

# Level of Perceived Stigma Among Caregivers of Persons with Severe Mental Illness in Jimma City, Ethiopia: A Cross-sectional Study

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**Abstract:** *Background:* Stigma associated with mental illness is a psychosocial consequence that causes indescribable suffering for the victim. Therefore this study aimed to assess the magnitude and factors associated with level of perceived stigma among caregivers of persons with severe mental illness in Jimma city, Ethiopia. *Methods:* A cross-sectional study was conducted with a face-to-face interview from September 20 to October 20/2012 G.C. Family interview schedule was used to assess perceived stigma. A total of 289 participants were recruited using a consecutive sampling technique. Data were analyzed using SPSS version 16 software. *Results:* The most frequently endorsed item was having felt grief or depression because of having a mentally ill family member or relative (96.5%). The mean stigma score was  $17.8 \pm 6.9$  and the majority of the respondents (54.7%) had a high stigma score. Caregivers/Family members who were spouse to the patient (AOR=4.25, 95%CI: 1.12–16.13) and longer duration of illness (AOR=3.60, 95%CI: 1.42–9.44) were associated with higher stigma. But a person with mental illness who had verbal/physical violent behavior towards caregivers/family members and other people at the time of the illness (AOR=0.34, 95%CI: 0.17–0.70) and among those family members who attributed the cause of mental illness as the loss of properties and unsuccessful life (AOR=0.27, 95%CI: 0.08–0.89) at  $p=0.032$ . Were associated with low stigma respectively. *Conclusions:* Perceived stigma was found to be a common problem among caregivers of persons with severe mental illness. Becoming spouse of the person, duration of illness, patient with violent behavior and, those caregivers who attributed the cause of mental illness as the loss of properties and unsuccessful life were significantly associated with perceived stigma.

**Keywords:** Severe Mental Illness, Perceived Stigma, Caregivers, Jimma, Ethiopia

## 1. Introduction

The term stigma was defined as "something that detracts from the character or reputation of a person, group, etc.; a mark of disgrace or reproach; a mark, sign, etc indicating that something is not considered normal [1]. It is also defined in terms of undesirable, "deeply discrediting" attributes that "disqualify one from full social acceptance" and motivate efforts by the stigmatized individual to hide the mark when

possible [2]. Health-related stigma is a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem [3]. Goffman states that it is not only stigmatized people who suffer from the social implications of stigma but also the people who are associated with them in some way. For example persons with mental health problems, as well as

people associated with them. He called this stigma by association, "courtesy stigma" [2]. In this study, the definition of Perceived stigma was adopted as families/caregivers of persons with severe mental illness perceived that society excludes, reject, blame or devalue them because they are associated with stigmatized group, mentally ill individual. They fear or perceive to be present in the community or society [4].

In both low- and high-income countries, there is a long history of people with mental illness being stigmatized along with their families [5]. Family members are often the primary caregivers of people with mental illness. They provide psychological and physical support and often have to accept the financial expenses associated with mental health treatment and care. In addition to the obvious distress from seeing a loved one being disabled by the consequences of mental illness, family members are also exposed to the stigma and discrimination associated with mental illness. Rejection by friends, relatives, neighbors, and the community as a whole can increase the family's sense of isolation, resulting in restricted social activities, and the denial of equal participation in normal social networks [5].

Regardless of its causes, stigma towards mental illness has been found to pose a major barrier to some of the most basic tasks of life, such as establishing and maintaining friendships, employment, housing, marital and relationship problems as well as increased risk of disability and advanced disease and poorer treatment prognosis in most conditions [6, 7]. The perception to be rejected in the community makes life even more difficult for the caregivers and families of people with serious mental illness.

The development and implementation of effective interventions to create more supportive and understanding communities would be a challenging and worthwhile endeavor [8]. Current researches indicated that public perceptions of family stigma negatively impacts family members, which in turn, negatively impacts their relatives with mental illness [9]. Perceived stigma may affect the lives of the people concerned in the same way as an experienced stigma. It also may cause the same negative effects on public health programs as experienced stigma [6].

