

An asymmetric burden: Experiences of men and women as caregivers of people with psycho-social disabilities in rural North India

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Abstract

Caring for a family member with a psycho-social disability can be both rewarding and burdensome. This study analyses the experiences of caregivers of people with psycho-social disabilities (PPSDs) in rural communities in North India using relational gender theory. In-depth interviews with 18 female and male caregivers of PPSDs probed the social, emotional and health impacts of their caregiving role. Nine themes were identified that were grouped under three meta-themes: intra-personal, inter-personal and institutional impacts. Under the intra-personal meta-theme, all caregivers experienced high tension, with women describing almost overwhelming stress. Women minimised their role as caregivers, and felt negative and hopeless about their futures, while men had a more positive view of the future and themselves. Embodied experiences of psychological and social distress were consistently described by women, but not by men. Within the interpersonal meta-theme, men experienced opportunity for social connection and social support that was seldom available to women. Interpersonal violence with

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other household members was described by both men and women. Within the institutional meta-theme, both men and women described strength in unity, and gestures leading to the reordering of gender relations. These findings underline the significant and diffuse impacts of a gender order that values males and disadvantages females as caregivers of PPSDs, with the asymmetry of a greater burden for women. The findings point to the urgent need for global mental health policies that support and empower caregivers and that strengthen gender equality.

Keywords

caregiver burden, gender, gender inequality, global mental health, India, psycho-social disability, qualitative

Introduction

Mental illness, as a psychosocial disability, is one of the leading causes of years lost due to disability, yet 90% of people in low and middle-income countries (LMIC) with psychosocial disabilities do not have access to care (World Health Organisation, 2011). Behind these numbers is the hidden social, financial, physical and psychological burden on those who care for people with a psycho-social disability (PPSD) (Pompili et al., 2014; Viana et al., 2013). Caregiver burden refers to quantifiable costs such as costs of care and loss of free time for caregivers. Informal care, the unpaid provision of care to a dependent person, is the backbone of care for people with a psychosocial disability (PPSD) in India and is predominantly performed by women (Balaji et al., 2012; Chatterjee et al., 2014; Jagannathan, Thirhalli, Hamza, Nagendra, & Gangadhar, 2014; Kate, Grover, Kulhara, & Nehra, 2013b; V Patel et al., 2006). Informal care is highly beneficial to society but can have a negative impact on the physical and mental health, and even mortality, of caregivers (del Río-Lozano, García-Calvente, Marcos-Marcos, Entrena-Durán, & Maroto-Navarro, 2013; Pinquart & Sorensen, 2006). Several studies have shown that the negative impacts of caregiving are unequally distributed, with greater burden among female caregivers (del Río-Lozano et al., 2013; Schulz & Sherwood, 2008). The concept of burden clearly does not describe all of the caregiving experience, and it is also known that caring for PPSDs can be a source of positive transformation, inner strength and satisfaction (Hunt, 2003). Nonetheless, caregiving is on the whole, a burden and it falls mainly on the shoulders of women.

Gender, as a social construct, ensures culturally bound conventions for relations between and among women and men, influencing many determinants of health (World Health Organisation, 2000, 2012). Women's health is tightly linked to their status in society, broadly improving with greater gender equality and exacerbated by discrimination (World Health Organisation, 2000). Many studies suggest that gender inequality is a key determinant of the differences in mental health between men and women (Das, Das, & Das, 2012; Fikree & Pasha, 2004; Loganathan & Murthy, 2011; V Patel et al., 2006; Shidhaye & Patel, 2010).

In India, one of the most gender-unequal countries in the world (United Nations Development Programme, 2014; World Economic Forum, 2009), a female caregiver of PPSDs has multiple pathways to disadvantage that cumulatively and differentially impact her well-being (Fikree & Pasha, 2004; Qadir, Khan, Medhin, & Prince, 2011). She is likely to be economically and socially vulnerable with diminished opportunity in her community (Fenstermaker & West, 2002; Loganathan & Murthy, 2011; Malhotra & Shah, 2015; Shidhaye & Patel, 2010). Added to the oppressive matrix of caste and gender, a psycho-social disability further oppresses women with disabilities in a cultural context that focuses on charity and welfare over rights (Addlakha, 2008; Davar, 1995; Mehrotra, 2011).

There is very little research describing the experience of caregiving in LMIC settings (Addlakha, 1999; Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Pompili et al., 2014; Viana et al., 2013), and particularly few accounts using a gender lens and qualitative methods (del Río-Lozano et al., 2013; Opie, 1994). Recent studies of caregiver experiences in India have primarily been quantitative (Chadda, 2014; Jagannathan et al., 2014; Kate, Grover, Kulhara, & Nehra, 2013a; Kate et al., 2013b; Koujalgi & Patil, 2013; Kumar & Gupta, 2014), which may miss nuanced understandings related to gender relations (Opie, 1994; Patton, 2002). Understanding caregiver experiences allows the formation of policy and programme interventions to promote the agency and mental health of caregivers.

