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Dimensions of invisibility: insights into the daily realities of persons with disabilities living in rural communities in India

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ABSTRACT

Persons with disabilities in rural India do not have the opportunity to lead a self-determined life and be included in their community as required by the convention on the rights of persons with disabilities. To investigate their experience of living everyday life and the amount of agency they are able to exercise, in-depth interviews were undertaken. The Capability Approach (CA) was used to analyse the situation that was seen in terms of outcome of the interplay between internal and external factors resulting in loss of agency. The results show that the dependency they experience due to lack of adequate support to undertake activities and being completely dependent on the family places them in a vicious circle of 'self-worthlessness'. Reducing the dependency disabled people face and changing perceptions of the community towards disability may break this circle.

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Rural India; invisibility; support structure; inaccessibility; capability approach

Points of Interest

- In rural India persons with disabilities are unable to live a self-determined life and to participate in home and community activities.
- The research shows that the interaction between personal, social and environmental factors makes it difficult for persons with disabilities to live a self-determined life and increase dependency.
- The dependency encountered, coupled with the negative attitude of the community towards disability, places the persons with disabilities in a vicious circle of 'worthlessness'.

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- The recommendations suggest reducing the dependency of persons with disabilities on their families, improving the perception of disability in the community and increasing self-esteem of persons with disabilities.

Introduction

The opportunity to live and participate in one's community is a basic human right but achieving this is difficult for most persons with disabilities. They have historically been isolated within their families and segregated from their communities. Constant discrimination has encouraged disabled people to mobilise themselves to attain more choice and control over their lives, to vocalise their need for enhanced support and for more inclusively designed community facilities, and to demand more appropriate living arrangements (UN Committee on the Rights of Persons with Disabilities 2017). The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted to address these needs and to acknowledge the human rights of disabled people. Article 19 of this convention, in particular, supports this struggle since it calls for an end to the isolation and segregation that disabled people face within their families and communities.

The implementation of Article 19 has varied in success in different countries. Although the committee on the Rights of Persons with Disabilities has offered guidance for implementation in different country contexts, developing countries have found it especially challenging to implement such rights-based protocols (Lang et al. 2011; Trani et al. 2011; Grech 2015). While countries have begun to translate the Convention into national laws and policies, often these lack an effective implementation mechanism and the potential will and understanding of the government and civil society to implement them (Lang et al. 2011). In this paper we use the capability approach (CA) that suggests that the implementation process of a human rights instrument such as the convention must recognise that disabled people have the same level of agency to lead a life they value as others and emphasises the need to address the additional resources required for achieving this (Sen 2009). Its proponents argue that the extent to which people can exercise agency is the result of their ability to convert personal, social and environmental factors into real opportunities to lead a life they choose and do things they desire (Sen 2009) and having agency and its lack is seen as the result of interplay of these factors in specific contexts. Therefore, to improve the implementation of Article 19 and enhance the agency of disabled persons, it is important to get insight into the interplay of these factors.

India has formulated laws and policies to harmonise with the convention. However, in the context of rural India, the government has faced challenges in reaching and bringing change even after the harmonisation (National

CRPD Coalition 2019). There is no existing research addressing how personal, social and environmental factors hamper or enhance the opportunities that exist for rural disabled persons to exercise agency, the absence of which results in their isolation and neglect. This paper aims to provide detailed insights into how these factors challenge persons with disabilities to exercise their agency in daily life. Such understanding can be useful for developing policies and programmes that are more responsive to the challenges faced by them. To achieve this understanding, the next section has a brief overview of rural India, specifically providing information on the incidence of disability, the legislative framework, access to public facilities for persons with disabilities and the cultural norms towards disability. The third section elaborates on the CA concepts used to investigate the everyday experiences of persons with disabilities in rural India.

Overview of disability in rural India

Incidence of disability

According to the 2011 census, 2.21% of 1.2 billion persons in India are persons with disabilities, 69% of whom live in rural areas. The UN and WHO estimate prevalence of global disability at 10% and 15% respectively, making the Indian census data significantly below these projections (WHO (World Health Organisation) 2011). This suggests a much higher incidence of disability. Moreover, two-thirds of the global population of such persons reside in the Asia-Pacific region (UN 2015) of which India is the second-most populous country. This further questions the official projections.

Scholars have argued that the low official disability-incidence rate in India is a result of the government's definition of disability; one that assesses the severity of impairment without considering the social and psychological barriers faced by disabled persons (Ghosh 2016; Palaniappan and Rodriques 2018). According to these authors, this rate coupled with a lack of data that is disaggregated based on disability in different areas, compromises on the comprehensiveness of the strategies the government adopts to address disability (Ghosh 2016; Palaniappan and Rodriques 2018).

