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Women's Capabilities and Challenges Of Caring for Persons with Disabilities: Experiences from Rural Areas Of Andhra Pradesh, India

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Abstract

Adequate support and care are a prerequisite for the full participation and inclusion of persons with disabilities (WHO, 2011). In rural India, it is predominantly the women of the family who offer such care and support. Consequently, their lives are closely linked to the lives of persons with disabilities. It is essential to understand this relationship and consider their experiences when developing strategies to improve the support system. This empirical research undertakes interviews with women caregivers in rural India and uses the capability approach (CA) to analyze their experiences. The results suggest that the prevailing invisibility and negative perceptions of such care work, coupled with the lack of agency of the women caregivers, make the situation unsatisfactory for both the women and the family member with disabilities they are caring for.

Keywords: disabilities, women caregivers, capability approach/CA, rural India, agency

Capacités et défis des femmes Prendre soin des personnes handicapées : expériences des zones rurales de l'Andhra Pradesh, en Inde

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Résumé

Un soutien et des soins adéquats sont indispensables à la pleine participation et à l'inclusion des personnes handicapées (OMS, 2011). En Inde rurale, ce sont principalement les femmes de la famille qui offrent ces soins et ce soutien. Par conséquent, leur vie est étroitement liée à celle des personnes handicapées. Il est essentiel de comprendre ce lien et de prendre en compte leurs expériences lors de l'élaboration de stratégies visant à améliorer le système de soutien. Cette recherche empirique mène des entretiens avec des femmes aidantes en Inde rurale et utilise l'approche par les capacités (AC) pour analyser leurs expériences. Les résultats suggèrent que l'invisibilité et les perceptions négatives de ce travail de soin, associées au manque d'autonomie des femmes aidantes, rendent la situation insatisfaisante tant pour les femmes que pour le membre de la famille handicapé dont elles s'occupent.

Mots-clés : handicap, femmes aidantes, approche par les capacités/AC, Inde rurale, autonomie

1.0 Introduction

Life in rural India is far from easy due to the lack of community services and facilities, as well as the limited employment opportunities (Mukunthan, 2015). Persons with disabilities face additional challenges due to the negative attitude towards disability, and the lack of support services and environmental accessibility (Gupta et al., 2019; 2020; Klasing, 2007). In the absence of support services, persons with disabilities become overly dependent on their families for physical, emotional and other support required for living (Ghosh & Banerjee, 2017; United Nations General Assembly [UNGA], 2017). The family providing support also encounters disadvantages (Ghosh & Banerjee, 2017; UNGA, 2017). Poverty compounds the burden because caregivers often must forego paid work to care for their loved ones, adding to their financial challenges (Brinda et al., 2014; Grech, 2015; UNGA, 2017).

Traditionally, the women of the family are responsible for providing care and support in addition to their domestic responsibilities (Folbre, 2004; Ghosh & Banerjee, 2017; Prasad & Rani, 2007; Ugargol & Bailey, 2018; WHO, 2002; 2012) and often are the only support available to persons with disabilities, linking their lives closely. There is a paucity of research on the experiences of women caregivers in rural areas. Moreover, the Rights of Persons with Disabilities Act 2016, which harmonizes with the United Nations Convention on the Rights of Persons with Disabilities (UNGA, 2007), fails to address the need to develop a community-based disability support system. The well-being and autonomy of the family caregivers must be considered when developing support services. This research investigates the lived experiences of women caregivers to gain an in-depth understanding of the enablers and challenges of caregiving for persons with disabilities.

Greater insight into the challenges faced by women is necessary when considering strategies for improving the situation, especially in rural India. We use the CA to understand how social, cultural, economic, and political scenarios influence the experiences of caregivers. We begin by examining the existing situation of care and support.

1.1 The Existing System of Care in India

Traditionally, the family is recognized as the main care provider for persons with disabilities. It is customary for them to look after disabled and older persons, and often is the only option available (Murthy, 2016; Prasad & Rani, 2007; Ghosh & Banerjee, 2017; Ugargol & Bailey, 2018). Being a patriarchal society, the responsibility is often inherited by male family members; however, women must take on the role of primary caregivers (Ghosh & Banerjee, 2017; Gupta et al., 2009; Prasad & Rani, 2007). This is a universally accepted notion, making caregiving a gender-specific task (Ghosh & Banerjee, 2017; Ugargol & Bailey, 2018).

The socio-cultural perceptions of rural communities also mould the way care is perceived. Having a disability is considered a tragedy for the person and equally unfortunate for families (Ghai, 2002). People with disabilities are seen as a burden because they are not expected to reciprocate and support their families (Gupta et al., 2020). Such beliefs often made the men of the family alienate themselves from persons with disabilities and their care, not considering it important enough to intervene (Ghosh & Banerjee, 2017). This left the care of the ‘unvalued’ persons with disabilities to the women and made caregiving an unimportant task, belittling the efforts of the caregivers (Ghosh & Banerjee, 2017; UNGA, 2017; WHO, 2012).

