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RESEARCH ARTICLE

Lived Experiences of Caregivers of Patient with Bipolar Affective Disorder

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Abstract: ***Introduction***: Bipolar Affective Disorder (BPAD) significantly disrupts the lives of patients and their caregivers. This study explores the lived experiences of caregivers for BPAD patients admitted in psychiatric units. ***Method***: A qualitative phenomenological approach was employed. Saturation of data was achieved with 12 samples. Twelve caregivers were selected by using the nonprobability convenient sampling technique. With the tool including the demographic information and guidelines to facilitate the interview were administered by conducting the one-to-one in-depth semi structured interview. Colaizzi's method was adopted to analyze the data manually. ***Results***: Based on commonalities within the data, themes and categories were formulated. By that method five major themes emerged: A. Experiences related to alteration in physical health with the support of subthemes such as (i) maladies, (ii) Inadequate sleep, (iii) Inadequate food intake, (iv) caregiver's fatigue. B. Psychological experiences supported by the sub themes like (i) Mental strain, (ii) Fearful apprehension, (iii) Mental distress, (iv) Psychological support, (v) Incorrect understandings, (vi) Resilience, (vii) Stress management approaches, and (viii) Psychological readiness. C. Societal experiences with subthemes identified were (i) Embarrassment, (ii) non-attendance at social events, (iii) Lack of family support, (iv) Self-perceived stigma, and (v) Altruistic support. D. Experiences related to hospitalization of patients with the advent of subthemes such as (i) Information about illness, (ii) Insight regarding illness, and (iii) Admission challenges. E. Finance related experiences with auxiliaries of subthemes identified were (i) Financial adjustments, and (ii) Expenditure. ***Conclusion***: The present study delves into the full spectrum of caregivers' experiences, revealing the dynamic interplay between their strengths and challenges in resilient behavior. The findings highlight the need for healthcare systems to implement support strategies for family caregivers to promote sustained and holistic patient care.

Keywords: Bipolar Disorder, Caregiver Burden, Lived Experience, Qualitative Research, Mental Health Nursing.

INTRODUCTION

The concept of "health" does not have a single, universally accepted definition. Many people endorse the notion that "health is wealth," emphasizing that neither individuals nor societies can flourish without good health. As Mahatma Gandhi stated in 1948, "It is health that is real wealth and not pieces of gold and silver." [1] Mental and physical health are intricately connected with mental health influencing multiple aspects of daily life, including stress management, lifestyle habits, sleep patterns, and interpersonal relationships. Recognizing its critical importance, policymakers, healthcare professionals, and communities across the globe including in India now consider mental health a central component of overall well-being. [2]

Bipolar Affective Disorder (BPAD) is a chronic, relapsing mental health condition characterized by alternating episodes of mania marked by elevated mood, increased activity, and decreased need for sleep and depression, which involves low mood, loss of interest, altered sleep and appetite, low self-esteem, and in severe cases, suicidal ideation. [3] According to the Global Burden of Disease Study (GBDS), the global prevalence of BPAD is approximately 0.7%, with 0.6% among males and 0.8% among females. [4] Epidemiological studies estimate the lifetime prevalence of Bipolar I Disorder to be around 1%. [5] Merikangas et al. (2011), in a study conducted across 11 countries, reported a lifetime prevalence of 2.4% for bipolar spectrum disorders—0.6% for Bipolar I and 0.4% for Bipolar II. [6] In India, the prevalence of affective disorders has been reported to range from 0.51 to 20.78 per thousand individuals. [7]

Diagnosing Bipolar Disorder is often challenging due to symptom overlaps with other psychiatric conditions and the common under-recognition of hypomanic episodes by patients. While treatment typically includes pharmacotherapy and various psychosocial

interventions, the disorder is marked by frequent mood relapses, necessitating continuous clinical monitoring and treatment modification. The disorder significantly affects both patients and their families. [8]

Caregivers of individuals with Bipolar Affective Disorder face a multitude of challenges, including declining family functioning, emotional distress, strained interpersonal relationships, financial hardship, and diminished social engagement. The illness often causes psychological distress within families, manifesting as guilt, grief, denial, and helplessness. [9] Caregivers frequently set aside their own needs, enduring considerable emotional burdens. Research has shown that they are at a higher risk for depression compared to the general population. [10]

The World Health Organization defines caregiver burden as the physical, emotional, and financial strain borne by family members because of caring for an individual with illness. [11] This burden encompasses personal care tasks, emotional support such as listening and mentoring, and informational support, including guidance on improving the patient's home environment. [12] Caregivers play a critical role in the management of Bipolar Affective Disorder—from providing daily support and monitoring treatment compliance to fostering a stable home environment. [13-18] Their responsibilities require patience, resilience, and adequate knowledge, as they assist in promoting recovery and enhancing the quality of life for affected individuals.

This study aims to explore the wide range of experiences encountered by caregivers while caring for individuals diagnosed with Bipolar Affective Disorder. By gaining insights into their challenges, coping mechanisms, and resilience, the research seeks to inform interventions that support and empower caregivers in their vital role.

MATERIALS AND METHODS

Qualitative research approach with phenomenological research design was used to explore the lived experiences of caregivers of patients with Bipolar affective disorder admitted in Psychiatric unit of selected Hospitals. The research was carried out in Psychiatric units of selected Hospitals located in Sangli, Miraj and Kupwad corporation area. Population of the study consisted of all caregivers of patients with bipolar affective disorders. The eligibility criteria included caregivers those were willing to participate, agreed to give written informed consent, Caregivers those have been caring for the patient at least for six months, caregivers of patient diagnosed with bipolar affective disorder and having duration of illness from six months to ten years and above and were able to speak and understand at least Marathi, Hindi, or English. Saturation of data was achieved with 12 samples. Nonprobability convenient sampling technique was used for data collection and for selection of psychiatric units' simple random technique was utilized. The tool consisted of demographic profile and guidelines. The data was collected through one-to-one in-depth semi structured interviews.