Legislative and administrative framework

Legislative harmonisation and its effective implementation are primary steps towards incorporating the human rights perspective proposed by the convention into national mechanisms. Having ratified the convention in 2008, the Indian government has taken several steps to implement it, of which enacting the Rights of Persons with Disabilities Act in 2016 (RPDA 2016) has been the most significant. RPDA 2016 replaced an erstwhile Persons with

Disabilities Act 1995 which focused on the distribution of entitlements rather than rights. The Department of Empowerment of Persons with Disabilities (DEPD) under the Ministry of Social Justice and Empowerment is the nodal agency for the implementation of the Act. A large part of the implementation is done through schemes run by the DEPD. However, according to the disability rights movement, schemes continue to be based on the former act without restructuring them to harmonise with the convention or the RPDA 2016 (National CRPD Coalition 2019, 4).

The key existing schemes impacting lives of disabled persons in rural areas include the District Disability Rehabilitation Centres (DDRCs) that aim to provide comprehensive rehabilitation services to disabled people at the grassroots level (Government of India 2015). However, only 256 districts of a total of 640 have DDRCs (Government of India 2016), creating a vacuum in villages for basic rehabilitation services. Another is the Scheme for Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP Scheme), which makes assistive devices available to persons living below the threshold family income. Here too, the unmet need for assistive devices, especially in rural areas, remains high (WHO (World Health Organisation) 2011). In addition to these schemes, the Indira Gandhi National Disability Pension Scheme (IGNDPS) offers disability pension to disabled people between 18 – 79 years of age who live below the poverty line (Government of India 2015). However, the pension amount given being very low, it has only a limited impact on the lives of persons with disabilities (National CRPD Coalition 2019).

Access to public services and facilities

It is not disabled persons alone; others also suffer due to inadequate public services and facilities. Rural India lags in basic infrastructural development indicators for public services and facilities such as education, health, livelihood and social protection (Ghosh 2017) that in turn reduce the opportunities for persons with disabilities living in these areas because they are faced with additional disability-specific barriers such as negative attitudes and inaccessibility of the environment. For instance, only 6% of villages have access to rehabilitation services that are within a reach of ten km (WHO (World Health Organisation) 2012, 11). Disabled people have to spend extra to travel long distances to get the service or remain without the rehabilitation that allows them to gain self-care skills (Klasing 2007; Mitra et al. 2017; WHO (World Health Organisation) 2011). The educational infrastructure is poor and even if a village has a primary school, often parents do not see the point in sending their children to it (Ghai 2002; Buckingham 2011). Livelihood opportunities remain out of reach for a majority of disabled

people. It makes them dependent on their families and necessitates their being provided for. This also renders persons with disabilities socially undervalued and excluded (Klasing 2007; Grech 2015).

Cultural norms

Finally, it is acknowledged that cultural perceptions of disability have a significant impact on the lives of persons with disabilities. Culturally, in the country and especially in rural areas, disability is viewed as an outcome of karma. The karmic theory is based on the principle of cause and effect and disability is seen as a result of past misdeeds. Such perceptions of disability stigmatise disabled people, rendering them invisible and causing them to be viewed as socially inferior (Miles 2002; Ghai 2002). Such cultural perceptions are so deep-rooted that according to Gupta (2011), the theory acts as a way to accept and cope with disability. The family is a part of the karmic retribution cursed by the birth of a disabled child because of their past sins, and therefore expected to assume the responsibility of caring for the disabled family member to wash away these sins (Miles 2002; Gupta 2011; Klasing 2007). Further, the inability of disabled people to perform religious rituals or undertake economic activities makes them unworthy of receiving an inheritance from their family (Buckingham 2011; Groce, London, and Stine 2014).

Although the government took initiatives to improve agency of persons with disabilities, environmental and social conditions in rural India seem to be far from ideal to enable this. How these conditions precisely impact everyday functioning of persons with disabilities is not known yet. The CA emphasises the need to look at such factors while considering the agency of people. Therefore, we use the CA to theorise the challenges faced by persons with disabilities to exercise agency by analysing the lived experiences of such people, based on their perception, to understand the impact of the interplay of such factors on their agency.

Theoretical framework

The CA offers a broad normative framework to evaluate aspects of people's well-being, including those related to inequality. Evaluation is undertaken in terms of disadvantages people face in leading a life they value (Robeyns 2005; Sen 2009). CA is increasingly used by researchers to theorise disability (Burchardt 2004; Mitra 2006; Trani et al. 2011), especially because it views disability as a social construct and encompasses the social model of disability by considering the external barriers faced by persons with impairments in their communities (Burchardt 2004; Mitra 2006; Robeyns 2005; Oliver 1996). It further goes beyond the social model and takes into account the lived experience and the pain of impairment, both physical and psychological,

while looking at the barriers that are arguably denied by the social model (Ghosh 2016; Shakespeare 2014; Mitra 2006; Burchardt 2004), making the framework suitable for this study.

