

Gendered nature of caregiving across the lifespan: A study on ‘disabled households’ in Assam, India

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Family support plays a significant role in the lives of persons with disabilities, particularly in the context of the global South where education, employment opportunities and marriage prospects are limited and social security benefits are inadequate. This paper elaborates on caregiving through a gendered lens in the context of an urban district in Assam, a state located in the north-eastern region of India. The study was conducted with 18 women with different locomotor impairments, ranging from mild to severe, in the age group of 18-57 years. Using intersectionality as the analytical framework, the paper highlights the dependence of the study participants on their family members across two phases of their lives— childhood and adulthood. The paper explores the gendered nature of caregiving in the family and shows how, even though the caregiver changes with the passage of time, from parents to siblings, the gendered division of caregiving responsibilities remains intact. The paper further delineates the heterogeneous experience of disablement by exploring different axes such as the nature of impairment, social class and place of residence (rural/ urban)

Keywords: Women with locomotor disabilities; disabled households; gendered caregiving; disability and family; intersectionality; Assam

Introduction

In most societies around the world, those who cannot work due to the nature of their impairments, inevitably become dependent on the state or the family. This dependency, however, is not intrinsic to their physical or medical condition, but is instead socially constructed because they are indiscriminately ruled out from actively participating in society (Dalley, 1998). Furthermore, in societies that do not have formal care systems, the principal structure of kinship provides the basis of caring. Due to this reason, the hardships that persons with disabilities experience in their everyday lives, depend on the care and support they receive from their families, which has the capacity to either mitigate their issues or to complicate them further through marginalization and stigmatization (ibid).

Literature on family support for persons with disabilities from the global North has highlighted the issue of disability and care work from different perspectives. For instance, feminists have

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critiqued the sexual division of labour that places the burden of care on women and contributes towards gender inequality (Tong, 2009). Others feminists have spent considerable energy in developing a feminist ethics of care that valorises care work (Gilligan, 1982). In contrast, disability scholars have vehemently critiqued feminist accounts of care work because of its sole interest on emphasizing upon the ‘burdens’ experienced by the caregiver, while completely overlooking the feelings and experiences of those who receive care (Morris, 1995). Due to the history of institutionalization of persons with disabilities (see Finkelstein, 1991), disability studies literature has focused on self-sufficiency and the ability to exercise choice and control over how necessary help is provided to persons with disabilities (Brisenden, 1986; Finkelstein, 1991). It is probably due to this reason that there has been reluctance in disability studies literature from the global North to explore the role of family support in the lives of persons with disabilities (Goodley & McLaughlin, 2008; Ryan & Runswick-Cole, 2008).

In contrast, studies conducted in different contexts of the global South have focused extensively on the informal familial care that persons with disabilities receive, which, in the absence of any state support, is sometimes the only form of care available to them (Dalal, 2002; Eide & Ingstad, 2011; Grech, 2009, 2015, 2019; Ghosh & Banerjee, 2017; Addlakha, 2020). In some cases, the concept of ‘the disabled household’ (Grut, Olenja & Ingstad, 2011; Ingstad, Baider & Grut, 2011; Grech, 2019) has been used to refer to the importance of family for persons with disabilities in the global South. It means that when there is an impaired individual in the family, it affects all the other members as it necessitates that the resources available to the family are reorganized to accommodate the needs of the person with a disability (Ingstad, Baider & Grut, 2011). In this way, along with the disabled individual, the family also becomes disabled (*ibid*). Furthermore, the concept also suggests that when poor disabled families in the global South do not provide opportunities for their disabled family members, it is not because they are hidden away by their families out of shame and embarrassment as is suggested by some (see Stone-Macdonald & Butera, 2012), but usually because they are not able to support their children or they do not have the requisite information to help them (Eide & Ingstad, 2011).

