

PSYCHOSOCIAL BURDEN AMONG CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA IN EGYPT

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ABSTRACT

Most studies of family burden have been conducted in developed countries, thus it is important to conduct studies in developing countries, namely Egypt.

Aim of the study: To evaluate the psychosocial burden among caregivers of schizophrenic patients.

Subjects and Methods: A total of 120 schizophrenic patients attending the outpatient Clinic of Zagazig University Hospital with their primary caregivers, using Caregiver Strain Index (CSI), Caregiver Self Assessment Questionnaire (CSAQ), Hamilton Anxiety Scale, Hamilton Scale of Depression.

Results: High level of burden was found mainly among caregivers of disorganized type followed by catatonic type, also high levels of anxiety and depression in disorganized type followed by catatonic type.

Conclusion: Schizophrenia is associated with high level of burden on caregiver. So effort should be made to alleviate the burden for better outcome in both patients and caregivers.

INTRODUCTION

Schizophrenia is probably the most misunderstood mental illness, it is a disabling, chronic psychiatric disorder and poses numerous challenges in its management and Consequences⁽¹⁾.

Schizophrenia affects about 7 per 1,000 of the adult population, most of them between the ages of 15 and 35 years.

The World Health Organization (2010) estimated that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to chronicity of this illness⁽²⁾.

Studies suggested that about 20% of people with schizophrenia show unremitting symptoms and increasing disability, and around 35% of them show a mixed pattern with varying degrees of remission and exacerbations of different lengths⁽³⁾.

In Egypt, schizophrenia is the most common variety of psychosis and represents the major bulk of inpatient in our mental hospital⁽⁴⁾.

With the advent of deinstitutionalization, most persons with schizophrenia are now being cared for in the community by their families. About 25%-50% of persons with schizophrenia stay with their family after discharge from hospital and depend on the assistance and continued involvement of their families. Some studies showed that 70% of clients with schizophrenia live with their family. They depend on the family for care provision⁽⁵⁾ were often served as an extension of the mental system. It is now recognized that globally, caregivers will continue to play an important and r-expanding role, as health and social services as are resource challenged⁽⁶⁾.

Schizophrenia can run a chronic course. Many sons with schizophrenia have a long duration of illness; they lack insight into their illness and have frequent readmissions and relapse various factors might influence the tent outcome in the community, such as the family caregivers' preparation and knowledge and the availability of community resources⁽⁷⁾. If caregivers do not have adequate knowledge and support, they might not be able to take up the responsibilities of taking care of the ill persons, thus leading to relapse or readmission. Some individuals with schizophrenia have impaired cognitive and social functioning and residual symptoms, and these could be a significant family concern⁽⁸⁾.

Living with a relative with severe mental illness is stressful. Numerous studies have demonstrated that family caregivers of persons with severe mental illness experience significant stresses and have a high level of burden⁽⁹⁾. The problem of family burden of caring for persons with schizophrenia is a common challenge in both developed and developing countries.

Families may have to take full responsibility in taking care of the clients or assist in taking care of the clients to certain extent depending on the available services, resource, and support to the persons with schizophrenia and their family caregivers. Family care burdens are echoed and encountered in many parts of the world.

Many often, family caregivers receive little recognition for this valuable work, and policies do not provide financial support for the care services they provide. As caregivers struggle to balance work, family, and caregiving, 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 caregiving begins⁽⁶⁾.

The adverse consequences of taking care of relatives with severe mental illnesses have been studied since early 1950s, when psychiatric institutions began discharging patients to the community^(10,11).

Burden on the family refers to the consequences for those in close contact with a severely disturbed person with mental health problems. Some authors further distinguish between objective and subjective burden. Objective burden relates to the patient's symptoms, behavior, and sociodemographic characteristics, and factors such as changes in household routine, family or social relations, i work, leisure time, and physical health. Subjective burden is the mental health and subjective distress among family members⁽¹¹⁾. From the 1970s to 1980s, the term caregiver burden has been used to describe the adverse consequences of mental disorders for family caregivers. Caregivers' I burden has been studied for determining the feasibility of discharging a patient into community or to refine the concept of caregiving and its underlying structure and contents⁽³⁾.

In recent years, the view of caregiving burden has been broadened to involve the physical, psychological, social, and financial problems experienced by families caring for a relative with a chronic or mental illness. This view has been accepted by the global community⁽⁶⁾.