Disability in the CA is considered a deprivation in terms of capabilities or functioning that results from the interaction of the internal and external factors individuals face (Mitra 2006). The impact of the interplay of these factors on the lives of people can either limit them or work to their advantage to meet the aim of leading a life they value (Sen 2009). Each individual faces peculiar restraining or enabling circumstances as a result of the interplay of these factors they encounter in their personal, social and environmental lives. For persons with disabilities, the additional personal factor of their impairment makes it difficult for them to benefit from the social and environmental factors such as assets, income, family support, social capital, political stability, cultural aspects, infrastructural development, deforestation and so on (Trani et al. 2011; Sen 2009; Mitra 2006). For instance, even if they have the financial resources, the real opportunities or capabilities to use these to lead a self-determined life are limited as compared to non-disabled persons, because of the way their personal, social and environmental factors affect them (Sen 2009).

Since the interplay of personal and external factors influences the way an individual lives, the CA considers any evaluations based on financial well-being as being inadequate, as it does not consider individual differences in the interplay of these factors that are an outcome of the individual's circumstances (Sen 2009). Instead, evaluation using the CA can be undertaken at two levels. First, at the level of 'functions' that refers to the state of being and the state of doing (Sen 1999; Mitra 2006). For example, being mobile and working respectively. Second, evaluation can be done at the level of 'capabilities' that are defined as the real freedoms or opportunities a person has to achieve these functions (Sen 1999; Mitra 2006). For example, if being mobile is a function, the real opportunity or capability for most individuals with mobility impairments would require them to have access to mobility devices (Sen 1999; Mitra 2006). The total of all the capabilities a person has is termed as their 'capability set', and this represents an individual's freedom to achieve well-being and agency (Sen 1999).

Agency is an important aspect and lies at the heart of the approach, where an individual may decide for themselves which capabilities they choose to achieve from their capability set. For example, persons with mobility impairments may have a mobility device and the means to go out of their homes when they desire, but how often they want to go out is their choice based on what they value. According to Robeyns (2005, 37) the CA looks at people

“...as agents, who can and should be given the power and the necessary conditions to take their lives into their own hands”.

Further elaborating on agency, Sen (1999, 2009) suggests that while agency is an individual virtue, exercising it is dependent on a combination of internal conditions such as skills, motivation and confidence, and external conditions such as the environment, support services and culture. In this research, by looking into the perceptions of persons with disabilities living in rural areas and observing their environments, we examine the interplay of these personal, social and environmental factors that influences the agency of persons with disabilities in undertaking daily living activities and in participating, to draw lessons from it and improve actualisation of the CRPD in rural India.

Methodology

This qualitative research is undertaken in the interpretive approach that is about understanding the lived experiences of persons in a certain place at a certain time based on their interpretation of their reality, thus examining the topic through the eyes of those being studied (Green and Thorogood 2013; Tolley et al. 2016). The interpretative approach enables a better understanding and insight of the circumstances of human behaviour (Tolley et al. 2016), which is particularly important for this research that looks at the lives of persons with disabilities in rural India that are impacted by other internal and external circumstances of the individual.

Participants

The respondents for the research were identified with the support of the Rural Development Trust (RDT), a development organisation working to improve the quality of life of the rural poor in the Anantapur district of Andhra Pradesh, which runs a CBR programme that focuses on establishing self-help groups for adults with disabilities. These groups include disabled people and their families and work towards ensuring equal rights and opportunities for their members. Opportunities include access to special education, rehabilitative aids and treatment, the right to open bank accounts and the chance to achieve economic independence. They have reached thousands of disabled villagers from the district in their five decades of existence (RDT 2016).

All the selected participants were from the villages of two talukas (an administrative district for taxation) of the Anantapur district. They were identified with the assistance of the RDT staff who work with the persons with disabilities in the villages and have a strong grassroots network. The general

level of awareness about pension was high in these villages and all participants received a disability or old-age pension. The pension was not necessarily thanks to RDT fieldworkers as not all participants were their service users; many participants who are not members of self-help groups accessed the pension with the help of their family.

The selection criteria included the participants being adults with physical disabilities who require some form of support for personal mobility and daily living activities. In the final selection, we made sure the respondents reflected relevant differences in personal characteristics, to attain rich data with all diverse and varying categories of persons accounted for even though it was a homogeneous group (Green and Thorogood 2013). The ages varied from 20-80 years and around half was female and half were male. All except one received pension and family income ranged from USD 128 TO USD 600 per month. Five participants had some basic education; two of these had a bachelor's degree. They all lived with the family with the woman of the family being the main care provider. Five were member of self-help group, the others not. Saturation was reached after 11 persons were interviewed as there was no incremental code development from the data that was being collected (Green and Thorogood 2013).