The intention of the current study was to investigate the lived experiences of caregivers for patients with Bipolar Affective Disorder. To accomplish this, the researcher created a tool that was prepared through extensive review of literature, referring the books and journals, abstracts, research articles, discussion with guide and through expert opinions that served as a guide for conducting interviews for the study. The data collection tool was divided into three sections.

- Section I - Demographic variables of caregivers of patients with Bipolar Affective Disorder.
- Section II - Patient profile information provided by caregivers.
- Section III - Semi-structured interview guidelines exploring the experiences of Caregivers of patient with Bipolar Affective Disorder.

The tool's content validity was confirmed through expert review and necessary revisions. The research proposal received approval from Institutional Ethics Committee of BVDUCON, Sangli. Permissions were secured from Hospital authorities in Sangli, Miraj, and Kupwad corporation area for participant access. Informed written consent was obtained from all participants. The data was encrypted, organized, and analyzed using descriptive statistics and thematic analysis with Colaizzi's method to identify themes and sub-themes. Data saturation was achieved with 12 participants, indicating that no new themes or significant information emerged after the 12th interview. A non-probability convenience sampling technique was used for selecting participants, while simple random sampling was employed to select psychiatric units within the study area. The data collection tool was developed by the researcher based on an extensive review of relevant literature, textbooks, journals, research articles, and consultations with the research guide and subject experts. The tool was divided into three sections:

- Section I: Demographic profile of the caregivers.
- Section II: Patient profile information as reported by the caregivers.
- Section III: Semi-structured interview guide to explore the lived experiences of caregivers.

The tool's content validity was established through expert review; triangulation of the collected information and necessary revisions were made based on the feedback received. Data collection was carried out through one-to-one, in-depth, semi-structured interviews conducted in a private and comfortable setting, ensuring confidentiality and allowing participants to share their experiences openly. Each interview was guided by open-ended questions and supplemented with probes to gain deeper insight into the caregivers lived experiences. Ethical clearance was obtained from the Institutional Ethics Committee of Bharati Vidyapeeth Deemed University College of Nursing (IECBVDUCON),

Sangli. Written permissions were secured from psychiatric hospital authorities to access participants. All participants provided informed written consent prior to data collection. The collected data were transcribed, organized, and analyzed using descriptive statistics for demographic variables. The qualitative data from interviews were analyzed using Colaizzi's method of thematic analysis, allowing for the identification of key themes and sub-themes that captured the essence of the caregivers lived experiences. Data confidentiality and anonymity were maintained throughout the study process.

RESULTS

Based on the objectives of the study, Analysis and explanation of the results are arranged under the following headings,

- Section I- Frequency and percentage of demographic variables.
- Section II- Frequency and percentage of patient profile information.
- Section III- Thematic Analysis and interpretation of the themes and sub-themes.
- Section I – Description of Demographic variables.

Table no 1: Frequency and Percentage Distribution of Demographic Variables

Sr. No	Demographic Variables	Categories	Frequency	Percentage
1	Age (In Years)	30-40	06	50
		41-50	02	16.66
		51-60	04	33.33
2.	Gender	Male	02	16.33
		Female	10	83.33
3.	Type of Family	Nuclear	07	58.33
		Joint	05	41.66
4.	Nature of Occupation	Salaried	02	16.66
		Business	01	8.33
		Farmer	03	25
		Others	06	50
5.	Family Income in (Rupees) per year	1,00000-2,00000	06	50
		2,00001-3,00000	05	41.66
		3,00001and above	01	8.33
6.	Relationship With The Patient	Parents	05	41.66
		Spouse	06	50
		Others	01	8.33
7.	Duration of care giving for the patient with Bipolar Affective Disorder	1 to 4 years	05	41.66
		5 years to 10years	03	25
		10 years and above	04	33.33

The data provided in table1 states that, out of 12 caregivers,06 (50%) were in age group of 30- 40 years, 02 (16.66%) were in 41-50 years and 04 (33.33%) belonged to 51-60 years age group respectively.02 (16.33%) were male and 10 (83.33%) were female caregivers. It was observed that 07 (58.33%) resided in nuclear families and 05 (41.66%) in joint families. Nature of occupation of the caregivers it was observed that, 02 (16.66%) were salaried, 01 (8.33%) had business whereas 06 (50%) contributed to the category of others, in which 03 (24.99%) were Housewives, 01(8.33%) was retired, 01 (8.33%) was a plumber and 01(8.33%) was a maid. The data related to family income per year was obtained in which 06 (50%) of caregivers had income ranging between 1,00000-2,00000/year, 05 (41.66%) had income between 2,00001- 3,00000/year and 01 (8.33%) had income 3,00001 and above. In regard to relationship with patient, 06 (50%) were spouses, 05(41.66%) were parents and one contributed to the category of others who was sister (8.33%).The caregivers had different duration of caregiving for their patient were 05 (41.66%) had duration between 1-4 years, 03 (25%) had duration from 5-10 years and 04 (33.33%) had duration of 10 years and above.

Section II - Description of patient profile information.

Table no 2 Frequency and percentage of patient profile information. N=12

SR. NO	PATIENT PROFILE INFORMATION	CATEGORY	FREQUENCY	PERCENTAGE
1	Duration of patient diagnosed with Bipolar Affective Disorder	6 months -1year	01	8.33
		1year–3years	03	25
		3– 5years	01	8.33

		5-10years	01	8.33
		10 years and above	06	50
2.	Most worrisome symptom observed by caregiver in patient for admission	Irritability	09	75
		Withdrawal from activities	02	16.66
		Thoughts of suicide	01	8.33
3.	What are various medications that are taken by patient regularly	Lithium	06	50
		Quetiapine	02	16.66
		Don't know	04	33.33
4.	Area of Residence	Urban	04	33.33
		Rural	08	66.66
5.	Patient's current episode in Bipolar Affective Disorder	Mania	06	50
		Depression	03	25
		Stable	03	25

The data provided in table2 states that, out of 12 patients, 06 (50%) had duration of 10 years and above of being diagnosed with Bipolar Affective Disorder, 03(25%) belonged to 1 to 3 years of category, 01(8.33%) belonged to 06 months – 1year, 01 (8.33%) 3-5 years and 01 (8.33%) 5-10 years respectively. Most worrisome symptom observed by caregiver in patient for admission was in which caregivers stated that 09 (75%) had irritability as a reason for admission, 02 (16.66%) had withdrawal from activities and 01(8.33%) had thoughts of suicide.

