# Caregiving Burden and Psycho-Educational Needs among Families of Patients with Psychotic Disorders

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#### Abstract

Background: Family caregiving causes stress, depression and financial difficulties. Therefore, caregivers require emotional support and psycho-education to effectively provide care and support to their relatives with mental disorders. Aim of the study: Assess the caregiving burden and psycho-educational needs among families of patients with psychotic disorders. Research **Design:** A descriptive design was used in the present study. **Setting:** The study was conducted in the outpatient clinic of El-Maamoura Hospital for Psychiatric Medicine. Subjects: A convenient sample of 150 family caregivers of patients with psychotic disorders was recruited. Tools: Three tools were used to collect the data (Caregiver Burden Inventory, The Educational Needs Questionnaire, and Family Caregivers Socio-Demographic and Clinical Data Structured Interview Schedule). **Results**: The majority of caregivers (93.3%) had a risk of burnout and near to two thirds of caregivers (64.0%) showed high interest in the educational needs. Conclusion: Caring for a patient with psychotic disorder within a family can put a great burden on whoever is providing the care to the extent of exposing them to the risk of burnout. In response, the need for psychoeducation is expected and highly expressed by the caregivers, especially in the areas of coping with stress, patient's social functioning, patient's symptoms and the resources available to help and support them. Recommendations: A routine assessment of the psycho-educational needs and caregiving burden of families' caregiver must be carefully considered while developing familycentered interventions.

**Keywords:** caregiving burden, psycho-educational needs, family caregiver and mental disorders.

### Introduction

Over the last few decades, the focus of mental health care worldwide has moved from extended institutionalization in inpatient settings toward shortened inpatient stays followed by a continuum of extended community-based services for these people and their families (Lee & Seo, 2020). As well, mental health professionals have begun to recognize families as primary long-term caregivers and as an important resource for their relatives with mental illness (Chadda, 2014). Based on that

shift, the New Egyptian Mental Health Law (2006 and revised 2009) emphasized the importance of developing and organizing such community mental health services, to provide more comprehensive care to mental patients and their families within the community (WHO, 2006), (Health and Human Rights Programs, 2009).

In fact, this deinstitutionalization movement resulted in many patients with an enduring course of psychosis being discharged into communities that are not well prepared to care for them. Therefore, families, by choice or by necessity, are faced by the fact of having the responsibility of caring and providing support for those ill relatives (Hsiao & Tsai, 2014). Most of these families are often inadequately prepared for the role of caregiving (Kate et al., 2013). Such as an example, family caregivers of adults with schizophrenia spend an average of six to nine hours per day providing care and attention (Kaushik & Bhatia, 2013). They may feel forced to undertake such a role, without having the needed knowledge and skills necessary to cope with this complex chronic mental illness (Vella&Pai,2013).

It was noted that family members are significantly distressed by the fact of having one of their members suffering from a psychiatric disorder (Chadda, 2014). As they take on the role of caregiving, family caregivers experience high burden along with multiple issues and challenges including coping with changes and loss, distress, frustration, helplessness, anxiety, depression, stigma of mental illness, exhaustion, "losing face", economic strain and lack of community resources and support (Caqueo-Urízar 2014). The burden of caregiving is a complex multifaceted construct which may defy a uniformly agreed simple definition. It is a dynamic process which includes a patient, and a person who is involved in long term care of this patient (Nguyen, 2016). The concept was first introduced by Treudley (1946) as the negative impact of caregiving on caregiver's mental health and quality-of-life. The caregiver burden has been described as having two dimensions; objective and subjective (Chadda, 2014), (Caqueo-Urízar 2014). The objective burden refers to the tangible and observable effects of the caregiving on the family resulting from the symptoms and behavior of patients such as disrupted family routines, constraints family's social and leisure activities and financial costs. On the other hand, the subjective burden relates that the psychological reactions or attitudes toward the caregiving experience includes the caregiver's negative appraisal of circumstances such as feelings of loss, guilt, shame, and/or anger (Hsiao et al., 2020), (Chadda, 2014).

To be specific, when a family member has been diagnosed with a psychotic disorder,

the illness may undermine the accomplishment of the family's tasks in the present, and change their hopes, plans, and expectations for their future (Abdul-Mulud & McCarthy 2017). Furthermore, psychotic illnesses have farreaching consequences not only for the quality of life of the patients but also for those who are caring for and living with them, such as parents, siblings or other informal caregivers. Caregiver's burden is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience for such a patient (Papalia et al. 2015).