Data collection

The researchers used qualitative interview techniques, which facilitated the capturing of diverse responses from the participants and enabled a deeper analysis of the lives of the disabled interviewees to emerge (Kelly 2010). Semi-structured open-ended questions were posed that explored the day-to-day realities of their lives, especially in terms of the choices available to them and whether they participated in family and community life (Kelly 2010). The interviews took the form of conversations that required the respondents to describe the details of their daily lives and were governed by an interview guide that was prepared in advance. Participants were provided with explanations about the nature and purpose of the interview. Before proceeding with the interview, consent – including the permission to audio record - was taken from each participant after explaining to them the purpose of the study and the process being followed. They were informed that anonymity would be maintained and that they had a choice of what they wanted to share. RDT workers - who are already working in and had the support of the local community - gained prior permission and meeting time suitability from the participants and their families.

The interviews were undertaken with the support of an interpreter who was bilingual and able to speak in both the local language used by the respondents, that was Telegu and English used by the interviewer. According

to Green and Thorogood (2004), the ability of the translator to add contextual information to what is being said adds to the quality, which the translator was able to as she was working as a special educator in a school with an extensive experience of working with persons with disabilities from the villages where the respondents resided.

Further, an independent person proficient in both languages, who gave feedback after the first recording, verified the quality of the translation.

Analysis

The data collected was analysed in inductive analyses where the themes and explanations are derived from a close reading of the data. Inductive analyses are more commonly used in the interpretive approaches (Green and Thorogood 2013).

The analyses began with transcribing the interviews followed by a close reading of the transcriptions. The close reading helped to identify the repetition of topics that aided the development of coding of these different topics (Green and Thorogood 2013). These codes were further divided into themes based on the social science literature related to disability (Green and Thorogood 2013) that include 'attitude towards the disabled person', 'infrastructural challenges faced by the disabled person', and 'choice and control on the activities they undertook'. The Atlas ti software used for the analyses helped organise the codes and themes (Green and Thorogood 2013). After the rigorous organisation of the data in different themes, certain interlinked common aspects emerged that were used for presenting the data in this paper. These four aspects identified were relating to basic functioning and daily lives of the persons interviewed and included:

1. Undertaking daily living activities such as toileting, bathing, grooming;
2. Relationship with their family and interactions with their community;
3. Going out;
4. Plans for the future.

Finally, the data was interpreted by making analytical conclusions on these four aspects to give symbolic meaning to the lived experiences of the respondents. These are presented in the next section.

Results

Daily living activities

The first aspect examined was the extent of support available to the participants to undertake daily living activities such as bathing, eating, dressing

and toileting, and the impact of this support on their lives. The women of the household provided support to all the participants interviewed. This was a common practice and the respondents were content in the way they led their daily lives and did not feel the need for additional support. They could not envision their life otherwise, therefore did not seek any change. Getting additional support at times from anyone other than the immediate family was unacceptable. Respondents saw their disability as a result of past misdeeds and seeking anything additional to cope with or reduce hardship was perceived as a hindrance to their karmic retribution.

According to J:

I would not like anyone to come to my house and serve. My wife will take care of me. I made some mistakes, because of which I am now disabled... If I have someone to come and serve me, it will add to my bad karma.

The participants resided with their families in one-room ground floor houses that often had steps at the entrance. The entrance doors had high thresholds and there was a lack of manoeuvring space inside the house, which made moving around with their mobility devices impossible. Consequently, it was common for them to crawl or be carried within the house. Most homes had a toilet and bathroom; however, only a few respondents mentioned using these. It was common to use the toilet and the bathroom for storage or as a shelter for hens and goats. Respondents felt that if their homes and toilets were more accessible, they would require less support in daily living activities, which would enable them to lead a more independent life. I, for instance, said:

I go crawling to the toilet and sit on the iron bowl my mother places there. It is not convenient, but there is no other way. I can wash myself. My mother will throw it out, once I finish.

Reflecting on life without his parents, he added:

If my parents are not around, I will do all my work myself. I will renovate my house in such a way that I don't require any help. Then it will be easy for me to go everywhere in the house. It's going to be difficult, but I will have to manage.

The overdependence on their caregivers made the respondents feel like a burden. As a response to these feelings, they adopted different ways to reduce the amount of care they required. At times this meant not undertaking activities such as bathing, turning at night and resting in the afternoon that they felt were not critical. For instance, B said:

My mother wakes up at 6 o'clock. She will finish everything, including *puja* (prayers), by 8:30am... I don't want to trouble her by asking her to bathe me.

