

# Perceived Stigma and Burden in Tunisian Natural Caregivers of Patients with Schizophrenia

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## Abstract

Natural caregivers of patients with schizophrenia are often subjected to stigma by virtue of their association with patients. This study aimed to assess perceived stigma and burden among natural caregivers of patients with schizophrenia. We conducted a cross-sectional, descriptive and analytical study, including 80 natural caregivers of patients with schizophrenia. We used the Stigma Devaluation Scale (SDS) to assess stigma and the Zarit Burden Interview (ZBI) to evaluate burden. The average age of natural caregivers was 55.7 years. The sex ratio (M/F) was 0.86. The mean score of perceived stigma in patients was 24.7. That of perceived stigma in caregivers was 15.34. Medium to high burden was found in 77.5% of participants. Perceived stigma scores were significantly higher among illiterate caregivers, those linking schizophrenia to hereditary causes, among parents, and in case of daily contact with the patient. Scores of perceived stigma in caregivers were also significantly correlated with burden score and patient self-stigma sub score. Natural caregivers of patients with schizophrenia are exposed to affiliate stigma, and experience an important level of burden. Our findings emphasize the need to develop strategies to combat stigmatization among patients, but also their natural caregivers.

**Keywords:** Schizophrenia • Caregivers • Social stigma • Burden • Family

## Introduction

Schizophrenia is a global public health problem. It is scheduled as the eighth cause of handicap in the age range of 15 to 44 [1]. The fall of the lunatic asylum and its gradual replacement by the psychiatric hospital led to the modern deinstitutionalization movement as that was the main source of caring shift from the formal health institution to natural caregivers. From this perspective, a natural caregiver is defined as an individual belonging to the patient's relative or friend perceived as the main person in charge of the patient, without being financially rewarded [2].

In patients with schizophrenia, the role of natural caregiver has usually been taken by relatives because of significant socio-occupational dysfunction in patients [2]. As a result, they have been suffering from not only physical and material consequences but also social and emotional distress. In fact, authors have described caregivers as "the hidden patients" [3].

Thus, previous psychiatric studies have focused on the negative impact of caregiving such as financial hardship, disruption of social activities and relationships, experienced burden as well as anxiety and depression. However, in addition to psychological impact, and as far as schizophrenia is a highly stigmatized mental disease, natural caregivers are also affected by stigma.

Indeed, "associative stigma" refers to the process of transferring stigma from the person with mental disorder to his relative or caregiver [4]. In 1963, Goffman identified "courtesy stigma" as the stigma that affects everyone surrounding the patient with mental disorder. In fact, stigma is not limited to patients dealing with schizophrenia but also affects their natural caregivers and may lead to discrimination and social rejection.

Typically, families encountering associative stigma are confronted with stereotypes of shame, blame and dangerousness. Thus, the experience

of stigma and discrimination is usually different because of the different ethos and cultural contexts [5]. Nevertheless, most studies on the subject are conducted in western developed countries. Culturally specific data concerning associative stigma are lacking as cultural factors play an important role in influencing the rate of stigma of mental illness. In view of lacking data, we aimed through our study to assess the experience of stigma among a Tunisian population of natural caregivers of patients with schizophrenia and to investigate the factors associated with a higher likelihood of social withdrawal.

## Materials and Methods

### Study design and participants

We conducted a cross-sectional study from March to August 2019, in Razi Hospital, located in the governorate of Manouba, in Tunisia. The natural caregiver of each patient was self-identified as the one who provided the most care to the patient and has spent the most time with since the beginning of the follow-up. 80 participants were recruited.

Inclusion criteria for this study were: (1) Natural caregivers of patients were fulfilling the diagnostic criteria for schizophrenia according to Diagnostic and Statistical Manual of Mental Disorders 5 (DSM5); (2) Natural caregivers aged 18 and over; (3) Natural caregivers informed and consented.

Non-inclusion criteria included: (1) Natural caregivers with psychiatric history (2) Natural caregivers unable to understand and communicate (3) Natural caregivers who refused to participate in the study.

