

Research Paper

Wives as Caregivers of Persons having Mental Illness: Structural Stigma and Intersectionality Revisited

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ABSTRACT

In India, family members as the caregivers of persons with mental disorders play a significant role in their recovery process. They face stigma and struggle while carrying out responsibilities that often goes unnoticed. This study explored caregivers' lived experiences as wives of persons with severe mental illness. In-depth open-ended interviews were carried out with 4 caregivers which were audio recorded, transcribed and analysed using grounded theory approach with situational analysis. Findings revealed pervasive effect of intersectionality of structural stigma in different domains (mental illness, gender, skin colour, socio-economic factors etc). Caregivers as wives, facing deprivation of agency while getting married and taking necessary actions to seek help for their husbands. Concealability, fear to be judged by the society and logistic impediments of getting help were crucial. Interestingly, the study revealed that spirituality, creativity embedded in the nuances of lived experience helped to locate alternative ways of coping.

Keywords: *Mental Illness Stigma, Caregivers, Marginalization, Gender Issues, Intersectionality.*

This study arose from the curiosity to explore how the wives who are direct caregivers of persons with mental disorder, perceive and conceptualize stigma in their lived experience; in their journey of caregiving over a long period of time. In India, generally family members are caregivers who are the most significant persons in the lives of the patients too. They come from a position of 'not knowing' very often about mental illness. Facing discrimination and stigma, experiencing human rights violations, are widespread in the lives of persons suffering from mental health conditions. Greater than 80% of such population, including persons experiencing substance use disorders and neurological disorders, lack affordability in mental health care (WHO, 2019). This community of caregivers also face stigma; they play the role of a nurse (completely different from a physical ailment); they shoulder major responsibilities of the PMI. Being a caregiver of a person with mental disorder, they also get affected by clinical & psychiatric discourses (Foucault, 1973). These discourses are embedded in our culture; traditions; rituals and customs which can only be unveiled with the tool of 'deconstruction' (Derrida, 1995).

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Caregivers are also members of multiple social groups which might be stigmatized. The socially constructed perception of gender has a profound influence on lives of women and caregivers as wives can be subjected to additional marginalisation. In Bengali culture, there are poems, songs and numerous artworks to portray otherization of women. ‘She has only learnt to please others; She has made herself ready to align with the practice; And so, she continuously misses her own sole’ (*Besur* a poem by Rabindranath Tagore). The poem is depicting a situation where the person is observing a piece of ‘OTHER’ in herself.

Such gender discrimination is customized habitually in a male dominated society like India (Sivakumar, 2008). The existence of intersectionality (Crenshaw, 2017) of marginalisation along with identity politics (Hancock, 2017) can make caregivers ‘OTHERS’ in the eyes of the society.

It has been observed across culture among an adequate number of participants that the subjective wellbeing of caregiving spouses of mentally ill persons is low compared to spouses of persons without mental illness (Istad et al., 2010; Yin et al., 2014). All caregivers feel high level of tension and stress in their intrapersonal world while females feel it almost over-whelming; interpersonal violence is common in those families. Male caregivers are exposed with opportunities of venting out the stress with social support and social connection in their interpersonal interaction which is rarely available for female caregivers and hence institutional asymmetry of gender order creates caregiving more burdensome for females (Mathias et al., 2018). Mental illness has an adverse effect on relationship and spouses are often dissatisfied with their married lives and it is responsible for many broken marriages (Khadirnavar et al., 2019).

People worldwide face and perceive stigma when they are caregivers of people with Mental illness. Felt and perceived stigma are more when women are caregivers, as despite many myths around equality of gender, discrimination still prevails (Raju, 2019). The diverse identities of informal caregivers are often understudied in research (Hengelaar et al., 2023). The current study aims to explore wives’ stories as informal caregivers of Persons with Mental Illness keeping in mind the prevailing gender discrimination in India and intersectionality.

METHODS

Participants

Four persons who were wives and Caregivers (CG) of Person with Mental Illness (PMI) volunteered in this research.

Age of CG	Educational Qualification of CG	Occupation of CG	Relationship with sufferer (PMI)	Duration caregiving (In years)	PMI Suffering from	Age of sufferer (PMI)	Educational Qualification of PMI	Occupation of PMI	Children
57	Graduate	Housewife	Wife	15	Bi-polar	61	Graduate	Bank Employee	1
47	Graduate	Music teacher	Wife	27	Schizophrenia	62	B. Com	Bank Employee	1
55	Graduate	Housewife	Wife	20	Schizophrenia	59	BSc, LLB	Bank Employee	1
53	Post Graduation	Housewife	Wife	28	Schizophrenia	57	BSc, LLB	Advocate	1

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Participant Recruitment Strategies

Purposive sampling technique had been adopted for conducting the present study. All participants were wives and sole caregivers with a minimum caregiving span of 15 years of adult PMIs over age 40 years who were clinically diagnosed with severe mental disorder by psychiatrists. All participants were from upper and upper middle socio-economic condition.