For critical activities such as toileting, they restricted their water and food intake to reduce the frequency. They did so also to cope during times when

they were left unattended at home. For instance, K's mother goes out for daily wages to work at 8 am and returns by 6 pm, leaving K alone at home. Addressing this, K said:

I do not drink any water during the day after my mother leaves for work because I am alone; if I want to pass urine when she is gone, who will help me?

Such practices have an impact on their health, as was evident when K reported having a persistent stomach-ache. Their lives revolved around the support that was available to them and they had no freedom to do things as and when they wanted.

The sense of being a burden due to the dependency they faced had a strong impact on their relationship with their family, especially with the primary caregiver. It was laden with a feeling of intense appreciation for and gratitude towards the caregiver. For instance, G said:

My wife is serving me, so I think that she is like my mother.

The dependence made them insecure about what would happen to them if their primary caregiver was no longer available. They had no idea how they would manage in such an eventuality. They expressed a fatalistic view, leaving it to God to sort the problem. For instance, when questioned about how he would manage if his wife was no longer around to take care of him, J said:

I have not thought about it. If someone else supports me, that's good. Else, God will take care of me.

Having lived in a certain support system, most respondents had no idea how to change their present situation and could not envision any alternative to improve their lives. They felt that their caregivers were over-burdened; having additional support for their primary caregivers would be beneficial. For instance, K said:

We need rations and for that, only my mother goes to work; if they help us with rations, my mother need not go to work and that would be nice for me.

To summarise, the respondents expressed not having any agency in when and how they undertook activities of daily living. Their agency was compromised as a result of the interplay between social and environmental factors that impacted them differently as compared to others without disability. Firstly, it was the inaccessibility of their home environment that made it difficult for them to undertake any activity independently. They were completely dependent on their families. Further, since the women alone in the family provided them support, the respondents felt they were overburdening them. That made them hesitant to ask for support unless it seemed critical. Such an attitude towards basic activities resulted in compromising their health and wellbeing. The cultural perception of disability impacted their agency by

limiting culturally appropriate alternatives for support. Their situation and support system were socially accepted and making changes to it was considered as hindering their karmic retribution.

Interaction and participation

The researchers examined the social networks of the respondents and their contribution to develop such networks further. The first finding was that most respondents did not contribute to any family discussion because, on account of their dependency, their sense of worthlessness made them feel that their opinion was unimportant. They lost interest in family matters. For instance, E who lives with her husband, his second wife and children, stated:

My family tells me about the discussions in the house, but they do not ask for my suggestions. I don't give any either.

Those interviewed felt incapable of undertaking any kind of physical work, as a result of which they did not contribute to any domestic chores. For instance, F said:

I don't help with any home activities. I cannot do that much work as my hands are weak.

Consequently, they felt that they were not expected to undertake any work outside in the community and were simply whiling away their time. For instance, I, a young paraplegic man stated:

I sit outside the house all day. If anyone comes to talk, I talk; otherwise, I just sit and watch passers-by.

A said:

I wake up at 7 am and switch on the TV. It is on all day except when there is no electricity.

According to them, their sole contribution to the family was financial, as they turned over the money from their disability pension to help with home expenses. For instance, G said:

I give my entire pension money to my son since he feeds me and takes care of me.

Other than not feeling capable of contributing to the family, they had a restricted social network. Their immediate families apart, the only people they interacted with were extended family and neighbours. However, this interaction depended on whether the immediate family got along well with such groups. For instance, A said,

Relatives who are close to us take care of me and sometimes give food and money too However, some relatives who have fought with my parents won't speak to me either, though I have no quarrel with them.

I said,

I go to the mango garden once a fortnight. My cousins take me there when I ask them I go there only for a change since I sit outside the house all day.

Good relationships with neighbours meant that the support provided could be supplemented by those living nearby. They provided additional food and helped with feeding the disabled person; this was especially crucial when primary caregivers were unwell. At times, the neighbours would assist in carrying the disabled person to the toilet. For instance, G said:

When I come out of the house for a bath, three or four people are required to help me. My neighbours and members of the SHG provide help.

Most respondents stated they had no friends. They had friends during their school days, but now, all of them were married and these friendships were lost. After they stopped going to school because of their disability, they stopped making new contacts. K said:

I do not have any friends. I had friends in school when I was 12 years old, before my accident. They are all married now and have gone off to other villages They must have forgotten me.

They considered their disability the prime reason for not interacting with others. For instance, I said:

I became disabled in an accident at 19. At that time, I had friends of the same age group ... But not anymore. They no longer come to meet me ... I also do not go to their house because I feel embarrassed about going there in a wheelchair.

