

# Mental health literacy among caregivers of persons with mental illness: A descriptive survey

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## ABSTRACT

**Background:** Despite of growing evidence of mental disorders in developing countries, research on mental health literacy is limited from India. **Aim:** To examine mental health literacy among caregivers of persons with mental illness **Materials and Methods:** A cross-sectional descriptive survey was carried out among 161 randomly selected caregivers of persons with mental illness at outpatient department of a tertiary care centre. Data was collected through face to face interview using a structured questionnaire. **Results:** Regarding the causes of mental illness, a majority agreed that genetic inheritance (69%), substance abuse (64%) and brain disease (59.6%) are main factors for developing mental illness. Although more than two-thirds agreed that anyone could suffer from mental illness, 61.5% also agreed that people with mental health problems are largely to blame for their condition. The majority of the participants also agreed that mentally ill are not able to maintain friendships (45.9%), are dangerous (54%), and not capable to work (59.1%). Just over half (55.9%) of the participants would not want people to know if they had a mental illness and nearly half of them also expressed that they would feel ashamed if a family member had a mental illness. **Conclusion:** Based on the findings of the present study researchers suggest that there is an urgent need to educate and change the attitudes of caregivers through mental health literacy programs specifically designed for them.

**Key words:** Attitudes, caregivers, India, mental health literacy

## Introduction

Mental illness is a global public health concern.<sup>[1]</sup> According World Health Organization estimation, mental disorders constitute 14% of the global burden of disease<sup>[2]</sup> and the overall prevalence rate of mental disorders in India is 10-12 percent.<sup>[3]</sup> In addition, the Global Burden of Disease Study 2010 (GBD 2010) stated that major depressive disorder is one of the top five leading causes of Years lived with disability (YLD) in India.<sup>[4]</sup> Being a developing country, in India there are paucity of mental health professionals for instance, psychiatrists <0.5 per 100,000 population.<sup>[5]</sup> Majority of the population live in rural areas and it was found that about 80% to 90% of

the mental disorders were undiagnosed and untreated<sup>[6]</sup> due to lack of knowledge and negative attitudes toward mental illness. Further, stigma and negative attitudes toward people with mental illness have been observed to be common worldwide among general population.<sup>[7]</sup>

In Indian culture, family is regarded as the most important structure in caring for vulnerable family members including those with mental illness and more than 90% of patients with chronic mental illness live with their families.<sup>[8]</sup> The caregivers not only provide the basic needs of care like long-term assistance of housing and financial aid,<sup>[9]</sup> they also take care of the day-to-day needs of the people with mental illness, monitoring the mental state, identify the early signs of illness, relapse and deterioration, and help the patient in accessing services. The family caregiver also supervises treatment and provides emotional support to the patient.<sup>[10]</sup> However, the lack of knowledge and relatively lower mental health literacy pose challenges to family caregivers, mental health patients and service providers.<sup>[11]</sup> Nevertheless, people's symptom-management activities will be

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influenced by mental health literacy. Mental health literacy has been defined as knowledge and beliefs about mental disorders, which aid their recognition, management or prevention.<sup>[12]</sup> Further, researchers have suggested that mental health literacy is not a single dimension but rather represents knowledge and beliefs about mental health disorders that emerge from general pre-existing belief systems.<sup>[13]</sup> However, most of the literature found that mental health literacy among the public is unfortunately poor.<sup>[14]</sup>

Most of the mental health literacy surveys have been conducted in western countries,<sup>[15-17]</sup> with few studies in Indian cultural context.<sup>[18,19]</sup> Furthermore, no published research available specially was focusing on mental health literacy among caregivers of persons with mental illness from India. Therefore, the present study was aimed to examine the mental health literacy among caregivers of persons with mental illness.

## Materials and Methods

### Research design

This study was a descriptive study carried out among caregivers of people with mental illness at Out Patient Department tertiary care centre, Bangalore, South India.

Participants were selected through a random sampling method from the outpatient follow-up cohort. Caregivers of every fifth patient among first hundred according to the outpatient register were invited to participate in the study. The study criteria included: (a) Their relative must be diagnosed as mentally ill as per ICD-10 criteria, (b) aged above 18 years old, (c) must be the main caregiver, (d) more than 6 months caring for mentally ill patients and (e) should be willing to participate in the study. The relatives of patients with substance abuse or mental retardation were excluded. In the concerned hospital, approximately 300 adult patients per day visit the follow-up OPD. Everyday approximately 15 caregivers were eligible to participate in the study. However, few refused to participate in the study due to lack of interest, lack of time and were unable to manage the patients. Overall 230 caregivers were included in the study over a period of 3 weeks and the final sample comprised of 161 caregivers with 70% response rate.