This research emerged from a study that identified social exclusion as prevalent for PPSDs (Mathias, Kermode, San Sebastian, Korschorke & Goicolea, 2015). However, gestures of inclusion, linked to caregiver identity, were also evident in the study, and the divergent experiences of men and women as caregivers prompted further data analysis. The emergent objectives were to investigate the emotional, social, economic and health experiences of caregivers of PPSDs from a gender perspective and to compare and contrast the relations among men and women using relational gender theory.

Methods

Theoretical framework

Relational theory conceptualises gender as comprising several structural dimensions: intra-personal (impacts within a person); interpersonal (impacts between people); and institutional (gender regimes acting at an intermediate level of social organisation, such as within families). These dimensions interact in complex ways with the gender order (the society-wide order at a set time that permeates most interactions). Gender involves active social processes enmeshed with bodies, that generate health consequences (Connell, 2012). Connell recognizes four structures of gender relations that, operating together, keep women subordinate: power, production, relations and symbolic relations (Connell, 1987). Relational gender theory understands gender as a fluid construct operating at multiple levels and providing opportunity for change.

Connell draws attention to the huge inequalities and gendered economic processes of a post-colonial world (Connell, 2007). These are highly relevant to North India, which is characterised by a proud history of both a non-violent independence struggle and non-alignment, as well as a history of being colonised with a dominant social hierarchy of caste. Caste is a formalised system of social stratification that is prevalent across the Indian sub-continent. It is assigned at birth and in census enumeration, and it is a powerful determinant of health in this region (Nayar, 2007; Subrahmanian, Nandy, Irving, et al., 2006; Vart, Jaglan, & Shafique, 2015). Belonging to an oppressed caste exposes one to social inequalities and affects health adversely (Vart et al., 2015). Social hierarchies of caste and disability, linking with gestures of self-determination in this political economy, critically contribute to the context of caregiving and gender, influencing access to education, employment, social capital and social support (Addlakha, 2008; Mehrotra, 2006, 2012).

Researcher stance

The first author (KM) was born and spent her childhood in urban South India and rural Nepal, although ethnically she is a white New Zealander. She has lived in towns in North India since 2006 and speaks fluent Hindi. The research assistant (PS) is an Indian woman from Uttarakhand. The co-authors MK, BD and IG are female and MSS is male. MK, IG and MSS are all researchers of Western origin who have spent many years living in LMIC. BD is an Indian academic and activist residing in western India.

Setting

This study was set in two administrative blocks of western Uttar Pradesh (UP), an area which is dominated by the cultivation of sugarcane, wheat and rice. Both were recently ranked in the second quartile of socio-economic development for UP (Rao, Kumar, & Brahmam, 2013). Both the Sadoli-Kadim and Seohara blocks are highly rural, with towns of 1500 – 8000 people dotted across the agricultural land; this land is highly inequitably distributed, with some large tracts of land held by *zamindars* (large land owners) (Jeffery & Jeffery, 2008). Table 1 summarises the socio-demographic profile of the study districts.

The gender order in western Uttar Pradesh is linked to unequal opportunity for men and women, rich and poor, and Muslim and Hindu. In order to maintain honour (*izzat*) for their families, women regularly experience controls to their demeanour and mobility that limit their access to health, education and employment (Jeffery & Jeffery, 1998). There is marked gender role differentiation for women responsible for housework, child-rearing and field work, and men primarily perform paid work. Men, Hindus and dominant castes are over-represented among health clinic staff and professionals (Jeffery & Jeffery, 1998; Narayana & Kantner, 1992). Caregiving work typically performed by men includes taking the affected family member to health providers, while women typically wash clothes, make

Table 1. Socio-demographic profile of study districts and national comparison data Socio-demographic profile of study districts and national comparison data. (Sources: Government of India, 2011; Ministry of Health and Family Welfare, 2016; Office of the Registrar General & Census Commissioner, 2013)).

Indicator	National (India)	Bijnor (Uttar Pradesh)	Saharanpur (Uttar Pradesh)
Total population (million people)	1,200	3.6	3.5
% population under 15 years	34.9	35.7	34.2
Sex ratio (female to 1000 males)	963	917	890
Literacy (% literate female)	65.5	59.7	61.7
Literacy (% literate male)	82.1	76.6	78.3
Maternal mortality	178	222	204
Infant mortality	40	62	76

food, and give medicines (Jagannathan et al., 2014; Kate et al., 2013b; Mehrotra, 2012). Gender inequalities are further evident in daily agricultural wages for women that are typically only 80% of those received by men (Raj, 2011), and in gender-based violence that affects one third of married women (Ahmad, Khan, Mozumdar, & Varma, 2015).

While a national District Mental Health Plan (DMHP) was launched in India in 1996, it has been imperfectly and incompletely implemented (Jain & Jadhav, 2009). Neither of the study districts were included in DMHP implementation at the time of research, and there were no mental health services provided by the government (State nodal officer for mental health, 2013). Studies of help-seeking preferences suggest that families consult religious and traditional healers as well as biomedical and unregulated rural medical practitioners (Banerjee & Roy, 1998; Ecks & Basu, 2009; Mishra, Nagpal, Chadda, & Sood, 2011; Naik, Pattanayak, Gupta, & Pattanayak, 2012; Pinto, 2004). Engagement of the poor with the health care market mostly results in debt and impoverishment (Duggal, 2005; Jeffery & Jeffery, 2008).