Research evidences from different countries on family caregivers of persons with schizophrenia generally support that there is inadequate help and support to the family caregivers⁽¹²⁾. Research has also consistently indicated that family caregivers report high levels of burden related to caring for their mentally ill family members. Family caregivers' mental health may become seriously impaired⁽¹³⁾. Many family caregivers reported not having the knowledge and skills necessary to take on the responsibilities of caregiving for these relatives. Thus, they are unable to cope with a considerable amount of the caring roles and responsibilities⁽¹²⁾.

SUBJECTS AND METHODS

This is a cross sectional study was done on a sample of patients with schizophrenia in addition to their caregivers.

The patients and their caregivers were collected from the Outpatient Clinic and Inpatient Psychiatric Department of Zagazig University Hospital from

December 2011 through May 2012. After being informed on the purpose & procedures of the study, all subjects (patients & caregivers) signed an informed consent form.

Patients and their caregivers were selected by randomized controlled trial:

120 patients with schizophrenia diagnosed according to structural clinical interview for DSM IV patients with disorders due to general medical condition, substances misuse and patient with no caregivers were excluded.

Caregivers:

120 caregivers of the selected patients they were spending most of the time with the patients, giving medications to the patients and legally responsible for the mental illness and history of drug abuse.

Psychiatric assessment:

Assessments were conducted using the following instruments:

(A) Caregivers:

(I) Caregiver Strain Index (CSI):

The Caregiver Strain Index (CSI) is a tool that can be used to quickly identify families with potential caregiving concerns. It is a 13-question tool that measures burden related to care provision. There is at least one item for each of the following major domains: employment, financial, physical, social and time. Positive responses to seven or more items on the index indicate a greater level of burden. This instrument can be used to assess individuals of any age who have assumed the role of the caregiver.

A positive screen (7 or more items positive) on the CSI indicates a need for more in-depth assessment to facilitate appropriate intervention. Various domains have been identified and should be addressed in a comprehensive assessment of the caregiving process⁽¹⁵⁾.

(II) Caregiver Self-Assessment Questionnaire:

The self-assessment tool is a questionnaire with 16 "yes/no" items and two global scale items designed to measure indices of emotional and physical distress.

The Caregiver Health Self-assessment Questionnaire (CSAQ) will help caregivers analyze their own behavior and health risks and with their physician's help, make decisions that will benefit both the caregiver and the patient⁽¹⁶⁾.

(III) Hamilton Anxiety Scale:

Objective rating scales for anxiety can be useful in clinical practice for documenting the anxious patient's clinical state. The total Hamilton anxiety Rating Scale (HAM-A) provides an indication of anxiety and, over time, provides valuable guide to

progress. The Hamilton anxiety Rating Scale (HAM-A) is a widely used anxiety scale, with each of its items is rated 0 to 4. The clinician evaluates the patient's answers to questions about symptoms of anxiety and the ratings are derived from the clinical interview. Classification of symptoms where more detail can be obtained can be expanded to: 0 = absent; 1 = mild; 2 = moderate; 3 = severe; 4 = incapacitating. In general the higher the total, score, the more severe the anxiety⁽¹⁷⁾.

(IV) Hamilton Scale for Depression:

Objective rating scales for depression can be useful in clinical practice for documenting the depressed patient's clinical state. The total Hamilton Depression Rating Scale (HAM-D) provides an indication of depression and, over time, provides a valuable guide to progress. The Hamilton Depression Rating Scale (HAM-D) is widely used depression scale with up to 24 items, each of which is rated 0 to 4 or 0 to 2, with a total score of 76. The clinician evaluates the patient's answers to questions about feelings of guilt, thoughts of suicide, sleep habits and other symptoms of depression, and the ratings are derived from the clinical interview⁽¹⁸⁾.

(B) Patients:

- 1) Psychiatric examination.
- 2) Physical examinations: to exclude patient with serious medical illnen.
- 3) SAPS and SANS.
- 4) Global assessment of function for evaluating clinical condition (GAF).

Statistical methods:

Data analyzed by WINPEP statistical program. All data are expressed as means ± S.D. Analysis of trends was performed using linear regression. When comparing two groups, a student's t test was used, and to analyze data among groups of three or more, a one way ANOVA was performed and secondary analysis was performed with the student's t test with Bonferroni Correction.

RESULTS

Table (1): Sociodemographic data of caregivers of patients with schizophrenia

Caregivers (n = 120)		
Age		
Mean ± SD	44 ± 5.4	
	No	%
Sex:		
Male	45	34.5
Female	75	62.5
Marital status:		

Single	12	10
Married	62	51.6
Divorced	15	12.5
Widowed	2	1.6
Education:		
Illiterate	48	40
Primary	32	26.6
Preparatory	16	13.3
Secondary	12	10
University	12	10
Occupation:		
Employed	68	57
Non-employed	52	43

Female gender and married persons predominate male gender and non-married persons, most of the patients were illiterate or with low educations and most of them with no work.