An exception was observed in the feeling of self-worth. Respondents with an achievement - for instance, a bachelor's degree, which was higher than the education level of most community members - had better self-worth and were able to foster relationships within the family, with their neighbours and with the community at large as they were able to reciprocate in several ways. For instance, C, a young graduate with a disability is a very social person, always going around in his village with his uncle (a person with an intellectual disability) who supports him. He claimed to have numerous friends, both disabled and otherwise. He was active in his self-help group, advocating the rights of persons with disabilities. Compared to other respondents, he had education and support to push his wheelchair as he went around the village. He said:

If anyone does not have an Aadhaar card, a ration card or pension, they ask me the procedure to get these. If there is some news in the papers that could affect the villagers, I tell them; for example, if the government is disbursing funds or helping villagers.

In short, it was the psychological impact of living with a disability and the high level of dependence on the family that made disabled persons feel

worthless. The worthlessness they experienced was a barrier to them having agency. Identification with their impairment made them feel incapable of reciprocating in any physical way for the care they received. This reinforced the worthlessness they experienced. However, they felt that their contribution to the family was financial as they gave their disability pension for family expenses. Self-worthlessness made them feel incapable of sharing their opinion on domestic matters. Their low self-worth denied them the personhood to forge relationships with those other than immediate family, leaving them dependent on their family for emotional support as well. Such feelings also prevented them from making friends and they felt forgotten and left behind as their childhood friends moved on. Consequently, they had no social networks; a result of external factors such as inaccessibility and lack of support, and social outlook towards disability. However, those better educated than others around them were more confident about reciprocating the care they received. Their knowledge compensated for physical limitations, enabling them to have better social networks, beyond the extended family and neighbours.

Going out

The respondents expressed regret at being unable to attend community activities or participate in family events. They only left their homes to see doctors, vote or appear for exams. They offered many explanations for feeling inhibited about going out. One reason stemmed from their sense of being a burden, something which has already been addressed under 'Daily living activities'. For instance, D said:

I want to go out more often but, how would I? I don't want to trouble my son and daughter-in-law.

The second reason was infrastructure inaccessibility and the lack of mobility devices. For instance, K said:

There are steps in front of my house, which I cannot negotiate in a wheelchair and the road in front of my house is in bad shape.

D confirmed that lack of mobility devices constricted his life, saying:

If I had a wheelchair, I would roam around with the help of my grandchildren.

The third reason for their being trapped was the high cost of transport. Unlike non-disabled commuters, the respondents were unable to share an auto-rickshaw because they had to travel with their mobility devices and their assistants, thus being forced to bear the entire expense of the journey themselves. For instance, I said:

If I take an auto-rickshaw, I have to pay a lot of money since I need to book the entire auto for myself; none else can share it because of my wheelchair.

Additionally, leaving the house meant paying the wages of their travel companions, since going out alone was not an option. For instance, B stated:

I like to go out, but I don't. Money is the main reason is money. [Because] when I go out, I need to call a worker - whom I need to pay - to help me.

Most respondents complained about pain in their limbs. It discourages them from doing things at home and from moving around or going out. The pain was not medically diagnosed but some respondents took painkillers from the local community health worker. F remembered the time she went with her family to watch a drama ten years ago and the trouble she put her family through, as they had to carry her. She did not enjoy the outing for this reason but ascribed the reason for not going out to the pain she experiences. She said:

I can't sit for long periods as it causes pain in my back and knees; that's why I don't like going out.

The respondents explained that, given external support, they would like to emerge from their isolation. B said:

When my relatives visit, they invite me to family functions along with my family. If they carry me, I would like to go. But if I have to go alone, I will not go.

D made the following observation:

If I had a personal assistant, he would always be with me and I would move around more easily.

To summarise, the respondents hardly ever ventured out of their homes except to visit the doctor, vote or write an exam, but wanted to go out more often. The key reasons for not going out as often included the inaccessibility of the external environment, transportation and the lack of a mobility device. The lack of support to accompany them was also an important reason. The persistent pain in their limbs diminished their interest in going out. Additionally, the cost of hiring an entire auto-rickshaw further discouraged them. All these internal and external factors restricted their agency by making going out a difficult experience, not an enjoyable one. However, not being able to go out impacted their participation in community events and interaction with community members.

The future

The participants expressed a sense of surrender to their dependency and the situation they were in. They were not happy with their lives but did not think that anything would improve. The only way things could improve was

if they went back to being non-disabled again. I, a young man who became disabled from an accident felt that he was no longer 'normal' and all he wanted was his normal life back. He said:

I am not satisfied with my life because I was a normal person and I am disabled now. That's why I am dissatisfied. I want my normal life back ... I just want my old life back.

It wasn't him alone; others also wanted a reduction in their impairment and wished for better medical treatment that could cure them of their disability. For instance, F said:

If I had a lot of money I would go to a hospital and get treatment to walk again. I want money for treatment and a cure.

Some expressed a sense of surrender to their dependency and to a situation where they were not happy with their lives, having reconciled to the fact that they could not get medical treatment or be better ever again. They had lost all hope for the future and left themselves at the mercy of God, with no will to live. For instance, K observed:

I aim to die. God has to take me. I don't like this life. I do not have any future plans or goals.

