Knowledge Attitude Practices and Burden among Family Caregivers of Elderly Persons with Mental Illness

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ABSTRACT

Background: Despite improvements in mental health literacy, public knowledge and attitudes have remained stable over time. The caregivers of elderly persons with mental illness face a significant burden of care hence the understanding of caregiver burden and practices to deal with the same is very crucial in formulating a comprehensive care plan for the elderly with mental illness. *Objectives:* To study knowledge, attitude and practices towards mental illness among family caregivers of elderly persons with mental illness and to assess family burden and wellbeing among them. *Methods & Materials:* It was a cross-sectional institution based descriptive study. Using consecutive sampling methods, 50 caregivers of elderly people with mental illness, fulfilling the selection criteria were recruited and assessed using tools like Family Burden Scale, Public Perception of Mental Illness Questionnaire, Carer Experiences Scale, Screening Tool for Assessment of Psychosocial Problems and PGI General Wellbeing Scale. Ethical clearance was taken from the institutional ethical committee. *Result:* Men on average are more likely to be involved as caregivers and felt significant burden due to disruption in routine family activities. Knowledge and awareness was found to be poor among caregivers, followed by social support and expressed emotions. Negative life events were perceived to be the main cause of mental illness as there was little knowledge and awareness about it. The negative experience of caregivers is highest in assistance from government and non-government organisations and activities outside caring. More than half of the caregivers had lower wellbeing. *Conclusion:* There is a need to address lack of knowledge, negative attitude and practices, and high burden among family caregivers of elderly persons with mental illness.

Keywords: Knowledge, attitude, practices, burden, family caregivers, elderly, mental illness

INTRODUCTION

The World Health Organization defined wellbeing, in terms of "physical, mental, and social well-being, and not merely the absence of disease and infirmity". The human brain carries a lot of intellectual aptitudes including awareness, recognition, thinking, judgment, and memory. An intellectually sick individual turns out to become a burden for the general public and simultaneously turns into a potential risk for self and the general public as they are frequently inclined to commit antisocial exercises (Basu, et al., 2017).

Mental illnesses are health conditions involving changes in emotion, thinking, behaviour or a combination of these. Mental illnesses are associated with distress and/or problems functioning in social, work or family activities. The National Mental Health Survey, 2015-16, conducted across 12 states indicated a huge burden of mental health problems: nearly 150 million Indians need mental health care services and only 30 million are seeking care which requires measures to boost and scale-up mental health care services, integrate mental health promotion into care and

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management and also strengthen rehabilitation in health, social, economic and welfare policies and programs. Unquestionably, all these should be based on equity to promote a right based approach and enhance ease of access (Gururaj et al., 2016).

Due to such increased difficulties with regard to mental health, elderly people with mental illness are in dire need of support; in most cases, we see such support from the family members (World Health Organization. 2015).

However, the caregivers are generally not much aware of the mental illness, its onset, course, aetiology and its probable prognosis; in other words, the knowledge about the mental illness greatly influence the way burden is perceived by the caregivers, which may be perceived as an objective or subjective burden (Von Kardorff et al., 2016), Hiseman, & Fackrell, 2017) and lack of awareness surrounding mental illness makes it more stigmatized (Prakash & Kukreti, 2013). The term caregiving may include caring for a loved one in any of the settings, the caregiver's home, the care recipient's home or in an institutional setting. It may include attending to an individual's physical health and mental well-being (Scharlach, et al., 2001).

The caregivers in the family are expected to assist and help their older relatives with performing activities of daily living and preventing falls and elderly abuse. Quite often, caregivers play a role in the physical, emotional, and psychosocial and sometimes financial assistance of older family relatives who cannot care for themselves (Bassah et al., 2018). Nevertheless, in absence of a family, anyone can be a caregiver and provide support (World Health Organization. 2015).

Despite improvements in mental health literacy, public knowledge and attitudes have remained stable over time. The caregivers of elderly persons with mental illness face a significant burden of care hence the understanding of caregiver burden and practices to deal with the same is very crucial in formulating a comprehensive care plan especially in the elderly with mental illness.

OBJECTIVES

- To study knowledge, attitude and practices towards mental illness among family caregivers of elderly persons with mental illness.
- To assess family burden and wellbeing among caregivers of persons with mental illness.

