

## Effect of mental illness stigma upon the quality of life among families with schizophrenic patients in Mental Health Centre, Sulaimaniyah, Iraq

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### Abstract

**Background and objective:** Family caregivers of members with schizophrenia are subjected to stigmatization that significantly affects the quality of life. And causes delays in caregiving and treatment seeking for schizophrenic patients. The objective is to assess the stigma of mental illness and QoL levels and to determine its association among family caregivers of schizophrenic patients.

**Methods:** A quantitative cross-sectional study was performed on 100 family caregivers with schizophrenia in 100 patients selected at the Mental Health Center, General Teaching Hospital in Sulaimaniyah, Iraq, from December 2022 to February 2023. A questionnaire used for data collection by interviewing the caregivers was composed of three parts; socio-demographic characteristics of family caregivers and patients, the stigma of mental illness scale, and QoL-BREF.

**Results:** Most family caregivers of patients with schizophrenia were males (72%) and siblings (49%). Moderate prevalence of stigma (78%) and low level of life (91%) were observed among caregivers. The likelihood ratio test results indicated that stigma was significantly associated with QoL (LR=4.912,  $P < 0.05$ ). The multinomial logistic regression model analysis showed that family caregivers with a high level of stigma were significantly four times lower QoL ( $P < 0.05$ , odds ratio=4.43).

**Conclusion:** Family caregivers experienced a moderate level of stigma and low QoL that reflects a failure to use practical approaches to prompt and satisfy their needs in the community.

**Keywords:** Family caregivers; Schizophrenia; Mental illness; Stigma; Cross-sectional study.

### Introduction

Schizophrenia is a major psychiatric disorder with a lifetime prevalence of about 1%, and over 21 million people live with schizophrenia worldwide.<sup>(1)</sup> Family engagement as the primary locus of care for schizophrenic members has resulted from the deinstitutionalization movement; as a result, more people with schizophrenia live with their families.<sup>(2)</sup> Mental health stigma is a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illness.<sup>(3)</sup>

Schizophrenia is a target of stigma due to

its distinctive symptoms, unusual behavior, and perceived dangerousness.<sup>(4)</sup> Family caregivers of patients with schizophrenia are subjected to stigmatization.<sup>(5)</sup> Studies observed reasons related to biogenetic and psychosocial explanations of schizophrenia, which are associated with a stigma against family caregivers.<sup>(5)</sup> The stigma against schizophrenic family caregivers is described as a courtesy or associative stigma, which is the process by which family caregivers are stigmatized by association with another individual who is a schizophrenic patient.<sup>(6)</sup>

Research has highlighted the detrimental

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effects of stigma on family caregivers, leading to negative consequences such as impaired psychological well-being and reduced QoL.<sup>(7)</sup> QoL can be understood as an individual's subjective evaluation of their overall life circumstances, considering their cultural and societal context, personal goals, expectations, values, and concerns.<sup>(8)</sup> Stigmatization experienced by family caregivers of individuals with schizophrenia can significantly impact their psychological well-being and overall perception of their life situation, resulting in a diminished QoL.

The QoL of family caregivers plays a crucial role in the care provided to individuals with mental illness, including schizophrenia. There is a significant negative relationship between mental illness stigma and the QoL of family caregivers. Caregivers who experience higher levels of self-stigma are more likely to have a poor QoL, especially when facing external stigmatization.<sup>(9)</sup> Improving the QoL of family caregivers directly impacts the health outcomes of patients living in a family environment.<sup>(10,11)</sup> When family caregivers have a better QoL, it positively influences the care they provide to their loved ones with mental illness, improving overall patient health outcomes.

Addressing stigma and enhancing the QoL of family caregivers are crucial for promoting the well-being of caregivers and individuals with schizophrenia. Stigma remains a significant barrier to treating and supporting individuals with mental illness. There has been relatively limited research on this topic, and to the best of the author's knowledge, no previous study has been conducted in Sulaimaniyah, Iraq. Thus, the current study aimed to investigate the impact of mental illness stigma on the QoL of family caregivers. Consequently, this study can contribute to filling the research gap in the region and provide evidence to guide interventions and support services for family caregivers.

## Methods

### Study design and setting

The quantitative cross-sectional study was conducted in the Mental Health Center in General.