In the Indian context, several studies have shown that the family plays a major role in the management of impairment and rehabilitation of persons with disabilities (Ghosh, 2016; Mehrotra, 2004; Ghai, 2003; Vaidya, 2015; Chakravarty, 2002), even though the general attitude of the family towards them has been paternalistic (Dalal, 2002; Ghosh & Banerjee, 2017). Due to the intersection of a number of factors such as poverty, lack of access to adequate healthcare, education, employment opportunities and other resources (Klasing 2007; Ghosh & Banerjee, 2017) and the absence of any form of state support (Chakravarty, 2002), the responsibility of caring for persons with disabilities in India falls squarely on the family, especially the mother (Chakravarty, 2002; Vaidya, 2015) in the younger ages. When the child grows up and the parents are either too old or are not around to help, it is usually the siblings who are expected to take up this responsibility, either willingly or out of compulsion (Chakravarty, 2002; Ghosh, 2016). However, different macro-level processes such as

urbanization, industrialization and globalization have resulted in the breakup of the traditional joint family system (Upadhyay & Singh, 2017). This, along with out-migration of the youth, increased workforce participation of women, while rising individualism in the younger generation has resulted in the marginalization of vulnerable family members such as widowed women and older persons (see Vatuk, 1995; Lamb, 2000; Upadhyay & Singh, 2017). We would suggest that persons with disabilities must also be suffering from a similar fate, although this facet has not been covered extensively in the existing research.

The aim of this paper is to elaborate on the care and support that women with locomotor disabilities who had acquired their impairments early in life had received from their families in a north-eastern state, where the experience of disablement has not received much attention. The paper argues that in the context of the global South where education, employment opportunities and marriage prospects are limited and social security benefits inadequate, women with disabilities have no other option but to depend on different members of their families throughout their lives. The paper explores the gendered nature of caregiving in the family and shows how, even though the caregiver changes with the passage of time, from parents to siblings, the gendered division of caregiving responsibilities remains intact. The paper uses the analytical framework of intersectionality to delineate the heterogeneous experience of disablement by exploring different axes such as nature of impairment, social class and place of residence (rural/ urban). The following section provides the context of the study.

Contextualizing disability in Assam

Assam is located in the north-eastern region (NER) of India and is surrounded by West Bengal and six other north-eastern states (viz. Arunachal Pradesh, Manipur, Meghalaya, Mizoram, Nagaland and Tripura) and two neighbouring countries (viz. Bangladesh and Bhutan). Historically, the NER was politically integrated with any north Indian empires prior to the advent of British rule in 1826 (Sharma, 1980). After independence in 1947, the NER is connected to the rest of the country through a 22 km stretch of land in West Bengal known as the Siliguri corridor (Baishya, 2016). Assam has the highest population in the region (31 million according to Census 2011) and comprises of districts in the Brahmaputra Valley and the Barak Valley which are separated from one another by three hill districts (Baishya, 2016). Assam comprises of people belonging to different national, ethnic, religious and linguistic groups (Srikantha, 2000). It is, however, very difficult to comment upon who constitutes the indigenous population in the state as most of the groups inhabiting the entire NER came here from different places at different points of time (Mahadevia, Desai & Mishra, 2014). The more recent demographic change, however, was initiated during British rule when they brought different communities of people from 'mainland' India with the primary aim to monetize Assam's underdeveloped economy to effectively serve its imperial interests (Boruah, 1980;

Goswami, 2001). Due to the multi-ethnic character of the state, sometimes Assam is called the 'melting pot' of diverse cultural streams, the Indo-Aryan and the Austro-Mongoloid being the central ones (Misra, 1999). This multi-ethnic composition of the population has also resulted in multiple socio-political problems after independence such as insurgency, economic underdevelopment, ethnic movements, resurgent sub-national movements and unchecked foreign infiltrations. As a consequence of these problems, Assam is one of the most underdeveloped and politically destabilised states in India (J. K. Das, 2005).