At the societal level, care responsibility is often assumed by the family, which normalizes the responsibility as being that of the family's women. Providing life-long care without additional economic or social support disproportionately impacts families with disabled members as compared to other families (Brinda et al., 2014; Staffi et al, 2016; Ghosh & Banerjee, 2017; Grech, 2015). More so in poverty-stricken rural areas. People with disabilities feel like a burden, making them adjust their daily-living requirements around the availability of the caregiver (Ghosh & Banerjee, 2017; Grech, 2015; Gupta et al., 2020).

The situation is harder due to the lack of rehabilitation services as caregivers do not have knowledge of how to provide care, and the persons with disabilities do not have daily living skills, making them more dependent (Ghosh & Banerjee, 2017). Government rehabilitation centres exist only at the district level. In theory, community-based rehabilitation (CBR) should reach people with disabilities in the villages, but such projects are few and unevenly distributed. Further, only a handful of CBR programmes offer self-care skill training or support the caregiving (personal communication, M. Balasubramanian, September 3, 2018; WHO, 2012). Moreover, inaccessibility of homes in rural India often requires that some persons with physical impairments be lifted and carried by their caregivers, making it more challenging (Gupta et al., 2019). One good CBR programme run in collaboration with Carers Worldwide, an international non-governmental organization, offers training to families in a few projects in two Indian states to develop and promote cost-effective, sustainable and replicable methods of providing support to carers in low- and middle-income countries (Staffi et al., 2016; SACRED, 2013).

Support services for persons with disabilities were recognized in legislation by the Rights of Persons with Disabilities Act (RPDA), 2016, which defines 'caregivers' as family members who provide care to a person with a disability without receiving any payment. According to the act, the government must provide alternate options for care and support only in the absence of a family caregiver for persons with high support needs living in poverty (Gupta et al., 2022). However, the provision has not yet been implemented. The government has attempted to establish a team of trained caregivers through the Sahyogi Scheme by funding organizations that provide training to family caregivers and others (Government of India, n.d.). However, its reach and impact are limited (National CRPD Coalition India, 2019).

Formal care services are provided by the private sector in cities and are considered a lucrative business opportunity, particularly for older adults (Dey, n.d.). Some enterprises also target individuals with disabilities, but the focus of these initiatives is on nursing care and well-being, rather than enabling client participation. There are no government regulations covering the ethics, quality, or cost of these services.

Given the underdeveloped support system in rural India, family care often perpetuates, placing the responsibility of caring on women.

This paper employs the capability approach to elaborate on and understand the lived experiences of women caregivers of persons with disabilities in rural India.

1.2 Theorizing Care Work Through the CA

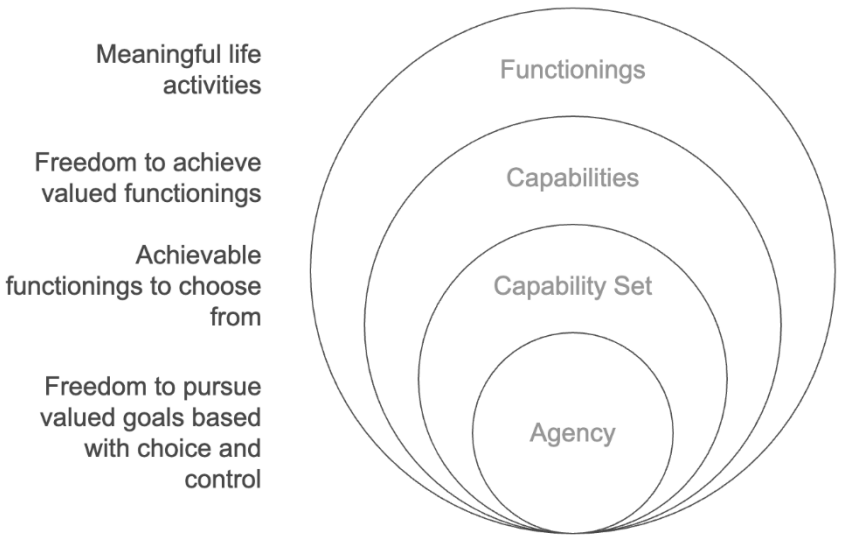
The CA is a development framework that offers an alternative to the welfare approach by focusing on the equality of opportunities people have to live a life based on their values and choices, rather than based only on the monetary resources available (Sen, 2009). According to the CA, one

person's opportunities are fewer than another's if the former has fewer capabilities or actual opportunities to choose from (Sen, 2009). These capabilities or opportunities are considered in terms of the well-being and agency of people (Crocker, 2008). Well-being is conceptualized in terms of capabilities and functionings.

Functionings are fundamental to well-being and refer to the activities that people can do and be as they want. According to Sen (2009), these 'doings' and 'beings' make life meaningful; doings might include walking, reading and resting, and beings, things like being cared for and being part of the community. Capabilities are conceptualized in terms of the achieved state of being and doing (functionings) from the options available, for which the freedom to choose from those options is critical (Robeyns, 2005). In the CA, this freedom that people must have to do or be what they value is critical and impacts their 'agency'. For instance, if a person's goal is to travel from home to school, the various functionings or opportunities available may include riding a bicycle, walking or taking public transport. The decision to walk to school represents their freedom to choose, and thus their agency, while 'walking to school' is one of their capabilities. The totality of all the options the person has is their capability set.