MATERIALS AND METHODS

It was a cross-sectional institutional based descriptive study. Using consecutive sampling method 50 consecutive caregivers attending to Geriatric Mental Health Clinic of the Department of Psychiatry, Government Medical College and Hospital, Chandigarh, India fulfilling the selection criteria and giving written consent to participate in the study were recruited and assessed using the following tools:

1. Socio-demographic and Clinical Data Sheet
2. Family Burden Scale (Pai, & Kapur 1981).
3. Public Perception of Mental Illness Questionnaire (Sadik, et al., 2010).
4. Carer Experience Scale (CES) (Al-Janabi, Coast, & Flynn 2008).
5. Screening Tool for Assessment of Psychosocial Problems (STAPP) (Sahu, K. K et al., 2019).
6. PGI General Wellbeing Index (PGIGWB) (Verma & Verma, 1989).

RESULTS

Socio-demographic Profile of the Participants.

The study sample was having a mean age of 68.64 ± 7.66 years, majority of the sample were males (62.0%), educated up to matriculation (66%), were not engaged in any work(72%) and 66% of them had income in the range of Rs ≤10000.

Clinical Profile of the Participants

In the study sample, more than half were having ≥ 10 years of illness or treatment duration, came through direct referral (66%), had progressive symptoms (52%), had a continuous course of illness (62%) and one-fourth were having both hypertension and diabetes in medical history.

Socio-demographic Profile of the Caregiver

Among the caregiver's majority were male (74%), married (84%), Hindu (66%) educated up to intermediate (52%), having family income of Rs≤ 10000 (32%), belonging to the nuclear family (52%), urban dwellers (64%)and belonged to Punjab(52%).

Caregiver Burden

Table 1 Burden of Care among Caregivers (n=50)

Domain of Burden	Score Range	Mean ± SD
Financial Burden	0-12	2.36(2.29)
Disruption of routine family activities	0-10	3.30(2.29)
Disruption of Family Leisure	0-8	2.70(1.82)
Disruption of Family Interaction	0-10	2.50(2.49)
Effect on Physical Health of others	0-4	0.82(1.04)
Effect on Mental Health of others	0-4	1.40(1.06)
Overall/total	0-48	13.32(8.51)

Table 1 describes that among the six domains highest burden is seen in disruption in routine family activities and the lowest is seen in effect on physical health. The overall burden was also high among the participants. The overall burden felt is more than 50% as depicted in the table.

Public Perception of Mental Illness

Table 5 (a) Causes of Mental Illness

Cause of Mental Illness	1 n(%)	2 n(%)	3 n(%)	4 n(%)	5 n(%)
Genetic inheritance.	14(28.0)	14(28.0)	2(4.0)	2(4.0)	**18(36.0)**
Substance abuse.	15(30.0)	18(36.0)	4(8.0)	3(6.0)	**10(20.0)**
Bad things happening to you.	32(64.0)	13(26.0)	0	0	**5(10.0)**
God's punishment.	9(18.0)	9(18.0)	1(2.0)	2(4.0)	**29(58.0)**
Brain disease.	40(80.95)	6(12.0)	1(2.0)	1(2.0)	**2(4.0)**
Personal weakness.	**16(32.0)**	**14(28.0)**	**5(10.0)**	**3(6.0)**	**12(24.0)**

1= Agree, 2= Agree Somewhat, 3= Neutral, 4= Disagree Somewhat, 5= Disagree

Table 5 (a) describes that in causes of mental illness 80% of respondents gave a positive response on ‘mental illness is caused by bad (negative life events) happening’ to the patient and the least positive response was given on ‘mental illness is God's punishment which is 36.0%. However, the personal weakness of the patient is perceived to be 60.0% contributing significantly to negative perception and high caregiver burden.

