

Burden of Family Caregivers of Schizophrenic Patients in Gaza Strip, Palestine

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Abstract

Background: Schizophrenia is one of the most devastating psychiatric disorders that affect the Palestinian families. Schizophrenic caregivers in Gaza strip experience more significant stressors and have a higher level of burden.

Objectives: This study examined the level of physical, emotional, economic and social burden experienced by the caregivers of schizophrenic patients in Gaza strip as well as determining the association between burden and socio-demographic characteristics of both caregivers and patients.

Method: Descriptive cross-sectional design was used. Eligible 120 caregivers of schizophrenic patients were randomly recruited from different governmental community mental health centers in Gaza strip. They were interviewed to complete a set of questionnaires including: socio-demographic characteristics of patients and caregivers, and the Caregiver Burden Assessment Scale (Cronbach's coefficient, 0.92). Descriptive measures, T-test, ANOVA and Pearson correlation coefficient (r) were used. P was significant at 0.05 or less.

Results: Most of the caregivers were females (68.1%), aged 40 years or more (45.3%), low educated (47.5%) and unemployed (72.0%). About 52.5% provide care for at least 10 years. The caregivers suffer from very high level of overall burden (Relative weight 74.5%). The physical burden was the highest (RW 81.0%), while the social burden was the lowest (RW 68.3%). There were significant differences in level of burden, and education, occupation and monthly income of both caregivers and patients. Whereas, no significant association was found between level of burden and caregiver's age, gender, period of care, and the relationship with the patient.

Conclusion: Burden on caregivers of schizophrenia patients was overwhelming which could be reduced by implementing psycho-educational and rehabilitation programs for schizophrenic patients' caregivers.

Keywords Schizophrenia, Burden, Stressors, Caregivers, Gaza Strip.

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أعباء مقدمي الرعاية من ذوي مرضى الفصام العقلي في قطاع غزة- فلسطين

ملخص الدراسة

خلفية الدراسة: يعتبر الفصام العقلي من أشد و أخطر الاضطرابات النفسية التي تؤثر على الأسرة الفلسطينية، حيث يلقي بالعديد من الأعباء والضغوطات على المرضى و القائمين على رعايتهم.

أهداف الدراسة: هدفت الدراسة لتقييم مستوى العبء الجسدي والعاطفي والاجتماعي والاقتصادي الملقى على عاتق مقدمي الرعاية من العائلة لمرضى الفصام العقلي، ومدى علاقته بالمتغيرات الديموغرافية للمريض و لمقدم الرعاية من عائلته على حد سواء.

إجراءات الدراسة: اعتمدت هذه الدراسة المقطعية المنهج الوصفي التحليلي، حيث ضمت عينة قوامها 120 شخصا من مقدمي الرعاية لمرضى الفصام العقلي المترددين على مراكز الصحة النفسية المجتمعية الحكومية في قطاع غزة، حيث تم اختيارهم باستخدام الطريقة العشوائية المنتظمة. تم جمع البيانات عن طريق اجراء مقابلات مع مقدمي الرعاية للإجابة على 3 استبانات تضمنت بيانات شخصية اجتماعية وديموغرافية عن مريض الفصام و مقدم الرعاية من عائلته و كذلك أسئلة تقيس الأعباء الاقتصادية، الجسدية، النفسية و الاجتماعية على مقدم الرعاية وذلك باستخدام مقياس من تصميم الباحثين. اعتمد الباحث التحليلات الوصفية و اختبار T و اختبار تحليل التباين و معامل الارتباط بالإضافة إلى تحليلات إحصائية أخرى.

النتائج: أوضحت النتائج أن معظم مقدمي الرعاية من عائلات مرضى الفصام كانوا إناثا (68.1%)، تزيد أعمارهم عن الأربعين (45.3%)، بمستوى تعليمي متدني (47.5%)، وبدون عمل (72%)، ويقدمون الرعاية لمرضى الفصام منذ أكثر من عشر سنوات (52.5%). كما أظهرت الدراسة أن مستوى العبء الكلي الملقى عليهم كان مرتفعا جدا، حيث بلغ الوزن النسبي للعبء (70.9%)، وقد سجل العبء الجسدي أعلى مستوى (81%) بينما سجل العبء الاجتماعي أدنى مستوى (68.3%). وقد كشفت الدراسة عن وجود فروق ذات دلالة إحصائية في مستوى العبء تعزى للمتغيرات التالية (مستوى التعليم، المهنة و معدل الدخل الشهري لكل من المريض ومقدم الرعاية). كما أظهرت الدراسة عدم وجود فروق في مستوى العبء تعزى للمتغيرات التالية (العمر، الجنس، وفترة تقديم الرعاية، وعلاقة القرابة بين مقدم الرعاية والمريض).