The multi-ethnic character of the state also makes it implausible to uphold a singular image of the women of Assam. Not many studies have focused on the everyday experiences of women belonging to different ethnic communities in the state. Instead, much of the literature on the status of women has either focused on the gendered dimensions of conflict and insurgency or on socio-political empowerment of women (Mahjebeen, 2018). There is, however, a commonly held belief among the people of Assam and the NER that women 'enjoy' far greater freedom than their counterparts in the rest of the country (ibid). This is primarily due to the absence of any apparent restriction on their mobility as well as the absence of certain evil practices that are widespread in the rest of India such as dowry, sati, female foeticide and infanticide and the practice of wearing a veil (Buongpui, 2013). Despite this visible gender equality, this picture of women enjoying a higher status in the society of Assam is questionable given the statistics that shows gender disparities in health, education, employment and income and the increasing crimes against women in the region (Assam HDR, 2014).

Method

This study was conducted as part of the author's PhD research on the lived experiences of women ageing with early onset locomotor disabilities in an urban district in Assam, India. The fieldwork for the study took place in Kamrup Metropolitan district¹. Kamrup Metropolitan was chosen as the study site due to the presence of multiple disability organizations that facilitated the recruitment of study participants. It is one of the 33 districts of Assam that was carved out in 2003 out of the erstwhile Kamrup District. In a predominantly rural state (86 per cent of the total population in Assam reside in rural areas according to the 2011² census), this district is an exception as out of a total population of 1.2 million, an overwhelming majority of 1 million individuals reside in the urban areas of the district (Official Website: Kamrup Metropolitan District Administration). The administrative headquarters of the district is located in the city of Guwahati. It is the largest city in the entire NER and considered to be the gateway of the region. The capital of Assam was shifted from Shillong to Dispur, a suburb in Guwahati, in 1972, when the state of Meghalaya was carved out of Assam and the city of Shillong became the capital of the newly formed state (Mahadevia, Desai & Mishra, 2014).

Eighteen women with different locomotor impairments, ranging from mild to severe, between the ages of 18-57 years were interviewed using the life history method (Kakuru & Paradza,

2007). The main inclusion criteria for the study were: onset of locomotor disability below 18 years of age; and their ability and willingness to share their lived experiences in detail. These women were recruited with the help of four disability organizations that responded to the author's calls/emails asking for their cooperation to facilitate the recruitment of the study participants. Out of these four organizations, three were located in the city of Guwahati, while one was located in a rural block in the vicinity of Guwahati. Apart from these women, in-depth interviews were conducted with the family members of these women, particularly their mothers, to gain deeper insights about the participants' lives and family situation. The interviews focused on different aspects of living with early onset disabilities such as nature and degree of impairment, care received from the parents and other family members, education, marriage and employment prospects, access to healthcare services over the life course, psycho-emotional well-being and concerns about their futures. The interviews typically lasted between one and half to two hours and were sometimes conducted over multiple sessions either in the disability organizations (where they worked/ or from where they accessed certain livelihood-related training) or their homes, as per their convenience.

The women were mostly literate but a majority of them had not passed high school due to different familial, social and infrastructural barriers (n=7). Others couldn't study further due to the same reasons (n=5) or had studied in a special school due to the nature of their impairments, making it difficult for them to retain anything they learned in 'normal' schools (n=2). One was still studying in school at the time of the study, while two were pursuing their graduate studies via distance learning and only one was a graduate. As a result of their lack of educational qualifications, a majority of them had no other option but to work in disability organizations (n= 8) that paid them a minimum stipend of 1200-2000 INR (USD15 to 24) per month for their services. Despite the poor pay, the women continued to work in these organizations because it was the only source of income available to them, and being able to find work outside of their homes increased their status in their family and the community where they lived. Others were self-employed (n=2) or unemployed due to the nature of their impairments (n=3) or were solely homemakers (n=2). Two were still in school (1 in a 'normal' school and 1 in a special school) while one was a founder of a disability organization. Out of the 18 women, only 5 were married at the time of the interview and one was widowed. Since marriage is considered to be an important sacrament in the socio-economic milieu to which these women belonged (Bhattacharyya, 2009; Mahjebeen, 2018), non-acceptance of women with disabilities as marriage partners was considered to be a matter of great misfortune by their parents.