### Study instrument

The first part of the questionnaire included socio-demographic details of participants such as age, gender, education, income, marital status, religion, residence and relationship with patient.

The second part of the questionnaire collected information regarding mental health literacy of the caregivers by using

“Public Perception of Mental Illness Questionnaire.”<sup>[20]</sup> This instrument had 33 items that measured mental health literacy of the participants regarding etiology of mental illness (6 items), knowledge of people with mental illness (6 items) and attitude toward people with mental health problems (12 items), and management of people with mental health problems (9 items). Answers were coded on a 5-point scale (agree, somewhat agree, neutral, somewhat disagree, disagree). The English version of the questionnaire was used to collect the data. There were no studies of its reliability. The scale’s reliability assessment was done by using the test-retest method. The researchers administered the tool among a group of caregivers ( $n = 16$ ) at the follow-up outpatient through face to face interview method over a 2 week period and it was found that the study was suitable to Indian context. The reliability coefficient for the structured questionnaire was 0.85.

Data was collected by the primary author through a face-to-face interview in a private room at the treatment facilities where the participants were recruited. The interview took approximately 25-30 min to complete.

### Ethical consideration

After obtaining formal permission from authorities, researchers explained the aims and methods of the study to all participants. Questions regarding the study were invited from the participants and they were given freedom to leave the study whenever they desire and also they were assured that withdrawal from this study will not affect the treatment of their relative.

### Data analysis

Descriptive statistics were used and results were narrated in the form of tables.

## Results

The present study investigated mental health literacy among 161 caregivers of the persons with mental illness, of whom 59% ( $n = 95$ ) of them were women. The majority of the participants ( $n = 92$ , 57.2%) were aged between 36 and 55 years. The majority of the participants were married ( $n = 139$ , 86.3%) and Hindus ( $n = 135$ , 83.9%). Nearly half ( $n = 68$ , 42.3%) of the participants were illiterates/primary education and 60.2% of them were from the rural background. Almost all participants (95.7%;  $n = 154$ ) of the caregivers were family members [Table 1].

Table 2 shows the responses of the participants to various dimensions of the public perceptions of mental illness questionnaire. Concerning the etiology

**Table 1: Socio-demographic characteristics of participants**

Variables	Groups	Frequency	Percentage
Age	<25	22	13.7
	26-35	31	19.3
	36-45	56	34.8
	46-55	36	22.4
	>55	16	9.9
Gender	Male	66	41
	Female	95	59
Religion	Hindu	135	83.9
	Muslim	15	9.3
	Christian	11	6.8
Income	<1700 Rs/-	52	32.3
	>1700 Rs/-	109	67.7
Marital status	Married	139	86.3
	Unmarried	17	10.6
	Widowed/separated	5	3.1
Education	Illiterate/primary education	68	42.3
	Secondary education	88	54.6
	Graduation and above	5	3.1
Residence	Rural	97	60.2
	Semi urban	48	29.8
	Urban	16	9.9
Relationship with the patient	Family members	154	95.7
	Relatives/friends	7	4.3

of mental illness, 69% of the participants agreed that mental illness caused by genetic inheritance followed by substance abuse (64%). However, 45.9% felt that mental illness because of personal weakness. Regarding knowledge of people with mental illness, a majority of the participants (68.4%) agreed that anyone could suffer from mental illness. However, 61.5% of them agreed that people with mental health problems are largely to blame for their condition and are usually dangerous ( $n = 87$ , 54%). The participants toward people with mental illness expressed mixed opinions. While 47.8% of them agreed that people with mental illness could get married, 54.7% of them disapproved to marry a person with mental illness. Nearly two-thirds (62.2%) approved that people with mental illness have the same rights as anyone else. However, 55.9% would not want people to know if they had a mental illness and feel ashamed if a family member had a mental illness. Concerning care and management of the people with mental illness, nearly half thought they could hide his/her mental illness from his/her family and believed that mental illness neither can be cured nor recover from mental illness. Nearly two thirds of them approved that people with mental illness should be in an institution under supervision and control. Nonetheless, 44.1% of the participants disapproved that Primary Health care Centers (PHC) provides good care for mental illnesses.