Tools

1. Information Schedule – constructed by the researcher for the purpose of the present study to collect personal and familial information about the participants.
2. Interview guide– It was a semi-structured interview guide constructed by the researcher to explore CG's live journey with human, non-humans and other components present in their situations; any discrimination and stigma they faced and how they addressed it in their meaning making of the term 'mental illness'.
3. GHQ-28 (Goldberg, 1978) for screening the presence of any mental illness in CGs.
4. Modified socio-economic status scale (Kuppuswamy, 2016).
5. Informed Consent Form.

Data Collection

The participants were invited for a face-to-face semi-structured open-ended interview (of a minimum duration of 1 hour 30 minutes and a maximum duration of 2 hours) followed by reflexive queries (if any) through telephonic conversation which were audio recorded and transcribed.

Ethics

Confidentiality, informed consent of all the interviewees maintaining the rights of the participants to participate & ethical criteria were given topmost priority. Institutional ethical clearance was attained.

Analysis

The transcribed interview verbatims were coded using Grounded Theory with Situational analysis (Clarke, 2005) employing 4 types of maps namely situational map (abstract/messy work version and ordered version), relational map, social arena map and positional map. Abstract Situational Map was drawn to take notes about the setting they lived; what was there in the situation; who else were involved; who & what were significant in the situation; human & non-human, discourses, ideas & concepts, discursive elements, economic political factors, temporal and spatial elements; structurally conditioned interactions; emotions etc. The ordered situational map specified the elements present in the situation in an orderly manner. Arena/Social Arena maps helped to map the interactions with a broader picture within intersectional arenas. In this study the CG and PMI were in the centre of the map. The Relational Map tried to specify the relationship with other elements present in the situation. Positional Maps helped to make visible the major positions taken and not taken in the situations related to the topic of concern. Reflective Dialogues and Member checking were used to authenticate the trustworthiness of data.

Worldview of researcher

This study had lent its overviews from post-modernist, feminist & critical theory paradigms where researcher is a facilitator and participants are partners in the research procedure. Dialogic methodology with reflective dialogue had explored the power structures, seeking out

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to alter them in positive direction. Moreover, gender order as a category of query played an important role.

FINDINGS

FIGURE 1: STORIES OF PARTICIPANTS (AT A GLANCE)

FOUR CAREGIVER(CG) WIVES OF HUSBANDS(PMI) WITH SEVERE MENTAL DISORDERS

Caregivers whose marriages were arranged by guardians (could identify some peculiarities in PMIs but could not say anything)	Caregiver with love marriage
<p>1Originally situated at a district town of West Bengal, she faced Physical & verbal abuse after marriage. She asked help of her maiden family to go back. Her wish was not fulfilled by her family and she came back to her in-law’s house with a broken mind and suicidal thoughts. She cried a lot with overwhelming pain and all of a sudden, she decided to live. ‘I cannot die in this beautiful world’ She thought of her marriage to be taken as a destiny and decided to take care of her husband as he was sick (it is a good <i>Karma</i>). She immediately decided to take professional help for which she had to struggle a lot. None of the family members was ready to accept any fault in PMI. She got help of a doctor and her younger brother-in-law who lived in Kolkata. At the same time, she resorted</p>	<p>4Originally from Kolkata CG came to know about some peculiarity in her ‘would be’ husband like tremendous anger or demands which seemed odd to her. After her marriage she observed some peculiar anxieties in PMI and immediately tried to consult doctors. Those thoughts were relating the body of the PMI so the choice was a general physician. After 3/4 episodes of such delusional thoughts the doctor referred a psychiatrist. PMI was not ready to go to a psychiatrist. CG never concealed the condition of PMI to anyone and with tremendous help of her parental family she</p>