A person's agency extends beyond what they can do or be; it is based on what is important to them, and it respects their freedom to determine what they want, what they value, and what they decide and choose (Sen, 2009). The agency or the freedom to choose is at the heart of the CA; it distinguishes between doing something and being free to do something (Sen, 2009). Such freedom to choose is dependent on the options or the capability set of a person. For instance, as caregivers of persons with disabilities, women may want to provide care only during certain hours and be engaged in other activities at other times. However, unless other options for providing care exist, they cannot choose. Therefore, the caregiver's agency depends on their personal choice and the external context. According to Sen (1999), people's agency is inescapably enhanced or constrained by the social, cultural, political and economic systems and the opportunities these provide.

Figure 1: Core components of the Capability Approach.



According to Sen (2009), a person may act as an agent and change the world around them intentionally or unintentionally. An agent is someone who rationally decides on a goal for themselves or others and acts to fulfil the goal alone or with others (Crocker, 2008). It is when the agent intentionally achieves their goal, even if it is with the support of others, that they act as the author of their life (Crocker, 2008). However, the social, cultural, political, and economic opportunities (or the lack of these) may affect the person's personal choices. For instance, a person may willingly accept the dominance of other family members because of the existing socio-cultural norms or a lack of economic independence and in such scenarios, they are prone to becoming a medium through which other agents impose their will (Nussbaum, 2006; Sen, 2009).

Finally, since a person's agency is affected by the internal and external forces that influence their decisions, it also affects the people around them (Crocker, 2008; Sen, 2009). This can be seen in the case of a woman who accepts the caregiver role 'naturally' because that is what is expected of her, but this has an impact on the agency of the woman and, consequently, on the nature of the care she can provide, as well as on other aspects of her life. Therefore, people's agency influences the world around them (Crocker, 2008; Sen, 2009). Applying this understanding, we examine the agency caregivers have in achieving their goals, as this will influence the amount and quality of care and support the family member with disabilities gets. Furthermore, the interrelatedness of agency with social, political, and economic systems, as well as the opportunities available, allows an individual to explore the reasons for losing agency based on their options and choices.

2.0 Methodology

This research is part of a larger study investigating the support structures available to persons with disabilities in rural areas who require assistance with mobility and activities of daily living. The larger research included a primary study with persons with disabilities to look at the support they had and its impact on their lives (Gupta et al., 2020). In continuation, this study examines the lived experiences of the primary caregivers and other family members providing support, focusing on aspects of life associated with care work described in the research design.

The participants were contacted with the support of the Rural Development Trust (RDT), a development organization in Anantapur district, Andhra Pradesh, and were mostly members of the families of persons with disabilities who had been interviewed for the earlier-mentioned research. There were a few new participants, too. These participants approached us through RDT field workers. All the participants were offering care to persons with physical disabilities.

The selection criterion was that the participant had to be someone who provided support to a person with disabilities. Of the fourteen participants, twelve were primary caregivers (unpaid family members providing care) and two offered care when such caregivers were unavailable (also unpaid). All participants were women; their relationship with persons with disabilities varied and included wives, mothers, sisters-in-law, daughters-in-law and aunts. All participants were between 40 and 60 years old. All families lived below the poverty line (with an annual family income of below INR 46080), were eligible for a disability/old-age pension, and depended on daily wages earned by working on the land or rearing animals.

Table 1: *Relationship Details of Caregivers*

Participant code	Relationship	Primary/additional caregiver	Age group
A	Mother	Primary	60+
B	Mother	Primary	60+
C	Aunt	Additional	40 – 50
D	Mother	Primary	60+
E	Daughter-in-law	Primary	40 – 50
F	Daughter-in-law	Primary	40 – 50
G	Sister & husband's second wife	Primary	40 – 50
H	Sister-in-law	Primary	40 – 50
I	Wife	Primary	60+
J	Niece	Additional	30 – 40
K	Daughter	Primary	40 – 50
L	Wife	Primary	60+
M	Daughter	Primary	60+

3.0 Research Design

This research investigated the lived experiences of women caregivers based on the theory of CA. To understand the experience of women caregivers, the research examined the capabilities and opportunities that women had to successfully live the lives they desired while providing care to family members with disabilities. The research examined the social, cultural, political, and economic aspects that influence the agency or freedom of these women to live a self-determined life. The research question aims to understand their caregiving experience and its impact on their lives, particularly in relation to achieving the following capabilities: (1) physical health; (2) mental well-being; (3) social relations, (4) domestic and care; and (5) paid work. According to Robeyns (2003), these basic capabilities can be used to assess gender inequalities. These five capabilities strongly influenced the research design.

