the neighbourhood social reciprocity has a significant relation to better mental health.

The Assamese society based on the principles of social reciprocity and social interaction, now faces a new reality of social distancing, which has been described and accepted by many as the 'new normal', but has left the older people to age alone. Moreover, an outbreak such as the COVID 19, which has an age specific vulnerability further attaches a stigma on the older generation. Everyday conversations such as 'You need to take more care or else you might infect others', seem to be loaded with censure and stigmatize the older person, although does not intend any harm. But it often causes a psychosomatic distress (Nayar and Mehrotra, 2015) to older persons who are already facing a state of physical ambiguity, creating blank spaces, with nothing to fill up with, but thoughts of uncertain presence amidst the chaos.

In the case of the 83-year-old woman, who was referred to as Borma, an equivalent to an aunt senior to one's own mother,² belonged to a single household, living in a two-bedroom apartment, having just a part time help who has not been able to come since the lockdown. Her two children lived in different cities with their respective families, in Mumbai and New Castle. Her building committee members have been very firm and abiding by the government rules and have not allowed any outside help to come into the premises. They continued to do so even after the government directives allowed the domestic helps to join their duties. The elderly woman has been performing all the household chores like cleaning, washing and cooking. This restriction of part timers, was seen as a precautionary measure, by the internal committee against the spread of the corona virus. However, overlooking the fact that there were older members living in the apartments who needed assistance for domestic chores. It was loaded with an assumption that older people are dependent on their family in their everyday life. The Assamese middle class on the contrary decided to be more independent in the light of their descendants being away. Which was encouraged prior to corona times is now looked at with deride, as it involved larger social responsibility. It is important to understand the desperate change in the behaviour of the committee, which is otherwise very respectful, decided to question her choice of autonomy and reprimanded her by saying 'Why do you live alone when you are an old person?' This is attached with a prejudice against older people's choice of autonomy and independent living, as through this case one can see a resurrection of a passive local belief, that old age in itself is a disability. This situation underlines what Mike Oliver (1989:17) described, that dependency among the disabled people is created, not due to the limitations of functionality, which effects their self-care, but because their lived experiences

are often shaped by the variety of practices that are produced by the political, economic and social forces of their times.

It provokes a dialogue, so as to if the need for care or assistance is viewed as a sign of dependence or an opportunity that allows one to be independent. Through this the paper unfolds the story of another participant, who is a 90-year-old disabled man, a widower and a father of four daughters. He awaits the conclusion of ‘the interval’ as he referred to the practice of social distancing brought by COVID, and says:

I have no idea how a smart phone works. I used to call Biren (the rickshaw driver) wherever I needed to go. He has not been able to help me much these days.... (pauses) He is not taking my calls. There is a lockdown!!! (emphasis) ...I understand. Social distance no?

In this situation the elderly man lives alone in the city of Guwahati, while his married daughters are spread out in different corners of the state. For the last seven years the old man’s support system in terms of mobility has been this auto rickshaw driver who would take him to his doctor’s visits, help him get his groceries and take him around the city. He had fractured both his knees about five years ago due to a fall in the backyard of his home, as a result of which he experiences limited physical movement. Being home bound he feels restless and the feeling of the unknown makes him weary. Popular notions might constantly suggest that it is not exactly social distancing but physical distancing. However, because this elderly man does not really understand the dynamic advantages of the internet or the smartphone, he experiences a lack of social connectivity as a result of which he feels anxious and also is prone to the ‘loneliness epidemic’ which is a part of the social suffering³ that the pandemic is gradually bringing the society into. His feeling of empowerment, was in the choice of autonomy, sitting at the back seat of the auto rickshaw, watching the world in action, while he experienced independence by participating in it.

He cannot step out now, even with his walking stick, in his front yard, as neighbours have observed reservation against it, due to the fear of COVID 19, and the apprehension of the him being a potential carrier. As in one occasion, his neighbour politely told him, ‘Stay inside Uncle. You do not want to get us infected, do you?’ This was a situation which the elderly could not make sense of, as he was confused, if he experienced care or abuse. The abuse of course was not characteristic in any of the words that his neighbour said, as he emphasised upon the politeness of his neighbour. However, it left him to experience an unwanted feeling of despair which he did not experience earlier in spite of his condition of physical disability. This despair could not be explained in a way familiar to him since he always admired his personal choice of autonomy. In addition, within the traditions of the Assamese society the older persons are primarily treated with a lot of regard, and not often reprimanded. The regard (when the neighbour addressed the old man as Uncle) was used as a camouflaged act of covert control,

over the older disabled body and his choice to venture into his front yard, while the neighbour too was indulging in the same activity.

With these circumstantial transitions that the society in general is a witness to, the invisibility of the aged during the social crisis of the pandemic is evident through the stories of the two participants discussed above as well as the ones that follow in the next section. When we say invisibility of the aged, it is in reference to the assumption that their experiences of possible despair, were not visible to the otherwise sensitive and reciprocal society, they lived in.

Feeling lost: ageing and disability in the absence of caregivers

The *daityo* (duty) towards *jotno* (care), is important for the caregivers who play a significant part in the lives of people with disabilities, and all the more if they are older people with disabilities. For older adults and people with disabilities, caregivers not only fulfil their essential everyday needs, but are also responsible in a large way, for their emotional wellbeing. During the nation-wide lockdown in India, which was announced on the 25th March of 2020, this support system of older people with disabilities, was heavily compromised. Many could not prepare themselves and plan any substitute for their regular caregivers (in this case the ones with the need for formal caregiving), as it was a sudden initiative by the government of India, with the hope of controlling the spread of the corona virus. As a result of this, in certain cases, elderly persons with disabilities were left stranded without the usual care facilities that they were dependent on⁴.