E said:

I pray that God takes me. There is nothing that I want. I have no desires.

A few anomalies were noticed, especially in young men, some of whom had some education. They seemed to envision some kind of future for themselves, where they wanted to do a job and were working towards achieving their goals. They expressed their frustration at the lack of opportunities and information available in their village to help them find a job or be meaningfully involved with life. For instance, I said:

I would like to earn money and give it to my parents, but, how can I? I want to, but I can't, and I don't know how.

To sum up, respondents expressed that their future was bleak and without their having any agency to mould it in a way that could have better outcomes for their lives. They were not satisfied with their lives because of their impairments and were seeking a 'cure' that could make them 'able' again. However, medical and rehabilitation services remained beyond their reach, as the public health system in rural areas was inadequate. Getting medical treatment in cities away from their homes was beyond their means. While they hoped for financial support to get medical help, knowing that things were unlikely to change left them 'hopeless'. They saw death as the only escape. Younger respondents, especially men, were not as hopeless and longed for a better future when they could work and earn some money.

However, they felt frustrated with the lack of opportunities, information and support in this regard.

Discussion

This paper reports on the insights gained into the lives of disabled people living in rural India based on the investigation carried out into the challenges they experience to exercise agency in their daily living activities. These challenges were looked at as a result of the interplay between internal and external factors in terms of their personal, social and environmental situations. These factors reinforce each other to create a vicious circle that prevents the disabled persons from having agency and restricts the possibility of them being able to exercise agency in the future. To begin with, disabled people are unable to fulfil even basic functions such as being well hydrated, using the toilet or turning at night as a result of the lack of support available to them. Their dependency for daily living activities increases because of the inaccessibility of their homes, preventing them from doing anything independently, leading to a feeling of being 'worthless'. The negative image of 'worthlessness' makes them feel incapable of reciprocating in any way for the support they receive. Not being able to contribute constructively not only reinforces the negative self-image but also impedes opportunities to create a social network for themselves, thus remaining dependent on their families for all kinds of support.

The 'vicious circle of worthlessness' they experience, reinforces the community's perception of disability. Disabled persons are limited by the sheer struggle to adjust to their situation and to lessen the physical and karmic burden they impose on their families. The concept of 'adapted preferences' proposed by the CA, enabled better understanding of the situation in which individuals adjust themselves and their lives, needs and aspirations in a way that they consider meets social perceptions and what is expected of them (Sen 2009; Trani et al. 2011; Nussbaum 2011). While it may appear 'natural' for the disabled people to alter their wishes as an outcome of their lived reality, these decisions cannot be considered as having been made out of choice (Begon 2014). Crucially, what happens is that disabled people seem to 'disappear' from their community because they are not able to exercise agency, a phenomenon that results in the community (and often the government) not recognising that there are 'unseen' people in their midst who have needs that must be met and that structures must be put into place to address those needs.

As at the internal level persons with disabilities adapted themselves to their situation with reduced self-worth without exerting agency, we explored the external factors that influence such outcome. We discuss other aspects

such as the role personal, social and physical environment factors play in enhancing agency. We address the challenges in reducing dependency that disabled people face in their daily living activities that were identified as the key reasons for loss of agency. We argue that the dependency they face is the outcome of the lack of support to undertake activities and the inaccessibility of their homes that prevents them from undertaking activities independently, putting further 'burden' on the family.

According to Ghai (2015, 107–108) "In developing countries like India, disability rehabilitation is always primarily considered the responsibility of the family, which provides essential physical, emotional and economic support to its members with disabilities". Such a system results in inadequacy of the support structures available that can enable disabled people to undertake activities without feeling like a 'burden'. The present system where only the family provides support, makes disabled people adapt themselves to the situation without even realising, as the adapted preferences proposed by the CA suggest (Sen 2009). This family-based social and cultural system, that leaves all aspects of care and support to the family, is reinforced by the legislative framework. The RPDA 2016 addresses the importance of personal assistants by making provision for a 'caregiver's allowance' to be given to persons with disabilities as a social security measure, but the definition of a 'caregiver' in the Act suggests only the family as playing that role. Thus, it may be important to broaden the definition by recognising professional care and support providers and non-family members in the role. This may not only bring better acknowledgement of the care and support work but also make it an entitlement for persons with disabilities rather than favour they receive from their family.

It may not be possible to replace the role of the family in providing support and care to disabled people because of the naturally existing manpower and free resources that the family constitute (WHO (World Health Organisation) 2011; 2012). However, there is existing evidence highlighting the negative impact of long-term caregiving on the informal care provider's social, mental and physical health that affects both, the caregiver and the care receiver (WHO (World Health Organisation) 2012, 2002). Therefore, there needs to be further investigation of the impact of providing care and support to disabled people in rural areas on the caregivers and its impact on the disabled persons they are providing care to. Further research is also required to look at ways of strengthening the existing system of care and support and further develop workable models for additional support structure for disabled people in rural areas.