Table 5(b) Knowledge of ‘people with mental illness (PWMI)’

Knowledge about People with Mental Illness	1 n(%)	2 n(%)	3 n(%)	4 n(%)	5 n(%)
Blamed for own condition	5(10)	9(18)	1(2)	8(16)	27(54)
Tell physical appearance	13(26)	8(16)	1(2)	5(10)	23((46)
Not capable of true friendship	18(36)	5(10)	4(8)	6(12)	16(32)
Can work	27(54)	14(28)	1(2)	3(6)	5(10)
Usually dangerous	6(12)	16(32)	1(2)	11(22)	16(32)
Anyone can have a mental illness	46(92)	1(2)	2(4)	0	1(2)

1= Agree, 2= Agree Somewhat, 3= Neutral, 4= Disagree Somewhat, 5= Disagree

70% of people disagreed with the statement that people with mental illness are to be blamed for their own condition. Also, 56 % said that one cannot tell a PWMI by his/her physical appearance.

A dichotomous response was recorded when respondents said that people with mental illness are not capable of true friendship. While a majority of people (54 %) do not think persons with mental illness are usually dangerous, but at the same time, 32% somewhat agreed that PMI is usually dangerous.

Most significantly 92 % said that anyone can suffer from mental illness. Similarly, 82 % respondent that people with mental illness can work. Data displayed peoples' skewed responses and self-biases towards mental illness.

From table 5(c) more than 50 % of the respondent mentioned that people with mental illness should be prevented from having children and a similar number agreed that they should not get married. However, 66 % disagreed completely that one should avoid all contact with the PWMI, and 68 % disagreed to marry someone with mental illness. 70% agreed that they could maintain a friendship with someone with mental illness. While responding to the decision making indicator, a mixed response was recorded with almost 50% to either allow making decisions or not to be allowed as well. This contradicts another indicator ‘access to similar rights’, wherein 74 % agreed that people with mental illness should have the same rights as anyone else.

Around 60 % said that people are not generally caring and sympathetic towards people with mental illness. A mixed response was recorded when they were asked whether they would like people to know about their own mental illness if they would be suffering from the same.

There were varied responses to being afraid to have a conversation with a PWMI or they would be disturbed while working with PWMI varying from ‘agree’ to ‘disagree. A sense of apprehension was revealed while recording these responses.

Table 5(c) Attitude towards 'people with mental illness (PWMI)'

Attitude toward People With Mental Illness	1 n(%)	2 n(%)	3 n(%)	4 n(%)	5 n(%)
PWMI should be prevented from having children	17(34.0)	3(6.0)	7(14.0)	10(20.0)	13(26.2)
PWMI should not get married	19(38.0)	7(14.0)	7(14.0)	7(14.0)	10(20.0)
One should avoid all contact with the PWMI	3(6.0)	3(6.0)	1(2.0)	9(18.0)	33(66.0)
PWMI should not be allowed to make decisions	17(34.0)	8(16.0)	5(10.0)	10(20.0)	10(20.0)
I could maintain a friendship with someone with a mental illness	29(58.0)	7(14.0)	1(2.0)	6(12.0)	6(12.0)
I could marry someone with a mental illness	6(12.0)	1(2.0)	4(8.0)	4(8.0)	34(68
I would be afraid to have a conversation with a PWMI	12(24.0)	14(28.0)	1(2.0)	3(6.0)	20(40.0)
PWMI should have the same rights as anyone else	37(74.0)	6(12.0)	1(2.0)	5(10.0)	1(2.0)
I would be upset and disturbed working on same job as mentally ill person	20(40.0)	5(10.0)	3(6.0)	11(22.0)	11(22.0)
I would be ashamed if family member diagnosed with Mental illness	5(10.0)	13(26.0)	1(2.0)	3(6.0)	27(57.0)
I would not want people to know if suffering from mental illness	19(38.0)	8(16.0)	1(2.0)	5(10.0)	18(36.0)
People are generally caring and sympathetic towards people with mental illness	11(22.0)	7(14.0)	1(2.0)	11(22.0)	20(40.0

1= Agree, 2= Agree Somewhat, 3= Neutral, 4= Disagree Somewhat, 5= Disagree

Table 5 (d) describes the practices regarding care and management of mental illness, their perception about availability of healthcare services for mental health and the course of illness. Almost 80 % of caregivers/respondents said that one should not hide his/her mental illness from family. Around 50 % would not feel comfortable discussing it with someone at their primary health centre (PHC).