<p>1Originally situated at a district town of West Bengal, she faced Physical & verbal abuse after marriage. She asked help of her maiden family to go back. Her wish was not fulfilled by her family and she came back to her in-law’s house with a broken mind and suicidal thoughts. She cried a lot with overwhelming pain and all of a sudden, she decided to live. ‘I cannot die in this beautiful world’ She thought of her marriage to be taken as a destiny and decided to take care of her husband as he was sick (it is a good <i>Karma</i>). She immediately decided to take professional help for which she had to struggle a lot. None of the family members was ready to accept any fault in PMI. She got help of a doctor and her younger brother-in-law who lived in Kolkata. At the same time, she resorted</p>	<p>2Originally situated at a district town of West Bengal, she faced a lot of physical and verbal abuse from her husband after marriage. Her In-law’s house was Bihar (now at Jharkhand, then Bihar) and her husband was posted at Bihar (now Jharkhand) too. Her husband was delusionally suspicious about her involvement with any male (of any age) and she faced tremendous anger outburst from her husband. She could not make out initially what was happening. She had felt a need to prove herself as fault-free. The family members in her in-law’s family were more or less indifferent and extended help only when the PMI was abusing CG physically. She concealed this peculiarity of her husband from everyone from her maiden family,</p>	<p>3Originally situated at a district town she got married after graduation and she noticed different peculiarities in her ‘would be husband’ before marriage. She did not have the capacity to stand against her own father as he was like a dictator to her. She also faced physical abuses from her husband but concealed it from everyone and never took any action to visit a psychiatrist. Her husband was posted at another district town and one of their neighbors influenced her to take him to a psychiatrist after 6 years of their marriage. He was diagnosed as bipolar and after taking medicine she observed much improvement in her husband. The family friends and coworkers of the PMI discouraged him to take the</p>	<p>4Originally from Kolkata CG came to know about some peculiarity in her ‘would be’ husband like tremendous anger or demands which seemed odd to her. After her marriage she observed some peculiar anxieties in PMI and immediately tried to consult doctors. Those thoughts were relating the body of the PMI so the choice was a general physician. After 3/4 episodes of such delusional thoughts the doctor referred a psychiatrist. PMI was not ready to go to a psychiatrist. CG never concealed the condition of PMI to anyone and with tremendous help of her parental family she</p>
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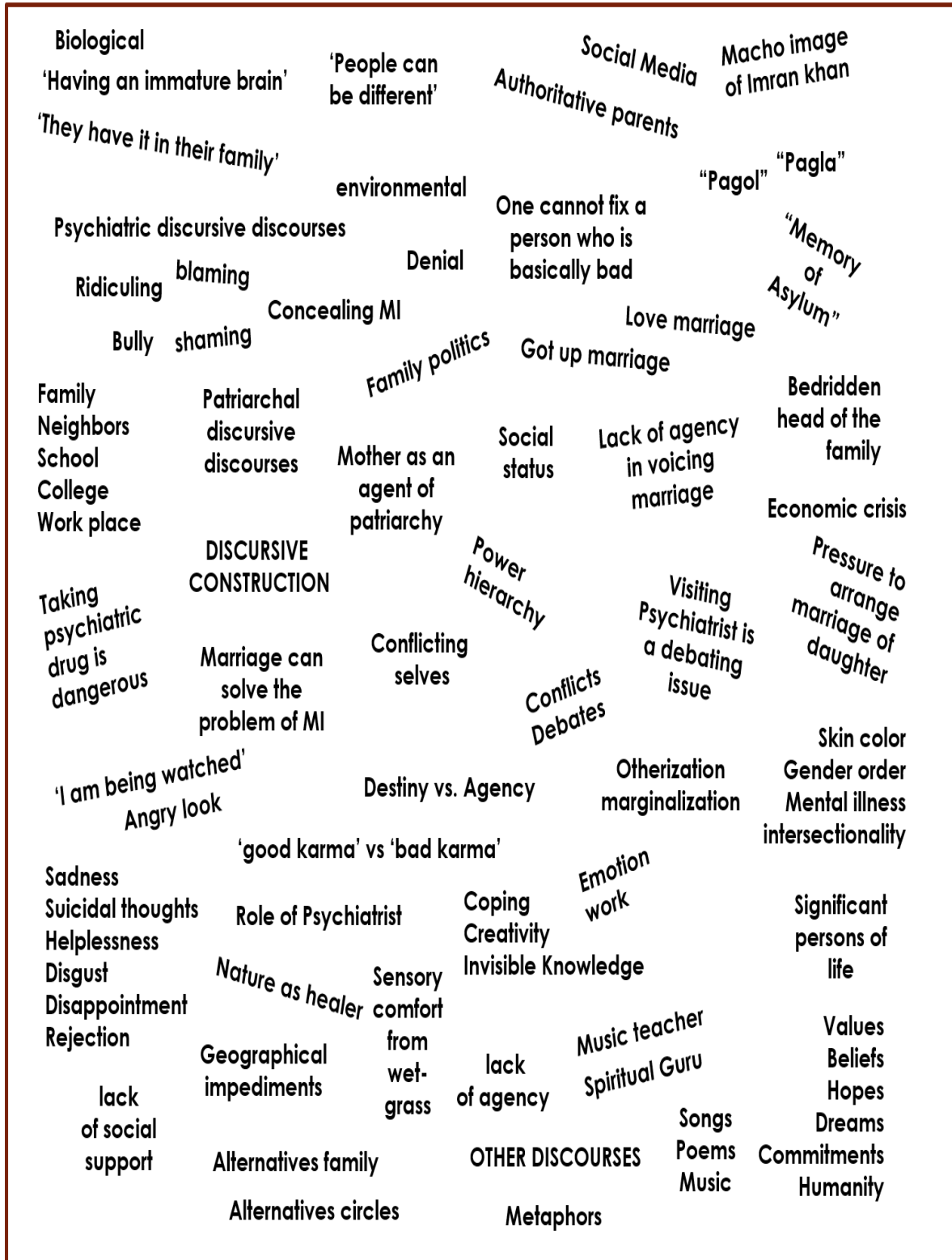