The first author screened potential PPSDs identified by trained community workers, using the Global Mental Health Assessment Tool (Sharma, Lepping, & Cummings, 2004). The first 20 PPSDs who fulfilled the criteria of a severe mental illness and consented to participation were included. Consent for participation was also given by 18 caregivers of these PPSDs. Eleven caregivers were women and seven were men. Table 2 provides a detailed description of participants.

Data collection

A research assistant, trained in qualitative interview techniques, conducted in-depth interviews in participants' homes during June 2013. The interviews lasted up to 90 minutes, using a semi-structured guide to probe experiences of social connectedness and support, stress, caregiving responsibilities, gender relations,

Table 2. Profile of caregivers interviewed.

Caregiver pseudo-nym	Care-giver sex, age	Person with a PSD sex, age	Likely mental illness PSD	Relation-ship to PSDs	Faith tradition	Household composition	Household responsibility in addition to caregiving
Rita	F, 33	M, 33	Chronic psychosis	Mother	Hindu	Lives with husband, and two sons. Three adult daughters are married and live elsewhere	Domestic; household owns a small landhold-ing; father works as an agricultural labourer
Parmila	F, 44	M, 24	Chronic psychosis	Mother	Hindu	Widow with three sons, two school-aged	Household head; bread-winner; sells milk and rents land to a neighbour
Sabeen	F, 22	M, 28	Bipolar disorder	Sister	Muslim	Lives in extended house-hold with parents and ten siblings, including wives and families of three brothers	Domestic; household income from family tai-oring business
Kavita	F, 45	M, 24	Chronic psychosis	Mother	Hindu	Kavita and Kishan were spouses living with son (PPSD), a further son and his wife /children	Domestic
Kishan	M, 45	M, 24	Chronic psychosis	Father	Hindu		Household head; bread-winner works as agri-cultural labourer; own no land
Salim	M, 36	F, 35	Post-partum psychosis	Husband	Muslim	Husband of PSD, with three daughters, two sons	Household head; bread-winner; sells vegetables from a cart
Siddarth	M, 46	F, 45	Bi-polar disorder	Husband	Hindu	Husband of PSD; they live with three sons, two of whom are married	Household head; bread-winner; owns land and a small shoe-making business

(continued)

Table 2. Continued

Caregiver pseudo-nym	Care-giver sex, age	Person with a PSD sex, age	Likely mental illness PPSD	Relation-ship to PPSDs	Faith tradition	Household composition	Household responsibility in addition to caregiving
Neeta	F, 45	M, 45	Bi-polar disorder	Wife	Hindu	Wife of PPSD living with their three children	Household head; co-breadwinner; domestic; sells buffalo milk; two daughters are teachers
Kavi	F, 25	F, 50	Chronic psychosis	Daughter	Hindu	Lives with mother (PPSD), father; and two younger brothers	Domestic; father works as agricultural labourer
Veena	F, 44	M, 22	Unipolar depression	Mother	Hindu	Mother of PPSD; lives with husband, adult daughter and son	Domestic; husband works as shopkeeper
Kailash	M, 30	F, 28	Post-partum psychosis	Husband	Hindu	Lives with wife (PPSD) and their three children	Household head; breadwinner; husband is agricultural labourer
Amrina	F, 30	F, 28	Post-partum psychosis	Sister	Muslim	Lives with husband and four children and next door to sister who is PPSD.	Domestic; household income not disclosed
Jahanara	F, 28	M, 28	Chronic psychosis	Wife	Muslim	Lives with husband (PPSD) and their three young children	Household head; breadwinner; agricultural labourer and also tailor
Sabbir	M, 40	F, 40	Chronic psychosis	Husband	Muslim	Lives with wife (PPSD), three sons, and their wives and children	Household head; Breadwinner; household income not disclosed

(continued)

Table 2. Continued

Caregiver pseudo-nym	Care-giver sex, age	Person with a PSD sex, age	Likely mental illness PPSD	Relation-ship to PPSDs	Faith tradition	Household composition	Household responsibility in addition to caregiving
Jameela	F, 40	M, 40	Chronic psychosis	Wife	Muslim	Lives with husband (PPSD), three school-aged daughters and one pre-schooler son	Breadwinner; domestic; agricultural and domestic labourer; also sells firewood
Sanjay	M, 41	F, 40	Post-partum psychosis	Husband	Hindu	Lives with wife (PPSD) and one unmarried daughter	Breadwinner; household income not disclosed
Anita	F, 55	M, 28	Chronic psychosis	Sister-in-law	Hindu	Lives with husband, two adult children, and extended family	Domestic; agricultural labouring (3 adult males) and a small grocery shop
Saji	M, 40	M, 44	Chronic psychosis	Brother	Muslim	Lives with his wife, their five children, and adult brother (PPSD); has three other adult brothers in a nearby community	Household head; breadwinner; owns land and buffaloes, sells milk, and agricultural labourer

PPSD: Person with psycho-social disability.