الخلاصة: خلصت الدراسة الى أن العبء بمختلف أنواعه على مقدمي الرعاية لمرضى الفصام في قطاع غزة كان على مستوى مرتفع، بحيث يزداد مع تدني المستوى التعليمي وانخفاض الدخل الشهري. وقد أوصت الدراسة بالتركيز على هذه الفئة واستحداث برامج تأهيلية و تثقيفية ودعم نفسي ومادي لهم لتخفف عنهم بعضا من هذه الأعباء الهائلة.

الكلمات المفتاحية: الفصام، العبء، الضغوطات، مقدمي الرعاية، قطاع غزة.

1. Background:

Schizophrenia is one of the most devastating psychiatric disorders that affects about 1% of the world's population [1], most of them are between the ages of 15 and 35 years [2]. The disorder is characterized by fundamental disturbances in thinking, perception, emotions and other features of behavior [3].

Globally, nearly 3% of the total burden of human disease is attributable to schizophrenia [4]. According to WHO, the number of people with schizophrenia around the world can be estimated at about 29 million, of whom 20 million live in developing or least developed countries [2]. There are many studies conducted worldwide affirming the existence of burden among caregivers of patients with schizophrenia. Patients and caregivers' characteristics, family size and economic status, role expectations and illness-related beliefs, such as wide variability, combined with cross-cultural differences, leads to estimates of prevalence of family burden ranging between 30% and 80% [5].

In Gaza strip, there is no accurate statistics about the real number of schizophrenic patients. However, the information collected from six governmental community mental health centers, revealed existence of about 1000 cases registered in those clinics.

The WHO has estimated that about 40-90% of patients with schizophrenia live with their families [6]. Family caregiver is the most important person who assumed the responsibility for persons with schizophrenia, and overwhelmed by the demands of caring for them [7, 8]. Numerous studies have demonstrated that family caregivers of persons with severe mental illness experience significant stresses and have a high level of burden [9]. Burden of care is more defined by its impact and consequences on caregivers. Caregiver burden in mental illness can be either objective or subjective. According to Ivarsson et al. [10], objective burden is the existence of problems and changes in family life (household routine, relationships, and

leisure time) that occur because a family member requires care due to an illness. While Subjective burdens comprise emotional strain on caregivers, e.g. fear, sadness, anger, guilt, loss, stigma and rejection [11,12]. The burden on relatives of people with schizophrenia may be influenced not only by patient and caregiver characteristics [13], it also correlates with patient's illness variables [14], availability of caregiver's resources as well as coping skills [15].

Few studies have examined the burden of caregivers of schizophrenic patients in Arab countries. Therefore, it was worthy to investigate this phenomenon in Gaza Strip where no such study has been conducted. The Palestinian families in Gaza are faced with additional difficulties such as limited resources, shortages of medications, lack of psychosocial interventions and rehabilitation services, and absence of psycho educational and intervention programs for their families, which can further complicate the problem of caring for those patients in home environment, especially after shifting care toward community setting.

1.1 Literature review: Research evidences from different countries on family caregivers of persons with schizophrenia indicated that family caregivers report high levels of burden related to caring for their mentally ill family members. Many family caregivers reported not having the knowledge and skills necessary to take on the responsibilities of care giving for these relatives. Thus, they are unable to cope with a considerable amount of the caring roles and responsibilities [16]. The most immediate impact of providing care is the use of the caregiver's time, which often infringes on the time available for other life activities. Caregivers have reported restriction on personal time and socialization as a result of care giving. This restriction on caregivers' activities has, in turn, been identified as a critical cause of depression among caregivers [17]. In addition, the objective demands of providing care impact other aspects of the caregiver's life and may manifest in