### Ethical consideration

The study was anonymous, and the confidentiality of the responses was assured after a clear explanation of the objectives. Considering

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**Received:** 20-Apr-2022, Manuscript No. CSRP-22-61364; **Editor assigned:** 22-Apr-2022, PreQC No. CSRP-22-61364(PQ); **Reviewed:** 09-May-2022, QC No CSRP-22-61364; **Revised:** 13-May-2022, Manuscript No. CSRP-22-61364(R); **Published:** 23-May-2022, DOI: 10.3371/CSRP.FZES.052322.

most participants were poorly educated and may have strain to read questionnaires by themselves, a unique interviewer asked the respondents and then filled their answers in the questionnaires. Ethics approval was granted by the Ethics Review Committee.

### Measurements statistical analysis

Assessments were conducted using the following instruments:

**Zarit Burden Interview (ZBI):** Developed by Steven H. Zarit in 1980, it was initially used to measure strain associated with the care of individuals with dementia [6]. Bachner showed through a meta-analytic study that responses to the ZBI are reliable across caregivers and care recipients (mental illness, dementia, cancer, dementia, physical illness) [7]. In 1993, it was translated and validated in French by Réjéan, et al. [8]. This instrument comprises 22 items. Each item is scored on a five-point Likert scale ranging from 0 (never) to 4 (almost always). The total score is calculated by summing the responses to all statements (score ranges from 22 to 88). Higher scores indicated greater burden. A score of 17 or more is considered as a high burden.

**Arabic Stigma Devaluation Scale (SDS):** Initially developed by link and his collaborators in 1989, the SDS is a 15-item scale that measures stigma from the perspective of family members. It assesses family members' beliefs about the extent of devaluation directed toward individuals with mental disorders and their families. The 12-item Arabic SDS was translated and culturally modified from the original 15-item English version in 2012 by Dalky [9].

It is divided into two sections. The first, consumers' scale, is composed of seven items, measuring patient-focused stigma. The second, consumer families' scale, consists of five items, intended to measure caregiver-focused devaluation. Each item is scored on a 4-point scale ranging from 1 (strongly disagree) to 4 (strongly agree). The total score is obtained by summing all items for an overall stigma score, with higher scores indicating greater perception of stigma [9].

### Statistical study

Statistical analysis was performed using Statistical Package for the Social Sciences (SPSS) 25.0 (IBM SPSS Statistics, New York, United States). Data entry and analysis were performed using the 20th version of the Statical Package for Social Sciences (SPSS) software. Quantitative variables were described using means and their standard deviations. Qualitative variables were described using frequencies. Comparison of means was made by Student's t-test. Comparison of frequencies was made by chi-square test or Fisher's test. The significance level was set at 5%.

## Results

Socio demographic characteristics of patients and natural caregivers

Socio-demographic characteristics of patients and natural caregivers are shown in Table 1.

**Table 1.** Characteristics of patients, natural caregivers, and caregiving relationship.

Age		Caregivers (N=80) Mean (S.D.)/N (%)	Patients (N=80) Mean (S.D.)/N (%)
Age in years		55.7 (12.6)	44.28 (13.9)
Gender	Female	37 (46.25%)	24 (30%)
	Male	43 (53.75%)	56 (60%)
Marital status	Married	48 (60%)	13 (16.25%)
	Single	13 (16.25%)	57 (71.25%)
	Divorced	4 (5%)	6 (7.5%)
	Separated	1 (1.25%)	1 (1.25%)
	Widowed	14 (17.5%)	3 (3.75%)
Educational level	Illiterate	49 (61.25%)	10 (12.5%)
	Primary education	24 (30%)	37 (46.25%)
	Secondary education	5 (6.25%)	27 (33.75%)
	University education	2 (2.5%)	11 (13.75%)

### Characteristics of caregiving relationship

Parents constitute 48.75% of caregivers. Participants have been caring for patients for an average duration of 15.9 years  $\pm$  12.67 years. Most of caregivers were living in the same household with patients (87.5%). Characteristics of caregiving relationship are shown in Table 1.

### Clinical characteristics

Patients had an average duration of illness of 17 years, with an average number of hospitalizations of 4. More than half of our sample patients were treated with classic antipsychotics (65%), namely long-acting antipsychotics in 48.8% of cases. 72.5% of patients were compliant with prescribed medication and had a regular follow-up in three quarters of the cases. Patients had healthcare coverage in 91.25% of cases. 26.2% of them displayed aggressive or threatening behaviour and 23.8% of them had a history of suicide attempts.

