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Challenges in Managing the Persons with Depression: A Qualitative Study

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ABSTRACT

Depression is a major public health concern. It not only affects the mood of the person but also his thought, perception of the world, interest in daily activities and the interaction with people around him. This nature of the disorder along with established risk of suicide associated with it can make it really challenging for the family care givers in managing the persons with depression. Exploration in this area would be helpful in identifying the need of this population so as to plan for further strategies.
A qualitative phenomenological design has been adopted to conduct the study with the aim of exploring the challenges faced by family care givers in managing the persons in depression. The study was carried out among the family caregivers of persons with depression currently under treatment in LGBRIMH, Tezpur. The family caregivers of persons diagnosed either with Depressive episode or recurrent depressive disorder with suicidal ideation, who have been taking treatment for at least 3 months were selected through purposive sampling technique. Written consent from the respondents has been collected before data collection. Data was collected through in-depth interviews from the respondents using an interview guide. Analysis of data has been done by thematic analysis.
The indentified challenges in managing persons with depression were, 1) Related to the persons with depression, like, difficulty in communicating, perceived burdensomeness; 2) Related to the family caregivers, like, lack of support, difficulty in treatment compliance, lack of knowledge; and 3) Related to the society, like, social pressure for faith healing and stigma.

Key words: Depression, family members, care givers, management, qualitative research

INTRODUCTION

Depression is a major public health concern in terms of its prevalence and the suffering, dysfunction, morbidity, and economic burden. WHO report projected that depression would likely be the second leading cause of disability worldwide by 2020[1] and leading cause of disability by 2030[2]. It not only effects the mood of the person but also his thought, perception of the world, interest in daily activities and the interaction with people around him. It plays a role in more than one half of all suicide attempts[3]. Depressed men and women are 20.9 and 27 times, respectively, more likely to commit suicide than the general population[4].

However, number of factors like inadequate number of mental health workforce[5], lesser dedicated bed for mentally ill patients in need for hospitalization[6], an uneven distribution of mental health facilities in India[7] focuses on an urgent need for focus towards involvement of the community and family members in the management of the persons with mental illness. A recent review[8] reported that the rate of recurrence of major depressive disorder treated in specialized mental health settings was very high (60% after 5 years, 67% after 10 years, and 85% after 15 years) but was significantly lower in the primary care population (35% after 15 years), which

again indicates the importance of community and home based care in management of depression. But the nature and symptomatic presentations of the disorder along with lack of understanding among the family caregivers and stigma associated with it in the community can make it really challenging for the family care givers in managing the persons with depression at home level. Exploration in this area in identifying the challenges faced by this population so as to enable them to better manage their relatives suffering from depression would be helpful to plan for further strategies.

Aim of the study: To explore the challenges faced by family care givers in managing the persons in depression.

MATERIALS AND METHODS

A qualitative phenomenological design has been adopted to conduct the study among the family caregivers of persons with depression currently under treatment in LGBRIMH, Tezpur. The family caregivers of persons diagnosed either with Depressive episode or Recurrent depressive disorder, who have been taking treatment for at least 3 months, and scored eight or more in the Hamilton Depression Rating Scale (HAM-D) on the day of interview was selected through purposive sampling technique. A self structured socio-demographic proforma and the Kuppuswamy socioeconomic scale were used to collect the demographic information from the participants. Data was collected from 8 participants through in-depth interviews using an interview guide till data saturation occurred. The participants who fulfilled the sampling criteria were explained about the purpose and the procedures of the study and the written informed consent was obtained. Respondent anonymity and data confidentiality was maintained.