<p>music as her career and started taking and giving tuition while pursuing her graduation degree. She had to struggle a lot to make a music school besides taking full caregiving activity for her husband. At the time of conversation, she was continuing caregiving of PMI who was just retired. She had created an alternative family with her music circle who helped her throughout her struggle. She has one adult daughter (in service) whom she had never pressurized to do anything. She advocated for humanity and freedom for girls.</p>	<p>friends and neighbors. She took her husband to a psychiatrist after 5 years of marriage when her brother-in-law insisted who lived in Kolkata. She used to take the PMI regularly from Jharkhand to Kolkata for consulting psychiatrist. The CG had shifted to Kolkata for higher education of her son and one of the principal reasons was to separate her son from his father. She herself had been pursuing her education in courses like psychology, counselling and geriatrics in the last 5 years. This alternative path helped her to get circles of social support where she could breadth.</p>	<p>medicine and he discontinued. The CG shifted to Kolkata with her son for his higher education and eventually the PMI got involved in an extra marital affair and ultimately, they got separated (not legally). CG raised his son single handedly but PMI provided the money. Her son was in service at the time of conversation and he had a good bonding with CG. She regretted that she destroyed her health in this journey and the journey was painful.</p>	<p>succeeded to take professional help. She perceived it as an illness and she took care of PMI in every respect; helped him to pursue his study to become an advocate; handled problems relating his delusional thoughts in the workplace and raised their child. She never received any help from the in-law's family and found overt pressure from the family which made her repent about her ill health and unfulfilled dreams.</p>
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All the PMIs were suffering from severe disorders like schizophrenia and bi-polar when CGs made the arrangement of visiting a psychiatrist. All of them were active in their work lives. The symptoms of their disorders (reality contact; hallucination & delusions; anger & aggression) were required to be handled by medicines which in turn were taken care of by their wives (CGs) without assistance of any professional caregivers. The nature of caregiving of CGs had different levels at different times; it started with fighting with family members for getting consent of seeking medical help for PMI; taking care of PMI with medicine and counselling (as taught by the doctors); taking care of the total household activities; raising a child and taking decision about husband (PMI) time to time. At the time of conversation, two of four caregivers were continuing active caregiving process staying with their husbands (PMIs), the other two CGs were separated from their husbands (not legally). One of them, to avoid the negative behavioural impact of the disorder on her son moved to a different place, but still taking care of her husband (like taking decisions about medical and other issues; consulting doctor for him; going for a trip in vacations etc.) (ref figure 1). The other caregiver got separated because PMI started a different living relationship. All the maps, findings revealed in this study were drawn from the narrated stories & reflective dialogues with CGs. In course of conversation there were also narrated stories about PMI which were presented as