Teaching Hospital at Sulaimaniyah, Iraq, from December 2022 to February 2023.

### Sample size estimation:

The required sample size for this study was determined using the G-power correlation analysis tool. The calculation was based on the following parameters:

- Effect size: Medium (0.5)
- Statistical power ( $1 - \beta$ ): 0.8 (80%)
- Significance level ( $\alpha$ ): 0.05 (5%)
- Confidence interval: 95%

Based on these parameters, the required sample size was 100 participants. To meet this requirement, 100 family caregivers were recruited using a non-probability convenience sampling method. During the study, these caregivers were selected from those attending the Mental Health Center in Sulaimaniyah. This sample size was sufficient to detect statistically significant associations between stigma and quality of life, ensuring the reliability of the findings.

### Inclusion and exclusion criteria

Eligible family caregivers aged >18 defined themselves as a relative of the patients, such as a parent, husband, wife, brother, sister, or children, living with the patients in the same household and being involved in their care and accompanying the patients for >1 year. The exclusion criteria include the family caregivers who do not consent to participate in this study.

### Questionnaire

A questionnaire was developed by the investigator of this study and used as an instrumental tool for data collection. Then, the questionnaire was translated into the Kurdish language through the forward-backwards method. The validity was achieved by five experts, the computation of Cronbach's Alpha, and the result was statistically adequate and reliable of  $P = 0.001$ . The questionnaire consists of 3 parts. Part 1 includes socio-demographic data of the patients and family caregivers,

while part 2 covers family caregivers' stigma of mental illness scale. This part consists of 28 items of 3 factors structure, including discrimination, disclosure, and potential positive aspects of mental illness. The scale items were scored on five levels of the Likert scale ranging from strongly agree (5) to disagree (1) strongly. The items on the scale were phrased in positive wording, except 9 items were in negative wording and rated on the reversed score. The levels of stigma were estimated according to the cut-off-point for the Likert scale as 1-2.33 (low), 2.34-3.67 (moderate), and 3.67-5 (high). The changed scoring of the total scale was categorized as the level of stigma as 35-65 (low), 66-103 (moderate), and 104-140 (high).

On the other hand, part 3 includes the family caregivers' QoL scale (WHOQOL-BREF), composed of 26-item in 4 domains of QoL, including physical health (7 items), psychological state (6 items), social relationships (3 items), environmental domains (8 items) and 2 items to measure the overall QoL and general health. Each item was scored from 1 to 5 on the response Likert scale, which is stipulated as a 5-point ordinal scale. The data was collected through face-to-face interviews with family caregivers to fulfill the questionnaire's items.

### Statistical analysis

The collected data were analyzed using the Statistical Package for Social Sciences (SPSS), version 25. Descriptive statistics were used to summarize the socio-demographic characteristics and study variables, including frequencies, percentages, means, and standard deviations. Cronbach's Alpha coefficient was applied to assess the internal consistency and reliability of the study tool. "For inferential statistics, the Chi-square test was employed to evaluate associations between categorical variables, including the relationship between stigma levels and quality of life (QoL). Additionally, the likelihood ratio test (LRS) and multinomial logistic regression were used to explore the

relationship between stigma and QoL further, identifying significant predictors and their effects. A *P*-value of less than 0.05 was considered statistically significant across all analyses."

### Ethical approval and consent for participation

Ethical approval was obtained from the scientific committee of the Psychiatric and Mental Health Nursing Department, College of Nursing, and the Ethical Committee, College of Medicine, University of Sulaimani (No. 75/01/05/2022/UoS). Also, permission was granted by the Sulaimani General Health Directorate. All procedures in this study were done according to the Declaration of Helsinki. On the other hand, written informed consent was taken from each patient and/or their legal guardians, and the study's aims were explained to them, and they had the right to withdraw at any time from the study. Informed them the data would be kept confidential, and verbal informed consent was obtained before data collection.

### Results

More than one-half of the schizophrenic patients aged 18-34 years old (51%) are males (51%) and with barely sufficient income (54%). Regarding occupation, 24% were unemployed or out of work; a large proportion of the patients (75%) were from an urban area and had a duration of illness of 1-5 years (79%) (Table 1).