In a crisis such as this, older persons with disabilities needed to negotiate a changing meaning of the social he/she understood in terms of care (*jotno*). What was expected to be a norm, suddenly faded, pushing one towards the direction of the uncertain:

The nurse taught me how to monitor his breathing in the machine here in the room. She told me I can call her for assistance whenever I need it. I get very nervous, (long pause) ...but I need to be strong in such times. (Quavering voice followed by a cough) ...His life depends on me!!

This is the story of an elderly couple who live alone in a three-bedroom apartment while their only son and his family live in the United Kingdom. The husband (83 years) is a patient recovering from stroke, and he needs to be constantly monitored. His primary caregivers over the last year since his stroke, were his wife (78 years) and two paid nurses providing medical assistance. During the lockdown, neither of the nurses reported to duty as they feared the elderly couple may be exposed to the virus, as they might carry it while travelling. They jointly decided to assist the elderly wife, through telephone and video calls, while performing the medical monitoring of her bedridden husband. The wife finds it a mental struggle to connect

through a regular call as she is partially deaf and relies on a hearing-aid. She finds the video calling better as the nurse could also check if everything is in order. As a result of this, the 78-year-old partially deaf woman, became the sole caregiver of the patient. Her caregiving duties included bathing her husband, dressing him, feeding him, reading to him as well as monitoring his medical health status, and reporting it to the nurses in order to check with any irregularities. Apart from performing these responsibilities with her husband, she also needed to ensure that the house was clean, as her husband has a lower immunity system due to his medical state and age, and should not be exposed to any infection. While doing so, she needed to do it all by herself, as unlike before the lockdown, her regular part-time carer could no longer come and perform her duties. This now extremely exhausted, sleep-deprived and anxious elderly woman complains of loneliness and fear. The act of continuous caregiving for a disabled husband, especially with the sudden absence of dependable resources has left her at risk of depression. Although caregiving is an otherwise positive experience which enriches a person by developing resilience and by acquiring a sense of self-worth, the continuous process of care could also leave one vulnerable to stress. This experience of stress could bring a negative impact on the caregiver's physical, psychological and emotional wellbeing. The experiences of the pandemic, are a matter of great worry for the entire population in general, but it has been primarily harsh on the ones who are elderly with disabilities. In both situations, one's physical abilities are compromised in their everyday lives, but now with diminishing support systems and the lack of resources of familiarity, one experiences a state of confusion often 'feeling lost'.

In another case, a 90-year-old blind lawyer is at a loss of understanding as to why his usual reader has not been coming to read the daily newspaper. His wife of 88 years of age, tries to reason with him that movement is restricted due to the pandemic. The childless couple, experience a lot of uncertainty as they see a major shift in the meanings of social that they previously understood. Their chauffeur has been granted leave which means that in times of medical emergency, no one can take them to a doctor. Even the medical caregivers in the hospitals are reluctant to provide medical advice over the phone without a physical examination. Finally, in the event of the elderly lawyer's death, there weren't many relatives who could participate in the rituals as there was a fear of infection caused by COVID. The funeral rituals were carried out by the elderly couple's house help. The elderly wife, while having a telephonic conversation mentioned her condition of diabetes, in addition to having hypertension and asthma and needed a doctor but could not afford one, as most of her calls go unanswered.

In the above stories, one can see a symbolic disability within the experiences of physical disabilities, whether of the recipient of care or the caregiver. This symbolic disability is the result of the social suffering one got exposed to unexpectedly, changing their personal meanings of ageing with disabilities. The experience of 'being lost', for being unable to access the 'normal' that one associated with, subsequently awakens a personhood characterised by uncertainty.

Conclusion

‘Uncertain personhood’ is therefore not only a term to define a state of mind at a particular point of time. It is rather the consequence of incorporations of unfamiliar social situations, demanding an extreme transition, away from the familiar meanings and enduring cultures of reciprocity of care, *jotno* bound by duty *daityo* in the Assamese society. Older people with disabilities are enabled through the culture of care, a virtue within South Asian societies, which is not just an act but a disposition, manifested in behaviour (the labour of love). In this virtue, an individual is transformed into a person, who puts the other who needs the care before his/her own personal needs and interests (Gastmans et al., 1998:53). Relations of affection facilitate care by both familiar people as well as strangers. This unexpected fading of the social structure based on care and social reciprocity, in the form of good neighbours or caregivers, who otherwise sees it to be their *daityo* (duty) to ensure *jotno* (care), symbolise a disability of the social system, causing a social suffering earlier unknown to the definition of personhood, of the Assamese older person.

Notes

¹ Liminality is a term coined by the Anthropologist Victor Turner to describe the situation of such individuals who do not have a clear status, because a prior identity has been expunged and re-allocation has not yet occurred. The disabled individual often experiences a phase of liminality posed by society.

² Like Indian personhood and in the context of the paper, Assamese personhood, rests on the fundamental principles of relationality, which is often seen in the way one addresses another, showing an aspect of respect. An individual older than oneself is often addressed with relational respect through terms such as *baideo* (older sister), *dada* (older brother), *bordeuta/khura/moha* (uncle), *borma/jethai/khuri/mahi/pehi* (aunt), *aitaa* (grandmother), and *koka* (grandfather). But an interesting aspect of this relationality is that these kinship terms which are used to address the elders, may not be actual blood relations. Therefore, in India an individual is often not just an individual, but is also someone in relation to others.

³ The pandemic is another experience of social suffering, leading to a symbolic disability.

⁴ This situation was a cause of concern during the first lockdown period, as subsequently the government, under the department of empowerment of persons with disabilities of the ministry of social justice, issued an advisory to the states and the union territories on the ‘protection and safety’ during the coronavirus outbreak.

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