Table (2): Comparison between the Socio-demographic data of patients with schizophrenia and mean of burden on Caregiver Strain Index (CSI)

	Burden CSI			
	No.	%	Mean	SD
Sex of the patient:				
Female	51	42.5	7.4	3.84
Male	69	57.5	8	3.36
Sex of the caregiver:				
Male	75	62.5	8.3	3.84
Female	45	37.5	7.2	3.36
Marital status of the caregivers:				
Single	12	10	9.3	3.4
Married	62	51.6	7.2	3.63
Divorced	15	12.5	8.5	4.18
Widowed	2	1.6	9.3	3.47
Separate	10	8.3	8.7	2.8
Relation of the caregivers:				
Parents	90	75	4	3.69
Spouses	15	12.5	8.2	2.28
Others	15	12.5	7	4.0
Occupation:				
Employed	68	57	7.2	2.9
Non-employed	52	43	9.2	3.8

Table (2) shows comparison between the sociodemographic data of patients with schizophrenia and mean of burden on CSI. It is noted that the male patients have greater burden than the female patients, however, the female caregivers have higher burden than the male caregivers respectively. As regard the marital status of the patients, it is noted that the divorced and single patients have greater

burden than the married patients. As regard the relation of the caregivers, it is noted that the spouses

have greater burden than other caregivers.

Table (3): Comparison between the burden of the different types of schizophrenia on caregiver strain index (CSI) and caregiver self assessment questionnaire (CSAQ) by Kruskal Wallis test:

Schizophrenia	No.	%	Burden on CSI		Burden on CSAQ		X ²
			Mean	S.D.	Mean	S.D.	
Paranoid	30	25	6.7	2.3	10.2	1.6	3.8
Undifferentiated	30	25	9.7	2.3	10.9	0.9	3.8
Disorganized	15	12.5	11.6	1.3	15.3	2.5	5.9
Catatonic	15	12.5	10.9	1.5	13.1	2.3	4.6
Residual	30	25	3.6	1.4	5.6	1.8	1.8
Total	120	100	42.6	8.8	54.1	9.1	

*Significant p < 0.05

X² = Kruskal Wallis test

Table (3) illuminates the burden of different types of schizophrenia on CSI and CSAQ, it is observed that: the disorganized type of schizophrenia shows the highest level of burden on CSI and CSAQ respectively, followed by the catatonic type of schizophrenia. The catatonic type of schizophrenia shows level of burden higher than undifferentiated type of schizophrenia on the above mentioned scales, followed by the paranoid

schizophrenia. The residual type of schizophrenia shows the lowest scores of burden on the scales. The difference in the scores of patients on the CSI and CSAQ are shown to be statistically significant for the disorganized, catatonic, undifferentiated and paranoid types of schizophrenia, but not statistically significant for the residual type of schizophrenia.

Table (4): Comparison between the level of anxiety and depression of the caregivers of patients with different types of schizophrenia on Hamilton Anxiety and Hamilton depression scales by kruskal Wallis test:

Schizophrenia	No.	%	Anxiety on HAS		Depression on HSP	
			Mean	S.D.	Mean	S.D.
Paranoid	30	25	27	1.3	21.7	1.4
Undifferentiated	30	25	29.7	1.4	30.8	1.8
Disorganized	15	12.5	40	1.3	41.2	2.1
Catatonic	15	12.5	34	1.1	38.2	0.8
Residual	30	12.5	17.1	1.5	15.6	0.9
Total	120	100	150.2	6.6	148.9	7

*Significant p < 0.05

Table (4) shows the comparison of different types of schizophrenia on both Hamilton Anxiety and Hamilton depression rating scales: it is found that: the caregivers of the disorganized type of schizophrenia shows the highest level of anxiety and depression on HAS and HSD respectively (mean ± SD = 40 ± 1.3, 41.2 ± 2.1) followed by catatonic type of schizophrenia (mean ± SD = 34 ± 1.1, 38.2 ± 0.8). The caregivers of the undifferentiated type of schizophrenia shows level of anxiety and depression less; than the catatonic type of schizophrenia on the above mentioned scales (mean ± SD = 29.7 ± 1.4, 30.8 ± 1.8) followed by the paranoid schizophrenia (mean ± SD = 27 ± 1.3, 21.7 ± 1.4). The caregivers of the residual type of schizophrenia shows

the following scores of anxiety and depression on the scales (mean ± SD =17.1 ±1.5, 15,6 ± 0.9). The difference in the scores of patients on the HAS and HSD as demonstrated are shown to be statistically significant for the disorganized, catatonic, undifferentiated and paranoid types of schizophrenia, but not statistically significant for the residual type of schizophrenia.