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secondary data too. All the interviews were taken in Bengali and some translated verbatims are used in the discussion.

Figure 2: Abstract Situational Map



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Figure 3: Ordered Situational Map

<p>INDIVIDUAL HUMAN ELEMENTS ACTOR CG, her family, friends, neighbours PMI and CG's in-law family, PMI's office colleagues Doctors, music teacher; spiritual guide Their children</p> <p>COLLECTIVE ELEMENTS Maiden family In-laws' family; neighbours PMI's office circle Medical help system Music circle Study groups Spiritual organisations</p> <p>NON-HUMAN ELEMENTS ACTORS Elements of nature Songs and music Ornaments Bicycle, trains; Psychiatric drugs Sweet (<i>Lagence</i> in Bengali as prasad)</p> <p>TEMPORAL ELEMENTS Change of idea about MI Repentance with time for late consultation Repentance of not being able to exercise agency Change of idea about going to psychiatrist and taking medical help Change of maturity of girls</p> <p>MAJOR ISSUES DEBATES Arrangement of the marriage Concealment Vs Disclosure Asking for help Vs. showing 'all okay' attitude Addressing mental health issues Lack of awareness of mental illness vs. self-blaming & self-judging attitude of CG as a good girl/good wife Conflicting Intersectionality of different selves a good girl, a good home-maker, a wife with some expectations from her husband, observer of the symptoms & pain of MI, feeling of being cheated deprived and abused; disgust in being in conjugal relationship with PMI without own consent; destiny Vs agency; Good <i>Karma</i> Vs. Bad <i>Karma</i>.</p> <p>IMPLICATED SILENT ACTORS/ACTANTS PMI, CG, Ill and aged guardian</p> <p>DISCURSIVE CONSTRUCTS OF HUMAN ACTANTS AND/OR COLLECTIVE HUMAN ACTORS</p> <p>ABOUT MENTAL ILLNESS Going to a psychiatrist is a matter of shame Being a <i>PAGOL</i> is fearful & blemishing Marriage can help to heal mental illness A mentally ill person is bad Person is the problem MI has a contrast appearance in a good peaceful life Concealment of MI is important for social status It is a matter of shame if the symptoms of MI are got exposed in front of people</p>	<p>PATRIARCHAL Girls should be submissive and obedient Getting abusive treatment from husband is common so, girls should be patient Good girls do not come back after marriage; Coming back to parents means it's the fault of the girl It is better to tolerate undesirable, abrupt, abusive treatment from husband rather than talking about it/addressing it With mental illness a person cannot be working Anger issues can be only problem from lack of sleep which is get corrected after marriage</p> <p>DISCURSIVE CONSTRUCTS OF NON-HUMAN ACTANTS The term <i>PAGOL</i> 'Macho' images created by mass media Skin colour; discourses as unwritten rules.</p> <p>SOCIOCULTURAL SYMBOLIC ELEMENTS Kalibari, "jalaporra" as a treatment of mental illness; Ornaments brought by the bride Social Prestige 'PAGOL' as a tabooed term</p> <p>SPACIAL ELEMENT A protective measure/arrangement was there in the rooms (connected rooms and there was no lock available from the room of the new couple's) so that the brother-in-law can understand when CG's husband beat her and can come for protection. Places like Kolkata, Malda, Siliguri, Durgapur in West Bengal, Dumka & Mander Hill (in the state of then Bihar; now Jharkhand) Logistic Impediments to address medical help</p> <p>RELATED DISCOURSES (HISTORICAL NARRATIVE, AND/OR VISUAL) Whatever negative happens, one should be practical and pragmatic to look for a positive solution by finding alternative and preferred path Do your work without keeping any expectation Keeping oneself calm & strong in any situation If someone thinks positive, something positive would happen Be non-judgmental One cannot die in this beautiful world Humanity is to look after a person who is sick Humanity is the priority Good Karma Different Metaphors</p> <p>POLITICAL / ECONOMIC ELEMENT Arrangement of marriage within economic crisis Intersectionality of marginalization in many domains Judgemental society</p> <p>OTHER KEY ELEMENTS/EMOTION Negative Emotions; Conflicting intersectional selves Self-reflection and emotion work Coping strategies Values, Dreams, Commitment and Hope</p>
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Figure 4: Arena/ Social Arena Map **Figure 5: Positional Map**