Although agreeing (68 %) that people with mental illness should be in an institution and under supervision and control, also majority (50 %) of respondents do not think that primary health care clinics are equipped with providing appropriate care. A majority of people(52 %) do not think that the required information about mental illness is available in their community.

Around 51/52 percent think that mental illness cannot be cured and 62 percent feels that majority of people with mental illness recover. This depicts a mixed picture of peoples' approach regarding seeking help for the management of mental illness.

Table 5(d) Care and Management of people with mental illness

Care and Management of people with mental illness	1 n(%)	2 n(%)	3 n(%)	4 n(%)	5 n(%)
One should hide his/her mental illness from his/her family members.	7(14.0)	0	0	4(8.0)	39(78.0)
There are mental health services available in my community.	7(14.0)	2(4.0)	7(14.0)	2(4.0)	32(64.0)
Mental illness cannot be cured.	17(34.0)	6(12.0)	1(2.0)	8(16.0)	18(36.0)
PWMI should be in an institution where they are under supervision and control.	24(48.0)	10(20.0)	4(8.0)	2(4.0)	10(20.0)
Mental illness can be treated outside a hospital.	24(48.0)	4(8.0)	1(2.0)	2(4.0)	19(38.0)
Information about mental illness is available in my community.	10(20.0)	0	14(28.)	4(8.0)	22(44.0)
The majority of people with mental illness recover.	21(42.0)	11(22.0)	5(10.0)	9(18.0)	4(8.0)
Primary health care clinics can provide good care for mental illness.	8(16.0)	3(6.0)	14(28.)	7(14.0)	18(36.0)
If I were concerned about a mental health issue with a member of my family or myself, I would feel comfortable discussing it with someone at my PHC	16(32.0)	3(6.0)	8(16.0)	7(14.0)	16(32.0)

1= Agree, 2= Agree Somewhat, 3= Neutral, 4= Disagree Somewhat, 5= Disagree

Table 6 Carer Experience Scale

Experience	Mean ± SD
Activities outside caring	1.82(0.71)
Support from family and friends	1.68(0.58)
Assistance from government and organisations	2.58(0.73)
Fulfilment from caring	1.46(0.57)
Control over the caring	1.28(0.45)
Getting on with the person you care for	1.38(0.63)

Table 6 describes that the negative experience of caregivers is highest in assistance from government & non-government organisations and activities outside caring.

Table 7 Psychosocial Problems of Elderly Persons with Mental Illness

Areas of Psychosocial Problems			Score			
	Mean	SD	0 n(%)	1 n(%)	2 n(%)	3 n(%)
Knowledge/Awareness	1.28	1.06	13(26.0)	20(40.0)	11(22.0)	6(12.0)
Medication/Treatment Compliance	0.76	1.06	25(50.0)	16(32.0)	5(10.0)	4(8.0)
Availability of Financial Resources	0.72	1.12	28(56.0)	19(38.0)	2(4.0)	1(2.0)
Social Support	0.96	1.19	25(50.0)	17(34.0)	6(12.0)	2(4.0)
Expressed emotion	0.90	1.16	27(54.0)	10(20.0)	4(8.0))	9(18.0)
Emotional/Physical/Sexual abuse	0.38	0.66	36(72.0)	9(18.0)	5(10.0)	0
Legal Issues	0.28	0.64	40(80.0)	7(14.0)	2(4.0)	1(2.0)
Conflicts (property/marital/other)	0.62	0.75	29(58.0)	19(38.0)	0	2(4.0)
Employment	1.20	1.27	24(48.0)	4(8.0)	17(34.0)	5(10.0)
Accommodation	0.18	0.38	41(82.0)	9(18.0)	0	0
Stigma	0.40	0.67	34(68.0)	13(26.0)	2(4.0)	1(2.0)
ADL	0.72	1.08	31(62.0)	12(24.0)	4(8.0)	3(6.0)
Total	8.32	7.02	2(4.0)	41(82.0)	7(14.0)	0

STAPP= Screening Tool for Assessment of Psychosocial Problems,
SD= *Standard Deviation,* ADL+ Activities of Daily Living,
0= No problem, 1= Mild, 2= Moderate, 2= Severe.