A qualitative interview method with semi-structured questions was used. An interview guide was prepared before undertaking fieldwork. The first question aimed to ascertain the participant's attitude towards disability, followed by questions exploring what their day looked like as the caregiver. Interviews were conducted in groups of three, with participants answering questions individually. Being in a group made the participants confident and comfortable answering questions they may have never articulated and addressed before (Kelly, 2010). None of the women requested an individual interview. There were no downsides

to using this method, as the women recognized similarities in their situations that empowered them to speak openly about matters that they may not have discussed in the past. It was interesting to see that the women in one group were enthusiastic about recommending other women for the next round of interviews. Each interview lasted for 45 minutes to 60 minutes. Answer saturation was achieved after 14 interviews.

The purpose of the interview was explained to participants verbally. Each participant was informed in advance that their participation was voluntary and that they did not need to answer if they did not want to. They were informed that they could withdraw from the discussion at any moment. The group members were asked to keep the entire discussion confidential, especially not to share what other participants shared.

Participant consent was also taken for audio-recording the interviews. All participants gave their consent by signing the consent form. Recordings were transcribed and anonymized. Data were securely stored and only accessible to the main researcher. The interviews were conducted in Telugu, the local language, with the support of a translator. The English translations of the interviews were transcribed into English.

4.0 Analysis

The qualitative data collected was analyzed using a general inductive approach. The inductive analysis enabled findings to emerge from the frequent, dominant, or significant themes that emerged in the data. According to Thomas (2006)

> Inductive analysis is known to establish clear links between the research objectives and the summary findings derived from the raw data and to ensure that these links are both transparent (able to be demonstrated to others) and defensible (justifiable given the objectives of the research).

Using this method allowed us to understand the experiences of women caregivers (the objective of this research) based on the theory of the capability approach in a justifiable and demonstrable manner.

5.0 Results

Based on identification of relationship between the themes and patterns identified this lead to four overarching topics. The result section is structured in line with these topics. The four overarching themes are:

1. Activities undertaken
2. Impact of providing long-term care
3. Reasons for accepting the caregiving responsibility
4. Additional support the caregivers wanted

5.1 Activities Undertaken

The participants were responsible for all the tasks that women in their village were responsible for, with an additional task of providing care to the disabled family members. The common tasks that the women undertook included cooking for the family, cleaning and earning money for the family. Earning money seemed to cause additional stress on the women.

For instance, G said, "When there is an opportunity to earn daily wages, I go for it. After returning, I cook for everyone and clean the house."

K said, "I must go out and earn… When I go out, my mother takes care of my father, but she is deaf and often cannot hear when he calls. So, when I return, I help them and do the other housework."

When the participants could not go out because of care work, they did some paid work from home. L said, "…because I can't go out for daily work now, I keep a buffalo at home and I sell its milk. That is the way I am earning."

The additional work that the women did to support the family members with disabilities, was demanding and included helping them with daily living activities. Participant L said, "He (her husband) crawls and goes to an open area for toileting, but he cannot clean or dress himself. I have to help him with everything."

The participants provided support at home and in outdoor activities. F said, "When my mother-in-law goes to a hospital, my husband and I have to carry her and take her in an autorickshaw."

The participants also performed additional activities to maintain or improve the health of the person with disabilities. Participant I said, "Someone prescribed an Ayurvedic oil … I massage daily…"

The participants had to work more compared to other women in the village. They multitasked, taking care of their home and family and being the primary responsibility for two critical tasks: To care and support for the family member with disabilities. Their support included helping them in activities of daily living such as toileting, bathing, grooming and feeding, outdoor activities such as visiting the doctor, and maintenance therapies. And to attend to domestic tasks such as cooking, washing and cleaning. They also needed to earn money for the family, which seemed difficult because they did not have alternate help to care for the family member with a disability when they went out to work. In this scenario, they, at times, found options that could enable them to work from home, which they preferred.

5.2 Impact of Providing Long-Term Care

It was difficult for the women to undertake all the activities that the village women did and also provide care. Due to the additional care work they undertook, they encountered several challenges, which had three main impacts: Negative outcomes on their physical, mental, and economic well-being.

Caregiving often demanded physical strength and being constantly available. This had a negative impact on their physical well-being, more so on participants who had been providing care for a long time and those who were older. Participant I, a long-term caregiver for her husband, complained, "My husband is very heavy. Because I help him with everything, I now get pain in my neck, shoulders and back. At times I take painkillers…"

A, who provides care to her adult son, said, "My son is quite heavy so I cannot lift him alone. When he was a child, it was fine but now he is a young man, caring is very difficult."

Caregiving responsibility also seemed to impact the mental well-being of the caregiver. At times they felt resentful and forced into it. The pressure of caregiving made them wish ill of the disabled family member. H said, "I get irritated with my sister-in-law and I am not caring for her from the bottom of my heart. When I am angry, I say things like: why are you alive, why don't you go away?

At times, the stress of being unable to cope with all the work and provide adequate care causes self-disappointment and is exhibited as frustration and anger toward the person they are caring for. This impacted their interpersonal relationships. B, who cares for an adult daughter, said, "I must carry my daughter to the toilet and clean her. Sometimes I get tired and start scolding her."