In Ethiopia, little is known about the extent of stigma on families/caregivers of persons with severe mental illness. However, indirect evidence shows that misconceptions about mental illness exist in the community. For example, a study was done on a community sample living in rural town southwestern Ethiopia found that less educated people have negative attitudes on the marital prospects and work opportunity of schizophrenia and illiterate people have a more negative attitude towards living with persons with epilepsy and schizophrenia in the same house [10]. Therefore, this study aimed to assess the magnitude and to identify factors associated with perceived stigma among caregivers of persons with severe mental illness in Jimma city, Ethiopia.

## 2. Materials and Methods

### 2.1. Study Setting and Sample

The study was conducted at Jimma city, located in the southwestern part of Ethiopia, from September 20 to October 20/2012. Jimma city is located 354 kms South West of Addis Ababa and has a total area of 46.23 square kilometers. It has four health centers and one general hospital. The city has also one teaching hospital which is providing inpatient and outpatient mental health services for approximately 126 new and 874 follow-up outpatients per month.

The cross-sectional study design was used to conduct this study on 289 family members/caregivers of persons with severe mental illness by using consecutive sampling techniques. The study population for this study was a sample of family members/caregivers of persons with severe mental illness living in Jimma city who came to Jimma University specialized hospital (JUSH) psychiatry clinic.

The sample size was calculated by using the single population proportion formula by considering the prevalence of perceived or experienced family stigma to be 75% from a previous study conducted in Butajira, Ethiopia in 200[11]. A structured questionnaire was first developed in English and translated to Amharic and Afan Oromo then back-translated independently into English to check for consistency and semantic validity.

### 2.2. Measurements

The family member/caregivers of a person with severe mental illness were interviewed by psychiatry nurses using the Family interview schedule (FIS) instrument which was developed as part of a WHO study on the course and outcome of schizophrenia and special attention were given to the stigma section [12]. This instrument (the stigma part) was used in Butajira, Ethiopia to assess the perceived stigma of family members of schizophrenia and affective disorders [11], the perception of stigma in people with epilepsy and their relatives [13], and also in Madras, India [14]. The whole instrument was used and translated into many different languages in the world [12].

Reliability test: In this study, the internal consistency of the Amharic version of Family Interview Schedule, stigma part, was found to be Cronbach's Alpha=0.78, and based on the standard items it was 0.771 which indicates that the scale was respectable and acceptable to the study participants. The stigma part has 14 items and a four-point Likert scale from "not at all" rated 0, "sometimes" rated 1, "often" rated 2 to "a lot" rated 3, concerning stigma. To assess the distribution of stigma responses between groups, a stigma sum score was computed by summarizing all positive responses (> 0) and a high stigma score was considered as above the meanwhile low stigma score considered as a score below the mean. In this study, severe mental illness (SMI) was operationalized as a clinical diagnosis from patients' charts that includes psychotic disorder or a severe mood disorder (schizophrenia, schizophreniform, schizoaffective, bipolar disorder, and

major depressive disorder).

### 2.3. Data Analysis

Data were entered into a computer using SPSS version-16 for analysis. The presence and degree of association between perceived stigma and the respondents' socio-demographic features and other variables were investigated by binary logistic regression and finally all independent variables whose  $p$ -value  $\leq 0.25$  were entered in multivariate analysis to identify independently associated factors for perceived stigma. A  $p$ -value  $< 0.05$  was considered statically significant.

## 3. Results

### 3.1. Socio-demographic Character

A total of 289 caregivers were interviewed. Among all, the majority 148 (52.2%) were females, 125 (43.3%) were Oromo by ethnicity and 123 (42.6%) were followers of the Islamic religion. The mean age of the family members/caregivers was  $39.7 \pm 12.7$  years. The median family monthly income of respondents was  $1000.00 \pm 929.13$  Ethiopian Birr.

Out of the total respondents, the majority 105 (36.3%) were siblings to the patients followed by 103 (35.6%) parents and the majority 176 (60.9%) of the family members/caregivers were living together with the patient in the same house. Among those who were living together with the patient, 107 (60.8%) were living together for more than 20 years (Table 1).