Table 7 shows that 82% of the study population have mild psychosocial problems, 14% have moderate psychosocial problems and none had reported severe psychosocial problems. Knowledge and awareness is the major problem found i.e. 40%, 22% and 12% followed by social support 34%, 12% and 4% and expressed emotions 20%, 8%, 18%in mild, moderate and severe category respectively. Problem-related to employment was reported as 8%, 34% and 10% in mild, moderate and severe category respectively.

General Wellbeing Measure

Mean	**13.46**
SD	5.06
Score Range	0-20

The mean score of PGI general wellbeing was 13.46 ± 5.06 with a range of (0-20) 60% of caregivers scored less, denoting lower wellbeing. High scores indicate better wellbeing.

DISCUSSION

The study is a cross-sectional, descriptive study that seeks to examine the knowledge, attitude, practices and burden among family caregivers of elderly persons with mental illness. Contrary to popular belief and various literature which shows greater involvement and role of women as caregivers, the findings of this study revealed that men on average are more likely to be involved as caregivers. Availability of support groups and availability of knowledge and awareness in society can further enhance the contributions of these caregivers.

Socio-demographic and clinical profile of the participants

In the present study the socio-demographic characteristics of the elderly persons with mental illness show that the mean age of the population was sixty-eight, the majority of the elderly persons with mental illness were married, almost one-fourth of them were non-formally educated and a nearly equal proportion was educated up to matriculation followed by intermediate/diploma and graduates, more than half of the participants were either retired or were housewives or engaged in household works, about one-fourth were working and mostly were earning up to 10 thousand rupees per month. Almost all the persons were able to comprehend the Hindi language. The socio-demographic and clinical profile is somewhat comparable to a study in the same Indian setting (Gupta et al., 2015). The current study also reflects the similarity with another study conducted on the geriatric population attending geriatric mental health clinic of Government Medical College and Hospital, Chandigarh wherein most of the participants were male (60.9%), and married (85.7%) having a mean score of HMSE as 2.95 ± 3.36 and EASI as 25.04 ±7.08 (Das et al., 2018).

In the present study, the mean age of the caregivers was 44 years, males were more than females, and more than two-thirds were married and employed. A similar finding is also noted in other studies (Venkatesh et al., 2015, Aggarwal et al., 2011).On the contrary, these present study findings are not consistent with a study where the majority of the sample were female and aged over 65 years (Rand et al., 2019). This inconsistency could be because of the different demographics of India in comparison to England in the other study site.

The present study is somewhat consistent with a study (Bassah et al., 2018) where the majority of the family caregivers had attained secondary level education (51%) and a few had attained post-secondary (29%) education and had knowledge about the common problems of the elderly like "joint pain", "blood pressure", "difficulty in walking" and "visual impairment" however, the majority of the caregivers were female, unlike the present study where most of the caregivers were male. One of the studies indicated that 94% of the caregivers were married and 49% of caregivers were educated above high school diploma and 71% of the caregivers had a negative attitude toward long-term caregiving that depicts a correlation between education level and attitude towards people with mental illness. The findings of the current study revealed that attitude towards people with mental illness had a mean score of 35.70 ± 6.77 which is somewhat low and similar to the above study (Bastani et al., 2017).

Knowledge, Attitude, practices and Burden

In the present study, the mean of the overall burden score was 13.32±8.51 where disruption of routine family activities and disruption of family leisure is the most common burden which was found to be consistent with other studies (Walke, Chandrasekaran, & Mayya, 2018, Von

Kardorff et al., 2016). Most of the elderly do not have a source of income to support their financial expenses and there is a significant emotional burden and lack of awareness perceived among the caregivers. In another study (Gupta et al., 2015) the major burden was reported in the domain of "physical", "mental" and "external support" which is comparatively high in comparison with the current study. The particular difference in burden could be for the fact that in the present study, the majority of caregivers were married and were living in joint families whereas in the above study (Gupta et al., 2015). The majority of caregivers belong to nuclear families leading to poor family support as less number of family members would find less time to provide timely and proper care to the elderly persons with mental illness.