Table 3. Example of coding and thematic development process

Original text	Codes	Interim theme	Final theme
There is so much of difficulty, but I had to work even while I cry. Where can we go? With his illness it has become more difficult and tough. I cry and I just keep working. I even feel ill at times.	Anxiety and stress for caregiver Compulsion to work Somatic symptoms - caregiver	Physical health impacts on caregiver	Embodiment

agency and social inclusion within the participants' households and communities. The interview guide was adapted from one previously piloted in India and used to assess experiences of social exclusion among caregivers and PPSDs. Interviews were conducted in Hindi and audio-recorded; the recordings were translated and transcribed. For components of analysis relying on grammatical constructs such as tenses, KM and the research assistant discussed the original Hindi words and intended meaning with community members to ensure that the correct meaning was conveyed. The initial analysis (Mathias, Kermode, San Sebastian, Korschorke, & Goicolea, 2015) focussed on data from the PPSD participants detailing their experiences of exclusion and inclusion. The findings from the analysis of the data from the interviews with a total of 18 caregivers are reported in this paper.

Analysis

The data were analysed inductively and thematically using a validated approach inspired by Braun and Clarke (Braun & Clarke, 2006). First, KM inductively coded seven representative transcripts line-by-line, yielding over 50 codes. The codes were reviewed and discussed by KM, MK and IG, and condensed into 9 interim themes through recognition of consistent patterns inherent in the data. The remaining 11 transcripts were then coded and analysed; then themes were again discussed and refined with MK and IG. Table 3 illustrates this process. The final thematic summary (Table 4) shows how themes were adapted and condensed into three themes.

Ethics

All participants, including caregivers, were informed about the nature and purpose of the study. A plain Hindi-language summary describing the purpose of the research and the possible uses of the data was read aloud. All caregivers gave informed consent, and participants were offered ongoing support by project

Table 4. Summary of themes describing gendered experiences of caregiving

Intra-personal	Interpersonal	Institutional
Zyada tension - High stress		Sab milkr is karya ko kar sakte hai – Through togetherness we can do it
Bleak to bright horizons	Losing and keeping friends	New gender relations
Self-blaming to self-affirming	Experiences of violence	
Embodiment of distress	Social judgement to social support	

staff. The study was approved by the Emmanuel Hospital Association Institutional Ethics Committee, New Delhi, in April 2013.

Findings

The nine themes finally emerging are shown in Table 3 under the three meta-themes derived from relational theory (Connell, 2012). The household is understood as an institution, i.e., reflecting complex norms around gender (Connell, 1987).

Intrapersonal

Zyada tension – high stress

Both men and women identified increased household “*tension*” (adopted from English, signifying stress) related to their family member’s illness, and presented caregiving as stretching the household ability to forbear.

As Jameela summarised: “We can endure so much and then no more (*Bardash itna kar sakte, is ke age hum nahi kar sakte hai*).” Some affected family members required many hours of caregiving each day (including in personal hygiene and feeding). Narratives by female caregivers conveyed a greater sense of duress and “tension.” They described persistent sadness (*dukh*) at their situation, cried during the interviews, and requested the interviewer to return soon. This burden (*bardash*) was greatest when the PPSD was also the traditional breadwinner, typically a man, due to the associated income needs. The overwhelming impact of having a PPSD for the household is described below:

My mind is always tensed because of his illness. For the past ten years our family life has turned upside down. I would even be prepared to sell everything I own if that money could make him well. . . Now my two daughters are of marriageable age (*shaadi ki umr ho gayi ha*), but how can I even think about that? (Neeta, F, 45 years)

Bleak to bright horizons

The greatest hope for the future for all caregivers was that their family member would become well. Men and women described anxiety about the challenge of getting their children educated and their daughters married. However, female and male caregivers diverged in their outlook on the future, with women describing lost hope for the future:

We are so poor and helpless. I am very worried about my children's future. I am unable to send them to school or give them good food... feel very bad for my destiny and my family. I think my life is useless and there is no meaning in living like this. At times I think I should just run away or commit suicide. ... It is very difficult to see my children with so many problems and my husband so unaware of all that's happening to us. (Jameela, F, 40 years)

A bleak view of the future was also evident when women described suicidal ideation, as articulated by Kavi:

It is very difficult [*sobbing*]. There are so many wrong thoughts (*galat khayal*) that come to my mind. I think about what a waste it is to be alive without happiness. ... These problems are continuing for years now. It would be better if I were dead. (Kavi, F, 25 years)

This level of despair was less evident among male caregivers, none of whom expressed any wish to be dead. Men envisaged a wider range of views for the future and saw positive options ahead. A 41-year-old described his views:

Now my wife is well enough to fully take care of herself. Why should I be worried about her in the future? I know she will not go anywhere in her old age (*laughing and nudging his wife*). My wife's destiny (*nazeeb*) is very good. (Sanjay, M, 41 years)