## Discussion

This present study was aimed to examine mental health literacy among caregivers of people with mental illness. The few studies that were conducted in India so far either mainly focused on relationship between first treatment contact and supernatural beliefs in caregivers of patients with schizophrenia<sup>[18,21-23]</sup> or religious and traditional modes of intervention which are still widely practiced, especially in rural areas, where mental health services are almost nonexistent.<sup>[24-26]</sup> Yet, we know very little about the caregivers attitude and knowledge toward mental illness. Thus, the present study attempted to investigate the caregivers mental health literacy factors such as etiology, knowledge, attitude and management of people with mental health problems.

In line with findings of the studies,<sup>[20,27,28]</sup> the caregivers in the present study demonstrated understanding about the reasons for mental illness as majority of them cited mental illness is caused mainly by genetic inheritance, substance abuse, brain disease. However, they also viewed bad things happening, personal weakness and gods' punishment as important factors. Similar to these findings, Kermodé *et al.* (2009) found that the most commonly acknowledged causes for mental illness were a range of socio-economic factors (conflict with family, at work and with neighbors; an addicted family member; not being married; crisis; bereavement; problems from childhood; financial difficulties; poverty), while neither supernatural causes nor biological explanation were widely endorsed.<sup>[18]</sup> On the other hand, a number of studies from India demonstrated peoples' belief in supernatural powers as the causative agents of mental illness.<sup>[29-32]</sup> However, it can be argued that similar to other studies the participants in the present study were caregivers and they learnt about mental illness through their experiences of caring for a person with mental illness.<sup>[11,33]</sup>

The majority of caregivers in the present study accepted that anyone can experience mental health problem reflecting the findings of the previous studies.<sup>[20,34]</sup> Like previous research, the participants hold negative perceptions such as mentally ill are to blame for their condition, not capable to work or to maintain friendships.<sup>[34]</sup> Similarly, the participants had negative attitudes toward mentally ill. However, nearly two thirds of the participants agreed that people with mental illness should have the same rights as anyone else. In a recent survey, 36.9% of rural subjects, 43.2% of urban subjects, and 44.7% of the medical professionals reported that they would oppose marriage with a person recovered from

**Table 2: Responses of the participants to the public perception of mental illness questionnaire**

Statements	N (%)		
	Agree/ strongly agree	Neutral	Disagree strongly/disagree
<b>Cause of mental illness</b>			
Mental illness is caused by genetic inheritance	111 (69)	7 (4.3)	43 (26.7)
Mental illness is caused by substance abuse	103 (64)	15 (9.3)	43 (26.7)
Mental illness is caused by bad things happening to you	84 (52.2)	19 (11.8)	58 (36)
Mental illness is god's punishment	56 (34.8)	21 (13)	84 (52.1)
Mental illness is caused by brain disease	96 (59.6)	15 (9.3)	50 (31)
Mental illness is caused by a personal weakness	74 (45.9)	36 (22.4)	51 (31.7)
<b>Knowledge of people with mental illness</b>			
People with mental health problems are largely to blame for their own condition	99 (61.5)	14 (8.7)	48 (29.8)
One can always tell a mentally ill person by his or her physical appearance	91 (56.5)	15 (9.3)	55 (34.1)
Mentally ill persons are not capable of true friendships	74 (45.9)	21 (13)	66 (41)
Mentally ill persons can work	95 (59.1)	23 (14.3)	43 (21.1)
Mentally ill persons are usually dangerous	87 (54)	24 (14.9)	50 (31)
Anyone can suffer from a mental illness	110 (68.4)	9 (5.6)	42 (26.1)
<b>Attitude toward people with mental illness</b>			
The mentally ill should be prevented from having children	79 (49)	12 (7.5)	70 (43.4)
The mentally ill should not get married	70 (43.5)	14 (8.7)	77 (47.8)
One should avoid all contact with the mentally ill	55 (34.2)	19 (11.8)	87 (44)
The mentally ill should not be allowed to make decisions, even those concerning routine events	75 (46.6)	9 (5.6)	77 (47.9)
I could maintain a friendship with someone with a mental illness	80 (49.7)	9 (5.6)	72 (44.7)
I could marry someone with a mental illness	53 (32.9)	20 (12.4)	88 (54.7)
I would be afraid to have a conversation with a mentally ill person	62 (38.5)	28 (17.4)	71 (44.1)
People with mental health illnesses should have the same rights as anyone else	100 (62.2)	17 (10.6)	44 (27.3)
I would be upset or disturbed about working on the same job as a mentally ill peers	64 (39.8)	18 (11.2)	89 (49.1)
I would be ashamed if people knew that someone in my family had been diagnosed with a mental illness	77 (47.8)	18 (11.2)	66 (41)
If I was suffering from a mental health illness, I wouldn't want people to know about it	90 (55.9)	16 (9.9)	55 (34.1)
People are generally caring and sympathetic toward people with mental illness	73 (45.4)	19 (11.8)	69 (42.9)
<b>Care and management of people with mental illness</b>			
One should hide his/her mental illness from his/her family	76 (47.2)	5 (3.1)	80 (49.6)
There are mental health services available in my community	78 (48.5)	12 (7.5)	71 (44.1)
Mental illness cannot be cured	72 (44.7)	24 (14.9)	65 (40.4)
Mentally ill people should be in an institution where they are under supervision and control	105 (65.2)	16 (9.9)	40 (24.9)
Mental illness can be treated outside a hospital	77 (47.8)	19 (11.8)	65 (40.3)
Information about mental illness is available at my PHC	67 (41.6)	27 (16.8)	67 (41.6)
The majority of people with mental illnesses recover	75 (46.6)	31 (19.3)	55 (34.1)
Primary health care clinics can provide good care for mental illnesses	67 (41.6)	23 (14.3)	71 (44.1)
If I was 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	80 (49.7)	19 (11.8)	62 (38.5)