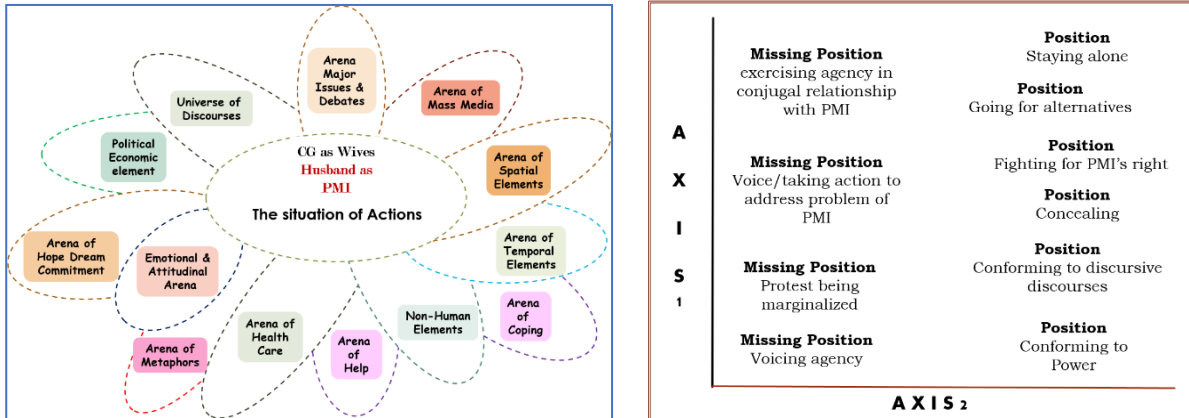
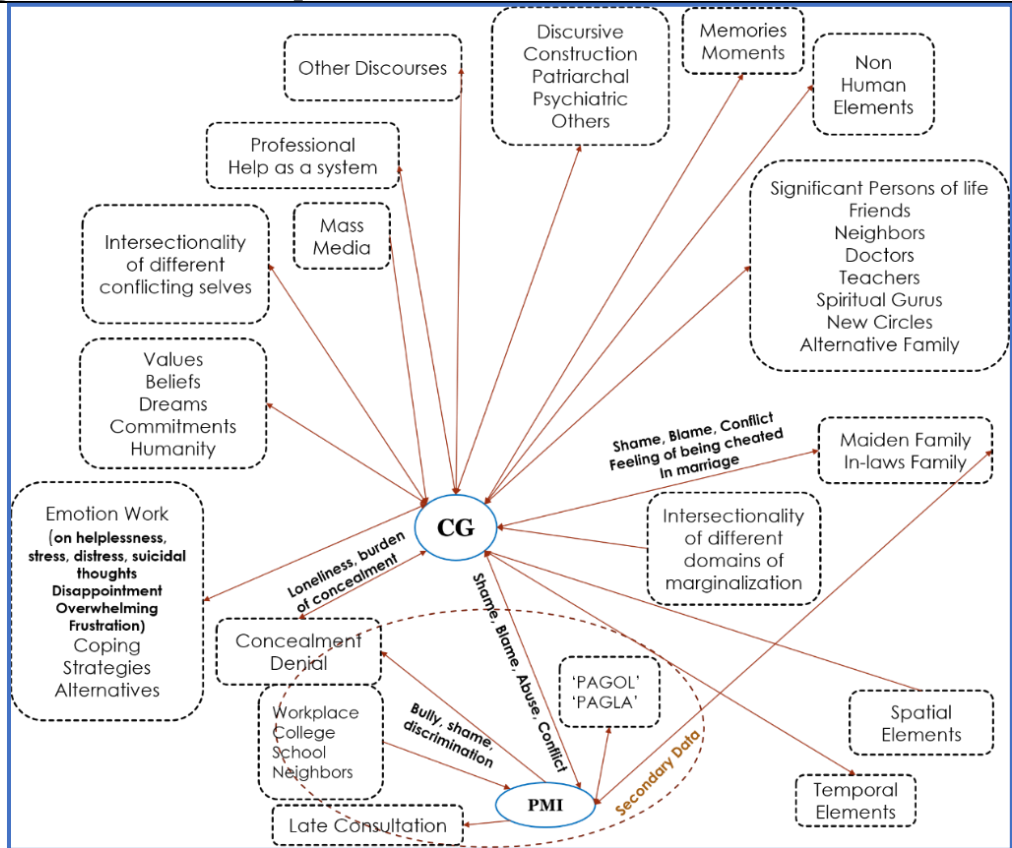


Figure 5: Relational Map



DISCUSSION

The findings unveiled how the discursive constructions in the situated context were very much gendered; it discriminated and controlled caregivers depriving them of their agencies. They became Implicated Silent Actors in different situations where intersectionality of stigma from domains like gender and association of mental illness worked dominantly.

None of them knew about the illness of their bridegrooms at the time of marriage although they could identify some peculiarities in their husbands (“In the day of the marriage I

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observed some peculiarities... laughing unnecessarily... there was incoherence in speech too...”; “... I observed his eyes... and the look in the eyes was a very violent look. I could feel him to be angry inside...”).

For three of the participants, the marriage was arranged by the elders of the family; for one the marriage was outcome of love relationship. In arranged marriages, neither they had any voice to comment on their own marriages nor it was expected as a rule. One of the participants felt that she was a prey of injustice as it was a ‘got up’ case organized by her mother (“I do not know why my mother did it...but it was tactfully done...like a ‘got up’ case...they admitted it afterwards”); her father was sick and he had no voice too. People with less power (terminal illness, age and economic condition) became an Implicated Silent Actor too. Participants failed to exercise autonomy.