perceptions of role conflict and overload [18]. As caregivers struggle to balance work, family, and care giving, their own physical and emotional health is often ignored. In combination with the lack of personal, financial and emotional resources, many caregivers often experience tremendous stress, depression, and/or anxiety in the year after care giving begins [19]. The prevalence of depression for caregivers of individuals with psychiatric illnesses has been estimated to range from 38 to 70 percent [20]. One of the most consistently found predictors of caregiver's depression as well as overall distress is the severity of the patient's symptoms. A considerable body of research has examined the specific ways in which caring for a patient with schizophrenia can impact mental well-being. Common consequences include feelings of uncertainty, shame, guilt, and anger [21]. A loved one's mental illness may lead to a disruption of household and work routines and a loss of productivity for the family unit [22]. On the other hand family members are often put in a position where they are required to pay for medical treatment for their loved one with a mental illness, as well as bear the brunt of a potential increase in medical costs for other family members [23].

1.2 Objectives of the study: This study aimed at investigating the burden of care experienced by the caregiver of schizophrenic patients in Gaza Strip, to better understand caregiver's views and personal perceptions of the stresses and demands arising from caring for relative with schizophrenia. It examined the level of physical, emotional, economic and social burden on caregivers, as well as the socio-demographic correlates of the burden on caregivers among relatives of patients with schizophrenia.

2. Methodology:

2.1 Design and study placement: A cross sectional, analytic design was employed in this study. This study was conducted at Gaza governmental community mental health

centers from December, 2012 to February, 2013.

2.2 Population: All families live with schizophrenic patient. According to registration offices in governmental community mental health clinics (CMHC) in Gaza strip; they are estimated by one thousand patients.

2.3 Sample and sampling: One-hundred and seventy primary caregivers were randomly selected to participate in this study. This sample size was calculated by using the following formula, $(n = \frac{N}{(\infty) 2 \times N + 1})$. (N) Refer to the population; (n) refer to the sample; level of significance = 0.05; N= 650, according to the inclusion criteria. $n = \frac{650}{(0.05)2 \times 650 + 1} = 169$ subject.

2.4 The pilot sample of study: The pilot study sample consisted of 30 family caregivers of schizophrenia patients in governmental community mental health services in Gaza Strip. They are excluded from the final sample because of the changes on the scale. The final sample were 140 subjects, only 120 participants were interviewed, the other twenty refused to participate.

2.5 Inclusion criteria: A caregiver must be: 18 years old and above; taking care of a patient with Schizophrenia as per the DSM-IV-TR criteria; taking care of a patient who is on medication and on regular follow up in outpatient department for the past 6 months and; primary caregiver for at least last 12 months.

2.6 Exclusion criteria: The caregiver will be excluded from the study: if the caregiver is less than 18 years old and; if the caregiver has a history of psychiatric disorder.

2.7 Instruments:

1. Demographic information sheet: It included demographic information for both the patients and their caregivers. For patients, these included patients' age, gender, marital status, duration of illness, education level,

occupation, income level. For caregivers, it included age, gender, marital status, education level, occupation, income level, relationships to the patient, and years of care giving.

2. Family Burden questionnaire: To assess caregiver's burden of patients with schizophrenia, the researcher has developed an instrument, which include 41 items, divided into four domains, the first 7 address financial burden, the next 10 address physical burden, the third 14 address emotional burden and the last 10 items address the social burden. The item scale is 3-point Likert type scale ('1'- 'little', '2'- 'To some extent' and '3'- 'very much').

2.8 Reliability of the scale: The Cronbach's alpha for the burden scale was 0.92 and the modified Spearman-Brown correlation coefficient was 0.79 which indicated high reliability of the scale.

2.9 Ethical considerations and data collection procedure: Ethical and administrative approval to conduct the study was obtained from the Islamic University of Gaza, and General Directorate of Mental Health. Patients' caregivers who met the inclusion criteria and agreed to participate in the study signed a consent form. Then, the caregivers were interviewed for approximately 20 minutes to complete the questionnaire upon their visits to the CMHC.

2.10 Data analysis: The Statistical Package for the Social Sciences (SPSS) was used to conduct analyses. The following statistical measures were used: a) Descriptive measures including count, percentage, mean and standard deviation. b) T-test to compare two independent means. c) One way analysis of variance (ANOVA) test used to compare means of more than two groups. d) LSD test to study the direction of significant differences between categories of demographic variables and their impact on the areas of questionnaire. The level of significance selected for this study was p equal to or less than 0.05.