Self-blaming to self-affirming. Men and women assessed their capacity as caregivers in contrasting ways. There were no women who identified themselves as good caregivers, instead belittling their caregiving role using the passive voice and first person plural grammatical structures, diminishing their agency. For example, while Jameela clarified that she herself had arranged care for her husband, she uses both first person plural and a passive voice in describing this ("We showed him..." and "So much was done"):

We showed him to the local doctor, and he gave some medicines and injections but still his condition was the same. We even took him to *pandits* and *bhagats* (Hindu traditional healers). They said it's a case of evil spirits. So much was done but nothing helped his condition. (Jameela, F, 40 years)

Women also described their feelings of shame and anger in relation to their caregiving role:

At times I feel very angry with her, and then I feel very angry at myself too, that being her child I could feel that way for my mother. I feel bad because I yell at my mother and say many things to her. Sometimes I want to hit her but until now I have not lifted my hand against her. My parents raised me with such love and affection (*bade pyaar se*), and yet see how I am behaving with them. (Kavi, F, 25 years)

Men were self-affirming about their efficacy as caregivers and their role in facilitating access to health care. Men underlined their personal merit in remaining with their unwell relative, while no woman mentioned merit in not having left her family member. One man described how blessed his wife was to have him as a caregiver:

I took my wife to so many doctors in Moradabad and other places... I don't know how many lives my wife must have prayed and meditated to get a husband like me and a family like ours... It is no easy thing to get treatment and provide good care for a patient. It takes a very strong heart (*bahut majboot dil*). (Sanjay, M, 41 years)

Embodiment of distress

Women consistently described many somatic symptoms that they linked to caregiving. Symptoms were correlated with the onset of their family member's mental illness and with the stressors (financial, physical, and social) associated with caregiving. Symptoms included heaviness, a feeling of the head bursting, body swelling and pain, weak eyes, headache, fits and fainting and stomach aches. In the quote below, a woman relates how the onset of her husband's illness catalysed her own loss of wellbeing:

I have difficulty sleeping and lie awake most of the night... I have headaches and body ache. I used to be a very healthy and jovial kind of person but since his illness everything has changed. (Neeta, F, 45 years)

A young woman perceived her brother's illness as impacting the health of the whole household below:

My mother is very sad because of him and she is in some kind of *mann me sadma laga hai* (shell-shock) since his illness and her health has worsened... my father is also becoming very weak and sad... We are all *tension ke sath* (stressed) and one or the other person is ill now. God knows what has happened to our family that sickness never leaves us. (Sabeen, F, 22 years)

Men's accounts differed: they did not mention physical symptoms as an impact of the stress of caregiving, or even mention symptoms at all, although one man said that his heart was troubled after the start of his wife's illness.

Interpersonal

Losing and keeping friends

Women and men described different opportunities for maintaining friendships which were interpersonal rather than institutional. Women, particularly household heads, described increasing social isolation and the severance of previous friendships since assuming the caregiver role. In the example below we are told of neighbours who laughed at the unwell son, and how Parmila felt she must limit her social interactions:

When my son was in school I would talk to everyone and I went out often to sit with my neighbours. . . Now I don't send my son outside because people tease him and make fun of him. I also don't like talking much and unnecessarily with neighbours and people. (Parmila, F, 44 years)

This contrasts with the men's accounts of an ongoing healthy social network of friends facilitated by female relatives and neighbours, as described below:

I spent lots of time with my friends while my wife was sick, and even until now I see my friends. I also would go away to visit my brother's place or my cousins. It was never any difficulty as my mother would look after the children when I went away and my sister-in-law would do the housework. (Siddarth, M, 46 years)

Social judgement to social support

There were stark differences, which seemed to span both interpersonal and institutional realms, in the accounts of social support experienced by men and women. Women described sparse social support. Three of the single head-of-household women explained that their unwell male family member had been disinherited, i.e., they had been required to move out of their in-law's house and were no longer allowed to cultivate their share of the family's land. The subsequent loss of access to agricultural fields and cattle resulted in loss of social status, as described by Parmila below.

If only you could see the house we used to have in my husband's village [*she became tearful*]. We had 30 *bighas*¹ (measure of land) and two buffaloes also in our house. And now we have nothing due to my husband's death and my son's mental illness. (Parmila, F, 44 years)

Head-of-household women understood their social and economic situation as so precarious that family members severed relationships to avoid sharing the responsibilities of care. Jameela describes the social isolation she experienced, and her understanding of why it occurred, below:

All our relatives, especially my in-laws side, have broken all contacts with us. They haven't given us any money or share in the property. Everyone feels that because of my husband's condition we will be a burden for them, so no-one keeps in touch with my family except my mother-in-law. . . . (Jameela, F, 40 years)

Women also described a sense of community judgement regarding their situation. One woman explained that all the neighbours believed her husband's illness was an elaborate "drama" to evade his duties as a breadwinner of the family. Neeta described the neighbours' negative judgment and felt that whatever she did, it would be criticised:

Yes, they talk amongst themselves and say that me and my daughters dress well and that we do not bother about a sick husband [*sighed*]. Now I ask you, just because my husband is unwell should we all stop wearing clothes? My daughters are teachers and they must dress well for their job. People do not allow a person to live either way. No one supports or comforts my children, they just pass comments on them. (Neeta, F, 45 years)