Their mental well-being was also impacted by the feeling that long-term care did not allow them a social life. They felt restricted in their social participation as they could not leave the person with disabilities unattended. They could not be a part of important family milestones like all the other women in the village. N, who provides care for her grown-up daughter, said, "I cannot leave my daughter unattended. Even when my other daughters needed my support during childbirth, I could not go."

N mentioned that this made her feel restricted, frustrated and mentally stressed.

Participant I narrated an incident when her husband was angry with her for leaving him unattended. She said, "Last week, there was a drama in the village. I went to see it after he fell asleep and returned late at night. He quarrelled all night, accusing me of leaving him alone in his condition. I can't go out."

Their poor mental well-being was also an outcome of the social isolation they experienced as a result of the community's negative attitudes towards disability and caregiving work. This prevented them from attending social gatherings, especially with the disabled family member. Facing unwelcoming enquiries as she went out with her son, D said, "Strangers enquire about our son's disability even though they see he is disabled being a wheelchair user. This makes us sad and frustrated, so we do not take him out often."

Another consequence of caregiving was the challenge of earning a livelihood along with supporting a family member with a disability. This added a layer of mental and physical stress on the women. N, a single mother, narrated her plight of not having additional support to care for her daughter when she went out to work and how it impacted her daughter. She said:

> I must earn for us to live. I help my daughter with toileting and other daily activities at 6.30 am, and I return home in the evening and help her with toileting at 7.30 pm. During the day, she sits in the veranda and does not drink as there is no one to help her.

The husbands of some participants did not contribute financially to the household. These women felt deprived as they were responsible for earning money, providing care, and doing domestic chores. This heightened their mental stress. H said, "He [her husband] drinks too much. He walks drunk on the streets and scolds and abuses me. He doesn't give any money to buy food."

The multiple stresses she faced trying to juggle everything made her anxious and vented on the person she was caring for. While narrating a fight she had with her disabled sister-in-law, H said, "I cannot serve you…, he [her husband] is a drunkard, I am providing food for him and his family, and I have to serve you. Why?"

E's husband wasn't contributing adequately to family expenses and had a negative attitude towards work. The lack of work opportunities in the village made it difficult for them to earn enough. She explained, "There is no work available here, and if we do fieldwork, we earn only INR 100 [a little more than 1 USD] a day. Also, it's seasonal."

Providing care to a family member with disabilities was a difficult responsibility, and all participants experienced some negative impact. Physical health challenges were increased for women who were providing long-term care and had to lift and carry the disabled person. As they aged, they encountered more challenges to their health. Most caregivers also experience mental stress due to caregiving. The caregiving responsibilities often isolated them, and they often did not have time to participate in community activities. They also had to face the negative societal attitudes towards disability and caregiving. The stress and pressure of unpaid caregiving and lack of autonomy often lead to negative interpersonal interactions with the person to whom they provided care. The physical and mental stress they encountered was also a result of their poverty and the financial hardships they faced because of having to do everything themselves, including going out to earn a livelihood without any additional support for anything. Not having adequate livelihood opportunities in the village made it more challenging for them. In summary, care responsibility had a negative impact on the caregivers. It reduced their capabilities to maintain good physical and mental health due to factors like social isolation, ridicule and economic hardships, lack of livelihood opportunities and absence of any additional support.

5.3 Reasons for Accepting Caregiving Responsibility

Irrespective of the negative impact of caregiving, the participants continued to provide care stemming from societal expectations, strong family ties and cultural norms. Elaborating on these, the first was the societal expectation and norm that a woman must provide care, which made it a moral requirement, making caregiving the responsibility of the woman of the family as the "right way" of living. G said, "Our family is decent. We will not ask anyone for help. We will work together and share whatever we have."

The women—the actual care providers within the family—felt that fulfilling this duty was important for them to gain social acceptance. Participant I said, "Everyone says that I am taking good care of him (her husband). I have to earn a good name from everyone."

With the care responsibility sitting with the woman of the family, families were not considering alternatives. F said, "My husband will not agree to send his mother to an old-age home. He says that as a son, he will care for her as long as she lives."

Where the primary caregiver had an in-law relationship with the person with disabilities, acceptance of the role was not natural, yet the women felt duty-bound due to social pressures. They felt cheated into a situation where they were forced to provide care without their consent. H started looking after her sister-in-law once she and her husband returned to the village after some years. She said:

> Five years ago, my husband and I were working in Bangalore. At that time the other brothers-in-law were taking care of my sister-in-law. When we returned, they left her with us, saying that, "Until now our wives have looked after her. Now, you must." I often quarrel with them to take her, but they don't.

The negative attitude of the community towards disability seemed to make families conceal this information when forging new relationships. As a result,

women were often not aware of the caregiving responsibilities they would need to take on after marriage. L, who is seeking a marriage proposal for her son, said, "When seeing a girl, we do not mention that his father is disabled."

E, too, did not know that her prospective father-in-law had a disability and needed support. Once married, she didn't have the option but to assume the responsibility. The main reason for doing so was the fact that society considered it improper for a woman to make a life for herself away from her husband's home. She said:

> After marriage, my husband said that I must take care of his disabled father. My mind was blank. I cried and told my maternal uncle that I had to take care of him and earn money too. My aunt advised me that if I stayed with them, people would say that I did something wrong. So, I had to return to my husband's house and care for my father-in-law as that was the only place safe for me.