In this respect, it was argued that family members who are caregivers for patients with psychiatric disorders have a need to know about such disorders, its nature, the prescribed medications, the disease process and outcome, signs of relapse, and so on (Bai et al. 2020). In other words, they need psycho-education. Psycho-education is an evidence-based practice providing information to the family about the illness, its treatment and the ways of coping with it. It has a significant place in increasing the families' functionality, in assisting them to cope with the illness, in reducing the sufferings experienced by the family and in decreasing the probability of recurrence of the illness (Alugo et al., 2017). It was stated that the intervention programs that focused on caregivers' needs, improve their experience in providing care and reduce the psychological distress suffered by those caring for people with severe mental illness (Mubin et al., 2020). Family-based interventions have proven efficacy in reducing relapse rates and negative impact of psychosis on caregivers and can reduce negative attitudes and increase the willingness of the caregivers in providing care to patients (Fitrvasari et al., 2021).

Family caregivers, who undertake the difficult task of managing a psychotic illness at home, have a variety of educational needs which psychiatric professionals, including nurses, infrequently meet. Paramount amongst these is providing families with information about the illness itself. Family caregivers need to learn sophisticated, up to-date methods for coping with the member with mental illness on

a daily basis, such as effective communication skills and procedures for improving compliance with the prescribed medication. Other caregivers need to be told as how to manage out or control behaviors and how to deescalate high levels of anger in a threatening family member (Alugo et al., 2017), (Wei et al., 2010).

Caregivers require emotional support and psycho-education to effectively provide care and support to their relatives with mental disorders. Offering emotional and practical support has been found to reduce burden among caregivers of patients with mental illness (Janah & Hargiana 2021). Furthermore, caregivers' psycho-education can increase sense of support from the treatment team and a nearly significant tendency toward a decrease in selfblame regarding the mental illness (Dastan & Kilic 2014). On the other hand, a lack of knowledge and information about the illness may lead caregivers to misattribute some of the patient's behavior, resulting in criticism, frustration or feeling of loss (Soliman et al., 2018), (Glick et al., 2011).

A full understanding and satisfaction of specific family psycho-educational needs can play an important role in the development of a holistic model for family-centered care for mental illness (Hsiao et al., 2020), (Hsiao & 2014). Determining these psychoeducational needs may be the first step to help psychiatric nurses develop psycho-educational programs to motivate the families of patients with psychotic disorders. As well, this will increase families' knowledge and skills in developing and maintaining successful management of patients' symptoms enhancing their effective coping methods. Consequently, their burden would be minimized and their patient's defaulting from outpatient follow up, relapse and re-hospitalization rates would be reduced (Fitryasari et al., 2021).

These aforementioned achievements are among the main objectives of shifting to deinstitutionalization and community mental health care.

Therefore, it is essential for psychiatric nurses to identify the burden on the caregivers

of the patients they are caring for. Early identification and suitable interventions would help in keeping this support base intact, healthy and effective. Nurses need to take timely assessment of the psycho-educational needs of the caregivers in order to provide necessary support and interventions. Without adequate understanding of family educational needs in caring for patients with mental illness, there is uncertainty about the impact of family education programs on meeting the specific needs of family caregivers and patients (Alugo et al., 2017), (Chadda, 2014).

## Aims of the study

The present study aimed to:

- 1. Assess the caregiving burden among families of patients with psychotic disorders.
- 2.Determine the psycho-educational needs among families of patients with psychotic disorders.

## Research questions

This study posed the following research questions:

- 1. What is the degree of caregiving burden among families of patients with psychotic disorders?
- 2. What are the psycho-educational needs of family caregivers of patients with psychotic disorders?

### **Materials and Methods**

### Materials

## I. Research Design:

A descriptive design was used in the present study.