Another external factor identified as increasing the dependency of disabled people is the inaccessibility of their home environments as a result of the absence of indoor mobility devices, forcing those unable to walk to crawl

or bottom shuffle, thus denying them to be mobile within their homes. Narrating from personal experience, Ghai (2015, 217) has elaborated on the resultant lowering of self-image. In rural India, bottom shuffling is a common unaddressed practice. Considering that the flooring is not always cemented and uneven, regular bottom shuffling may result in injuries and medical complications. Therefore, it is important to address home accessibility in terms of the appropriate mobility devices for rural homes, which are significantly different from urban homes.

Investigating this further, one sees that the government as a social security measure under the Indira Awaas Yojana (IYA) scheme often pays for the construction of houses in rural India. A typical house built under this scheme is small with one room and a kitchen and lacks wheelchair manoeuvring space and accessibility. Closely related to the home design and manoeuvring space is the suitability of mobility devices for indoor mobility. Presently, persons with mobility impairments are given wheelchairs and tricycles under the scheme for Aids and Appliances (ADIP). However, these devices cannot be used indoors because of the lack of manoeuvring space, forcing users to bottom shuffle or crawl (Planning Commission of India 2013). Thus, further investigation is recommended to look at accessibility and house modification in rural environments along with the mobility devices that are suitable for use in these homes.

The use of the CA, whose core characteristic is focusing on the achievements of people in everyday life on the one hand, and options from which one can choose on the other, was suitable for this research in two ways (Robeyns 2016). First, it gave the flexibility to analyse the data at the level of capabilities where agency was important. Second, it allowed analysis at the level of functioning where agency did not play a role (Robeyns 2005b). Considering persons with disabilities in rural areas have no agency, such flexibility allowed the understanding of reasons for the loss of agency. The loss in agency was seen as an outcome of persons with disabilities not being able to achieve certain beings and doings (functioning) as a result of personal, social and environmental conversion factors (Robeyns 2005b).

To summarise, using the capability approach framework to look at the agency persons with disabilities in rural areas can exercise shows that they seem trapped in a vicious circle that makes them feel 'worthlessness'. This self-perpetuating circle is a result of the interplay between internal and external factors in their personal, social and environmental spaces. The circle is further reinforced by the community's expectations from and attitudes towards disability that persons with disabilities imbibe, making themselves invisible. Therefore, it may be said that interventions made must be two prongs. First, they may address the external factors, especially those associated with decreasing their dependency. That includes the development of a better support structure, access to appropriate assistive devices and more

enabling design of the environments they live in. Persons who had better education seem to have more agency but yet they struggle with basic functioning and the feeling of being a 'burden' remains. Second, and equally important is the need to influence the internal factors individuals live with as a result of adapting to their circumstances by addressing the 'worthlessness' they feel. This may require interventions that influence community attitude towards disability and those that work towards building self-esteem of persons with disabilities. Addressing the external or internal factors alone may not break the 'circle of worthlessness' that persons with disabilities in rural areas find themselves in. This research reaffirms that indeed it is a lack of different aspects related to the internal and external factors that prevents persons with disabilities from achieving even basic functioning. This research has not gone beyond discussing different reasons for not being able to achieve basic functioning. Further research is required to systematically look at how to address these barriers faced by the persons with disabilities through policy and institutional frameworks.

Conclusions

Persons with disabilities living in rural India are still 'isolated' in their own homes and communities without having any agency. The research used the capability approach that enabled a robust investigation into the lived experiences of persons with disabilities in rural areas. The results show that the causes for persons with disabilities not able to live a life they value because of the interplay of personal, social and environmental factors they face. The approach enabled us to look at these factors as being internal and external to the disabled persons and their interplay that seemed to create 'vicious circle worthlessness', for the persons with disabilities. The key factor identified was the high level of dependency for daily living activities that the person with disabilities had on the family. Related to this was also non-availability of additional support other than the family. Inaccessibility of home environment and lack of appropriate mobility devices increased their dependency for daily activities on the family. Adding to this the CA also helped to correlate the negative attitude of the community towards disability that the disabled persons accepted and imbibed further increasing the 'sense of worthlessness' and a feeling of being a 'burden'. Therefore there is a need to address the dependency persons with disabilities face, by creating more awareness about disability, developing self-worth of persons with disabilities living in these area, besides creating more enabling and inclusive environments; developing better support structures for persons with disabilities in their community reducing their dependency on their family in a systemic manner that impacts the policy and institutional framework.

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