The women belonged to different ethnic and linguistic groups (Assamese, Bengali, Nepali and Karbi) but the interviews were conducted in Assamese, a language they were all familiar with. The interviews were audio recorded with the permission of the participants and were later translated and transcribed to English by the author. The transcribed interviews provided a wealth of material and it was supplemented with copious field notes to understand the lived experiences of the study participants better. Thematic analysis was used to interpret the data

which involved an inductive and iterative process of rereading the interview transcripts and field notes until patterns emerged from the data which then helped in forming themes and categories (Braun & Clarke, 2006). After reading the transcripts multiple times, it was found that in the absence of any kind of social security, different members of their natal family played a significant role in their lives not only in their formative years, but also later in their adulthood. This paper focuses on these two stages of life to emphasize the atypical roles that parents and siblings of women with disabilities play in the cultural context of Assam. The paper employs intersectionality as its analytical framework, which recognizes that human lives are multi-dimensional and their lived realities are shaped by diverse social factors and power dynamics that are interlinked but can change over time and space (Hankivsky, 2014). Intersectionality also acknowledges that individuals can experience privilege and oppression simultaneously at the micro level, and a multi-level analysis that links individual experiences to broader social structures and systems is crucial for understanding how power relations are shaped and experienced (Ibid).

The study received ethical approval from the Institutional Ethics Review Board of Jawaharlal Nehru University, New Delhi. Before starting the interviews, the study participants were explained the nature of the study and their participation and the questions that they would be asked. They were informed that participation in the study was voluntary and they have the right to withdraw at any point. Written consent was obtained from the participants before the interviews and they were assured that their identities would remain confidential in the papers that would be published from this research.

Findings

Support from the family in the early stages of life

In the early stages of their lives, children with disabilities, like all other children, typically remain dependent on their parents for care (Chakravarty, 2002). A prominent theme in the literature on family and disability in India is the rigid gendered division of labour in the family, whereby mothers take the entire responsibility of caring for the disabled child, while the fathers work outside of the home and remain distant from the mother-child dyad (Chakravarti, 2002; Mehrotra, 2004; Vaidya, 2015; Ghosh, 2016). Similar division of labour in the family was also observed in the current study, where mothers were overburdened with care and domestic work, which are equally trying and unrewarding. Risha (35, cerebral palsy) said that even though both her parents looked after her in her childhood, her mother was her primary caregiver since she was a housewife and was always available at home. She further said that things were particularly difficult for her mother as she had to look after Risha and her younger brother as well as the household responsibilities. In order to ease her mother's workload, her father had hired a live-in domestic worker, but in spite of this, her mother had to manage most of the work.

Similar socio-economic advantage, however, was not available for the parents of several other study participants. Sobiha's (18, cerebral palsy) widowed mother had to juggle between looking after her two infant daughters, household chores and earning a livelihood for her family as she was not able to avail any sort of financial support after the death of her husband. These narratives suggest that even though the fathers may not help with care work, their assigned gender role of being the provider of the family helps in lessening the burden on the mothers.

In other cases, it was found that, despite living in poverty, mothers of children with disabilities were not allowed by their husbands to work to supplement the family income as their primary responsibility was considered to be care work. Nayana (30+, post-polio residual paralysis), whose father worked as a domestic worker for a rich family, said that after she grew up and started going to school, her mother conveyed her desire to engage in paid employment in order to supplement the family income. Nayana's father, however, was strictly against this proposition, as according to him, working outside the home would divert her attention from her primary responsibility of providing care for their disabled daughter. This narrative suggests that even in poorer households which need the income of both the parents, the mother is expected to devote solely to her care-giving responsibilities, while the father fulfilled the role of a breadwinner, thus keeping intact the rigid gendered division of labour in the family. Nayana considered her father's response as his love towards her. Like Nayana, several other study participants and their mothers lauded their fathers when they did the bare minimum and *cared for* or *cared about* (Traustadottir, 1991) their children, primarily because in the cultural context of Assam, they were not expected to show any form of care at all. Mayuri's mother said that after Mayuri acquired her impairment (57, post-polio residual paralysis), their family doctor prescribed her two body massage oils which were to be rubbed softly on her limbs. Her mother said that after Mayuri's initial management at her maternal grandparents' home, when she and Mayuri went back to their home in Shillong (the erstwhile capital of Assam), Mayuri's father took this responsibility from his wife saying that she will not be able to do it properly. Instead of feeling offended by his comments, Mayuri's mother praised her husband for his caring nature towards their daughter, because such form of caregiving was outside of his domain, and therefore, was not expected of him.