Data collection and analysis:

Data was collected by carrying out face-to-face in depth interviews. Each interview lasted approximately for 45 minutes. The Interview sessions were audio recorded along with the field notes that have been kept securely for data analyses and future reference. A 'zigzag' approach was adopted for data collection where the transcribed data were discussed with the participants to establish respondent validity till data saturation occurred. All the recorded data then were transcribed, coded in three phases, where the first and second phase involved structural and pattern coding respectively of the collected data. In the third phase data triangulation was done. Following this, the complete set of data was checked by two independent readers to increase validity and reliability. Principles of constant comparative analysis was used, where, the transcripts were read on a number of occasions to determine how the emerging analysis fitted in with existing data. Frequency was calculated to find out the demographic characteristics of the participants. A thematic analysis was undertaken to analyze the qualitative data where initial codes were grouped together into similar concepts to form the categories and themes.

RESULT

Characteristics of the participants:

Table 1: Sociodemographic characteristics of the family care givers of persons with depression

	P1	P2	P3	P4	P5	P6	P7	P8
Age	55years	50years	42years	59years	45years	38years	52years	47years
Sex	Male	Male	Male	Male	Female	Female	Male	Female
Education	XII	X	M.Sc	BA	B.Sc	XI	BA	V
Occupation	Office peon	Carpenter	Asst Prof	Retired employee	House wife	House wife	Teacher	Cook
Marital status	Married	Married	Married	Married	Married	Married	Married	married
Relationship with PwD	Husband	Husband	Son	Husband	Mother	Wife	Father	Mother
Presence of alternative care giver	No	No	No	Yes	Yes	No	Yes	Yes

Three husbands, two mothers, one father, one wife and one son were interviewed. The participants aged between thirty-eight to fifty-nine years. Five out of the eight participants were male whereas three were female. One participant had primary, two had secondary, one higher secondary, three had graduate and one had post-graduate level of education. Out of the eight participants one was office peon, one was carpenter, one asst professor, one retired employee, two house wives, one teacher and one cook. All the participants were married. Four of the participants reported that there was absence of an alternate caregiver whereas four reported presence of care giver.

Main findings:

After interviewing the eight participants the identified challenges in managing the persons with depression were mainly categorized into three themes. These are,

1) Challenges related to the persons with depression
2) Challenges related to the family caregivers and
3) Challenges related to the society.

Challenges related to the persons with depression:

Among the challenges that have emerged from the interviews some were related to the persons with depression themselves. The three subthemes of challenges identified in this category were disinterest in treatment compliance, perceived burdensomeness and difficulty in communicating.

Disinterest in treatment compliance:

The identified two factors behind this disinterest of the persons with depression were firstly the nature of symptoms of depression, as one participant described,

"I need to make her understand to come to the hospital. At times she is very stubborn…Won't go out anywhere, not even to the hospital" (P1)

Secondly lack of patience in adhering to the treatment, as one participant expressed,

"Initially he himself tried for his improvement. As he couldn't sleep at night, kept worrying and apprehending, he brought his medications and took. Now a day he doesn't want to go for check up. He would say how long he will keep on taking medications, it's not improving even…" (P6)

Perceived burdensomeness:

One out of the eight participants expressed that he was not being able to take care of the depressed family member as she perceived herself as a burden to the family. He described,

"…what I later came to know is that she (person with depression) would go out to the neighbors and verbalize, "I will go out of this house some day and would jump in some river somewhere. This problem will then get over. My family members also will be free, so many problems they are facing because of me." Now I have never shown a lack of concern towards her or lack of interest in her treatment. If she keeps this sort of thought in her mind how will I be able to take care of her? " (P2)

Difficulty in communicating:

Some of the participants expressed that difficulty in communicating by their depressed family member was a challenge for them in their management as they could not understand their feelings. The participants expressed,

"when I go to talk to her (person with depression) I find that there is sort of a resistance from her part, like she should not listen to me or she should not confront me..like this kind of resistance is there.." (P3)

"…at times I lie down with her and ask "what happened? Why are you not feeling well? tell me." " ehh.. you all will not understand and simply will get tensed. Leave it" (P5)

"I keep asking him to tell what is he tensed about, but wouldn't tell a thing. He would only say I am just not feeling well" (P6)

Challenges related to the family caregivers:

Some challenges in management of persons with depression were related to the family care givers. The seven subthemes that were categorized under this theme are, lack of alternative care giver, care giver burden, difficulty in understanding the person with depression, lack of knowledge and skills of management, financial crisis, deprived biological need, emotional issues related to care giving.