### Caregivers' beliefs about schizophrenia and their attitudes towards the first symptoms of schizophrenia

40% of participants think that schizophrenia is due to magical-religious causes and 37.5% due to a traumatic event. 18.75% of them believed in biological causes including heredity, 2.5% in substance consumption and 1.25% in organic causes (Table 2). Caregivers' attitudes towards first symptoms of schizophrenia are shown in Table 3.

### Burden of caregiving

The mean score on the ZBI was 58, indicating a high burden of caregiving. Almost half of the participants reported moderate to high burden (47.5%). Higher levels of burden were found among younger, illiterate and unemployed caregivers. Burden scores were also proportionately correlated with socioeconomic level. Parents and caregivers who had spent more time caring for the patient experienced greater burden. Indeed, the level of burden was higher when patients had no social security coverage and behaved aggressively and was correlated with the mean dose of antipsychotics (Chlorpromazine equivalent doses).

### Stigma and discrimination among patients and caregivers

The mean score on the consumer scale was 24.7; the mean score on the consumer family scale was 15.34. 28 caregivers 'strongly agreed' on the totality of the items, indicating a very high level of stigma experience.

### Correlates of caregivers' stigma

Participants whose ill relative was of younger age reported higher stigma as assessed in the SDS score. Further, caregivers who were illiterate experienced higher levels of stigma as assessed by total SDS score. Compared to parents, siblings, and other relatives (including spouses) reported significantly lower levels of stigma. Moreover, caregivers who believed schizophrenia was linked to inherited causes or genetic susceptibility experienced a higher level of devaluation (Table 4). Significant correlations were found between caregivers' stigma score and patients' stigma score as well as burden score assessed by ZBI (Table 5).

Professional activity	Active	21 (26.25%)	69 (86.25%)
	Unemployment	38 (47.5%)	0
	Long-term leave	1 (1.25%)	0
	Retirement	20 (25%)	p
		Caregivers (N=80) Mean (S.D.)/N (%)	Patients (N=80) Mean (S.D.)/N (%)
Socioeconomic level	Low / middle	72 (90%)	72 (90%)
	High	8 (10%)	8 (10%)
Locality	Urban	69 (86.25%)	69 (86.25%)
	Rural	11 (13.75%)	11 (13.75%)
Relationship caregiver/patient	Parent	39 (48.75%)	
	Spouse	8 (10%)	
	Sibling	25 (31.25%)	
	Descendant	5 (6.25%)	
	Other	3 (3.75%)	
Time spent in caregiving	Daily contact	78 (97.5%)	
	Less than 1 time/day	2 (2.5%)	

**Table 2.** Beliefs about schizophrenia among caregivers.

Questions	% of "yes" responses	% of "no" responses
Do you know your loved one's illness?	32.5	67.5
Have you ever heard of schizophrenia?	18.75	81.25
Where do you get this information from?	1. Health professionals	75
	2. Traditional media	43.75
	3. Entourage	81.25
Do you think this disease is chronic?	83.75	16.25
Do you think this disease is curable?	25	75
Do you think this disease can be stabilized with treatment?	96.25	3.75
Do you think a patient with schizophrenia can lead a normal life?	47.5	52.5
Do you think a patient with schizophrenia can get married?	43.75	56.25
Do you think a patient with schizophrenia can work?	63.75	36.25
Do you think a patient with schizophrenia can have children?	43.75	56.25
What do you think is the cause of schizophrenia?	1. Hereditary	81.25
	2. Witchcraft, jinn, or prearranged fate	60
	3. Substance use	97.5
	4. Traumatic event	62.5
	5. Organic cause	98.75