In the literature on family support for children with disabilities it has been observed that most studies have focused on the important roles played by mothers, while very few studies have looked at the roles played by fathers (Ryan & Runswick-Cole, 2008). Similar to Mehrotra's (2004) study, this study found that while mothers provided care to the child within the private domain, major decisions that are in the public domain regarding treatment and rehabilitation were taken by the fathers. Due to this rigid division of labour, the study found that when the fathers were not able to take their children for treatment due to work commitments or in most situations, due to their untimely deaths, the participants had to forgo their treatment completely. Nayana said that one of the things that she remembered from her childhood was the frequent fights between her parents. She said that her mother always blamed her father for his inability

to take Nayana to the hospital on time. She was angry with him for not adhering to his gender role of being the saviour when needed. Her father, on the other hand, fought back by saying that his work commitments gave him very little time to think about his sick daughter. This narrative shows that due to the rigid gender division of care work, it was considered the father's responsibility to take the child to the hospital for treatment. While most studies have revolved around mother-blaming for the child's disability (Chakravarty, 2002), in this study it was found that Nayana's mother blamed her father for their child's disability due to his inability to do the work that was in his domain.

Several participants in this study unfortunately lost their fathers at a very early age. Their deaths hindered the treatment and rehabilitation of the women in myriad ways. Pronoti (26), who had acquired her impairment after a bout of fever, was seeking rehabilitation from a government rehabilitation centre in Guwahati. Her father passed away in an accident during this period. In the absence of a working member in the family, Pronoti had to abruptly stop her treatment since her mother decided to move her family back to their village as they could not bear the expenses of living in the city. Unfortunately, there were no rehabilitation centres in the village so she could not continue her treatment after the move. Similarly, Gargi's (18, cerebral palsy) physical rehabilitation sessions also stopped after the sudden death of her father in an accident. Gargi's father also took her for her physical rehabilitation sessions to Guwahati which is about 40 km away from their village. After his death, however, these sessions stopped as her mother could not travel all the way alone. Apart from this, as a dependent widow, Gargi's mother also lost her bargaining power in a patriarchal joint family setup and could not ask her husband's brothers to take her daughter to the city for her rehabilitation sessions.

Unlike the untimely death of fathers that restricted their treatment and rehabilitation, the untimely deaths of mothers led to other kinds of problems for the women. Anamika (38, impairment due to medical negligence) said that the death of her mother in childbirth when she was three years old was a catastrophic event, far more devastating for her and her family than her impairment. This was because she and her younger sister were left to fend for themselves from a very early age, while their father whiled away most of his time by drinking with his friends. Anamika said that she and her sister had to manage all the household and agricultural chores from the age of around 10 years which left them with very little time to concentrate on their studies. According to her, lack of basic education proved to be a major hurdle for her in having access to a better paying job in her adult life.

The study also found that the place of residence determined the nature of support available to the families of persons with disabilities. For instance, in the urban areas, since families are usually nuclear in size, no other person from the extended family was available to support the parents in taking care of their disabled children. As a result, the mothers were overburdened with care work. This was true for those who were settled in the city of Guwahati and belonged to affluent backgrounds, as well as for poor migrant families who came to the city for work.

This is viewed in the narratives of Risha, Sobiha and Nayana whose mothers struggled a lot in bringing up their children. In contrast, in rural areas, the families were either joint or the father's brothers lived contiguously to one another. This meant that there was always someone available to ease the mother's caring workload. Gargi and Lata said that both of them were brought up by their paternal grandmothers that helped their mothers in concentrating on their other chores.