Regarding medications which were taken regularly by the patient caregivers expressed that 06 (50%) took tablet lithium ,02(16.66%) took tablet Quetiapine as regular medication by the patient and 04 (33.33%) caregivers contributed to the category where they had no idea regarding the medication taken regularly by their patient. Area of Residence in which out of 12 patients, 08 (66.66%) resided in rural areas whereas 04 (33.33%) in urban areas respectively. The information related to the current episode observed in the patient by caregiver, in which 06 (50%) caregivers stated Mania, 03 (25%) Depression and 03 (25%) stable.

Section III – Analysis and interpretation of the themes and sub-themes.

TABLE No 3: Analysis and interpretation of the themes and sub-themes

SR.NO	THEME	SUBTHEME
1	Experiences related to alteration in Physical Health	Maladies Inadequate sleep Inadequate food intake Caregiver's Fatigue
2	Psychological Experiences	Mental Strain Fearful apprehension Mental Distress Psychological support Incorrect understandings Resilience Stress management approaches Psychological readiness
3	Social experiences	Embarrassment Nonattendance at social events Lack of family support Self-perceived stigma Altruistic support
4	Experiences related to Hospitalization of patient	Information about illness Insight regarding illness Admission challenges
5	Financial experiences	Financial adjustments Expenditure

Table no 3 explains about a total of 5 themes, 21 subthemes that are given in the table. For comprehension each theme is grouped into subthemes. To explain the experiences related to alteration in physical health were Maladies, Inadequate sleep, Inadequate food intake and caregiver's fatigue were categorized as subthemes. Psychological experiences were mental strain, Fearful apprehension, Mental Distress, Psychological support, Incorrect understandings, Resilience, Stress management approaches were clarified as subthemes. Social experiences were clarified with subthemes of Embarrassment,

Non attendance at social events, Lack of family support, Self-perceived stigma, Altruistic support. Information about illness, insight regarding illness, admission challenges were identified as subthemes for experiences related to hospitalization of patient. Experiences related to finance were financial adjustments and expenditure were the subthemes identified.

Theme: I- Experiences related to alterations in Physical Health

During the conversation with caregivers, it was observed that most of the caregivers had experienced various ailments which disturbed their act of caregiving but still caregivers managed and continued caring for their loved one's without paying attention to their own sufferings.

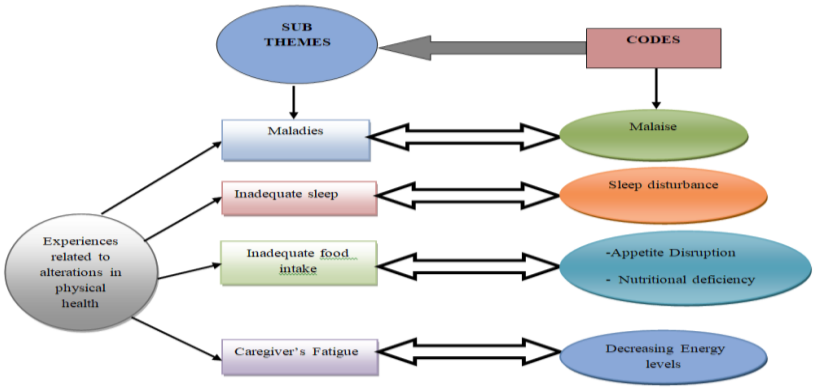

Fig No 1 Theme, Subthemes and codes used to represent the Experiences related to alteration in Physical health.

i. Maladies

Caregivers reported about various ailments which they experienced while care giving, where participant no 2 a wife expressed, "looking after my husband I started with severe backache". where participant no 3 a wife stated, "Taking care of my husband, I found it difficult to sleep properly at night due to worries, which led to the development of acidity issues". Participant no5 who was a mother looking after her son reported that, "I experienced tingling sensation in my left hand which was later reduced after treatment". In the same way participant, no 6 who was a sister reported that, "initially she experienced tightness in the head but later started with Headaches" and participant 8 who was a mother communicated, "I am not able to do anything as I used to do it previously now, I have started experiencing giddiness".

- Participant(2) expressed, Hyacha sagla kare paryant maji kambar purn geli, "mala kambar dukhicha tras suru zhala"
- Participant(3) stated….Zhop vyavastit hoth navti dokyat vichar hya saglya mule parat "mala pitacha tras suru zhala parat".
- Participant (5) stated, " Hath mein mungya aye jaise hota tha" phir muje 5 injection lene pade phir taklif kam hui meri
- Participant (6) said,….Hyachi bad-bad aikun adhi doka gach hoycha pan ata "Doka dukhayla suru zhala ahe"
- Participant(8)expressed….Mala ata adhi sarkhaka hi jamat nahi"ata chakkar yala suru zhali ahe"

Inadequate sleep

Most of the caregivers stated, that they were unable to sleep Adequately in terms of overall quality and quantity which resulted in sleep disturbances where participant no 1 a wife stated, "The thought of him possibly going somewhere at night kept me awake". Participant no 3 and 7 who were wives reported, they used to struggle with thoughts that kept them awake, resulting in less sleep. In the same way participant, no 5, a mother said, "Once he began shouting at night, I would wake up, and then I would end up staying awake the entire night, which prevented me from getting a full night's sleep". Participant no 8, a mother expressed, "The thought of her future and how things would unfold in her life kept me awake at night".