**Table 1.** Socio-demographic characteristics of the families of the persons with severe mental illness in Jimma city, 2012 ( $n=289$ ).

Socio-demographic Characteristics		Number	Percent
Sex	Male	141	48.8
	Female	148	51.2
Age in year	<30	65	22.5
	30-40	96	33.2
	41-50	55	19.0
	$\geq 51$	73	25.3
Religion	Muslim	123	42.6
	Orthodox	111	38.4
	Protestant	50	17.3
	Others*	5	1.7
Ethnicity	Oromo	125	43.3
	Amhara	61	21.1
	Dawuro	29	10.0
	Gurage	18	6.2
Marital status	Others**	56	19.4
	Married	160	55.4
	Single	63	21.8
	Divorced	35	12.1
Education al level	Widowed	31	10.7
	Illiterate	25	8.7
	1-8	92	31.8
	9-12	118	40.8
Work status	>12	54	18.7
	Unemployed	20	6.9
	Employed	205	71.0
	Others	64	22.1

### 3.2. Patient Characteristics and Illness Condition

Regarding the persons with severe mental illness, the majority 173 (59.9%) were males, and their age was ranged from 18-80 years with a mean of  $32.9 \pm 12.7$  years. The majority of patient's diagnosis 120 (41.5%) was schizophrenia as shown in Table 2. For the majority 206 (71.3%) of the patients, the onset of the illness was between 15 and 34 years of age. The median age of onset of illness was  $24.0 \pm 12.2$  years. Regarding the duration of the illness, the majority of the patients 168 (58.1%) had less than 5 years. The range of the duration of illness was 4 months to 43 years and the median year of the duration of illness was  $5.0 \pm 5.2$  years. The majority of the patients 152 (52.6%) had no history of hospital admission and among those who had admission, 71 (51.8%) were admitted two times and above.

The majority of the respondents 238 (82.4%) had no family members with a mental illness other than the current patient. A high proportion of the patients 199 (69.0%) had verbal/physical violent behavior towards their family members/caregivers or other people at the time of their illness but only 90 (31.0%) had no verbal/physical violent behavior at all.

According to the family members/caregivers report, 85 (29.4%) of patients were drinking alcohol. Among those who drank alcohol, 53 (62.4%) were drunk daily and 126 (43.6%) were chewed khat. Of those patients who chewed khat, 99 (78.6%) chewed daily. The majority of the patients 189 (65.4%) were able to accomplish their daily activities during the time of data collection (Table 2).

**Table 2.** Socio-demographic characters and illness conditions of the persons with severe mental illness in Jimma city, 2012 ( $n=289$ ).

Variables		Number	Percent
Sex	Male	173	59.9
	Female	116	40.1
Age group in year	<25	77	26.7
	25-34	113	39.2
	35-44	46	15.9
	$\geq 45$	53	18.3
Age of onset of illness (in a year)	<15	21	7.3
	15-24	133	46.0
	25-34	73	25.3
	$\geq 35$	62	21.4
Diagnosis	Schizophrenia	120	41.5
	Bipolar disorder	63	21.8
	Major depression	93	32.2
	Other	13	4.5
Duration of illness (in a year)	<5 yr	168	68.1
	6-10 yr	80	27.7
	>10 yr	41	14.2
History of admission	No	152	52.6
	Yes	137	47.4
Family history of mental illness	No	238	82.4
	Yes	51	17.6

### 3.3. Perceived Stigma of Caregivers of a Person with Severe Mental Illness

When at least one positive response to the items was regarded as having perceived some sort of stigma, all respondents had more than one positive answer giving 100%

perceived stigma by the caregivers.

The mean stigma score of the responses to stigma items was  $17.80 \pm 6.95$  and the minimum and maximum scores were 2 and 32 respectively for the total positive answers. For analysis purposes, the stigma score was dichotomized into high stigma, above the mean, and low stigma, below the mean. Based on this category, the majority of the respondents 158 (54.7%) had a high stigma score. Concerning the specific items, the most frequently endorsed item 279 (96.5%) was

felt grief or depression because of the presence of a mentally ill person in the family followed by 252 (87.2%) explaining to others that the patient isn't like their picture of "crazy" people. The third frequently endorsed item 225 (77.8%) was helping other people to understand what it is like to have a family member with a psychiatric problem. The least frequently endorsed item 118 (40.8%) was to feel that somehow it might be your fault as shown in (Table 3).