Family support in adulthood and the important role played by siblings

In the literature on family support for persons with developmental disabilities, it can be seen that parents go through the grief cycle twice, once when their child is first diagnosed, and the second time when the child is around 20 years of age (Chakravarty, 2002). This is because as the child grows up, parents are usually consumed by different kinds of anxieties like their own age, their ill health, death anxiety and the fact that the future of the disabled child has to be secured before they die (Chakravarty, 2002). Additionally, parents also live in the morbid fear that their disabled children might outlive them and they worry about who would look after their children once they have passed on (ibid). In order to prepare for such an eventuality, parents usually prepare their nondisabled children to look after their disabled siblings from a very early age (Vaidya, 2015). In this study, this was found to be true in the case of the women with severe disabilities. Sobiha and Gargi's mothers expected their younger nondisabled daughters to look after their older disabled siblings. For this purpose, they had also educated their nondisabled children to make them capable of earning a decent income to look after themselves and their disabled sisters.

The women with severe disabilities in the study, on the other hand, were not very keen about such an arrangement and worried about what would happen to them after their parents passed on. Ananya (23, cerebral palsy) said that she was very concerned about her future after her parents had passed on as she did not have a very cordial relationship with her older sister and did not want to depend on her in the future. Korobi (51, head injury and later severe burn injury) also said that when she was younger, her second sister had suggested that she would remain unmarried and take care of Korobi throughout her life. Korobi, however, refused such an arrangement as she did not want to stand in the way of her sister's life. Instead, she was keen on getting married herself. Her parents arranged her marriage with a nondisabled man and at the time of the study, she had an adolescent son. After her marriage, her husband became her primary caregiver. He was not engaged in paid employment and they lived with her mother and were dependent on her for their sustenance. While Korobi's mother appreciated Korobi's husband for his commendable care and support towards her daughter, his lack of earnings was a matter of grave concern for her daughter's future. This is to be understood in the cultural context of a patriarchal society where a *ghor juwai*, a son-in-law who continues to live with his wife's family, is looked down upon and ridiculed. In Korobi's situation, although her disability neutralised some of these negative connotations, his lack of earnings was still frowned upon

by her mother.

Unlike women with severe disabilities, the study found that women with mild to moderate disabilities did not usually experience any difference between themselves and their nondisabled siblings in their younger ages. This has also been observed in other studies (Mehrotra, 2004; Ghosh, 2016). It was only after they grew up that the women realised that they were different from their siblings. One of the forceful ways this difference was made clear to them was when, unlike their nondisabled siblings, these women were not considered to be desirable for marriage. Since marriage is considered to be a very important sacrament in the society of Assam (Bhattacharyya, 2009; Mahjebeen, 2018), women with disabilities find themselves to be 'roleless' (Ghai, 2003) in their natal families in their adulthood. Their situation is further compounded by the fact that due to their lack of educational qualifications, these women also failed to find employment in better paying jobs. Due to all these factors, women with disabilities, irrespective of the degree of their impairments, have no other option but to remain dependent on their families throughout their lives. In most cases, the women emphasized that they did not have any worries about their situation in the family till their parents were alive. However, they were not sure whether their male siblings and their families would look after them in the future. This fear was also accentuated by their concerns over their own deteriorating physical condition and whether or not it would allow them to work in the future – at home or outside, for those who were engaged in paid employment. As shown in other studies (Ghosh, 2016), their productivity determined their social standing in the family, especially with their brothers and their spouses, and due to this reason not being able to work in the future was a matter of grave concern for the women. Minakkhi (42, syndactyly), who was employed in a disability organization, said that her relationship with her brothers and their families was very good at the moment and they helped her out with all her activities, but she was unsure whether such a relationship will be sustained in the future. Similarly, Dolly (34, amputation of right upper limb after a workplace accident at the age 14), who was also employed in a disability organization, said that she had a very cordial relationship with her younger brother, but she did not know if things would change for her once he gets married.