Most (90%) of respondents responded bad (negative life events) happening to the patient as a cause of mental illness and the least (36%) responded that mental illness is God's punishment which is consistent with another study (Gupta et al., 2015), where it was suggested that 30% of the caregivers did not have prior knowledge about the cause of illness although more than half of the population have no formal education or primary level of education which is an indication of lack of awareness. The level of education was not consistent with the present study where (36%) were intermediate/diploma and 28% were graduate, which is significantly higher. The findings depict that 71% of the caregivers had a negative attitude toward long-term caregiving attributed to low education level, other family members of the patient with psychiatric disorder and weekly care hours had a significant statistical relationship with attitude, however, the gender statistics are not consistent in the current study as in most other studies the majority of the caregivers were females. The findings of the current study revealed that attitude towards people with mental illness had a mean score of M 35.70 SD ± 6.77 which is somewhat comparable to M 39.39 ± SD 5.32 in another study (Bastani et al., 2017).

A study by Abi Doumit et al., (2019) also suggested that a higher score of public stigma toward mental illness was found in 67.8% of the participants. Having a high level of education was associated with less stigmatizing attitudes, the study also suggested that lower scores on public stigma against mental illness were associated with the belief that evil eye, magic and punishment from God might cause mental illness which is similar to the current study.

The knowledge, attitude and practices of caregivers in the current study revealed a mixed picture. A majority of respondents said that people with mental illness cannot be blamed for their condition. The caregivers (80 %) also said that people with mental illness should not hide their illness from family members. Their appearance cannot tell if they have a mental illness, but half of the people said, that people with mental illness are not capable of true friendship. They do not think mentally ill persons are usually dangerous and 82 % said that people with mental illness can work. While asking about the causes, 92 % said that it can happen to anyone, and a significant number even agreed that it is caused by genetic inheritance. Around 52% think that mental illness cannot be cured but 62% said they can recover. A majority of them agreed that people with mental illness should be in an institution and under supervision. However, a significant number (52%) of respondents said that the required information regarding mental illness is not available at PHCs, and they (50 %) do not think that PHCs are equipped with appropriate care for mental illness. At the same time, they (50 %) do not feel comfortable discussing it with someone at their PHC.

In the present study, the negative experience of caregivers is higher when it comes to getting assistance from government and non-government organizations as well as in activities outside caring which is consistent with a study depicting low social support as the reason for higher

negative experience (Sangeeta & Mathew, 2017). The current study is consistent with another study, (Rand et al., 2019) regarding assistance from government and organizations which suggests that experience of caregiving is important and may affect the broader aspects of quality of life like the ability to stay in work or maintain social relationships. Considering the bigger picture, social care interventions through services or policy are often designed to address these broader aspects of quality of life, rather than health (Rand et al., 2019).

CONCLUSION

The present study was an attempt to assess knowledge, attitude, practices and burden among family caregivers of elderly persons with mental illness attending Geriatric Mental Health Clinic using the following tools: Family Burden Scale, Public Perception of Mental Illness Questionnaire, Carer Experience Scale (CES), Screening Tool for Assessment of Psychosocial Problems (STAPP), PGI General Wellbeing Index (PGIGWB). The following major findings were drawn:

1. The findings of the present study indicate that the overall burden felt by the caregivers of elderly persons with mental illness is reported to be more than average.
2. The most common causes of mental illness perceived by the caregivers are negative life events, God's punishment and personal weakness of the patient contributing significantly to negative perception and high caregiver burden.
3. The negative experience of caregivers is higher in matters related to getting assistance from government and non-government organizations and activities outside caring as inferred from carer experience.
4. The psychosocial problems reported by the caregivers were of milder level but the need for knowledge/awareness about mental illness among family caregivers of elder people with mental illness was high, as well as major psychosocial problems, followed by social support and expressed emotions.
5. The majority of the caregivers in the study were also found to have a lower feeling of wellbeing.
6. There is a need to address the issue of lack of knowledge, negative attitude and practices and high burden among family caregivers of elder persons with mental illness, besides pharmacological and other treatments for better outcomes.
7. Clinicians/Mental health care professionals need to be sensitized towards the elderly population as a special category requiring special care. They may participate in providing awareness to the caregivers about the impacts of knowledge, attitude, practices on the caregiving and associated burden.

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Ethical Clearance: Taken

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