- Participant (1) said… He ratri tun kute tari uthun gele tar ya vicharane "mala zhop lagaychi nahi"
- Participant (3) reported,….Suruvatila dokyat vichar yache jyamule zhop lagaychich nahi, " zhopkami hoychi"
- Participant (5) stated… "Ye chikne chillane shuru kiya toh meri neend tut ti" phir uske baad aage jaagte baitna padta ta phir, neend poori nahi hoti thi phir.
- Participant (7) expressed….. Mala hyancha khup vichar yacha dokyat tasech mulancha "kalji ne ratri zhop lagat navti"
- Participant (8) commented…Hicha pude kasa honar hya vicharane "zhop kai lagaychi nahi bagha"(Her eyes filled with tears)

Inadequate food intake

Not only ailments or in adequate sleep, Caregivers experienced inadequate food intake where participant no 1 a wife communicated, "Seeing his condition, I started feeling uneasy, which eventually led to a decrease in my food intake". Participant no 5 a mother, "Observing his condition, I would feel tensed, making it difficult for me to eat". Participant no 6 a sister stated, "Many a times, it was necessary to sit with him continuously, which made it difficult for me to eat, resulting in a reduction in my food intake later on". Participant no 12 a wife said that, "Due to constant thoughts of him, I lost my appetite, leading to a decrease in my calcium and hemoglobin levels".

- Participant (1) said…… Hyancha hey sagla baghun-baghun mala khup kasa tari vataycha nantar-nantartar maja "jevanach kami zhala hota"
- Participant (5) expressed…. Iski halat dekh ke muje bahot tension ata tha, "Tension shi muje khana khaye jata nahi tha"
- Participant (6) reported….. Kahi vela asa zhala ahe ki hyachya kade basun rahava lagayche mag mala jevata pan yacha nahi hyamule halu- halu " jevan kami zhale hote".
- Participant (12) stated…… ...maja angatla rakt ani calcium kami zhala hota hyanchya vichara madhe aslyamule "mala bhukach lagat navti"...(her eyes filled with tears)

Caregiver's Fatigue

Caregivers even experienced fatigue due to their tiring role of caregiving where participant no 3a wife expressed that, "Many times, I would feel exhausted, but I couldn't allow myself to rest because I felt responsible for looking after him". In the same way participant, no 7 a wife stated, "while I'm there to provide him with support, the constant care has left me feeling tired, and I've noticed a decrease in my stamina".

- Participant (3) said…… mala baryachda "khup thakalysarka vataycha" pan jar ka mich thakle tar hyanchikalji kon ghenar
- Participant (7) said……Hyana adhar dyala mich ahe hyancha sagla kare paryant mala "maji takat kami padat ahe"asa vat ta, maja stamina tevda nahi rahat ata.

Theme: II- Psychological Experience

Caregivers expressed that they experienced mental strain, fearful apprehension, and mental distress, but few also stated that they received psychological support through various channels, which had helped the caregivers in continuing their journey of caregiving.

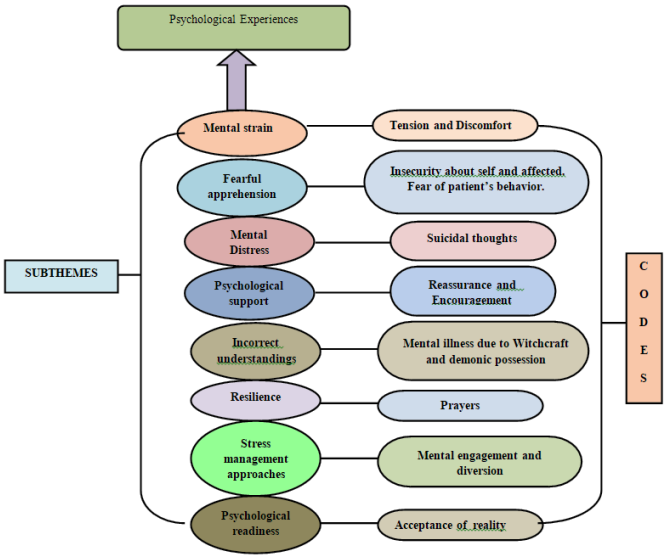

Fig No 2 Theme, subthemes and codes used to represent the psychological experiences.

Mental strain

Caregivers had mental strain for different reasons while caregiving were, Participant no 2 a wife said, "I feel like there's nothing left in my head; sometimes I think I might lose my sanity". Participant no 2, a wife said, "This man would sometimes behave in a very different and forceful manner, causing me significant mental discomfort". participant no 3 a wife expressed that, "As he used to get admitted my tension would increase".

- Participant no 4 who was a father said, that "The thought of why this illness arose in this generation only would often lead to tension for me".
- Participant (2) stated…… Dokyat majya ata kahi rahilach nahi "Malach ved lagaychi pali ali ahe" (loud voice)

- Participant (2) said…… "Ha manus kadi kadi khup vichitra vagaycha majyavar jabardasti karaychajyamule mi mansik ritya khup asvasth hoyche"…(Silencefollowed byCrying)
- Participant(3)expressed…… Hyana admit kelaki"Maja taantanav vadaycha"...
- Participant(4) reported……Ha tras attach ka udbhavla ha vichar ala"ki tension yacha" (furrowed brows)

Fearful Apprehension

Caregivers also experienced fearful apprehension were Participant no 3 and 7 who were wives expressed that caring for their husbands with mental illness resulted in fear that they might also develop similar symptoms, causing them to feel scared. Whereas Participant no 5, 8 and 10 who were parents communicated, their concern about who will care for their children after them and how things will unfold in the future would often trigger their worry, and even fear.