In other cases, the women reported feeling neglected and discriminated after their brothers got married. Chitra (30+, cerebral palsy), who was a homemaker, said that she and her sister-in-law could not stand each other and they have had multiple fights in the past. This is one of the reasons that she did not want to continue living with her brother's family and decided to get married when a proposal came for her from a disabled man. She said that even though her husband is a disabled person and is not earning a good income, at least she has 'peace of my mind' in her own household. Similarly, Hema (34, puncture wound that resulted in the amputation of her right lower limb), who was self-employed, said that her relationship with her brother changed drastically after he got married. She said that her sister-in-law had brainwashed her brother and then her father to throw Hema and her mother out of the house so that they do not have to look after her in the future. These narratives, therefore, show the precarious

condition of women with disabilities in the family after their parents grow old or are no longer around and their siblings take control of matters in the family.

It is to be noted that in accord with the prevalent cultural norms, the women only had expectations of support from their brothers and their families, and not their sisters and their families, who were considered to be outsiders after marriage. This is because in the Indian context, a married woman's allegiance is demanded exclusively by her marital family after marriage. Due to this reason, women who did not have brothers worried more about their futures as they would be left with no potential caregivers after their parents. Anamika, who did not have a brother, said that she was very concerned about her future as she may not be able to work and earn a livelihood in her old age. According to her, women with disabilities who have brothers are lucky as they can depend on them and their families for their upkeep. In another case, Surabhi's (30+, cerebral palsy) older sister refused to get married in order to look after her disabled sister in her old age. Not getting married, therefore, was the only option available to women in cases where they wanted to look after the members of their natal families.

Discussion

Using intersectionality as an analytical strategy, this paper highlighted the support received by women with early onset locomotor disabilities in Kamrup Metropolitan District of Assam, India, across two phases of their lives – childhood and adulthood. The care and support received by the women was found to be gendered in nature and depended on a variety of intersecting factors including their age, nature and degree of impairment, social class and place of residence. The study found that the women received considerable care and support from their parents in their childhood. This care and support, however, was gendered in nature, with mothers both *caring for* and *caring about* their daughters (Traustadottor, 1991), resulting in their overburden. This workload was exacerbated if there were no working male members in the family, while it was eased if they hired domestic workers, a class privilege not available to many. In contrast, the fathers were mainly responsible for making decisions regarding treatment and rehabilitation and taking their children to these centres. The study found that the death or absence of either parent resulted in great misfortune in the lives of the study participants, which is an aspect not often discussed in the literature on family support for persons with disabilities. Future studies should also delve deeper into the role of fathers in the lives of their disabled children. Additionally, the study also found that the place of residence (rural/ urban) determined the nature of support available to the parents of persons with disabilities. In contrast to urban areas, where no form of family support was available to the families of the women, in the rural areas, the mothers received considerable support from the extended family that eased their workload to a great extent. This was also found to be true in already existing literature from India (Chakravarty, 2002; Mehrotra, 2004).

In contrast to their childhood experiences, where the women relied heavily on their parents for

care and support, the study found that in their adult lives they were haunted by the fear of who would look after them in their old age. As mentioned above, different macro-level factors such as urbanization, industrialization and globalization have resulted in the break-up of the traditional joint family (Upadhyay & Singh, 2017) and have affected the bonding between different family members, which in turn has further marginalized vulnerable members in the family. Due to such reasons the women in the current study were very concerned about whether their brothers and their families would provide for them in the future. Due to the prevalent gender norms, the women did not have similar expectations from their sisters and their families. Their fear was compounded by the women's relatively low educational qualifications, which made it difficult for them to compete in the job market and limited their options for employment. Due to the history of conflict and insurgency, the private sector in Assam and other states in the NER is relatively underdeveloped (G. Das, 1998; 2012), making government jobs the only option for many. Even with a reservation of five percent in government jobs for persons with disabilities under the Right to Persons with Disabilities Act, 2016, they faced challenges due to poor educational qualifications, social prejudice and infrastructural barriers (Zutshi, 2004; Shenoy, 2011). The situation of women with disabilities is made even more precarious by the fact that unlike their non-disabled sisters and friends, they usually do not have the option to get married as they are considered undesirable for marriage (Ghai, 2003; Ghosh, 2016). In order to understand the predicament of these women better, it is important to contextualise that unmarried middle aged woman is a rarity in the society of Assam. Even among career-oriented middle class women who are pursuing higher education in Guwahati, it has been found that they are brought up with the mind-set that they will have to eventually prioritize their domestic and family roles over their ambitions (Bhattacharyya 2009). Thus, traditional feminine roles of marriage and motherhood are important rites of passage for women in the society of Assam and anyone who is deprived of this experience is usually looked down upon with pity and sympathy.