“She is not regarded as autonomous being” (Beauvoir 1948)

They faced both verbal and non-verbal abuses from their husbands; sometimes it was like a forceful involvement in activities which the wife was unwilling to do(“... From the very first night it was brutal... and I am not talking about it...”);sometimes it was physical torture(“A lot of anger... means extreme anger... means...he used to beat me if I didn’t”); sometimes it was colour shaming by PMI & in-laws’ family; sometimes there were subtle and overt suspicions (“He came from outside...I went to open the gate with the key...He thinks that I am standing there watching some man in the front house”. Initially they could not understand that it could be symptoms of untreated mental illness. Gradually they understood that to be something, not normal; may be mental illnesses.

One of the participants who immediately reported her mother asking help and rejected was in overwhelming pain for some days with suicidal thoughts (“I told my mother... ‘he is ill...I do not think I would be able to stay in this marriage...he is beating me a lot...’ she said ‘be patient... many girls face this”). Other two participants concealed those facts and tried to maintain an ‘all okay’ image in front of friends, maiden family and social circles for more than 5 to 6 years (“Being there was not at all bearable ... but nevertheless I had all my friends ... I took him there...tried to maintain socializing ...I never let anyone understand what I was facing.”; “If I go back after marriage... It means my failure”).

They were trying to protect their social image by concealing.

“The one who practices bad faith is hiding a displeasing truth or presenting as truth a pleasing untruth. Bad faith then has in appearance the structure of falsehood. Only what changes everything is the fact that in bad faith it is from myself that I am hiding the truth” (Jean Paul Sartre 1966: 49).

The Caregiver who selected PMI as her husband in love-marriage felt that as he was sick it was important that he would be treated with professional help. She never concealed PMI’s problem to anyone; informed her maiden family immediately and got support.

Rawat in 2014 noted that “Patriarchal beliefs and practices de-power women. Women feel powerless when they believe they are unable to cope with the physical and social demands of the environment”. If we deconstruct the universe of discourses of the situations in the present research, we can find social relationships in discursive interaction control a person especially a girl to be in a particular way in this world. In spite of being educated, participants internalized those patriarchal rules.

Example are given in the box below-

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Girls are expected to be submissive and obedient
Good girls do not argue
It is the mandatory duty of the parents to arrange marriage of their daughter
Coming back in the maiden family is the fault of the girl
Social prestige is shattered if someone goes back after marriage
Beating by husbands or demands of husbands are common and so normal

(“Marriage!!... Couldn't say anything... Nothing... there was a lot of age difference...”; “I'd be physically assaulted...broken fingers...these are the two fingers that are broken”; “I was so scared... I mean... when he would do what... beat me... push me... always in a panic and panic...”) In a patriarchal society where men are the main breadwinner in the family, the normalisation of domestic violence is common (S. Sahu, 2020).

“She is defined and differentiated in relation to man, while he is not in relation to her; she is the inessential in front of the essential. He is the subject; he is the absolute — she is the other” (Simon De Beauvoir: 1948).

Being ‘OTHER’ in her own family and in the family of their husbands were evident in the study. The task of caregiving started for all of them without their awareness that ‘they were caregivers of persons with mental illness’.

Out of four PMIs three of them never visited a psychiatrist before marriage; one visited in his childhood but did not continue. Not Seeking treatment is common in case of psychiatric illness. A survey in USA among a significant number of respondents (9282) revealed low perceived need in 44.8% of participants to seek treatment in case of mental illness (Mojtabai, 2011). The peculiarities within PMIs were noticed by all the participants in a short span of time which were overlooked and denied by the family of PMI for years. Although we have achieved advanced knowledge about psychiatric disorders, stigma relating psychiatric illness continues to prevail (Sethi et al., 2016). The reason behind those late consultations seemed to look like error of omission by the families but the embedded inhabiting discursive constructions and structural stigma associated with mental illness present in those situations probably could vouch these to be errors of commission. The views of sociolinguistics about stigma associated with mental health are expressed as discursive construction and constitution, i.e., they both get manifested, reinforced, negotiated, or contested in the use of people’s language (Zayts-Spence et al., 2023).

All the participants (CGs) reported that they (PMIs) were ridiculed, bullied, controlled and discriminated in family, neighbourhood, school; colleges and office circles. As reported by the participants PMIs were mostly implicated silent actor in their lives (except with their wives). The discursive discourses acted like truths for the family like -

Going to a psychiatrist is a matter of shame
Being a 'PAGOL' is fearful & blemishing

According to the participants the word ‘PAGOL’ (meaning ‘crazy’ or ‘mad’) which was a tabooed term and it was embedded in the mental continuum of people in such a way that it brought immediate fear, shame blame and judgement. (“No one even says mental patients... say PAGOL”; “That society has stamped in the backsaying PAGOL”). Numerous researchers specify that individuals who bully are at bigger risk of consequent emotional, behavioural and mental problems, specifically internalizing problems (“Preventing Bullying”, 2016).