3. Results:

3.1 Scio-demographic characteristics of caregivers: The final sample of the caregivers consisted of 120 participants. Table 1 presents the socio-demographic variables of caregivers. About 44.1% of the caregivers of the schizophrenic patients aged (31-40) years, 9.2% aged (20 -30) years, and 46.7% aged 40 years or more. The vast majority of caregivers were females (68.1%), while the percentage of male caregivers was 31.9%. Regarding marital status, most of the caregivers were married (85.8%), while 10 % unmarried, 2.5% widowed, and 1.7% divorced. The educational level of the caregivers indicated that about 10.8% were illiterate, 36.7% completed basic education (primary and/or Preparatory), 32.5% completed secondary school, 5.0% have a diploma and 15% have a university degree or higher. The majority of the caregivers were unemployed (72.5%) while 27.5% of them were employed. Monthly income of 66.7% of the caregivers was low (less than 1000 shekel), 20.8% was middle monthly income (1000 to 2500 shekels), while only 12.5% had high monthly income (2,500 shekels and more).

The relationship of caregivers with Patients showed that 38.3% of caregivers were wives of the patients, 19.2% were mothers, 11.7% were fathers, 10.8% were brothers, 9.2% were patients' sisters, 5.8% were patients' husbands, 2.5% patients' sons, and 2.5% were the patients' daughters. Finally, 52.5% of caregivers provide care for 10 years and more, 28.3% provide care for 6-10 years, while 19.2% was 1-5 years.

3.2 Scio-demographic characteristics of schizophrenic patients: Table 2 presents demographic variables for schizophrenia patients. The results showed that 31.7% of patients with schizophrenia aged (31-40) years, 28.3% aged (20-30) years, 24.2% aged (41-50) years, while 15.8% of patients with schizophrenia aged 50 years and over. The majority of patients were males (62.5%) while the female patients with schizophrenia in the sample were 37.5%. About half of schizophrenic patients in this study were

married (53.3%), 28.3% were single, 16.7% divorced and 1.7% widowed. The duration of illness for 63.3% of patients was 10 years or over, 22.5% ranging from 6-10 years, while 14.2% was 1-5 years. The educational level showed that about 10.0% of patients with schizophrenia were illiterate, 40.9% completed their basic education (Primary-Preparatory), 29.2% completed secondary schools, 5.8% had diploma, 13.3% had Bachelor degree, and 0.8% had a master degree or higher. The employment status showed that 87.5% of patients with schizophrenia were unemployed while 12.5% were employed. Regarding the monthly income, 81.7% had less than 1,000 NIS, 13.3% had 1000 to 2500 NIS, while only 5.0% had monthly income of 2500 NIS and more.

Table 1 Social profile and demographics of caregivers of a patient with schizophrenia (N=120)					
Age	N	%	Work	N	%
20-30 years	11	9.2	Employee	33	27.5
31-40 years	53	44.1	Unemployed	87	72.5
40 years and more	56	46.7	Monthly income		
Gender			less than 1000 NIS	80	66.7
Male	39	31.9	1000-2500 NIS	25	20.8
Female	81	68.1	2500 NIS and more	15	12.5
Marital status			Social relation with patient		
Single	12	10.0	Father	14	11.7
Married	103	85.8	Mother	23	19.2
Divorced	2	1.7	Husband	7	5.8
Widowed	3	2.5	Wife	46	38.3
Educational level			Son	3	2.5
Illiterate	13	10.8	Daughter	3	2.5
Primary and prep	44	36.7	Brother	13	10.8
Secondary	39	32.5	Sister	11	9.2
Diploma	6	5.0	Caregiving period		
Bachelor	17	14.2	1-5 years	23	19.2
Master and higher	1	0.8	6-10 years	34	28.3
			10 years	63	52.5

Table 2 Demographic characteristics of the schizophrenic patients in study sample (N=120)					
Gender	N	%	Monthly Income	N	%
Male	75	62.5	less than 1000 NIS	98	81.7
Female	45	37.5	1000-2500 NIS	16	13.3
Age			2500 NIS and more	6	5.0
20-30 years	34	28.3	Educational level		
31-40 years	38	31.7	Illiterate	12	10.0
41-50 years	29	24.2	Primary and prep	49	40.9
50 years and more	19	15.8	Secondary	35	29.2
Marital status			Diploma	7	5.8
Single	34	28.3	Bachelor	16	13.3
Married	64	53.3	Master and higher	1	.8
Divorced	20	16.7	Disease duration		
Widow	2	1.7	1-5 years	17	14.2
Work			6-10 years	27	22.5
Employee	15	12.5	10 years and more	76	63.3
Unemployed	105	87.5			