- Participant (3) said…… Madhe ase vatu lagle ki mala pan asa tras hoto ki kai hya vicharane " bhiti vataychi"
- Participant (5) stated…… Aage iska kaisa honewala , mere baad isse kaun deknewala ye sochkar " tension bhi ata aur darr bhi lagta tha"
- Participant (7) said…. …" Bhiti vataychi tyanchi kalji gheta-gheta mala pan asa zhala ahe ka"…
- Participant (8,10) expressed…. Amchya nantar hyala kon bagnar"kalji tar lagun rahati var bhiti pan vat ti vichar ala ki"(eyes filled with tears)
- Fear of patient's behavior Caregiver who was a father expressed about "Feeling scared by his son's changes in behavior, when the son would start fighting and shouting, it would instill fear in the family members, making them think if he would harm them in any way".
- Participant (9) told….."Ha bhandan, Danga karayla lagla ki "amhala bhiti vataychi"ki ha ata kai karel? Amhala marto ki kai ase vatayche

Mental Distress

- Caregiver who was a wife expressed that, "many a times she felt like committing suicide ,due to the perceived lack of meaning in life".
- Participant (7) expressed …..Kiti vela ase vatle ki "athma hathya karuya" jagnyala kahi arth nahi.

Psychological Support

Caregivers who expressed about mental strain, distress but few also mentioned about the psychological support they received during their journey of caregiving where participant no1 and 3 who were wives said they received psychological support and reassurances from their relatives and familiar faces which had helped them in moving forward during this journey.

- Participant (1) told…..Maze natewayik, kaka, kaku, chulat bahin bolayche "kalji karu nkos sagla thik hoil"
- Participant (3) stated… Mala majya kamavarche tasech olkiche lok samjavayche ki ek divas nkki toh bara hoil tu dhir dhar.

Incorrect Understandings

Caregivers dealt with both physical difficulties and emotions linked to things they cannot see. The unseen became a big part of a caregiver's experience. It adds emotions, spirituality, and a constant question about what's really going on beyond what the eyes can't see.Participant no 1,3 and 5 expressed that whether their loved ones were been possessed or it was a result of witchcraft.

- Participant (1) expressed… "Karni vagere keli asel konitari" asa vichar ala hota mala mag mi baher vicharun bagitla hota.
- Participant (2) stated…. "Hyala kahi laglela ahe ka", Lok amhala mhanayche tumcha kuldaivatacha kara mala pan asa vatlahota
- Participant (5) reported….. Mere dimag me aya ki ise "Asar hain kya karko" main hamare maulana ko bulake dikhayi.

Resilience

Caregivers adapted to the situation by using various methods like praying for their loved ones where Participant no1 a wife said,"whenever I feel tensed, I just pray and ask god to provide me strength and also visit a temple which is near to my house". Participant no 5 a mother reported, "I read Quran, pray to allah that cure him out of this illness". Participant no 7 a wife stated, "I pray to God that even if we don't receive money it's alright, the only thing I want is let his hospitalization reduce".

- Participant (1) expressed… Mala jast tension ala ki "Mi devala magte mala takat de" javal ek mandir ahe Tikde jaun pooja karte.
- Participant (5) stated… "main quran padti hun, duwa karti hu" upar wala isse thik karande mere beteko accha karan de aisa main duwa karti hun.
- Participant (7) said…Mi devala magte paise nahi dile tari chalel pan "hyancha davakhanatevda kami hou de"…
- Participant (10) expressed… Mi devala hech magte ki " hyala lavkar bare kar hyachapan lagna houde"

Stress management Approaches

Stress management approaches were employed by the caregivers to tackle the stressful situation by various means were participant no 2 a wife expressed that, "I go out for work with other people when I start experiencing tension". Participant no 3 a wife said, "I speak and ventilate to my close friend whenever I feel tensed.

Participant no 4 a father reported, "I involve myself in people around me whenever I feel tensed". Participant no 8 a mother said, "I just keep on performing the household work whenever I feel tensed".

- Participant (2) communicated…. "Mala tension ala ki mi baher nighun jate"kaam karayla itar baikan sobat.
- Participant (3) expressed…. Maji ek maitrin ahe jila mi sagla sangte "Mala tension alaki mi tila bolte"
- Participant (4)stated…..Mala tension ala ki "milokan madhe jato tyanchyashi bolto"
- Participant (8)reported…..Mala jast vichar kiva tension ala ki mi bhaji swach karte, gharatla ahitar kaam karte.

Psychological Readiness

The difficult and courageous part of caregiving were 2 caregivers participant no 1 and 2 who were wives expressed that, they have accepted the reality and chosen to keep moving forward, accepting fate's decision. It feels like the same story every day.

- Participant (1) communicated…. Majya nashibala ahe tar kai karayche te "mi ata manya kele ahe" pude baghun chalat rahayche ata.
- Participant (2)said….Mi ata jast vichar karat nahi adhi sarkha"Roz cha mada tyala kon rada asa zhala ahe

Theme: III- Social Experiences

Most of the caregivers expressed that they had positive experiences and few expressed about negative. Caregivers encountered feelings of embarrassment, lack of family support, non- attendance at social events due some or other reasons and self-perceived stigma whereas few expressed regarding the altruistic support they received in the form of community and relational aid.

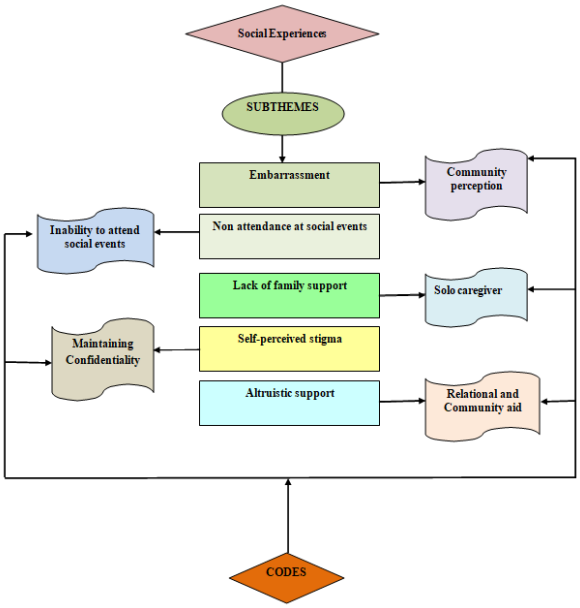

Fig No 3 Theme, subthemes and codes used to represent Social experiences.