### II. Setting:

The study was conducted in the outpatient clinic of El-Maamoura Hospital for

Psychiatric Medicine which is affiliated to the Ministry of Health and Population. The hospital serves three governorates, namely; Alexandria, Matrouh and El-Beheira. The psychiatric outpatient clinic provides free treatment services for all patients suffering from mental illness, having drug dependency and organic brain diseases. It works 6 days a week (Saturday through Thursday), from 9 am to 1 pm. The services provided at the outpatient clinic include medical examination, diagnosis, dispensing necessary medications and referral to the inpatient departments when necessary. Follow up of previously discharged inpatients is another important service made to ensure smooth course of the disease and predict or identify early signs of relapses.

### III. Subjects:

The Epi info 7 program was used to estimate the sample size based on using 10% acceptable error, 99% confidence coefficient, 60% expected frequency and population size of 1260, the program revealed a minimum sample size to be 113 patients with psychotic disorders. Thus, it was decided in the present study to recruit a convenience sample of 150 family caregivers of patients with psychotic disorders who meet the following inclusion criteria:

- a) Living with the patient in the same household.
- b) Currently engaged in physical, financial, and/or emotional caregiving for this patient.
  - c) Aged 18 years or older.

### IV. Tools:

In order to collect the data of this study, three tools were used:

## Tool I: The Educational Needs Questionnaire (ENQ):

This self-report questionnaire was developed by **Mueser et al.**, (1992) to assess the educational needs of family caregivers. The

ENO has 45 items which are classified into six general domains; basic facts about mental illness (13 items, e.g., symptoms, medication, genetics); coping with patient symptoms (11 items, e.g., negative symptoms, persistent hallucinations, delusions, anxiety, anger); enhancing social functioning (6 items, e.g., improving social relationships, independent living skills); community resources (6 items, e.g., alternative living situations, patient and caregiver self-help groups); coping with stress and family problems (6 items, e.g., stress management, family problem solving); and miscellaneous (3 items: dealing with weight gain, coping with stigma, and planning for when a caregiver dies).

Family caregivers are ought to rate their interest in learning more about each item on a five-point Likert scale, with 1 denoting "not interested" and 5 denoting "very interested". In that case, the total score ranges from 45 to 225, with higher scores indicating greater interest in educational needs (Mueser et al., 1992). In the present study, the questionnaire scaling was reduced to three-point Likert scale (1 "not interested" to 3 "very interested"), with a total score ranging from 45 to 135. This total score was divided statistically into three levels; 45–75, 76-105, and 106-135 for low, moderate and high interest in educational needs respectively. Wei (2008) found that the ENQ was valid and reliable (Cronbach's alpha coefficient ranged from 0.72 to 0.89 for the six domains and it was 0.89 for the total scale which indicates high internal consistency) (Wei, 2008).

## Tool II: Caregiver Burden Inventory (CBI):

The CBI is a 24-item self-report instrument developed by Novak and Guest (1989) to explore the caregiver burden (Novak & Guest 1989). It has five different dimensions (factors) which are time dependent burden (5 items); developmental burden (5 items); physical burden (4 items); social burden (5 items); and emotional burden (5 items).

Each item is rated on a Likert scale from 0 (not at all descriptive) to 4 (very descriptive). A participant's total burden score can range

from 0 to 96, with higher scores indicating higher burden. Subjects with a score of 0 - 23 indicates no need for assistance, 24 - 35 indicates a need to seek some form of respite care, and 36 or more denotes a risk of burnout and reflects a higher degree of burden (Novak & Guest 1989). In the present study, the inventory scaling was reduced to four-point Likert scale (0 "never feel" to 3 "nearly always feel"), with a total score ranging from 0-72. On that base, the total score was modified statistically into scores of 0-17, 18-26, and 27-72 for no need for assistance, a need to seek some form of respite care and risk of burnout respectively.

Validity and reliability of the CBI were tested by Novak and Guest (1989). The CBI proved to be valid. The Cronbach's alpha values for the five factors were 0.85, 0.85, 0.86, 0.73, and 0.77 respectively (Novak & Guest 1989). The Caregiver Burden Inventory was successfully applied on patients with psychiatric disorders as well as on their caregivers in previous studies (Wei, 2008), (Bademli et al., 2017).

## Tool III: Family Caregivers Socio-Demographic and Clinical Data Structured Interview Schedule:

This interview schedule was developed by the researcher to elicit data about the general socio-demographic and clinical characteristics of family caregivers. Such as kinship to the patient, age, sex, marital status, educational level, occupation, income, and family clinical history and caring process, family history of having mental illness, the responsibility of patient care, duration of the caregiving role, and the availability of others helping carers.