3.3 Level of burden on caregivers:

The burden on caregivers of schizophrenic patients was measured using the Burden Assessment Scale. Figure 1 and Table 3 showed that the caregivers suffer from very high level of total burden (Relative weight

RW: 74.5%). For the mean scores in each domain, physical burden was the highest (RW 81.0%), followed by financial (RW 79.3%), then psychological (RW 72.4%), while the social burden was the lowest (RW 68.3%).

Table 3 Total burden and ranking of four dimensions of burden on caregivers of patients with schizophrenia in Gaza Strip					
Domain	N	Mean	S.D	Relative weight %	Rank
Financial	5	11.9	3.1	79.3	2
Physical	10	24.3	4.4	81.0	1
Psychological	14	30.4	4.8	72.4	3
Social	10	20.5	5.1	68.3	4
Total Burden	39	87.2	13.2	74.5	-

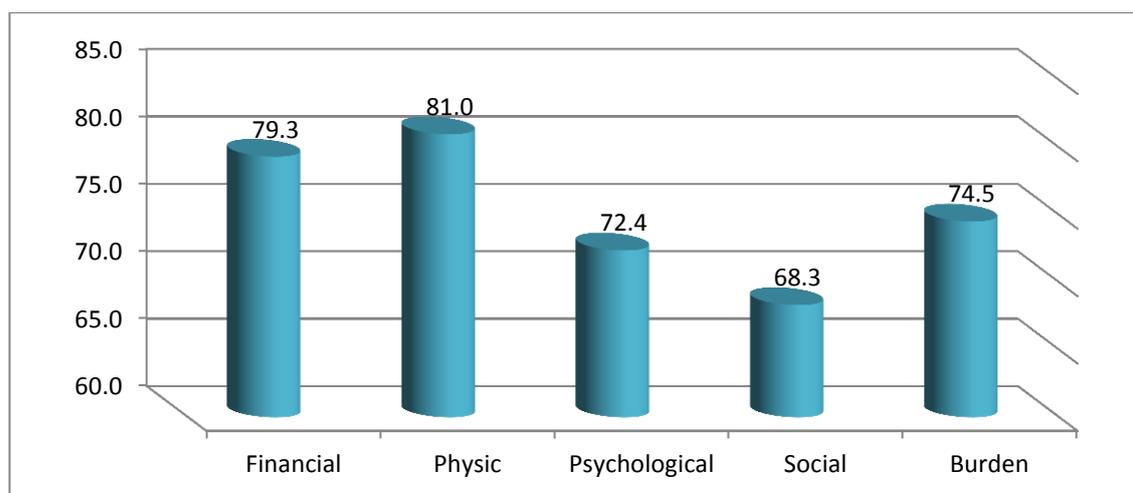


Figure 1 Dimensions of burden of the family caregivers

3.4 The relationship between patients' socio-demographic characteristics and level of burden on caregivers:

There were significant differences in level of burden and gender (t-test= 2.84, p= 0.005), level of education (F-value = 3.98, p-value = 0.036), type of occupation (t-test = -2.48, p-value = 0.041) and monthly income of patients (F-value = 5.11, p-value = 0.007). However, burden had no significant relationship with patient's age (F=1.19, p=0.315), marital status (F=0.660, p= 0.578) and duration of illness (F=0.161, p= 0.851).

3.5 The relationship between caregivers' socio-demographic characteristics and level of burden on caregivers:

There were significant differences in level of burden and education (F-value = 4.51, p-value = 0.004), marital status (F-value = 3.80, p-value = 0.012), occupation (t-test = -2.48, p-value = 0.041) and monthly income of caregivers (F-value = 13.37, p-value = 0.001). Whereas, no significant association was found between level of burden and caregiver's age (F-value = 1.81, p-value = 0.168), gender (t-test = -0.44, p-value = 0.660), period of caregiving (F-value = 1.43, p-value = 0.243)

and the relationship with the patient (F-value = 1.39, p-value = 0.216).