**Table 3.** Stigma items were presented to family members and the corresponding responses in Jimma city, 2012 (n=289).

Items	0	1	2	3	positive answer
Worried about being treated differently	97	107	71	14	192 (66.4%)
Worried people would know out about it	82	105	90	12	207 (71.6%)
Felt the need to hide this fact	95	66	110	18	194 (67.1%)
Helping other people to understand what it is like to have a family member with a psychiatric problem	64	135	78	12	225 (77.8%)
Making an effort to keep this fact a secret	83	50	118	38	206 (71.3%)
Worried about being avoided	110	89	76	14	179 (61.9%)
Explaining to others that (name) isn't like their picture of "crazy" people	37	124	73	55	252 (87.2%)
Worried that people would blame you for his/her problems	162	42	69	16	127 (43.9%)
Worried that a person looking to marry would be reluctant to marry into your family	84	29	109	67	205 (70.9%)
Worried about taking him or her out	78	123	74	14	211 (73.0%)
Felt ashamed or embarrassed about it	90	18	66	115	199 (68.8%)
Sought out people who also have a family member who has had a psychiatric problem	118	78	63	30	171 (59.1%)
Felt grief or depression because of it	10	23	53	203	279 (96.5%)
Felt that somehow it might be your fault	171	29	64	25	118 (40.8%)

Not at all (0), Sometimes (1), Often (2), A lot (3).

**Table 4.** The proportion of stigma category with socio-demographic and other variables of the respondents in Jimma city, 2012 (n=289).

Variables	N	Low stigma	High stigma
Sex of family			
Male	141	58 (41.1%)	83 (58.9%)
Female	148	73 (49.3%)	75 (50.7%)
Age of the family in years			
<30	65	32 (49.2%)	33 (50.8%)
30-40	96	48 (50.0%)	48 (50.0%)
41-50	55	15 (27.3%)	40 (72.7%)
≥51	73	36 (49.3%)	37 (50.7%)
Marital status			
Married	160	72 (45.0%)	88 (55.0%)
Single	63	30 (47.6%)	33 (52.4%)
Divorced	35	16 (45.7%)	19 (54.3%)
Widowed	31	13 (41.9%)	18 (58.1%)
Educational status			
Illiterate	25	10 (40.0%)	15 (60.0%)
1-8	92	47 (51.1%)	45 (48.9%)
9-12	118	52 (44.1%)	66 (55.9%)
College/University	54	22 (40.7%)	32 (59.3%)
Work status			
Unemployed	20	11 (55.0%)	9 (45.0%)
Employed	205	82 (40.0%)	123 (60.0%)
Others	64	38 (59.4%)	26 (40.6%)
Relation to the patient			
Parents	103	48 (46.6%)	55 (53.4%)
Siblings	105	50 (47.6%)	55 (52.4%)
Child	28	9 (32.1%)	19 (67.9%)
Spouse	26	8 (30.8%)	18 (69.2%)
Other	27	16 (59.3%)	11 (40.7%)

Living together with family

No	113	50 (44.2%)	63 (55.8%)
Yes	176	81 (46.0%)	95 (54.0%)
Sex of the patient			
Male	173	80 (46.2%)	93 (53.8%)
Female	116	51 (44.0%)	65 (56.0%)
Age of the patient in a year			
<25	77	34 (44.2%)	43 (55.8%)
25-34	113	50 (44.2%)	63 (55.8%)
35-44	46	24 (52.2%)	22 (47.8%)
≥45	53	23 (43.4%)	30 (56.6%)
Age of onset of the illness			
<15 yr	21	13 (61.9%)	8 (38.1%)
15-24 yr	133	60 (45.1%)	73 (54.9%)
25-34 yr	73	32 (43.8%)	41 (56.2%)
≥35 yr	62	26 (41.9%)	36 (58.1%)
Diagnosis			
Schizophrenia	120	63 (52.5%)	57 (47.5%)
Bipolar disorder	63	24 (38.1%)	39 (61.9%)
Major depression	93	34 (36.6%)	59 (63.4%)
Others	13	10 (76.9%)	3 (23.1%)
Duration of the illness			
<5 yr	168	68 (40.5%)	100 (59.5%)
6-10 yr	80	33 (41.2%)	47 (58.8%)
>10 yr	41	30 (73.2%)	11 (26.8%)
History of admission			
No	152	77 (50.7%)	75 (49.3%)
Yes	137	54 (39.4%)	83 (60.6%)
Daily activity			
No	100	53 (53.0%)	47 (47.0%)
Yes	189	78 (41.3%)	111 (58.7%)