Lack of alternative care giver:

The interviews revealed that the lack any alternative care giver was a challenge for some of the participants in managing their depressed family members, as three of the participants expressed,

"My only son never came to mental hospital. It has been around 5years. He never saw what medication his mother (person with depression) is taking…" (P1)

"I don't have other people to see her (person with depression) at home. I have two daughters, one got married and the other one has to go college, when my wife is sick she (daughter) has to stay at home in order to look after her mother by missing her classes. But that is not possible everyday" (P2)

"My wife also doesn't stay here, so managing everything alone in a way is very hectic for me." (P3)

Care giver burden:

The some participants expressed care giver burden as a challenge in management of the persons with depression in family. This burden was mainly due to the need for constant observation of the persons with depression, as some participants said,

"I have to keep really observing her when the illness aggravates. I cannot go out anywhere till the time she is doing household chores or is in toilet. I have to keep observing her constantly" (P2)

"I was unable to manage him alone at home, he would silently go out somewhere if I move out of his sight for dong the household chores. So his father too couldn't go for work. Around fifteen day we were constantly after him." (P8)

Another factor identified causing the care giver burden was the need for 'lot of attention' towards the person with depression. One participant verbalized,

"It is difficult for me to manage my office and again looking after my mother after coming back, considering the fact that it(depression) requires a lot of attention. You have to see that she is taking medicines on time, you need talk to her politely, ask every time whether she ate or not, accompany her everywhere, and what not. My whole goes in office and looking after her.." (P3)

Difficulty in understanding the person with depression:

Participants identify their difficulty in understanding the person with depression as a challenge in their management, as some of the participants expressed,

"Every day minimum ten times there will be some misunderstanding between us. You do something for her sacrificing your own happiness, she interprets it differently, you know.. I just don't understand what would make her happy" (P3)

"…I keep telling her "we won't take tension. How will we understand your problem if you only keep it to yourself? Why don't you tell us if you are facing any difficulty?" (P5)

"If he wants something he doesn't ask it directly, may be he things, his father will not be able to afford it..but he will be irritated, wouldn't talk properly, at times show anger .. Initially we didn't understand at all what he was up to, now at least I can guess" (P7)

Financial crisis:

Few of the participants described financial crisis as a challenge in managing the person with depression. The identified factor due

such financial crisis was decreased work function of the persons with depression and inability of the family caregivers to 'go for work' so as to provide care to their depressed family member at home. They verbalized,

"…Coming all the way to hospital for check up every moth takes a lot of money. We have borrowed some money from others which has to be returned back. Till now we have returned only half but some more has to be returned. When he (person with depression) could work well we did not have such problems, but I don't know how to run a shop efficiently. I sit in the shop now a day though.. it's not is not running well." (P6)

"All the money got ever since we could not go for work these days, few days back I borrowed some from a relative..so that I can bring him to hospital." (P8)

Deprived biological need of the care givers:

Some participants have felt that their biological needs like sleep and food intake was deprived due to the active symptoms of depression among their family members with depression, which in turn have affected managing the persons with depression.