4. Discussion:

The current study showed that the general burden reported by family caregivers of schizophrenic patients was high. The highest scores of burden were found in physical, financial, psychological and social dimensions respectively. This alarming burden could be attributed to many factors including financial difficulties, unemployment, political and economic siege, stigma and discrimination towards mentally ill person as well as their families. Moreover, the burden of caregivers is aggravated by the stress associated with the care giving when the caregiver struggle to balance work, family responsibility and household duties, the illness chronicity and severity of symptoms, and the lack of caregiver knowledge, coping skills , social resources and support.

This finding is supported by Yusuf [24] who reported that a high level of burden was found in 47.3% caregivers and Hassan [25] who found, the total mean score of burden among caregivers was 77.16 ± 15.91 and this indicates that they were suffering from high level of burden. Furthermore, the study of [25] showed that more than half of the participants found to be psychologically distressed. Similarly, many studies on burden of caregivers of patients having schizophrenia conducted so far report significant burden of caregivers with over 90% of families,

experiencing moderate to severe burden [7, 15, 26].

Caregivers' characteristics in this study showed similar pattern with various studies conducted worldwide. In this study, most of the caregivers were females, aged 40 years or more, married, low educated, unemployed, wives or mothers of patients, and provide care for at least 10 years. This findings are congruent with many studies [7, 25, 27-30]. High burden among the caregivers, especially those with old age not only have to take care for the patients; they also have to take care of their own health, as well as other family members which may result in the higher burden they perceived [31]. As the time goes by and the caregivers get older, the caregivers' abilities to fulfill the need of patients or function well in their roles as caregivers are impeded. They are also more likely to worry who will take care of their ill family members in the future [32]. Moreover, schizophrenia is considered a chronic and deteriorating disease, as well as being unstable in nature. Thus, the higher age of the caregivers, the higher burden they reported.

Interestingly, there are some studies that reported different findings. They revealed that age has a negative relationship with burden [33]. From their findings, as caregivers aged, their burden was decreased. The possible explanations for this is that as time goes by, the older caregivers were more familiar with their care giving roles as well as being able to accept their roles as caregivers. Burden of care is most intense during the early years of illness. In other words, even though the age of caregivers is getting higher, but their experiences, knowledge, understandings, as well as abilities to care for and meet the needs of patients are also getting better as well. The intense level of burden diminished when caregivers begin to accept the situation and lower their expectation for the patients. The caregivers felt fewer burdens through an accumulation of day-to-day experience [34].

The results obtained from this study indicated that the majority of caregivers were females, this finding supported by [24, 25]. It can be explained by social gender role. Related to social role, women were predominant in care giving, in other words women spent more time in care giving than men. The findings of this study revealed that caregivers who had lower level of education, reported more burden. This finding was supported by previous studies [7, 30]. This could be explained by the point that the higher level of education of the caregiver tends to have more knowledge of the disorders and how to deal with the stressful event. Therefore caregiver's education level influences burden of the caregiver.

Regarding income status, this study finding stated that low income leads to high burden. This finding was supported by [21, 31, 35, 36]. The possible explanation for this result is that lower income acts as a stressor that influence stress feeling during providing care for ill family member. Beside caregivers providing care for ill member, they also had to solve financial problem and find out source of money, to meet needs of the patient.

Finally, most of the caregivers in this study were mothers or wives of the schizophrenic patients. Findings of this study were consistent with these findings by [7, 28]. This could be explained also by social gender role which is related to stronger normative ties between mothers and daughters and sons.

5. Conclusion:

Burden on caregivers of schizophrenia patients was overwhelming. It is aggravated by caregiver's low education, unemployment and low monthly income. The findings could be used to develop strategies, and intervention to reduce distress and negative consequences in caring for persons with schizophrenia in families in Gaza strip. Therefore, increasing mutual understanding and harmony among the family members, strengthening the patient's functioning and the family members' understanding of psychiatric symptoms and

caring skills are the most important tasks of community psychiatric care to lighten caregiver burden as well as promote quality of life for both the caregivers and the patient.

6. Limitation of study:

Although, this study brought about important information related to burden and its related factors, some limitations need to be addressed. Firstly, although the sample was selected randomly from the patients' lists, it was drawn only from caregivers in governmental mental health centers. Secondly, this study was cross-sectional study which is unable to investigate causal relationships and change overtime, since data were collected at a single point in time.

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