Regarding the socio-demographic characteristics of the family caregivers of the schizophrenic patients, most of them were aged 35-50 years (38%), males (72%), married (68%), and had secondary school degrees (32%). Furthermore, most caregivers were siblings (brothers/sisters) (49%), followed by fathers (24%), then wives (12%), and least were mothers (3%) (Table 2).

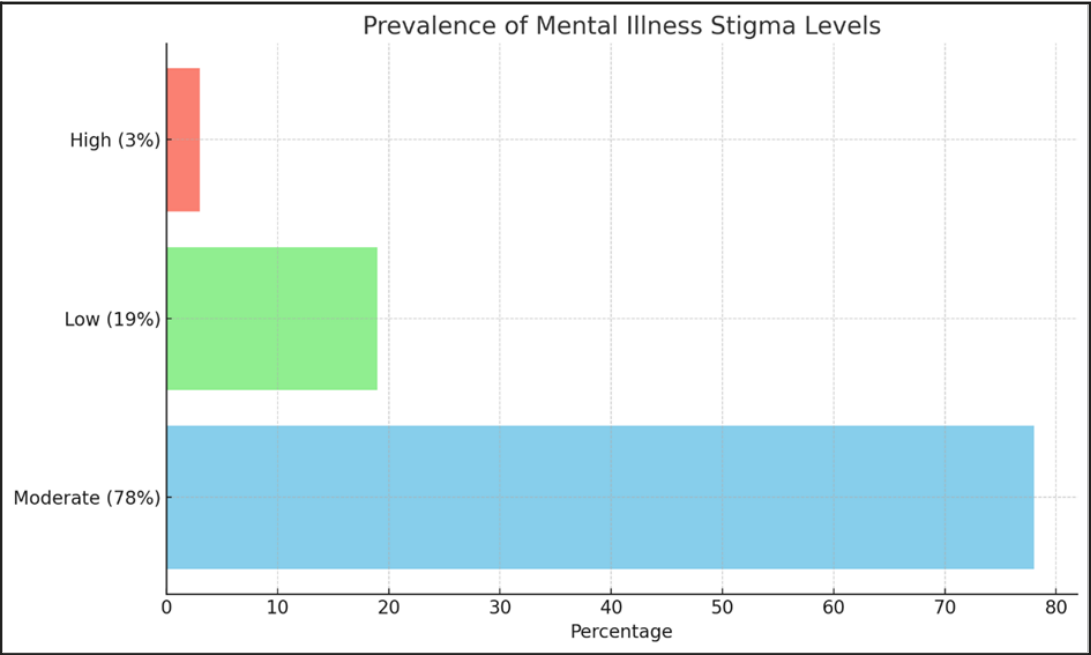
**Table 1** Socio-demographic characteristics of schizophrenic patients

Variable	Frequency	Percentage
<b>Age (Years)</b>		
<18	1.0	1.0
18-34	51.0	51.0
35-50	35.0	35.0
>50	13.0	13.0
<b>Gender</b>		
Male	51.0	51.0
Female	49.0	49.0
<b>Duration of illness (Years)</b>		
1-5	79.0	79.0
6-10	19.0	19.0
>10	2.0	2.0
<b>Occupation</b>		
Governmental employee	19.0	19.0
Private employee	11.0	11.0
Self-employee	17.0	17.0
Unemployed	24.0	24.0
Retired	5.0	5.0
Out of work	24.0	24.0
<b>Income</b>		
Sufficient	44.0	44.0
Barely sufficient	54.0	54.0
Insufficient	2.0	2.0
<b>Residency</b>		
Urban	75.0	75.0
Sub-urban	22.0	22.0
Rural	3.0	3.0
<b>Total</b>	<b>100.0</b>	<b>100.0</b>