In contrast, men were almost universally supported by relatives and neighbours in their caregiving roles. Support included help with housework, childcare, and even harvesting the fields while a man took his family member to hospital, as recounted below:

Neighbours took care of my children while my wife was very ill and I was busy taking her to treatment. Neighbours knew that I was at work and my wife was unable to look after the children, so they looked after my children. Also my mother would come to stay with my wife and children during the day while I was out at work. (Sanjay, M, 40 years)

Experiences of violence

Interpersonal violence and family responses to it were located in both the interpersonal and institutional meta-themes. Both men and women described experiences of interpersonal violence. The dominant patterns involved women being assaulted by male PPSD, and caregiver men assaulting both men and women with a psychosocial disability. Caregivers told of hitting out at a PPSD in anger as well as using physical violence as a form of discipline. After being asked how she felt about their

brother not helping the family, Sabeen describes how her brother is beaten by his father:

We feel angry sometimes and also sad for him and his condition. . . but we just remain silent. But my father beats my brother when he feels angry although he really tries his best not to beat him. (Sabeen, F, 22 years)

The unpredictability and constant threat of violence by the PPSD was a major source of stress for caregivers. Interpersonal violence was also described between spouses and towards children. The risk of physical violence towards children required caregivers to return home to protect their children, as described by Jameela:

I and my children live in the shadow of fear. My daughters do not talk too much to their father as they are not sure what his reaction will be. He even beats up the children, so I have to be at home when he is around. . . . Each night we sleep in stress and we lie awake most of the time. (Jameela, F, 40 years)

Institutional

Sab milkr is karya ko kar sakte hai – through togetherness we can do it

The majority of caregivers described that, though beleaguered by difficulties, they felt a sense of unity and strength with family members. Several described how all household members worked collaboratively to manage problems such as the PPSD's behaviour and neighbours' complaints. Some conveyed a sense of pride and dignity in their forbearance. Women and children becoming breadwinners contributed to a sense of self-efficacy, as conveyed below:

Whatever money we generate is from our own efforts. I sell the buffaloes' milk, my two daughters are teaching in a school, and through togetherness we can do it (*sab milkr is karya ko kar sakte hai*)(). My son. . . is also joining some factory to earn money. . . . All my children are trying their best to earn for the family. (Neeta, F, 45 years)

New gender relations

Men as caregivers described taking the time to explain their family member's behaviour to the people around them, and described new ways of relating, often in ways not typically associated with being male.

Men described how their social interactions had changed as they took on more caregiving responsibilities, including duties less typical of men. Siddarth describes not wanting to go too far from home, a level of caring that is more often associated with women:

My interaction with other people has become less because wherever I go, in the back of my head I keep thinking of her. My wife is a big responsibility and I do not go far because I know my wife and my daughter are at home. Since my mother died *main bahut tension me hoon* (I feel very stressed) as I am solely responsible now. (Siddarth, M, 46 years)

While men described assuming new gender roles that demanded empathetic communication, the most frequently narrated emerging gender relation for women caregivers (5 of 11 women) was to take on income generation, traditionally a man's responsibility. Jameela describes below her three strategies for earning:

My day starts with care and cooking. My children also help with housework so I can go to earn. Then I have to go to work at someone's place for money. Or else I go to the fields to work as a daily labourer. ... Some days if there is no labouring work then I go to collect wood in the forest to sell. (Jameela, F, 40 years)

Discussion

The role of caregiving leading to increased stress and subjective burden is experienced by both men and women caregivers. The factors that have been shown to increase the subjective burden for caregivers in India include long hours in caregiving, duration of the affected person's illness, and the severity of illness of the family member (Jagannathan et al., 2014; Kate et al., 2013a). Most of these factors affected the participants in this study.

The differences in caregiving experiences for male and female caregivers were more apparent than the experiences they had in common. Most of the identified themes presented a spectrum of caregiving experiences that were highly gendered, where predominantly women experienced the negative end of the spectrum, while men tended to locate themselves on the more positive end. To understand the greater caregiving burden described by women caregivers, we need to consider the gender order operating across India that confers greater status, resources, authority and freedom to males (Das et al., 2012; Fikree & Pasha, 2004; Jeffery, 2000; Jeffery & Jeffery, 1998; Qadir et al., 2011). This leads to greater tension for women as caregivers for the following reasons: women work more hours in caregiving, perform heavier manual caregiving tasks, have fewer opportunities for respite, and have fewer social interactions outside the house in a context where it is more socially acceptable for men to devote time to leisure activities (Addlakha, 1999; Jagannathan et al., 2014) and where there are additional social hierarchies at

play that include caste, creed, class and disability (Mehrotra, 2012). The caregivers' feelings of being able to cope and pursue their own activities are linked with a lower caregiving burden (Jagannathan et al., 2014), a protective factor less available to women than men, adding further to the women's heavier burden. The impact of this greater burden is linked to greater psychological distress and a poorer quality of life (Kate et al., 2013b).