In the descriptive analysis, the majority of male respondents 83 (58.9%) had a high stigma score; and more

than half of those family members/caregivers 40 (72.7%) whose ages were between 41 to 50 years were found to have high stigma score. Regarding educational status, 60% of the illiterate and 59.3% of those educated colleges and above had a high stigma score. When it was compared by employment status, the majority (60%) of the employed had a high stigma score as compared to unemployed (45.0%). Majority of the respondent who was a child to the patient (67.9%) had high stigma score next to spouses (69.2%). As the age of onset of the illness increases their high stigma score percentage increases (Table 4).

Regarding responses to the attribution of causes of mental illness, 16.3% of the respondents attributed mental illness to substance abuse followed by loss of properties and unsuccessful life (15.9%), and grief from the loved one (14.2%).

Various coping mechanisms were also suggested to deal with the illness difficulties; the majority (75.7%) was suggested by "went to health professional" followed by "went to holy water" (36.3%)

#### 3.4. Factors Associated with Perceived Stigma

In the bivariate logistic regression analysis, family/caregiver perceived stigma was significantly associated with age (41-50 years) and work status (other=student, housewife & daily labor) of the family members of persons with severe mental illness at  $p$ -value  $\leq 0.05$ . It was also significantly associated with the diagnosis of the patient (major depressive disorders), duration of illness ( $<10$  years), and those patients who had verbal/physical violent behavior towards family members and other people at the time of their illnesses at  $p$ -value  $\leq 0.05$ . Multiple logistic regressions were performed including all variables with a  $p$ -value  $\leq 0.25$  in the bivariate logistic regression to increase

our confidence of having adequately controlled for confounding variables. Only variables with a  $p$ -value lower than 0.05 remained in the final model and were taken as statistically significant (Table 5).

After multivariate analyses were computed, family perceived stigma was significantly associated with relationship to the patient (spouse), duration of the illness ( $<10$  years), and the patient's behavior (verbally/physically violent towards family members and other people at the time of the illness). The odds of the perceived stigma of the spouse of the patient were 4.25 times higher than those of the parents of the patient (AOR=4.25, 95%CI: 1.12–16.13) at  $p=0.034$ .

The odds of the perceived stigma of the family members/caregivers of the patient who had less than 5 years duration of illness were 3.60 times higher than from those family members of a patient who had greater than 10 years duration of illness (AOR=3.60, 95%CI: 1.42– 9.44) at  $p=0.009$ ; and those family members/caregivers of a patient who had 6-10 years duration of illness had also more perceived stigma than from those family members/caregivers of a patient who had greater than 10 years duration of illness. The odds of perceived stigma were more than 3 times higher when the patients' duration of illness was 6-10 years (AOR=3.44, 95%CI: 1.31–9.07) at  $p=0.012$ .

Those family members/caregivers of persons with mental illness who had verbal/physical violent behavior towards family members and other people had a less perceived stigma.

The odds of reporting perceived stigma were 0.34 times less when the patient was verbally/physically violent towards family members and other people at the time of the illness (AOR=0.34, 95%CI: 0.17–0.70) at  $p=0.004$ . Age of the family members, work status, and diagnosis of persons with mental illness were confounding variables (Table 5).

**Table 5.** Associated factors for the perceived stigma of families of persons with severe mental illness in Jimma city, 2012 (n=289).