The second reason for accepting the caregiving responsibility was the caregiver's strong family ties, which made them feel morally responsible for the disabled family member. The women stood by their families, and if not driven by love and affection, their moral scruples that were enforced by the society did not allow them to shirk their responsibilities. L said, "We must share our troubles. When he was not disabled, we fell in love and married. Now, when we have a problem, we must bear it."

G—who's younger sister is married to the same man as her—expressed sympathy for her disabled sister and willingly accepted the role of caregiver. She said, "I am happy to take care of my sister because it was only after my marriage that she became disabled. I feel sad for her, so I take care of her."

Any voluntary support offered to the primary caregiver was often by the caregiver's side of the family out of concern for the caregiver rather than the disabled family member. They supported the primary caregiver because caregiving is seen as a burden, and seeking help from outside the family was not acceptable. J, whose aunt is a primary caregiver for her husband, said, "I am married and settled in their village, so I sometimes support them. I cook for them and sometimes support her in caring for her husband. I help only when my aunt asks me to."

C, who is the sister of a primary caregiver, said, "We don't ask anyone to help take care of my niece. When her mother is unwell, I take care of her. If both of us are ill, we ask my children to help."

The third reason expressed was the cultural belief in the karmic theory that good deeds are rewarded and bad deeds are punished. They seemed to find solace in the belief that God was witnessing the caregiving work they were undertaking. Though E felt deceived into supporting her father-in-law, she found acceptance and solace in the fact that God appreciated her work. She said, "He is my husband's father; I must, and I will serve him. God exists, and He is aware of everything."

They believe that God had assigned them the duty of providing care, which they had to undertake to earn divine approval. C, who is a maternal aunt of a disabled woman, said, "God punished her with a disability, and she must bear it. She was born into our family, so we had to care for her. God will bless us for it."

Though such beliefs consider disabled persons as being undesirable and incapable of reciprocating, they ensure that the families continue providing care. D, talking about her son, said, "It would have been better to not have a disabled child. If he did not have a disability, he would study, go out, work and look after us."

Further, she recognised that if he had better functionality and required less care, it would have made things easier. She said, "If he could sit in his wheelchair himself, it would have been good for us. But that is not possible, so no point in being sad. I will serve him."

The participants accepted the responsibility for reasons related to social practices and cultural beliefs. Social norms left no choice for the women but to accept the responsibility, at times unwillingly, but by choice in blood relationships. With in-law relationships, the women caregivers often felt cheated and forced to take on the responsibility after marriage. Most often, before marriage, they didn't know about the family member whom they would be expected to care for after marriage. They were bound as it was not considered righteous for women to live away from their husband's family. On the other hand, these social beliefs also held families together, creating strong family ties where caring for a disabled member was a family responsibility. Strong family ties sometimes favoured women caregivers as their maternal family occasionally supported them in caregiving and housework. Lastly, cultural beliefs that God was aware of the service they were providing and that they would be justly rewarded made them accept the responsibility. However, this belief reflects on the way the caregivers and the community perceive care at large. The perception of disability was also framed in such socio-cultural beliefs. Though providing care was seen as an unrewarding task because no reciprocation was expected from persons with disabilities, it was considered a good deed worthy of being rewarded by God. The caregivers recognised that caregiving would be easier if the person with disabilities were more functionally independent. In summary, the women had no say in accepting caregiving responsibility due to the social expectations and cultural norms that denied them the agency to think differently. Such beliefs not only reinforced the women's role in the family and community but also dictated the way care work and disability were considered—a punishment to be borne by the family.

5.4 Additional Support the Caregivers Wanted

Considering that the participants seemed to have no real choice in the matter, they appeared burdened by the responsibility differently. Living in poverty, the only source of income for these families came from daily wages and the government disability pension. Managing with much less income was difficult for them. They all experienced financial challenges emerging from their general poverty, and the support they unanimously wanted was not additional caregiving support, rather more food and medical support for the family.

Their poverty and thus struggles increased as the caregivers grew older and could not earn daily wages. M—a caregiver for her mother—said, "As I age, I do not have the strength to provide care and do labour-intensive work. I need help. I am asking for food ration, not money."

Since they were eligible and used to getting a government ration subsidy, they could articulate the demand for more rations. E said that the rations they received were insufficient and they needed more, "We don't want money, we want food. My children, my disabled father-in-law and I must eat. We get government rations, but that is not enough."

Other than buying food, they also expressed the need for financial support to address the additional health issues of the person with disabilities. A narrated an accident that hurt her son and put a financial burden on them, "One day, when I was carrying him, he fell and hurt himself. Now he has a lot of pain in his leg, and we have to take him to the doctor, and we are spending a lot on that."

They found the medical expenses—whether their own because of caregiving or those of the person with disabilities—difficult to bear and wanted additional money to cover them. L said, "Last month, he [her husband] had a skin problem, and my son had to take him to the doctor. It cost INR 2000, and our monthly income is INR 2500."