Embarrassment

Caregivers expressed various situations where they felt embarrassed, were participant no1awife stated,"When I walked on the roads, I felt like people were looking at me and talking about me", participant no 4 a father reported, "people used to simply ask even when everything was fine, people would still ask, "Is everything okay?" for no apparent reason". Participant no 5 a mother said, " no one in the family invites or talks to us which makes me feel sad". Participant no 6 a sister stated, "We used to live in a place where the house owner and the people around us looked at us in a different way". Participant no 7 a wife said, "People thought his wife might not be good, and that's whyhe behaves in this way, possiblyleading to disturbance in his mental state".

- Participant (1) stated…. Vatene jaat astana "lok mala baghayche"asa vataycha malach kahibolat ahet"
- Participant (4) reported……."Kahi nastana pan lok chaukashi karayche" ugach vichairayche ata tabyat bari ahe ka mulachi muddamun kelya sarka karayche (Touchinghead)
- Participant (5) communicated….. "Koi humko kuch bolte bhi nahi aur bulate bhi nahi", aisa karte hain bura lagta hain.

- Participant (6) expressed…..Amhi eka thikani rahayla hoto tithle "Gharmalak va lok amchya kade veglya nazrene baghayche "… (Averted gaze with silence.)
- Participant (7) stated…..“Hyachibaikonitnasel”mhanunhaasawagatasel,hyachya dokyavar parinam zhala asel hyamule ase lok mala bolayche (Silence)

Non-attendance at social events

As caregivers were responsible for looking after their loved ones due to different reasons they were not able to attend the social events were participant no 1 and 11 who were wives stated, they avoided attending social events because they were afraid of people would say something about or even insult them. Whereas another participant7whowas also a wife said,“for the past 3 years I have never left him alone and gone anywhere not even attended any social programmes”.

- Participant (1) stated…… “Mi Gharabaher padat navte kute karya kramat jaat navte” lok kahitari baghun boltil ase vatayche mala.
- Participant (7) said……geli tin varsh zhali “Mi hyana sodun kutech jaat navte” agdi karyakramana pan nahi” mala kute jatach yacha nahi
- Participant (11) expressed…… Karyakramala janyache amhi talaycho gelo tar parat“Lok, natevayik parat kahi tar boltil apman kartil mhanun amhi jaat navto”.

Lack of Family support

Performing and managing the role of caregiving was not simple and easy for the caregivers where participant no 4 a father reported, “Whenever it's for hospitalization or ECT, I am the only one who has to bring him here.

I believe it's important, and there's no other option”. Participant no 10 a mother expressed, “I have an elder son, but he doesn't offer to help, so I end up doing everything myself. I call people for assistance, and later, I pay them for their help”. Participant (4) reported…… Hospital la kivan ECT la gheun yava lagta karan “Paryay nahi malach karava lagta” ani hey mahatvacha ahe.

- Participant (10) stated…… “Maja motha mulga ahe pan toh mala vicharat pan nahi” mag mich sagla karte lok bolavun ghete tyana paise dete yala admit karayla.

Self-Perceived Stigma

Stigma related to mental illness was like treating people differently or unfairly because they had a family member suffering from mental disorder because of this fear some caregivers kept confidentiality regarding the illness by concealing it with different options. Participant no 4 a father expressed, “I never told them when admitting my son to the hospital. If they called me during that time and asked, I would simply say I was going out for work”. Participant no 7and 12 who were wives stated, they never told anyone about mental illness why to simply open up a chance for discussion on the topic for people instead they concealed the illness with other reason for which they were receiving treatment. Participant no 8 who was a mother said, “We stay in village where I had kept it confidential because my elder daughter is not yet married”.

- Participant (4) expressed,Mi konala kalu deth navto “admit kartana natevayikancha phone ala ki mi tyana bolaycho maja kaam ahe mi baher ahe” ase bolaycho.
- Participant (7) stated…. “Amhi hya ajarababat konalach sangitle nahi” kashala ugach charche la vishay”…
- Participant (8) reported,… Gavat konala kalu dilela nahi dusrya mulichlagna vhayche ahe "…
- Participant (12) said,….“Amhi konala sangitla nahi mansik ajar ahe mhanun mendu la rakt pochat nahi asa sangitla”

Altruistic Support

Caregivers expressed about their experiences related to feeling of embarrassment, non- attendance at social events, lack of family support but few also expressed about the altruistic support they received in the form of relational and community aid. Participant no 1 a wife said, “my mother has always helped me a lot whenever my husband required hospitalization she used to come and stay at my home looking after everything”. Participant no 3 a wife reported, that, “my brother- in-law has always helped me a lot whenever my husband required hospitalization”. Participant no 5 a mother reported, “my brother – in- law had helped me by providing me financial assistance of five thousand rupees”. Participant no 8 a mother said, “one of the patient’s relative who was admitted in the same ward had helped me by providing two hundred rupees when I had less money for an investigation”.

- Participant(1) expressed… “majya aai ne maji khup madat keli ahe” hyana jevha admit karava lagaycha tevha aai yeun sasri rahaychi. (Smiling)
- Participant (3) stated… Hyana admit kartana majya nandechya mr ni “mala khup madat keli ahe”…
- Participant (5) said… Ek baar Hamara devar hospital me leke gaya aur 5 hazar rupaye bhi diya "…(Smiling)
- Participant (8) expressed……“Ikde rakta chi tapasni sati paise kami padat hote ithlya eka patient chya natevayikani mala 200 rupaye dile"…

Theme: IV- Experiences related to Hospitalization of patient.

Caregivers communicated regarding their experiences during the hospitalization of patient like how, where, when they gained insight, clarity about the illness from which their loved ones were suffering. In the same way they also expressed what struggle they had to face while admitting their relative to hospital and how they managed things during this process.