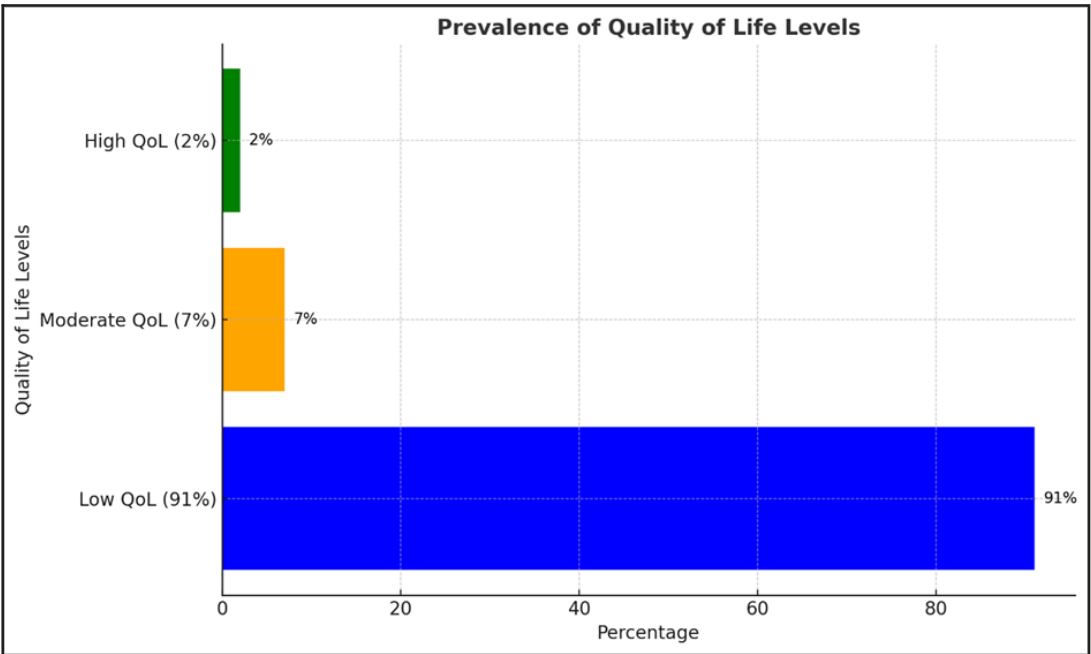
**Table 2** Socio-demographic characteristics of the family caregiver of the schizophrenic patients.

Variable	Frequency	Percentage
<b>Age (Year)</b>		
18-34	32.0	32.0
35-50	38.0	38.0
>50	30.0	30.0
<b>Gender</b>		
Male	72.0	72.0
Female	28.0	28.0
<b>Marital status</b>		
Single	32.0	32.0
Married	68.0	68.0
<b>Education level</b>		
Illiterate	3.0	3.0
Read & write	6.0	6.0
Primary School	30.0	30.0
Secondary School	32.0	32.0
Institute/College	29.0	29.0
<b>Family member</b>		
Father	24.0	24.0
Mother	7.0	7.0
Husband	8.0	8.0
Wife	12.0	12.0
Sibling (sister or brother)	49.0	49.0
<b>Total</b>	<b>100</b>	<b>100</b>

Regarding the prevalence of mental illness stigma level among family caregivers, most of them (78%) attributed to moderate levels, 19% to low levels, and a marked least prevalence to a high (severe) group (3%) (Figure 1). The distribution of QoL among family caregivers regarding its domains (physical, psychological, social, and environmental) was summed to provide a total level. The results revealed that low (poor) QoL was highly prevalent (91%), followed by moderate level (7%), and only 2% reported be high level (Figure 2).



**Figure 1** Prevalence of mental illness stigma levels among family caregivers



**Figure 2** The prevalence of quality of life levels among family caregivers

Furthermore, the analysis of LRS indicates a significant association between mental illness stigma and QoL ( $P < 0.05$ , model of fitting=8.156, 13.008, LRS=4.912). The result reflects a strong probability of stigma's effectiveness on family caregivers' QoL (Table 3).

The multi-nominal logistics regression test results indicate that mental-illness stigma levels are a significant ( $P = 0.05$ ) independent factor affecting the validation in QoL levels. The results proved that a high stigma level was four times lower QoL (odds ratio=4.439) confidence interval,

CI=1.079-8.297) in family caregivers with members with schizophrenia (Table 4).

Table 5 summarizes the distribution of QoL levels across different age groups and genders. Caregivers aged >50 years had the highest proportion of low QoL (95%), whereas caregivers aged 18–34 years exhibited slightly better QoL outcomes, with 10% reporting moderate QoL. Female caregivers displayed higher moderate QoL levels (12%) compared to males (5%). These findings indicate that both age and gender significantly influence QoL among caregivers.