		COR(95%CI)	AOR (95%CI)	p- value
Sex of family				
Male	141	1.393 (0.875 - 2.218)	1.155 (0.657-2.030)	0.616
Female	148	1.00	1.00	
Age of family				
$<30$ yr	65	1.003 (0.514-1.958)	0.700 (0.249- 1.967)	0.498
30-40 yr	96	0.973 (0.529- 1.788)	0.632 (0.263- 1.518)	0.305
41-50 yr	55	2.595 (1.225- 5.493)	2.051 (0.833- 5.049)	0.118
$\geq 51$ yr	73	1.00	1.00	
Ethnicity				
Oromo	125	1.00	1.00	
Dawuro	29	1.754 (0.755- 4.072)	1.369 (0.525- 3.571)	0.521
Amhara	61	1.423 (0.764- 2.651)	1.342 (0.645- 2.792)	0.431
Guragie	18	1.451 (0.528- 3.985)	1.520 (0.463- 4.988)	0.490
Others	56	0.800 (0.425- 1.504)	0.608 (0.289- 1.281)	0.191
Work status				
Unemployed	20	0.545 (0.216- 1.374)	1.240 (0.399- 3.855)	0.711
Employed	205	1.00	1.00	
Others	64	0.456 (0.258- 0.808)	0.526 (0.265- 1.046)	0.067
Relation to the patient				
Parents	103	1.00	1.00	
Siblings	105	0.960 (0.557- 1.655)	1.235 (0.518-2.944)	0.634
Child	28	1.842 (0.762- 4.453)	3.740 (0.835-16.758)	0.085
Spouse	26	1.964 (0.784- 4.919)	4.249 (1.119-16.136)	0.034*
Other	27	0.600 (0.254- 1.418)	0.807 (0.253-2.578)	0.718

		COR(95%CI)	AOR (95%CI)	p- value
Diagnosis				
Schizophrenia	120	1.00	1.00	
Bipolar disorder	63	1.796 (0.964- 3.346)	1.482 (0.713- 3.082)	0.292
Major depression	93	1.918 (1.103- 3.336)	1.183 (0.575- 2.437)	0.648
Others	13	0.332 (0.087- 1.265)	0.307 (0.061- 1.538)	0.151
Age onset of illness				
<15 yr	21	0.506 (0.197- 1.301)	1.643 (0.468- 5.769)	0.438
15-24 yr	133	1.00	1.00	
25-34 yr	73	1.053 (0.593- 1.871)	1.031 (0.507- 2.097)	0.933
≥35 yr	62	1.138 (0.619- 2.093)	0.840 (0.311- 2.273)	0.732
Duration of illness				
<5 yr	168	4.011 (1.882- 8.545)	3.603 (1.382- 9.394)	0.009*
6-10 yr	80	3.884 (1.708- 8.835)	3.440 (1.305- 9.071)	0.012*
>10 yr	41	1.00	1.00	
History of admission				
No	152	1.00	1.00	
Yes	137	1.578 (0.989- 2.518)	1.634 (0.913- 2.925)	0.098
Violent behavior				
No	90	1.00		
Towards family only	95	1.196 (0.657-2.175)	0.835 (0.410-1.699)	0.558
Towards other only	1	0.000	0.000	1.00
Towards both	103	0.421 (0.236-0.751)	0.342 (0.166- 0.704)	0.004*

NB: - \* p- value < 0.05 is considered as significant

Multiple logistic regressions were also performed for responses to the attribution of causes of mental illness. Among those family members who attributed the cause of mental illness as the loss of properties and unsuccessful life were less stigmatized than those who did not attribute (AOR=0.27, 95%CI: 0.08-0.89) at p=0.032. Those family

members who attributed the cause of mental illness as other medical illness like head trauma, tuberculosis, injuries, and participating in the battle were less stigmatized than those family members who did not attribute (AOR=0.24, 95%CI: 0.07- 0.8 1) at p=0.021 (Table 6).

**Table 6.** Attributions of causes of mental illness by the family of persons with severe mental illness in Jimma city, 2012 (n=289).