Table No. 3.4: Description of the theme experiences related to Hospitalization of patient. N=12

Sr.No	Subtheme	Codes
i	Information about illness	Understanding about Mental Health Disorder at hospital
ii	Insight regarding illness.	Clarity about illness
iii	Admission challenges	Struggle

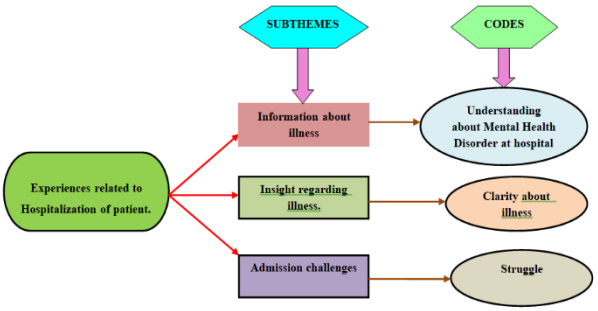

Fig No 4 Theme, subthemes and codes used to represent experiences related to hospitalization of patient.

Information about illness

Caregivers could not understand what exactly was going wrong with their family member who was well suddenly started behaving in a strange way that made them think about it, but they had no answer. Caregivers visited possible areas to understand the reason behind this behavior but failed. Finally, through some or other medium they brought their family member to the hospital where participant 2 (wife), 3 (wife) and 5 (mother) communicated, as they admitted their loved ones in hospital the healthcare professionals specially the doctors and Nurses helped them in understanding what was wrong and why their loved ones had suddenly started behaving in a strange way.

- Participant (2) communicated….Amchya chultya kadun hospital baddal mahiti milali mag ikde alyavar " yethe asnarya doctoran kadun kalale ki kai zhale ahe nakki te"
- Participant (3) expressed…."Doctorani samjavun sangitle ha ajardon bhagat hou shakto" harshvayu kivan nairashya mala adhi hya baddal mahit navte ki hey asa ka karat ahet.
- Participant (5) stated….."Doctor muje samjaye ye taklif kyu ho rahi hain" iski wajah kya hain aur usse aisi taklif kyu ho rahi hain.

Insight regarding illness

Insight was about understanding the illness in a true way without any incorrect ideas or perception about it. where participant no 3, a wife said, "I have decided whatever it may be, let people speak or discuss anything we are not supposed to pay attention or think over it. It is a mental disorder which requires treatment". Participant no 8 a mother said, "I know that it is nothing supernatural or any black magic which causes this it is a mental disorder which surely requires proper treatment". Participant no 9 a father said, "This disorder requires immediate attention we can't delay if we do, again it increases in its severity".

- Participant (3) reported….. Mi tharavla ahe Mansik ajar ahe treatment tar ghyachich "apan konihi kahi bolla tar farak nahi padu dyacha.
- Participant (8) said… Koni 10 limbu takle tari kahi nahihoth "ha mansik ajar ahe mala ata samjala ahe."
- Participant (9) expressed…. Ha ajar aaj asude udya baghu asa nahiye tyala jya tya veli dakhavla pahije nahitar toh parat vadto"…

Admission challenges

During of patient hospitalization, Admission challenges were reported by the caregivers where participant no 9 a father stated, "we used to face lot of problems it was a difficult task for us when it came to his hospitalization, we used to make him sit on the bike by placing him between two people because he wouldn't listen to me or anyone else; he would often hit us". Participant no 11 a wife said, "He was not all ready to get hospitalized the doctors and nurses explained him the importance then somehow after lot of efforts he agreed and got admitted".

- Participant (9) expressed… Hyala admit kartana khup tras hoycha hyala amhi gadivar basvun doghana mage basvun dharun gheun jaycho toh dhakka bukki maraycha pan tari tyala anaycho.
- Participant (11) stated…He ikde admit honyas tayar navtey ethe asnarya doctor, sisterva itar lokani khup samajavla hyana mag tyanantar te tayar zhale.

Theme: V- Financial Experiences

Caregivers expressed that their loved one's receiving treatment required regular medications, hospital stay, transportation costs. All these factors lead to financial crisis they had no sufficient finance to manage these situations. Yet caregivers managed by choosing one or other options which helped them in making financial adjustments.

Table No. 3.5: Description of the theme financial experiences. N=12

Sr.No	Subtheme	Codes
i	Financial Hardships	Financial Adjustments
ii	Expenditure	Transportation and Relocation expenses
		Superstitious advice cost

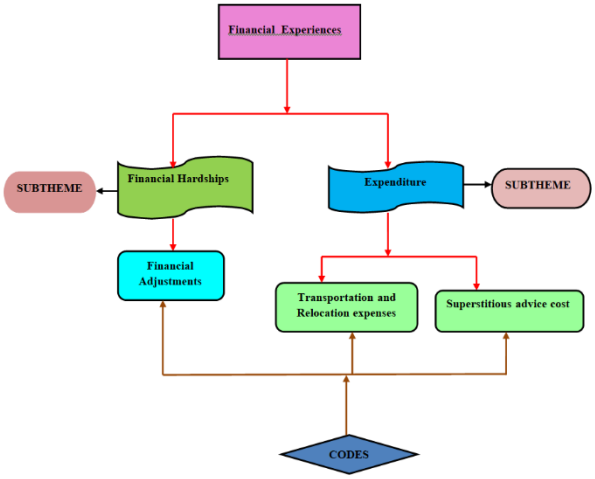

Fig No 5 Theme, subthemes and codes used to represent Financial experiences.