**Table 3** Association between mental illness stigma and quality of life of family caregivers

Effect	Model Fitting Criteria	Likelihood Ratio Tests (LRS)		
	-2 Log Likelihood of Reduced Model	Chi-Square	df	P-value
Intercept	8.156 <sup>a</sup>	0.000	0.0	
Stigma scale	13.068	4.912	1.0	0.05*

\*Significant difference using chi-square test

**Table 4** Multinomial logistic regression model predicting quality of life (dependent variable) based on mental illness stigma (independent variable) caregivers

Stigma Level (Independent Variable)	B	Std. Error	Wald	df	P-value	Exp(B)	95% Confidence Interval for Exp(B)
Low (Reference Category)							
High	1.096	0.520	4.439	1.0	0.05*	2.991	1.079 – 8.297

\*Significant difference

**Table 5** Distribution of QoL levels by age and gender

Variable	Low QoL (%)	Moderate QoL (%)	High QoL (%)	Significance (P-value)
<b>Age (Years)</b>				
18-34	85	10	5	<0.05
35-50	90	6	4	<0.05
>50	95	5	0	<0.05
<b>Gender</b>				
Male	93	5	2	<0.05
Female	88	12	0	<0.05



## Discussion

The result shows that almost half of the schizophrenic patients were in the age group 25-34 years, and there was no difference in the prevalence of the disease between males and females. These results are similar to that of Albikawi and Abuadas, 2021,<sup>(12)</sup> but contrary to Hussien, 2012,<sup>(13)</sup> who found that the most common age distribution ranged from 30-44 years. However, different studies reported different findings, which can likely be attributed to the age of onset and subtype of schizophrenic, which tend to appear at other times.<sup>(14)</sup> In addition, we found that the studied schizophrenic patients participated less in occupation, where about half of them were unemployed and out of work. These findings were confirmed by Pongsaksri, 2018.<sup>(15)</sup> The result may be relapses, rehospitalization, or being a housewife.<sup>(16)</sup> Furthermore, Bejerholm and Eklund, 2007<sup>(17)</sup> reported that many people with schizophrenia perform occupations with little meaning.

This study revealed that a significant proportion of the patients (79%) had a duration of illness of <5 years. This finding is consistent with the observations of Sefi, 2016<sup>(2)</sup> and Mohammed (2014).<sup>(16)</sup> However, it contrasts with other studies that reported a lower proportion of schizophrenic patients with a duration of illness ranging from 1-5 years (21.3%).<sup>(18)</sup> The disparity in findings among different studies may be attributed to various factors such as the onset and manifestation of symptoms, the age of the patients, access to psychiatric services, early diagnosis, and the presence of stigma.<sup>(14-19)</sup> These factors can influence the timing and accuracy of diagnosis and the initiation of appropriate treatment and support. Stigma, in particular, may affect the willingness of individuals to seek help and disclose their illness, which could impact the observed duration of illness. Understanding the factors contributing to the duration of illness is crucial for improving early detection and intervention strategies. Further research is

needed to explore the complex interactions between symptom presentation, access to services, stigma, and other relevant factors to develop effective interventions that minimize illness duration and improve outcomes.<sup>(2)</sup>

The current study showed that most family caregivers were males and married; the most observed age ranged from 35 to 55. These outcomes are aligned with those found by Ebrahim et al. 2020 who used a sample of family caregivers of schizophrenic patients.<sup>(20)</sup> However, it disagreed with Girma et al. (2014), which found that most family caregivers were females.<sup>(4)</sup> Furthermore, Boyer et al. 2012<sup>(21)</sup> found that the age>54 years among 2/3 of the Chilean family caregivers. Moreover, our results revealed that the siblings ranked first as family caregivers (49%) and the father ranked second (24%). This result is similar to that of Hussien, 2012,<sup>(13)</sup> who showed that brothers and sisters ranked first as caregivers. However, in contrast to our result, Boyer et al. 2012<sup>(21)</sup> found that primarily the mothers of Chilean and French were the family caregivers of schizophrenic patients. This difference could be related to patients' socio-demographic characteristics and the caregivers' availability. In addition, Alyafei et al. 2021<sup>(5)</sup> reported that in Eastern cultures providing care for ill members by family caregivers is rooted in cultural beliefs and is more likely to be a culturally appreciated practice and a cultural obligation.