The findings of the study highlight that the study participants faced multiple social problems that made them dependent on their families throughout their lives. As can be seen from the above findings, this dependence on their families is not associated with their physical disabilities, but is socially constructed by being systematically excluded from actively participating in society (Dalley, 1998). In order to ease the situation for women with severe disabilities, their parents prepare their nondisabled children from a very early age to look after their disabled sisters. In spite of this, some of these women refuse to be dependent on their siblings and nurture the hope that they would get married someday. The women with mild to moderate disabilities, on the other hand, were better aware that marriage will not be easy for them. Due to this reason they get involved in paid employment wherever possible, mostly in places where they were severely underpaid, in order to redefine their relationships with their brothers and their families. In spite of the fact that they were proud of their working status, these women were worried of a future when their bodies will not allow them to work anymore. The findings of the study highlight the heterogeneous experience of disablement. It is

imperative to emphasize this heterogeneity and, in this regard, the analytical framework of intersectionality is very helpful because it makes it clear that human lives are multi-dimensional and their lived realities are shaped by multiple social factors (Hankivsky, 2014). In the study of social problems, no category or structure can be predetermined and it can also be studied during the process of the study (ibid). In this study of disabled households, it can be seen that some of the categories that have determined the lives of study participants, include nature of impairment, social class and place of residence. Other highly researched social categories in the context of this region, on the other hand, such as ethnicity, caste, religion and linguistic identities have not emerged as important categories.

The findings in this study highlight that in the global South where people with disabilities are dependent on their families for their care and support throughout their lives, the concept of *disabled household* aptly defines the predicament of all the family members. It means that when there is a disabled person in the family, it affects all the other members in myriad ways. While existing studies that have used this concept have elaborated it in the context of poverty and deprivation (Grut, Olenja & Ingstad, 2011; Ingstad, Baider & Grut, 2011; Grech, 2019), in this study it is seen that even in situations of relative affluence, people with disabilities continue to remain dependent on their different family members throughout their life course due to systematic discrimination that relegates them to the margins of the society.

Conclusion

Using intersectionality as the analytical framework, this study has elaborated on the care and support that women with disabilities receive from their family members throughout their life course. The study found that even though parents may face financial hurdles in taking care of their disabled children, they would somehow provide for them as they consider themselves responsible for their daughters' well-being. However, once they have passed on, this responsibility automatically shifts on the shoulders of their male siblings and their spouses, which they might find to be burdensome. Such a situation creates greater vulnerabilities for women with disabilities as they have no other source of support available. Due to the absence of any form of state support, different disability organizations have sprung up in the region that employ persons with disabilities for a very meagre pay, if their bodies permit them to work. The findings in this paper, therefore, call for the necessity that government and non-governmental organizations should pay greater heed to the disabled household as a whole, instead of a single disabled individual in that household.

Notes

¹ The fieldwork for the study was divided into two stages. In the first stage, the study participants and their families were interviewed. These interviews were conducted between April 2015 and December 2016. Following the analysis of these interviews, members of the

disability organizations and healthcare providers involved in caring for patients with locomotor disabilities (physicians, orthopaedics and physiotherapists) were interviewed.

² The 2011 census has been quoted in this paper as 2021 census has been postponed till the end of 2024 apparently due to political reasons (see Rajalakshmi, 2023).

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