The disabled persons willingly gave their pension to the family in return for the care they received. However, the pension amount was insufficient, considering the person with disabilities had needs other than food, which the pension amount could not cover. F said:

> She gets only INR 1000 as a pension, but she demands so much. She wants bread in the morning and biscuits in the evening. We also provide food. For INR 1000 we are giving her everything. If she is ill, we give her some tablets because we cannot take her to the hospital with that money.

Remarkably, the participants did not, in general, consider it important to have additional support to compensate for the toll on their physical and mental health because of caregiving. They expressed mixed feelings about engaging a formal caregiver. Some, especially the young, found the idea not worth discussing. L, who is her husband's caregiver, said, "I can take care of my husband. Why do we need someone to help us?"

However, once the caregivers became old and unable to provide care, they saw value in engaging a formal caregiver. B, who looks after her disabled daughter, felt, "If we have more money, we will engage a servant after three/four years when I become old and cannot do the work."

Some older caregivers were ready to pay for formal caregiver themselves. I said, "These days, because I don't feel well, I am looking for someone in the village who will help. I'm ready to pay INR 5000, but nobody is ready to work."

Participant I further explained that it was a challenge to find people willing to provide care since supporting the person in toileting was considered a dirty task, and she did not feel anyone would agree to help, even for a good salary. She said, "Who will clean him? People earn only INR 150 as daily wages for working in the field but consider that better than doing this dirty work."

The caregivers themselves did not think that they would provide support to a person with disabilities outside their family, even if paid. E said, "No, I would not like to. Even if I agree, my family will not allow me."

G had similar thoughts. She felt that she could volunteer caregiving support at times, but not as paid work. She said, "I'm already serving my sister. I would not like to serve someone for money. However, if someone close to my house occasionally asks for help, I may go, but not for money."

The participants did not expect any additional caregiving support as for the woman of the family to provide care was an unwritten rule, except for some older participants, who had been providing care for a long and were able to pay

for employing a caregiver and wanted to hire someone to support them but did not think anyone would even for a good salary. They did not think that they would do paid care work either, as, according to them, providing care and support in toileting was a dirty job. These families experienced that all the participants wanted financial support that could reduce the pressure on the caregiver to earn a livelihood and could instead focus on caregiving, which may be due to the poverty they experienced. It was common for family members with disabilities to hand over their disability pension for home expenses such as food. However, the participants did not think the pension money was adequate to enable them to care for the person with disabilities well. They hoped for support in getting rations for the family and support in covering the health expenses of disabled persons.

6.0 Discussion

This paper reports on the well-being and agency of primary caregivers of adults with disabilities through their daily experiences. The analysis revealed that the primary caregivers were all women and responsible for supporting the disabled and older family members, with hardly any support from the other family members or the community. In terms of the CA-theory, we can conclude that they had no agency but acted as agents for the achievement of many basic functionings of all other members of the family and were responsible for helping the family member with disabilities to achieve basic functionings for survival, such as toileting, feeding and dressing (Sen, 2009). Caregiving had a significant impact on three of the basic capacities as identified by Robeyns (2003): their physical health, their mental well-being and severed their social relationships. They were unable to go out and faced indirect discrimination from the community because of family members with disabilities. They accepted the responsibility despite the negative impacts of long-term caregiving.

The results show several reasons why women caregivers lack agency and have neither a choice nor control over whether they want to take on or how they want to fulfil their caregiving responsibilities. The most striking reason was the social norms and cultural beliefs. Existing literature suggests that in India post-marriage, it was customary for the daughter-in-law to take on the responsibility of providing care to the husband's disabled or older family members (Gupta et al., 2009; Ugargol & Bailey, 2018). This research highlights that the women often did not know about the caregiving role they were expected to play after marriage. Not accepting the role could make them outcasts. Culturally, the idea that disability was an outcome of bad deeds and that families providing care would be rewarded by God (Ghai, 2002; Gupta et al.,2011; Ugargol & Bailey, 2018) helped the caregivers cope and continue to provide care (Gupta et al., 2011). These social and cultural norms played an important role for the women caregivers in accepting the caregiving responsibility naturally, without feeling the need to have any agency in the matter, or recognise its absence (Nussbaum, 2006).

The community perceptions of disability and gender intersected to make the caregiving task considered not valuable or important. As a patriarchal society, women caregivers passively accepted oppression and adapted to meet the expectations of their families and communities (Nussbaum, 2006, 2013; Sen, 1999), limiting choice with regard to the 4th basic capability Robeyns identified (2003). This research shows that they could neither oppose this situation nor think of any change to improve their lives; adapting to the situation was the only option. Such adapted preferences, as identified in the CA (Sen 1999; 2009), have also been seen amongst persons with disabilities, who perceived themselves as

a burden and, hence, compromised on their basic care requirements (Gupta et al., 2020).