The results indicated that most participants reported a notably low level of QoL. This finding is consistent with other studies demonstrating a generally low QoL among caregivers of individuals with schizophrenia.<sup>(10,21)</sup> It is essential to acknowledge that the role of the family has shifted to include responsibilities traditionally performed in mental hospitals. However, family caregivers often lack sufficient preparation and support, and their specific needs usually go unmet.



Boryeet al. 2012 emphasized that the emotional and psychological impacts related to shame and stigma have a more significant effect on the caregivers' QoL than the burden of household care tasks.<sup>(21)</sup> This suggests that the stigma associated with schizophrenia and the resulting emotional and psychological challenges family caregivers face play a significant role in their perceived QoL. The focus should not solely be on the practical aspects of caregiving but also on addressing caregivers' emotional well-being and support needs to improve their QoL. Thus, these findings underscore the importance of recognizing and addressing stigma's emotional and psychological impacts on family caregivers. By providing appropriate support and interventions to address the caregivers' emotional well-being, it may be possible to enhance their QoL and overall caregiving experience.

Furthermore, Ebrahim et al. 2020 reported that family caregivers are crucial in supporting and caring for their schizophrenic relatives.<sup>(20)</sup> Their struggle to face stigma and shouldering the caregiving burden is marginalized, undervalued, and invisible to mental health services. Additionally, the result of this study proved that the overall mental illness stigma among family caregivers of patients with schizophrenia was found to be of moderate level (79%), which is similar to the finding of a study conducted in Ethiopia.<sup>(4)</sup> However, in contrast to other studies in India<sup>(22)</sup> and Egypt<sup>(20)</sup> where caregivers had a different level of stigma. Likewise, it has been found that family caregivers' experience of stigmatization is commonly feeling discouraged, hurt, angry, and lowering self-esteem and QoL.<sup>(23)</sup>

findings indicated a significant association between stigma and QoL. These results are aligned with those studies that used a sample of family caregivers of schizophrenic patients.<sup>(24,25)</sup> In the previous investigation, factor analysis showed that a high stigma level is a significant independent factor that decreases the QoL

due to multidimensional logistic analysis. The result of this study proved that a high level of stigma was four times more likely to lower QoL than those without a high stigma level ( $P < 0.05$ , odd ratio 4.43). These findings are consistent with other studies,<sup>(9,26,27)</sup> which reported that the perception of stigma significantly contributed to lower QoL and increased psychological distress among family caregivers of individuals with schizophrenia.

It is essential to highlight that this study was the first investigation to precisely assess the stigma of mental illness among family caregivers of schizophrenic patients in Sulaimaniyah City. However, it is essential to acknowledge that the sample of caregivers included in the study may not fully represent the entire population. This limitation arises from the exclusion of caregivers of outpatients with schizophrenia, which restricts the generalization of the study's findings. Further research with a more diverse and representative sample of caregivers is necessary to validate and extend the results of this study. Including caregivers of both inpatients and outpatients with schizophrenia would provide a more comprehensive understanding of the stigma experienced by family caregivers and its impact on their QoL.

Furthermore, significant associations between QoL levels and demographic variables such as age and gender among family caregivers of patients with schizophrenia. Older caregivers ( $\geq 50$  years) were more likely to report low QoL, potentially due to the cumulative burden of caregiving responsibilities and age-related physical and mental health challenges. These findings are consistent with earlier studies, such as Ebrahim et al. (2020),<sup>(20)</sup> which emphasized the compounded effects of age on caregiver stress and QoL. Gender differences were also evident, with female caregivers reporting slightly better QoL than males. This may reflect differences in coping mechanisms or

societal roles, as women might receive more social support in caregiving roles compared to men.

## Conclusion

Family caregivers of patients with schizophrenia experienced the moderate stigma of mental illness and low QoL levels. A high stigma among caregivers was significantly four times lower than their QoL. The finding reflects a failure to use practical approaches to satisfy family caregivers' needs. Furthermore, the QoL of family caregivers was substantial when experiencing stigma affects their ability to care for and support the patients. Family caregivers of schizophrenic patients should conduct psychoeducational programs, including knowledge about schizophrenic coping strategies. Also, social support, interpersonal contacts, and community awareness about mental illness help reduce stigma and improve QoL.

## Competing interests

The author declares that she has no competing interests.

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