Deprived sleep:

Some of the participants expressed that they 'couldn't sleep' as they had to constantly observe their depressed family members to make sure that they do not 'go out somewhere at night' or 'do something bad' to themselves. They verbalized,

"…couldn't sleep enough for so many days, even at night when we go to sleep I keep holding her hand because of the tension that she might go out somewhere at night. I also wait outside the toilet when she goes for the elimination at night." (P4)

"Me and my wife used to sleep alternately at night. Even if I went to the bed I couldn't sleep, there was always this tension that he might go out and do something bad to himself .." (P7)

One of the participants expressed that they were unable to sleep as the person with depression 'wouldn't let' them sleep at night. She verbalized,

"He(the person with depression) wouldn't let us sleep at night, would keep arguing on silly matters. He remained so restless" (P8)

Decreased food intake:

One of the participants expressed that he had to 'force' himself to have food. He described,

"…some days I could eat, some days I couldn't. I had to force myself to have food. It felt like I couldn't swallow." (P7)

Lack of knowledge and skills in management:

Six out of eight participants indicated that the lack of their knowledge and skills in management of a person with depression was the challenge that they were facing in management of their depressed family member.

Some expressed that they were 'wondering' about the cause, prognosis of the disorder or 'didn't realize' need of the medication adherence as they thought 'he was already cured'. The participants verbalized,

"I keep wondering whether he will ever get cured totally..whether for the life time he will have to depend on medication.." (P7)

"I keep wondering why it(depression) happened? How it will be cured? What should I do to make him alright? (P6)

"…That time he thought he was already cured and stopped taking medicines. He even seemed fine to us. We didn't realize medication is needed any more" (P8)

Some participants also expressed that they 'didn't know' how to act in certain situations related to management of the person with depression or tried convince the person not to attempt suicide saying 'who dies jumping off the third floor'. They described,

"I was also helpless because first time in my life I was such in a situation, so I didn't know how to react, how to deal with it(depression of the mother)." (P3)

"I was bringing her for therapy sessions twice every week. Then slowly she stopped crying, and to me she once verbalized that, Maa, I can't even cry any more [teary eyes][…] I didn't know exactly what to say to her"(P5)
"At times she would tell me that she would jump from the third floor. Those times I would try to make her understand not to take such step. I would say, why do you want to jump off? Anyways you won't die jumping from here. May be you will fall, break your limbs or get paralyzed. Won't I be a matter of shame then? Who dies by jumping off the third floor" (P4)

Emotional issues of the care givers related to care giving:
Six out of eight participants felt that their own emotional issues like frustration, guilt feeling, hopelessness and fear related to care giving have emerged as a challenge in managing the persons with depression.

Frustration:
Some participants expressed frustration related to continuous care giving towards the management of persons with depression. They verbalized,
"At times I feel very irritated. But no other way[sudden increase in speech volume]..I have to keep coming (to the hospital). If her illness worsens it's only me who will have to run for her treatment. It happened in the past too" (P1)
"If at all you want to commit suicide why don't you go and jump in Brahmmaputra? I would say in anger (teary eyes)[…] may be she thinks these things doesn't affect me at all[lower volume]" (P4)

Guilt feeling:
The suicidal behaviour of the persons with depression have invoked guilt feeling among some of the participants, as they described,
"when she consumed poison I was wondering whether there was anything from my part, anything that I couldn't fulfill.." (P2)
"I asked her, Baba, what makes you do this? Tell me we have not been able to provide you enough .." (P5)

Hopelessness:
One participant expressed that his feeling that 'there was nothing more' that he could do to manage the person with depression was a challenge in management of the persons with depression. He described,
"…I felt like there was nothing more that I could do to get out of this situation (repeated suicidal attempts), nothing was working I felt…" (P7)

Fear:
One participant describes fear of relapse and suicide as a challenge in managing the person. He expressed,
"…even if he seems well, till now somehow we keep fearing what if suddenly he would commits something unexpected, or his condition deteriorates again…" (P7)

Challenges related to the society:
Few challenges in management of persons with depression that have been identified from the interviews were related to the society. Two subthemes that were categorized under this theme are social pressure for faith healing and stigma.