Furthermore, seeking support for caregiving from people other than close family was not considered respectable. It was not until they were old and unable physically to provide care that they considered getting external support. Unfortunately, when they tried to hire someone, they were unable to find anyone because the work was considered of low status. Ironically, while providing care work is seen as a noble task to be rewarded by God, it is also seen as a dirty task that non-family members would not take on, even for good money. In fact, the women caregivers felt that they would not consider providing care to anyone other than family members for money and did not think their families would allow them to do so either.

The non-availability of possibilities to hire an external caregiver could also be due to the communitarian value set that prioritizes the family, rather than others, as the primary source of support. This finding warrants further investigation, as communities that expect the family to be the sole care provider may be reluctant to establish a formal care system, thereby preserving their traditional beliefs.

Further, the undervaluation of care work reduced the agency and self-worth of the caregivers. On the one hand, due to the care work, caregivers often have to forego daily wages or settle for reduced wages; on the other, providing care to a family member with disabilities was unvalued, which made their work unimportant. This put them in a situation where their contributions to the family were not appreciated. Scholars suggest that the unpaid nature of care work renders it invisible and unregistered in conventional accounting for welfare expenditures (Bittman et al., 2004; Folbre, 2004). One reason for not recognizing care work in economic terms is that the consumers of this work were persons with disabilities, who are already undervalued. As a result, the care work had no utility (Folbre, 2004).

This is compounded by the patriarchal systems that require women to earn for the family in addition to caregiving, when the men of the family are not earning, influencing the 5th basic capability Robeyns identified (2003). Such a situation not only puts them at a disadvantage within their homes but also treats them unfairly as compared to women without such care responsibilities. Thus, no matter what they did, they were prevented from becoming agents of their own lives and living in the way they valued. Therefore, further research is needed to explore ways of increasing the value and importance of caring for people with disabilities in the economic market.

Finally, the lack of agency in deciding how much work they can do has an impact on the agency of the family member with disabilities who receives care from them. Being responsible for multiple activities, including domestic work, caregiving, and earning a living, leaves them with little choice or control over their time. They struggled to balance the time required to undertake these activities with their personal and social commitments (Armstrong et al., 2008; Robeyns, 2011). This intern impacts the agency of the person with disabilities as the caregivers were not always available to support them when needed and required them to adapt their lives including their daily living activities around the times when the caregiver was available (Sen, 2009, Ghosh & Banerjee, 2017; Grech, 2015; Gupta et al., 2020).

Such beliefs and practices have percolated into policy. Despite the women being the primary caregivers, this role is not recognized in the Rights of Persons with Disabilities Act 2016, nor do any women's rights discourses address this. In policy, providing care as a prerogative of the family, inadequate attention is paid

to developing a sustainable formal support mechanism that could complement the support provided by the family or offer respite care (Gupta et al, 2022). While the government's Sahyogi Scheme offers caregivers training, it has no financial mechanism to enable a disabled person to hire trained caregivers. It may be that the 'caregiver's allowance' announced under the RPDA 2016 could be used to complement the Sahyogi Scheme by adding a financial support component for hiring trained caregivers. Furthermore, more substantial efforts are required to provide rehabilitation services to persons with disabilities in rural areas, which makes them more dependent on caregivers, resulting in caregivers having to dedicate more time to care work (Ghosh, 2016; Gupta et al., 2020).

To summarize, the women caregivers had a difficult time providing care and maintaining their agency. Their care work remains invisible due to the social, cultural, economic and political reasons discussed. Because caregiving is regarded as a duty, there is no demand from the women or the community for developing disability support alternatives and more community-based support structures. The existing social, cultural, economic and political systems maintain the oppression of women caregivers and ensure that care is available to persons with disabilities. Therefore, to create alternate support structures in the community, care work needs to be visible and recognised in the economic market, for which enhancing the choice and control of both women caregivers and the persons with disabilities receiving care is important, as only when caregiving work is considered useful will its economic value be recognised (Folbre, 2004). However, the social and cultural systems that oppress women and disvalue persons with disabilities diminish the chances of care work becoming more visible and leave the family care system unchallenged, making the development of other care and support alternatives unessential (Stone, 1984). The research findings validated the capabilities Robeyns (2003) suggested (presented in the research design) for evaluating gender inequality, except for the capability 'paid work', which did not emerge as a separate theme but rather as an important aspect impacting all the other four capabilities.

7.0 Conclusion

This research shows that women caregivers of persons with disabilities have no agency because of the existing complex and deep-rooted social, cultural, economic and political systems and structures. Negative perceptions of disability and care work further devalued them. This makes life difficult for both the women and the people with disabilities they care for. There is an interconnection between the time available to the women caregivers and the autonomy of persons with disabilities. When the former has less time, the latter are not able to receive support at the time and in the manner of their preference. The negative perception of disability and disability care reduced the possibility of creating community-based disability support structures, reducing options for creating additional or alternate support for caregiving. The lack of agency of women made it difficult for them to bring about any positive changes in their own lives or in the lives of the disabled. It is important for the government to build more supportive community-support structures by recognising the economic value of care work and investing in building it, raising positive awareness about disability and care work, and investing in better rehabilitation services for persons with disabilities that make them more functionally independent and reduce the amount of care they require.

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