### Methods

1.Official written permissions were obtained from the General Secretariat of Mental Health in Cairo and the Director of El-Maamoura Hospital for Psychiatric Medicine in Alexandria.

- 2. Arabic translation and retranslation of tools I and II (ENO and CBI) was done.
- 3.The Socio-demographic and Clinical Data Structured Interview (tool III) was developed by the researcher.
- 4.The translated tools were subjected to face validity by a jury composed of 5 experts in the psychiatric nursing field. This was done to ascertain the appropriateness of these tools for measuring what they are supposed to measure.
- 5.A pilot study was carried out on 15% (20 outpatients' family caregivers) in order to assess the clarity, applicability of the tools as well as the time needed for their application. These subjects were excluded from the actual study subjects.

6. The pilot study revealed that tools I and II needed some modifications. These modifications necessitated reducing the scaling of tool I (ENQ) from five-point ("not interested", "slightly interested", "somewhat interested", "rather interested", and "very interested") to three-point Likert scale (1 "not interested", 2 "somewhat interested", 3 "very interested"). This was done because of the difficulty subjects were facing in differentiating between "slightly interested" and "rather interested" on the Likert scale. On that base, the new total score ranged from 45 to 135, with higher scores indicating greater interest in educational needs. Subjects' scores of 45-75, 76-105, and 106-135 indicate low, moderate, and high interest in educational needs respectively.

7.The same process was applied on tool II (CBI) where it was scaled on five-point Likert scale ("never feel", "rarely feel", "sometimes feel", "quite frequently feel", and "nearly always feel"), to become four-point Likert scaled (0 "never feel, 1 "rarely feel", 2 "sometimes feel", 3 "nearly always feel"), i.e., the item "quite frequently feel" was omitted as subjects were unable to differentiate themselves on it. Accordingly, a participant's total burden score then ranged from 0 to 72, with higher scores indicating higher burden. Using the same

ratio of the original scale, caregivers with a score of 0 - 17 indicates no need for assistance, 18 - 26 indicates a need to seek some form of respite care, and 27 or more denotes a risk of burnout and reflects a higher degree of burden.

- 8.Reliabilities of the translated tools (ENQ and CBI) were tested on a sample of 20 patient's family caregivers using Cronbach's Alpha test. Tools I and II proved to be reliable (0.82 each).
- 9. The actual study started by reviewing all medical charts of the outpatients attending the previously mentioned setting. This screening aimed at identifying those diagnosed with psychotic disorders.
- 10. Family caregivers who accompany the above-mentioned patients and who meet the predetermined criteria were recruited as study subjects. Recruited subjects were then interviewed on an individual basis in the outpatient clinic using tool III. This data was double checked with data from medical charts. Tools I and II (ENQ and CBI) were then applied.
- 11. This process continued until the required number of family caregivers (150) is reached.
- 12. Data collection was done during the period from mid of May to the end of August 2015.

### **Ethical considerations**

Throughout the study phases:

- 1. An informed written consent was obtained from each patient's family caregiver after explaining the purpose and nature of the study.
- 2. Patients and their family caregivers' privacy and anonymity were considered and respected.
- 3. Confidentiality of data was assured and respected.

4. The right to participate and to withdraw from the study was emphasized to the studied subjects.

## **Statistical Analysis**

- After data collection, data were revised, coded and fed to the computer and analyzed using SPSS software package, version 20.0.
- Qualitative data were described using number and percent.
- Quantitative data were described using range (minimum and maximum), mean, and standard deviation.
- Reliability of tools was assessed using Cronbach's Alpha test.
- Student t-test was used for normally quantitative variables, to compare between two studied groups.
- F-test (ANOVA) was used for normally quantitative variables, to compare between more than two groups.
- Pearson correlation coefficient test (r) was used to correlate between two normally quantitative variables.
- Statistical significant level in the study was (p) equal to or less than 0.001, 0.01 and 0.05.

### Results

**Table (1)** presents the distribution of the studied caregivers according to their sociodemographic characteristics. It was found that 61.3 % of caregivers were females. Caregivers' age ranged between 19 and 70 years, with a mean age of 45.55±12.44 years. Caregivers whose age ranged from 41 to less than 51 years and from 51 to less than 61 years constituted 31.3% and 21.3% respectively of the total sample.