**Table 3.** Attitudes of caregivers towards the first symptoms of schizophrenia.

Questions	% of "yes" responses	% of "no" responses
What was your attitude when the first symptoms appeared?	1. See a doctor	26.25
	2. Consult a traditional therapist	73.75
If you saw a doctor in the first place, which one?	1. A psychiatrist	36.21
	2. A general practitioner	63.79
If you used traditional therapy in the first place, which one?	1. Quran reading	45.45
	2. A general practitioner	63.79
If you used traditional therapy in the first place, which one?	1. Quran reading	45.45
	2. Visit to sane tombs	86.36
	3. Medicinal potions and herbs	68.18
Have you already combined the two methods?	17.5	82.5
Do you think traditional therapy is effective?	3.75	96.25
Do you think modern medicine is effective?	96.25	3.75

**Table 4.** Factors associated with caregivers' stigma.

Variables	Consumer families scale	p value
<b>Patients' age</b>	<b>44.2</b>	<b>0.05 (r=-0.2)</b>
Patients' marital status	Married (n=13)	13.4
	Not married (n=67)	15.4
Caregivers' education level	Illiterate (n=54)	16.3
	≥ Primary education (n=26)	13.3
Caregivers' beliefs about schizophrenia causes	Hereditary causes (65)	15.7
	Other causes (15)	13

**Table 5.** Correlation between caregivers' stigma, patients' stigma and caregivers' burden.

	Caregivers' stigma		
	Mean score	p	r
Patients' stigma (SDS consumers' scale)	24.7	<10 <sup>-3</sup>	0.6
Caregivers' burden (ZBI)	58	<10 <sup>-3</sup>	0.5

## Discussion

### Summary of the findings

The natural caregiver profile was consistent with a 55-year-old married first degree relative (mostly parent) with a primary education level and a relatively low household income. Caregiving negative impact was obvious, including caregiver burden but also discrimination.

### Socio-demographic profile of natural caregivers

In this study, the natural caregivers were mainly middle and old aged people, which is comparable to the literature's data [10-13]. Indeed, we found there were more female caregivers than males, which added evidence for estimates by many oriental studies showing the female constituting the crucial force of caregiving [10,14-16]. 60% of our participants were married as marriage is a well-established norm in Tunisian society. However, data suggest that caregivers of patients with schizophrenia have higher rates of divorce and separation as caregiving may lead to family dysfunction [12,17]. Primary caregivers were mainly illiterate, unemployed, with a relatively low socioeconomic position, which reflects the socio-economic situation our country is going through.

The finding that parents were the predominant type of natural caregivers (48.75%) is consistent with the results of other parts of the Middle East and reflects the traditional Arabic culture that focuses on caring for the sick children within a family [13]. Most of the natural caregivers have been caring for the patient for over 10 years. In fact, schizophrenia is a chronic debilitating illness that needs lifelong care [18].

The socio-demographic profile of caregivers in the present study was globally consistent with that in other parts of the world such as China, Taiwan, Sweden, and Italia, which shows a world pattern for natural caregivers of patients with schizophrenia [19-22].

### Beliefs about the causes of schizophrenia among caregivers and their attitudes towards the first symptoms of schizophrenia

The greater amount of magical-religious beliefs among the participants in our study was expected. A possible explanation may be that Arab culture and Islamic faith are deeply intertwined. Thus, Muslim patients believe illness is a test from God as well as a trial by which one's sins could be removed. Furthermore, caregivers use religious and spiritual approaches as coping strategies in handling their relatives with schizophrenia. Secondly,

caregivers mentioned genetic causes which may be linked to the integration of the biomedical model of explanation among caregivers via the varied mental health services.

As for the attitudes of caregivers towards the first symptoms of schizophrenia, the use of traditional healers is still widespread. In fact, the practice of psychiatry in Tunisia and in Arabic countries still encounters concerns about acceptability of care as this pattern of health-seeking behavior is influenced by cultural beliefs regarding the role played by witchcraft, demonic control and the evil eye in causing symptoms of schizophrenia. Alongside beliefs that are strongly held in Arab countries, stigma perceived by caregivers could encourage the use of traditional healing. In fact, mental illness is a source of shame for the family who, in order to keep the illness secret, visit healers before seeking medical services [20-23].

### Caregivers' burden

The experience of caregiving subjects' caregivers to negative aspects which are commonly known as "burden". The concept of burden has been defined through the literature as emotional and psychosocial issues, negative events, tough situations, and major life changes as a result of caregiving. Burden includes objective burden associated with the concrete problems and observable consequences on the family, as well as subjective burden being the psychological reactions and resulting in affecting well-being.