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Other discourses which were running in the situation were –

Marriage can help a male to get rid of the mental problems After having a child everything would be okay A person who has a profession cannot have mental illness

The participants as caregivers were facing and perceiving many disadvantages from many domains. They were facing discrimination, abuse for their gender order, skin colour, economic condition of their paternal families and as wives of a mentally ill person. All of them were struggling in their own situations. There were many conflicts which were interpersonal and also intrapersonal. There were debates sometimes contested and sometimes uncontested (ref fig 3 & 4). The areas were - arrangement of marriage, concealment vs disclosure, destiny vs agency, Good *Karma* vs Bad *Karma* etc (“It is also gradual self-destruction for me too...I am doing a good *karma* in one hand but I would call it a bad *karma* too as it is destroying my health”). There was conflicting intersectionality of different selves among participants- a good girl, a good home-maker, a wife with some expectations from her husband, observer of the symptoms & pain of mental illness, feeling of being cheated deprived and abused; disgust in being in conjugal relationship with PMI without own consent etc. The caregiving was mingled with oppressive control of patriarchy.

Participants who concealed also expressed the pain of concealment; it was like a felt shame; a need to protect the social prestige and the judgmental attitude of others (“I did not let other people know... If people were generous then it wouldn't have happened - because of the lack of generosity - it was hidden”).

“There are some stigmas that are so easily concealed that they figure very little in the individual's relation to strangers and mere acquaintances” (Goffman, 1963).

One of the participants who tried to patch up and visited a psychiatrist after 5 years of marriage used to conceal PMI's symptoms from almost everyone still now (after 15 years) except the new circles she had created. Throughout she had been trying to present her husband in a socially desirable manner (“I was presenting him in front of people like a well-dressed monkey in monkey-shows”). The metaphor she used revealed her deep frustration & irritability of past feeling of being cheated, frustration of not being able to continue her own profession, burden of concealment, lack of support from PMI's family, anxiety of getting blame as her husband was suffering from persecutory delusion; burden of continuing conjugal relationship with PMI. The quality of life can be adversely affected by affiliated stigma or internalised stigma among family members of stigmatised individual (Zhang et al., 2018). “Concealment often becomes cumbersome” (Goffman, 1963).

CGs who did not conceal from the very beginning, saw the peculiarity as an illness, got better social support and pursued their own dreams, experienced better subjective well-being. Satisfaction of autonomy & relatedness were associated with well-being (Shi Yu & others, 2018).

There were other discourses, values, beliefs and commitment in the situations

A 'PAGOL' is also a human being, s/he should be treated with proper care, it is a medical cause, needs to be treated, Humanity is not to abandon an ill person
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All these through rationalisation acted as defenses to protect them from bearing the painful everyday experiences of caregiving. These discourses are ways of ensuring conformity to the normative.

The caregivers in their day-to-day interactional world (within different arenas, ref figure 4) were handling their negative emotions in many ways. Coping strategies involved enduring pain with help of music where wordings of Tagore's song played a very important role. The influence of Tagore, his creation and the stories of handling pain in his life events worked as a pathway for some participants. "Oath taking" with PMI standing in front of the Sun and say let "today be a good day" was worth mentioning as a spiritual one. It reminded the phrase of 'One day at a time' which was an upright slogan of mental health care. Reading spiritual books, practice of positivity, deep breathing exercises, spending time with significant ones, getting support from alternative family, going for new activities and courses were some of the strategies too. Non-human elements and participants relationship with them like sun, wet grass, sky, banana tree, river, cows, drawing books, colours and stationaries although apparently look mundane but they were significantly important in participants' life.

CONCLUSION

Discursive constructions were grounded in the institutional hegemony of mental world; be it in patriarchal inhibition, psychiatric labelling or any other domain of unwritten inhibiting rules. Caregiving as wives of PMI was burdensome, the struggle was silent and pathetic especially when they felt cheated in the marriage. Lack of awareness about mental illness and structural stigma associated made the journey more tough. Concealment to the social world about their struggle made the situation even worse. Subjective well-being was better in case of people who faced the situation and got social support to vent out. Interestingly, the study revealed that spirituality, creativity and some cultural habitual of performing art embedded in the nuances of local cultural factors helped to locate alternative ways of coping.

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Conflict of Interest

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