Causes		N	P-value	A OR	95%CI.
Hereditiy	No	284		1.00	
	Yes	5	0.132	0.195	0.023- 1.639
Supernatural force	No	280		1.00	
	Yes	9	0.285	0.396	0.072- 2.162
Thinking over	No	277		1.00	
	Yes	12	0.282	0.410	0.081- 2.083
Addiction	No	242		1.00	
	Yes	47	0.061	0.317	0.095-1.055
Annoyed	No	253		1.00	
	Yes	36	0.198	0.499	0.173-1.438
Grief	No	248		1.00	
	Yes	41	0.509	0.651	0.183-2.322
Love	No	271		1.00	
	Yes	18	0.748	1.263	0.304-5.240
Loss & unsuccessfulness	No	243		1.00	
	Yes	46	0.032*	0.267	0.080-0.891
Evil eye, magic &devil	No	266		1.00	
	Yes	23	0.304	0.496	0.130-1.892
Others	No	219		1.00	
	Yes	70	0.021*	0.241	0.071-0.810

NB: - \* P- value < 0.05 is considered as significant

## 4. Discussion

The results of this particular study showed that nearly all family members expressed their concern about stigma despite they were from a different socio-demographic group and having relatives with different mental illnesses. In this study,

conducted in Jimma city health institution, perceived stigma among families/ caregivers of persons with severe mental illness was high which is supported by the study done in rural Ethiopia, Butajira there was more perceived stigma among family members of persons with schizophrenia and major affective disorders in the urban residents than in the rural [11].

The findings in this study are consistent with the findings of other studies which report the existence of clear evidence of stigma among family members of patients with severe mental illnesses [11, 14-18]. However, how the respondents experience stigma might be different from our study, because of the differences in the culture, setting, and other factors.

The mean stigma score was  $17.80 \pm 6.95$  and the majority of the respondents had a high stigma score above the mean (54.7%); which is also consistent with the study done in India [14] (mean stigma score was  $18.84 \pm 3.69$ ), and Butajira, Ethiopia [11].

The most frequently endorsed item from the 14 stigma items was felt grief or depression because of the presence of a mentally ill person in the family (96.5%), which is similar to the study done in India [14] using the same instrument on the primary caregiver of a person with schizophrenia (80%), and the second most frequently endorsed item in this study was explaining to others that the patient is not "crazy" (87.2%) whereas it was the least endorsed item in India (16%); this difference could be due to socio-cultural difference and the caregivers of persons with different diagnoses in this study. Family members/caregivers worried about being treated differently by neighbors was 66.4% which is higher than from the study done in Butajira (42.1%), India (37%), and in Morocco (41%) [11, 16, 18]; the difference might be due to sampling size difference in addition to the above-mentioned differences. Two third of the family members felt the need to hide their relatives' mental illness which is also higher when compared to the study done in India [13] and Butajira [11]; these could be the study participant differences. The study was done in the U.S.A. [17] showed that about half of the family members reported concealing the hospitalization of their mentally ill relative at least to some degree which was in agreement with this study, history of admission was associated with high stigma in bivariate logistic regression analysis even though it was not in the final model.

In multivariate logistic regression analysis the independently associated factors of perceived stigma were spouses as family members/caregivers, duration of the illness (<10 years), and verbally/physically violent behavior of the patient towards family members and other people at the time of their illness. Those family members/caregivers who were spouse had more than 4 times higher perceived stigma than those family members/caregivers who were parents to the patient but the study was done in the U.S.A. which included only parents and spouses of the recently hospitalized patients, spouses were twice as likely to report avoidance by others as parents at the  $p < 0.10$  level [17]. This difference could be due to the instrument used to assess stigma difference (only avoidance and concealment in the U.S.A.).

Regarding the duration of the illness, if the patients' duration of illness was less than 10 years, the family members had nearly 3.5 times higher perceived stigma than those family members of patients whose duration of illness was greater than 10 years. This was consistent with the study done in India (short duration of illness) [14]. This was

also consistent with the study done in Calgary, a higher level of distress among newer caregivers of schizophrenia [19], and the study was done in China (range from 1.5-4.3 years) even though it was said long duration [16], it was a short duration when compared to this study. In another study in New York City on stigma in families of individuals in early stages of psychotic illness, associative stigma was endorsed more by family members of patients with recent-onset psychosis than by family members of prodromal individuals [20].