Men as caregivers received much more social support than women. In a gender order where typically women perform household responsibilities, a male caregiver with an incapacitated wife is immediately recognised as needing help with the "female" responsibilities. Men are also more likely to ask for help from their informal networks and to share caregiving with others in the household (Kate et al., 2013a). Social support seems less forthcoming for women, who are required to care for their affected family member, perform household duties, and also earn income because the male breadwinner is incapacitated. Perceived social support shows a significant inverse relationship with caregiver burden (Jagannathan et al., 2014), further explaining the greater burden felt by women.

Female household heads (4 of 11) were more socially isolated, and economically deprived, with their status as widows and deserted wives conferring an additional disadvantage. The significantly increased poverty associated with female headship has been linked to lower income, lower control over land resources, and lower education compared to households led by men (Chen & Drèze, 1992; Panda, 1997). For the three women whose son/husband had been disinherited, the additional disruption of patri-local residence with consequent losses of social and economic support added to their vulnerability. At the same time, some female household heads also described a sense of family unity and strength in their ability to earn income and manage alone.

Embodiment refers to the way that social, psychological and biological experiences are incorporated into our bodies and epidemiological profiles. Human expression of distress and illness is filtered through cultural and personal explanatory models to present as somatic syndromes (Kirmayer & Sartorius, 2007). The prominence of somatic symptoms as an idiom and culturally acceptable expression of mental distress in South Asia has been well described (Grover & Ghosh, 2014; Kirmayer, 1989; Shidhaye, Mendenhall, Sumathipala, Sumathipala, & Patel, 2013). While relational gender theory captures much of the lived experiences of caregivers, we found Krieger's eco-social theory a more useful framework for understanding embodiment. Embodiment is the central concept of eco-social theory, which proposes that inequalities in health must be understood within the dynamic social, material and ecological contexts in which people live (Krieger, 2001).

In the context of rural North Indian villages, eco-social theory considers pathways to embodiment, and in particular focuses on the cumulative interplay of risk, vulnerability and resistance (Krieger, 2004), which are played out throughout the life-course (Mehrotra, 2012; Qadir et al., 2011; World Health

Organisation, 2000). Gender constructions and the inequalities they generate are incorporated into the biology of women in this study. The embodiment of stress was witnessed intra-personally, interpersonally and at the institutional level of the household. The female caregivers' narratives of somatic symptoms are a likely product of the prevailing gender order. The vulnerability is increased when members of marginalised groups lack the resources to deal with health-damaging stress (Campbell & Jovchelovitch, 2007). Poor access to health care, low personal and financial autonomy, and reduced social connectedness cause distress that finds legitimate expression as physical symptoms (Kirmayer, 1989; Kirmayer & Sartorius, 2007).

A further vulnerability is the social isolation experienced by female caregivers which is in part linked to the stigma and exclusion experienced by PPSDs. It seems to be differentially experienced (no male caregivers talked of experiencing community critique or social isolation), and this probably means exclusion is differentially "applied" to female versus male caregivers (Koschorke et al., 2014; Mathias et al., 2015).

There are also some gestures of resistance to the prevailing gender order seen in the new gender relations emerging for caregivers. Several male caregivers described higher levels of attentiveness, empathy and sensitivity, and prized their spouses' health above financial considerations. Women heading their households also demonstrated enterprise, opportunism and independence as they sought to generate a livelihood. These steps point towards new constructions of masculinity that may enhance men's emotional health and broader social health (Courtenay, 2000), while the financial independence of women-led households also challenges patriarchal values and prejudice, and provides new models for the future. Gender relational theory (Connell, 1987, 2012) provides a framework to understand the gendered experiences of caregivers and provides space for positive change, where relations are more fluid than roles, and the concept of resistance signposts pathways to a new gender order.

Methodological considerations

The involvement of researchers (KM and research assistant) with a concurrent community project may have influenced respondents to provide socially desirable responses. The convenience sampling method that was used to identify participants for the initial study resulted in 7 male and 11 female caregivers being identified. Although this results in asymmetric weighting, with a greater volume of data from female caregivers, it also reflects the prevailing identity of caregivers in India as women. As the research assistant conducting interviews was female, it is possible that male participants may have censored their responses due to contextual gender relations (Patton, 2002), but the participation of a male community worker at interviews with male caregivers may have mitigated this somewhat. The Western ethnicity of the co-authors performing data analysis (KM, MK and IG) risked misunderstanding cultural nuances, but also held the possible benefit of cultural

distance which can increase attention and curiosity (Patton, 1999). Reflexivity on positionality may have mitigated these limitations.

Given the high impact of caste, class and household income on community attitudes and social exclusion, insufficient detail collected about participant caste and social class is a limitation in this study. As this analysis emerged from data collected for a study in which caregiver experiences was not the main focus, we may have missed deeper probing into relevant issues.

To address methodological rigour in this study, we incorporated four strategies to promote the trustworthiness of the findings (Lincoln & Guba, 1985): credibility, transferability, dependability and confirmability. Triangulation using different sites and analysis by authors with different ethnic backgrounds increased the study's credibility. Dependability and confirmability were increased through the familiarity of KM and the RA with the study area, and by the authors working together to develop the thematic overview and by using inductive and emergent analysis. We tried to maximise transferability by providing detailed contextual information.