PHC: Primary health care center

mental illness.<sup>[32]</sup> Our present study concurs with these findings. However, in both low-income and high-income countries, the stigmatization of people with mental disorders has persisted throughout history. Stigma is manifested as bias, stereotyping, fear, embarrassment, anger, rejection, or avoidance. For people suffering from mental disorders, there have been violations of basic human rights and freedoms, as well as denials of civil, political, economic, and social rights, in both institutions and communities. In a recent descriptive study carried out among recovered mentally ill demonstrated that irrespective of gender,<sup>[35]</sup> literacy,<sup>[36]</sup> socioeconomic

status<sup>[37]</sup> and residence,<sup>[38]</sup> human rights violations are occurring at family and community level. The current study also reveals negative attitudes of participants regarding social participation of mentally ill in the community as they cited they would be ashamed if people knew that someone in their family had been diagnosed with a mental illness as well they would not want people to know about their illness. It clearly shows that stigma and discrimination toward people with mental illness exists. In India, it was found that the main predictor of a variable of social distance from people with mental illness perceived the person as

dangerous.<sup>[18]</sup> The present study findings concur with this study as majority (54%) perceived mentally ill as dangerous. On the other hand, it was generally argued that people do not sympathize with a mentally ill person because they impart value to the patient and believe that the person lacks the will power to pull him or herself up and is just not making an effort.<sup>[39]</sup> However, nearly half of the participants in the present study agreed that people are generally caring and sympathetic toward people with mental illness. In general, the public tends to view the mentally ill as dangerous, unpredictable and prone to violence. In addition, a recent body of research evidence suggests that patients who suffer from serious mental conditions are more prone to violent behavior than persons who are not mentally ill.<sup>[40]</sup> Likewise, in the present study also nearly two thirds of participants opined that mentally ill people should be in an institution where they are under supervision and control. These findings were similar to previous studies.<sup>[22,23,41]</sup> Like other studies, in current study, nearly half of them agreed that they are free to discuss mental health issues related to them or their family members.<sup>[20,32]</sup> In contrast, most of the studies found that in general people were reluctant to discuss mental disorders with relatives and friends than physical disorders.<sup>[42,43]</sup> In India, due to stigmatizing attitudes patients have been found to present their distress in somatic rather than psychological terms.<sup>[44]</sup>

### Limitations

The present study has certain limitations such as small sample that was restricted to one tertiary care centre and lack of compare group. Further, the research tool was not validated and there may be the possibility of bias due to social desirability (especially due to the face-to-face interview). Hence, the findings of the study may not be generalized and future research should focus on larger sample and comparative studies with qualitative methods (focus group discussions) may be helpful to understand in depth about this issue. Despite of these limitations, random sample of the present study represent the target population.

### Conclusion

In summary, the present study highlighted that participants had understanding about the causes of mental illness. However, the majority of the participants are holding stigmatizing attitudes toward people with mental illness in relation to social participation, treatment, work, marriage and recovery. Thus, there is an urgent need to educate and change the attitudes of the caregivers regarding mental illness through mental health literacy programs specifically on certain groups

within the population who have a particular need for mental health education. Further, mental health professionals should take responsible role in educating these specific populations.

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