On the other hand, the duration of illness greater than 10 years was associated with a low perceived stigma might be due to the family members may adopt the illness and develop coping mechanisms.

Regarding patients' violent behavior, those family members or verbally/physically violent patients towards family members and other people at the time of the illness were less stigmatized than those family members of nonviolent patients at all. This is somewhat consistent with the study done in the U.S.A in which concealment by family members was higher among patients with less severe positive symptoms (hostility) at baseline [17]. It seems an unexpected finding but it might be due to the family members might not spend time worrying that people know about it if the patient was verbally/physically violent; no need of effort to hide and secrete the illness rather want help from others. On the other hand, if the patient had no violent behavior, the family members spent more time worrying that people may know about the illness and effort to keep secrete and try to hide the illness.

Although not statically significant, the majority of male respondents (58.9%) had a high stigma score; and more than two-third (72.7%) of those family members whose age were between 41 to 50 years were found to have high stigma score. Being male gender for family members/caregivers had more stigma might be due to having more responsibility to the mentally ill relatives, taking them to health institutions, covering the cost of treatment, and have been more contact to other people as an employee and for many issues than the female family members in this country context. This might make them vulnerable to develop fear and worry about being avoided by friends and coworkers.

Regarding responses to attribution of causes of mental illness, the majority (16.3%) of the respondents attributed mental illness to substance abuse followed by loss of properties and unsuccessful life (15.9%). which is inconsistent with the study done in India [14]; could be due to socio-cultural and diagnosis differences. In a community study in the Butajira area, the majority (27%) of the respondents attributed to supernatural forces [11], but in this study supernatural force was attributed by only 3.1% which might be due to knowledge differences among respondents in the two studies since this study was conducted at the hospital, the respondents might get psycho-education about the causes of mental illness.

In general, our findings suggest that stigma is a concern and a problem for families/caregivers of persons with severe

mental illness. The family perceived stigma made a double burden for them in addition to giving care for their mentally ill relatives; especially for Ethiopian families/caregivers who are the primarily responsible body to give care for their ill relatives including taking them to health institutions and providing medication at home.

The result has also great social implications in that the stigma might restrict the families/caregivers to involve in many social activities, in which many days to day activities are directly related to social gatherings in Ethiopia as well in the study area. Stigma can be a major obstacle to treatment delay, recovery and can limit opportunities of work and social functioning of both persons with mental health problems and their family members/caregivers.

## 5. Conclusion

Perceived stigma was found to be a common problem among caregivers of persons with severe mental illness. Becoming spouse of the patient, duration of illness, patient with violent behavior and, those caregivers who attributed the cause of mental illness as the loss of properties and unsuccessful life were significantly associated with perceived stigma. Hence, counseling and acceptance to the concern of care giver about stigma and set strategies for the prevention of stigma helps them to cope with rejection by others.

## Lists of Abbreviations / Acronyms

AOR: Adjusted Odds Ratio

SMI: Severe Mental Illness

WHO: World Health Organization

SPSS: Statistical Package for the Social Sciences

FIS: Family interview schedule

U.S.A: United States of America

## Declaration

### *Ethical Approval and Consent to Participants*

Ethical clearance was obtained from the ethical committee of Jimma University College of public health and medical sciences. An official letter of co-operation was also written to Jimma city administration offices and specifically to the city health office. Verbal informed consent was obtained from each respondent. Individuals who do not volunteer to continue from the beginning or any part of the interview have respected the right to do so.

### *Consent for Publication*

Not applicable.

### *Availability of Data and Material*

The data was available when it is requested.

## Competing Interests

The authors declare that they have no competing interests.

## Authors' Contributions

MS was the only author involved in proposal development, conducting the analysis, and writing the manuscript. The second, third involved advising the principal author in proposal development and analysis of data. The fourth author contributed to writing, editing the manuscript and process the publication. All authors read and approved the final manuscript.

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