Social pressure for faith healing:
Two of the participants expressed that they faced social pressure for faith healing of the persons with depression in their family, which they felt was a challenge in management that have caused delay in medical treatment of the persons with depression.
"…they (villagers) thought may be something has happened, may be some ghost and evil have attacked him. It is a matter of shame though. I am an educated man, by occupation I am a teacher. Still I got influenced by their belief. Everyone in my neighbor was asking me to take him to one particular temple..then I took him. Even after taking him two three times there

nothing improved. I then brought him here (hospital)" (P7)

" all our relatives and neighbors kept repeatedly asking to take him to the faith healer. So we took. The faith healer after checking him thoroughly said it was not any evil but a problem in his brain, he asked us to bring him(person with depression) here. " (P8)

Stigma:

One participant expressed that the person with depression, i.e. his son was taunted and avoided due to his illness, which he identified as a challenge in proper management. He verbalized,

"He(Participants only son) never came to mental hospital. I never asked him to come even. May be he is not comfortable to come to Mental Hospital. It's okay.. till the time I am there I will look after (wife, The person with depression). I can't force him to come nah…" (P1)

"…some people used to taunt him. His school kids as well as adults in the village. His mates would avoid him. (P7)

DISCUSSION

Current study indicated that the challenges in managing the persons with depression were related to the persons with depression themselves, the family care givers or the society.

The family care givers expressed disinterest in treatment compliance and difficulty in communicating by the person with depression as a challenge in their management which may be were due to the nature of symptoms in depression.

Another challenge as expressed by the family care giver was perceived burdensomeness of the persons with depression, which may be due to the fact that depressed persons often find it difficult to make sense of their situation which has also been reported by the young people diagnosed with depression in a study conducted by Mccann at al[9].

The study reveals that the family care givers perceive lack of alternative care giver, care giver burden and financial crisis as challenges in the management of their family members with depression. This indicates the need of supportive therapy and counseling services to the family care givers which will enable them to better manage the persons with depression at home.

Six out of eight participants expressed that their lack of knowledge and skills in management of a person with depression was a challenge in management of their depressed family member, which focuses on the need of family education to enhance the family care givers' knowledge as well as the functional skills of managing a person with depression at home. The study conducted by Sandra et al also shows that knowledge of caregiver tasks predicted decreased caregiver burden and depression[10] among the care givers.

Six out of eight participants have felt that their own emotional issues like frustration, guilt feeling, hopelessness and fear related to care giving have emerged as a challenge in managing the persons with depression. This was consistent with the findings of the study conducted by Gregorey et al[11], where caregiver perceived emotional difficulties were associated with the course of patient psychiatric illness. This also indicates the need of psychosocial interventions for the family care givers.

One of challenges related to the society as expressed by the participants was social pressure for faith healing which may interfere with the medical treatment by delaying treatment and deteriorating depression. This also may be due to the fact that mental illness in community is still identified by the positive symptoms if psychosis and not with the typical depressive symptoms.

Both social pressure for faith healing and stigma indicates the importance of increased emphasis in the community awareness programs. Involvement of local faith healers in case identification and referral also may be considered towards the community involvement in management of depression, as one participant verbalized,

"The faith healer after checking him thoroughly said it was not any evil but a problem in his brain, he asked us to bring him(person with depression) here (hospital)."

Limitation of the study:

Lack of willingness by the participants for interview as the interviews were time taking.

Future recommendation:

In view of the study findings the researcher recommends conducting same studies among the persons with depression to identify their perceived needs for their home based management.

Interventions if formulated based on study findings conducted among both the family care givers as well as the persons with depression will be more beneficial for both the group.

CONCLUSION

Difficulty in communication by the persons with depression, lack of knowledge and skills of the family care givers in managing the persons with depression, emotional issues of the care givers, difficulty in understanding the depressed persons needs by the care giver as well as social pressure for faith healing were some of the more frequently expressed challenges in management of the persons with depression. Nurses by virtue of being able to work closely with the patients, family members and the community can play an active role in enabling the family members to better manage the persons with depression at home as well as to increase awareness of the community people regarding depression.

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