FINANCIAL HARDSHIP

Nothing can replace money, Caregivers who were experiencing a lot of things also encountered financial problems but with some or the other options they tried, making adjustments as it was necessary for the treatment. Participant no 3 a wife reported, "During his hospitalization sometimes I had limited funds which was not sufficient I used to borrow money from my parents and return it later". Participant no 6 a sister said, "Sometimes, due to limited funds for treatment and medication, we would buy fewer medications than prescribed". Participant no 7 a wife stated, "Many times, we paid his hospital bills by using my gold, which I would then exchange for money". Participant no 11 a wife communicated, "We had less money were treatment or consulting a doctor was not affordable then we used to go for options like asking people like "Devrushi" we somehow managed to get through for five years".

- Participant (3) stated….Mala hyana admit kartana " Paise kami padle ki mi aai-vadilan kadun piase ghyache nantar parat karayche"…
- Participant (6) reported….Kadhi-kadhi aushadh upcharan sati paishyanchi adchan hoychi " paise chi adchan ali ki hyache aushadh kami ghyacho"…
- Participant (7) communicated….."Hyanchya upcharasati maje sona thevun paise kadle" paise kadle mag bill bharli baryach vela
- Participant (10) expressed…..baryach vela paise chi adchan asaychi "Paise chi adchani mule majya lahan mulane paise dile mala"
- Participant (11) stated…..Paise nasayche upcharasati mag kami paise madhe ikde- tikde devrushi baghaycho " asach karat amhi vel kadli 5 varsh ashich odli.

Expenditure

Expenditure was another concern where caregivers, in spite of financial problems, had to spend money on transportation and relocation. Participants 6 and 7 stated it was not possible to take him to hospital by public transport as every time he required a private vehicle which cost us a lot. Participant no 6 and 9 reported that because of his mental illness he used to react, shout due which the house owner asked us to shift to other house this was repeated many times. Participants no 9 and 10 said, we thought that the change in behavior of our family member was due to some witchcraft, black magic or some vow which we failed to fulfill, and it was due to all this, this inquiry of confirming resulted in lot of expenses.

- Participant (6 and 7) communicated…. Hyala gheun jaycha matla ki "private gadi karavi lagaychi khup kharch hoycha "ST madhun tar gheun jau nahi shakat mag dar veli private gadi karavi lagaychi
- Participant(6) expressed….Gharmalak bolayche ha khup danga karto dusri kholi bagha mi 5 vela ghar badalle "khup kharch zhala"
- Participant (9) stated…..Hyachya hya ajaramule va arthik adchanimule mala 3-4 vela ghar badalava lagle hyamule "khup kharch vhaycha"

- Participant(10) stated….Mala ase vatte ki amchya Nateveyikani amchyavar "kahitar kele ahe" mi baher vicharle hyat pan paise khup gele"…
- Participant (11) reported…. Tumhi hya devala bolay tya devala bolay, navas bolla kela nahi asa bolun maji disha bhul keli tyat pan paise kharch zhale"…(Tapping own head)

DISCUSSION

The findings of the study were similar to other studies which were conducted by different researchers such as, the theme experiences related to alteration in physical health, Psychological and social experiences were similar to the study conducted by Ntsayagae EI, Myburgh C, Poggenpoel M. (Africa) the study Experiences of family caregivers of persons living with mental illness.14,15

CONCLUSION

The qualitative analysis of data has revealed 05 themes, 21 subthemes and 25codes with a spectrum of experiences encountered by individuals struggling with health challenges. From physical discomfort to the profound psychological, social, hospitalization- related, and financial implications, the narratives shared by participants underscore the multifaceted nature of health adversity. These findings highlight the need for comprehensive support systems that address not only the medical aspects but also the complex interaction of psychological, social, and financial dynamics. By acknowledging and understanding these diverse experiences, healthcare providers and policymakers can work towards implementing tailored interventions that enhance the overall well-being and resilience of individuals facing health-related hardships.

Limitations

The study has several limitations. First, the small sample size of 12 caregivers restricts the ability to fully capture the complexity and diversity of their experiences, limiting the generalizability of the findings to a broader population. Additionally, caregivers may have felt pressured to disclose or withhold certain experiences, particularly those related to physical harassment by their loved ones, due to a perceived expectation from the researcher, which could have influenced the authenticity of their responses. Moreover, since caregivers' experiences are shaped by diverse social and cultural factors, capturing the full depth and nuance of these experiences within the scope of a single study poses challenges and may require alternative methodologies or longitudinal research for deeper insights.

Implications for Nursing Practice, Education, Administration, and Research

The findings of this study carry significant implications across multiple domains of nursing. In practice, they emphasize the need for nurses and students to employ holistic assessment approaches to identify caregiver and patient needs, integrate strategies to reduce caregiver burden, and adopt psychoeducational interventions addressing symptoms, treatment, and stress management in Bipolar Affective Disorder. Such approaches enable more compassionate and person-centered care. In education, the results highlight the importance of incorporating caregiver-related challenges into nursing curricula and providing clinical experiences involving patients with Bipolar Affective Disorder and their families. Bedside teaching and periodic health education sessions for caregivers should also be promoted. From an administrative perspective, the study underscores the need to establish structured caregiver support programs, implement staff training to enhance sensitivity and awareness, and foster interdisciplinary collaboration to ensure comprehensive care. In research, the findings provide evidence to be disseminated through journals, conferences, and workshops, while serving as a foundation for future studies exploring caregiver well-being and comparative caregiving experiences in other mental health conditions.

Recommendation

Future research can be strengthened through several approaches. Longitudinal studies could be conducted to track caregivers over an extended period, allowing for a better understanding of changes in their experiences and overall well-being. Comparative studies between family caregivers and professional caregivers would also be valuable in highlighting differences in caregiving roles, responsibilities, and challenges. Additionally, assessing the impact of caregiving on mental health outcomes, using standardized tools such as the Beck Depression Inventory or the Generalized Anxiety Disorder Scale, could provide deeper insights into psychological effects. Furthermore, comparative research exploring the quality of life of caregivers of individuals with Bipolar Affective Disorder versus those caring for patients with other mental health disorders would help in identifying specific needs and tailoring supportive interventions.

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Conflict of Interest

No conflict of interest is involved.

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