While this study was carried out in rural villages in Uttar Pradesh, these unequal gender relations operate across rural South Asia and beyond (Jeffery, 2000; Jeffery & Jeffery, 1998) and we believe that the experiences documented here are relevant to many other settings.

Implications

Important implications for social policy, legislation and research priorities emerge from this study. The caregiver burden for men and women in this study was compounded by almost no access to mental health services for PPSDs. The inclusion of mental health in the United Nations Sustainable Development Goals (United Nations, 2015) in Goal Three (ensuring healthy lives and promoting well-being for all at all ages), will be an important impetus for nations to invest in mental health promotion and services. The United Nations Convention on the Rights of People with Disability (United Nations, 2008, 2015), which includes a focus on the additional disadvantage associated with female gender in Article 6, has been signed by India and proposes an environment both enabling and empowering PPSDs to increase their autonomy and to reduce caregiver responsibilities (del Rio-Lozano et al., 2013; World Health Organisation, 2012). Increased mental health services and access to care, with the implementation of the National Mental Health programme (National Mental Health Programme, 1982) in rural locations of India is urgently needed.

While India's new Mental Health Care Act (Mental Health Care Act, 2017) contains provisions, such as providing for advance directives, to support caregivers, it is not clear that there are resources and processes to ensure it is meaningfully implemented (Kar & Tiwari, 2014; Vikram Patel, 2013). The bill fails to refer to gender, and several have questioned whether it genuinely engages with the enabling framework of the UNCRPD (Davar, 2012; Kar & Tiwari, 2014; Sarin, 2012). Informal caregivers need a stronger understanding of mental illness, increased skills (such as strategies for behavioural management), and access to financial

and social support services (such as respite care services), all of which are poorly addressed by current programmes and policies (Addlakha, 1999; Addlakha, 2008; Kate et al., 2013a). A promising pathway to address the multi-dimensional social and health needs of caregivers are approaches that integrate action in both mental health and community development (Chan, 2010; Lund et al., 2013; Plagerson, 2014). Further research in North India must develop and assess effective actions to increase social inclusion, community development, gender equality, and knowledge and skills in mental health in communities.

Social exclusion of female caregivers of PPSDs, linked to the stigma associated with mental illness, emerges from a complex network of beliefs (Jadhav et al., 2007; Littlewood, Jadhav, & Ryder, 2007). NGOs and government programmes need to build community awareness, and ensure that “mental health literacy” (Jorm, 2012) initiatives use culturally acceptable explanatory frameworks (Jadhav et al., 2007; Kermode, Bowen, Arole, Pathare, & Jorm, 2009; Kohrt et al., 2009). The actions to promote social inclusion must expand opportunities for PPSDs and their caregivers to participate as active agents (Addlakha, 2008; Mathias et al., 2015).

The structural determinants of health revealed here in a focus on “local” and “community” (Bemme & D’souza, 2014)—i.e., gender-determined burden, impoverishment, embodied distress and exclusion—by caregivers sitting on the hard dirt floors of rural Uttar Pradesh must receive greater attention from the global mental health agenda, which has focused primarily on access to care (Kirmayer & Pedersen, 2014). The policy actions for gender equality that need resources and political commitment include increasing access to, and completion of, secondary education and ensuring structures for economic independence such as rights to inherit and own property (Grown, Gupta, & Pande; Pande & Astone, 2007). Foremost, we need actions at every level and in all sectors to explicitly address gender inequality and the social determinants of health.

Conclusion

Women providing care for PPSDs in these rural North Indian communities are oppressed by the prevailing gender order which disadvantages them in a range of ways. While men as caregivers also experience high stress, they and their families benefit from social support, personal autonomy, and respite from caregiving. Communities are diminished when those who care for PPSDs are so heavily burdened. Our qualitative study describes the differential impact—which is diffused, harsh and substantial—of gender on caregiving.

The cumulative forces of disadvantage linked to disability and gender evident in this study point to an urgent need for trans-disciplinary and multi-disciplinary research that continues to investigate and describe the impacts of social determinants of health and the processes leading to social exclusion (Davar & Ravindran, 2015; Mehrotra, 2011, 2012). This analysis of caregiving through the lens of gender underlines the urgent need for policy, and policy implementation, that ensures

access to mental health care, social support systems, collaborative engagement with stigma and knowledge frameworks, and ultimately a new gender order that supports social inclusion and equality for all.

Acknowledgements

We would like to especially thank the 18 caregivers for their participation. We also thank the Community Health and Development programme of the Emmanuel Hospital Association for supporting this research in multiple ways, the SHARE team led by David Abraham at Seohara, Bijnor and the SHIFA team led by Raj Kamal at Sadoli Kadim, Saharanpur for help with recruitment and logistical support. Thanks also to Prerana Singh (research assistant) for support to data collection.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: a small private donation covered the costs of translation and transcription by the research assistant. There was no other funding received for this research.

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