In our sample, the mean score on the ZBI for caregivers was 58 which are considered as a high burden. Analysing caregivers' characteristics that might modulate the perception of burden results showed a higher level of burden in younger caregivers. In fact, younger caregivers who have spent less time with the patient may develop maladaptive coping strategies [24].

Our results also showed a higher level of burden among parents. This result is consistent with the data in the literature [20,24], and could be related to their greater involvement both practically and psychologically, which seems obvious within a patriarchal society as this is the case in Tunisia [20].

In our study, burden of care was associated with the number of years that the relative has been caring for the patient. In fact, extended exposure may affect coping strategies and impact caregivers' physical and moral health [20,24,25]. We also found higher levels of burden in caregivers when patients had aggressive behavior. In addition, burden was proportional to the mean dose of antipsychotics in chlorpromazine equivalent, which could be an indicator of the severity of the disease.



## Caregivers' stigma

The average caregiver stigma score was 15.34 for a maximum possible score of 20. Almost all caregivers reported experiencing stigma in at least one of the suggested areas. Our results are similar to those of other studies [20,24,26], assessing the stigma of informal caregivers in developing countries but go against those published in developed countries, which may be related to the cultural dimension of stigma [14,17,19,22].

In a study conducted in Ethiopia, stigma was described as high in 47.4% of caregivers and very high in 52% of them [24]. Indeed, the attitude of society towards schizophrenic patients and their families varies according to the cultural representation of schizophrenia and cultural beliefs about mental illness. Studies in this regard have shown greater tolerance and less stigmatization in developed countries with, as a corollary, a lesser sense of worthlessness of schizophrenic patients and their families, allowing them to live far from prejudices, shame, and secrecy [21,27].

As shown in the literature data caregivers' stigma was inversely proportional to the age of the patients as it is associated with disillusionment and disappointment about their future perceived as now hampered by schizophrenia. Caregivers perceived significantly more stigma when the patient had judicial records which is an even more plausible argument to marginalize these patients and their families are thus affected, in a collateral manner, by social discrimination [14,15].

As for caregivers' characteristics, those who were less educated had significantly higher stigma scores which could be explained by the fact that stigma is a social product based on the ignorance of the aspects of schizophrenia as a mental disease [28]. In this regard, several authors have described anti-stigma programs incorporating interventions to improve knowledge about mental illness [29]. Furthermore, parents had significantly higher stigma scores, compared to spouses, descendants, and siblings. Indeed, being the carriers of pathological genes that have caused schizophrenia in children is a source of shame for parents [30,31]. In this same context, significantly higher levels of stigma were found among caregivers explaining schizophrenia by hereditary causes.

## Limitations

To the best of our knowledge, our study is the first to report the experienced stigma in caregivers of patients with schizophrenia in Tunisia, which will provide a possible comparison to other studies from different cultures and countries. However, it has a few limitations; the first is related to the sample size that is not representative of the entire caregivers' population. Second, the transversal nature of the study will not permit us to follow the longitudinal changes. Other prospective studies are therefore recommended to better monitor the impact of stigma. Besides, the lack of a control group, and the lack of randomization and performing the study in a single center are other limitations to this study.

## Conclusion

Caregivers of patients with schizophrenia, although thought to be a privileged source of emotional and social support, are hardly considered following the deinstitutionalization movement. Perceived stigma scores were significantly higher among illiterate caregivers, those linking schizophrenia to hereditary causes, among parents, and in case of daily contact with the patient. Stigma perceived by natural caregivers of patients with schizophrenia is an issue of vital importance as it affects not only the caregiver but also the course of the mental illness as well as the patient's care.

## Declaration of Interest Statement

The authors declare that they have no conflict of interest.

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**How to cite this article:** Farah, Znaidi, Ellouze Sahar, Jenhani Rim and Bougacha Dhouha, et al. "Perceived Stigma and Burden in Tunisian Natural Caregivers of Patients with Schizophrenia." *Clin Schizophr Relat Psychoses* 16S (2022). Doi: 10.3371/CSRP.FZES.052322.