DISCUSSION

Care for schizophrenic patients relies heavily on the informal care provided by relatives regarding sociodemographic characteristics of the studied group female gender and married persons was higher than male gender and single persons.

These findings are consistent with the tradition of the Egyptian community especially in Sharkia Governorate, females are the caregivers for patients with mental illness this finding.

The mean ages of the caregivers were within the productive age group which leads to loss productivity and economic implications on the family and the society.

The majority of caregivers were working (mostly in farming) with low income insurance to pay for patients medical expenses.

The mean (CSI) scores were lower among married group may be due to mutual support between spouses, these finding is consistent with⁽¹⁸⁾.

Parents especially mothers were the caregivers with the highest score (CSI), this finding is consistent with⁽¹⁹⁾, this is because a large percentage of them are primary caregivers, taking responsibility for all the care of their schizophrenic son. This is due to the greater involvement of mothers, both psychologically and in practice (in their role)⁽²⁰⁾ and is an aspect that needs to be addressed more actively by mental health professionals^(12, 22, 23). Some authors have even argued that the care given by mothers is a 'moral obligation' within a patriarchal society, in that this care towards others represents the way they connect with the social sphere⁽⁸⁰⁾. Whatever the case, most studies report that the mother is the one who takes care of the patient^(81 - 85), and even when they share the patient's care with other relatives it is likely that the women, the primary caregivers and other experiences a greater burden.

The mean (CSI) score were higher among nonemployed caregivers the absence of an effective health insurance to pay for patients medical expenses, as a result the entire burden of medical of the medical bills is borne by patients and their relatives, this finding are consistent with findings of^(24, 25, 26, 27).

In our study we found that caregiver burden is the highest in disorganized and catatonic types of schizophrenia and it is the lowest in residual type of schizophrenia, this finding is consistent with finding of^(29, 30, 31).

The present study showed that high levels of anxiety and depression among caregivers of the patients, this findings is consistent with the finding of^(32, 33, 34).

The results confirmed that caregivers have depressive disorder in high levels, these findings are consistent with most of the recent researchers^(35-37, 38-40, 42-44, 45).

High prevalence of depression among caregivers of schizophrenia can be explained primarily due to many burdens financial burdens role burden, physical burden, time burden and emotional burden. A result consistent with many previous studies^(35, 42, 44).

So, reducing stress, isolation and stigmatization is very important for reducing depression among caregivers of schizophrenic patients^(38, 46) and must be taken into account when planning for intervention by mental health professionals⁽⁴⁷⁾, better liaison is required between psychological medical professionals and caregivers to see whether they are psychologically helping caregivers of schizophrenic patients to know about their severity of depression and treat it⁽³⁶⁾.

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العبء النفسي الاجتماعي بين المعتنين بمرضي الفصام في مصر

المقدمة:

يعد مرض الفصام من الأمراض النفسية المزمنة والتي تسبب الإعاقة وتضع الكثير من التحديات في علاجه ومضاعفاته. كما أن الرعاية الأسرية لمرضي الفصام تمثل عبئاً كبيراً علي القائمين برعايتهم، ومع ذلك فإن معظم الدراسات المتعلقة بالعبء الأسري قد أجريت في الدول المتقدمة ولذلك فإنه من الضروري القيام بهذه الدراسات في الدول النامية وخصوصاً مصر.

الهدف من الدراسة:

تقييم العبء النفسي والاجتماعي بين المعتنين بمرضي الفصام.

المرضي وطرق البحث:

أجريت الدراسة علي مائة وعشرون مريضاً بالفصام من المترددين علي العيادة الخارجية بـالطبيب النفسي بجامعة الزقازيق مع راعيهم الأساسي وذلك باستخدام مؤشر عبء الرعاية ، استبيان التقييم الذاتي للرعاية، مقياس هاميلتون للاكتئاب ومقياس هاميلتون للقلق.

النتائج:

وجد أن معدل العبء مرتفع بين المعنيين بمرضي النوع غير منتظم من الفصام يليهم النوع التخشبي كما وجد أن معدل القلق والاكتئاب عالية بين المعتنين بمرضي النوع غير المنتظم يليهم النوع التخشبي.

الاستنتاج:

مرض الفصام مصحوب بمستوي عالي من العبء علي القائمين علي المرضي.