Speaking about the caregivers' kinship to their patients, 42% of them were either mothers or fathers, while 41.3% of them were either brothers

or sisters. It was noticed that 62.7% of the studied caregivers were married and 20.0% were divorced or widowers.

As regards the educational level, 58.0% of caregivers were illiterate or read and write, while only 4.7% of them had basic level of education. The table also revealed that 42.7% of studies caregivers were working, 37.3% were housewife, whereas those who were not working and retired constituted 10% each. Those who were working in free business constituted 48.4%, employees constituted 21.9%, being workers or farmers constituted 15.6%, while craft workers constituted 14.1%. It was observed that 60.7% of the caregivers considered their income enough.

**Table (2)** shows the distribution of the studied caregivers according to their clinical history and caring process. More than one third of family caregivers (37.3%) had a family history of mental illness. In 39.3% of carers, a father or mother affected with mental illnesses. This table also shows that 24.7% of caregivers were suffering from physical or mental diseases, with most of them (83.8%) were suffering from physical diseases.

Concerning the responsibility of patient's care, 44.7% of the caregivers reported doing it alone. This table also reveals that the duration of caregiving ranged between 1 and 20 years, with a mean duration of 7.67±4.96 years. In relation to the other helping carers, 77.1% of caregivers reported that mothers and/or fathers were the other helping carers.

**Table (3)** illustrates the distribution of studied subjects according to their results on the Caregiver Burden Inventory. It was noted that the majority of caregivers (93.3%) had a risk of burnout, while the rest of the subjects need to seek some form of respite care or had no need for assistance (6.0% and 0.7% respectively).

The total score of caregivers' burden ranged between 16.0 and 72.0, with a mean of  $43.31\pm10.37$  denoting a mean percent of  $60.15\pm14.41$ .

**Table (4)** shows the distribution of studied caregivers according to their scores on dimensions (subscales) of CBI. The total mean score of CBI ranged from 16.0 to 72.0, with a mean of

 $43.31\pm10.37$  expressed as a mean percent of  $60.15\pm14.41$ .

Speaking about the mean scores of CBI subscales, the studied subjects had a score ranging from 0.0 to 15.0 and a mean score of 10.71±2.81 on the "time dependent burden" subscale denoting a mean percent of 71.42±18.70. A score ranging from 0.0 to 12.0 and a mean score of 2.21±0.99 on the "developmental burden" subscale expressed as a mean percent of 14.12±6.62. A score ranging from 0.0 to 12.0 and a mean score of  $6.23\pm2.75$ , reflecting a mean percent of 51.89±22.91 on the "physical burden" subscale. A score ranging from 0.0 to 15.0 and a mean score of  $7.05\pm3.17$  on the "social burden" subscale denoting a mean percent of 46.98±21.16, and a score ranging from 1.0 to 15.0 and a mean score of 9.05±3.23 expressed as 60.31±21.51 on the "emotional burden" subscale.

**Table (5)** shows the distribution of studied caregivers according to their total degree of interest in educational needs using ENQ. It was noted that near to two thirds of caregivers (64.0%) showed high interest in the educational needs, while the rest of the subjects had moderate and low interest in the educational needs (35.3% and 0.7% respectively).

The total score of caregivers' interest in educational needs ranged between 71.0 and 135.0, with a mean of 110.12±16.17 denoting a mean percent of 72.36±17.97.

**Table (6)** illustrates the distribution of the studied caregivers according to their scores on the domains (subscales) of ENQ. Concerning the total mean score of ENQ, the studied subjects had a total score ranging from 71.0 to 135.0, with a mean of  $110.12\pm16.17$  expressed as a mean percent of  $72.36\pm17.97$ .

The same table showed the mean scores of ENQ subscales, the studied subjects had a score ranging from 20.0 to 39.0, with a mean score of 30.28±4.67 on the "basic facts about mental illness" subscale, donating a mean percent of 66.46±17.95. A score ranging from 15.00 to 33.00 and a mean score of 27.09±5.24 on the "coping with patient symptoms" subscale expressed as a mean percent of 73.12±23.80. A score ranging from 7.00 to 18.00 and a mean score of 15.03±2.69 on the "enhancing social functioning" subscale reflecting a mean percent of 75.22±22.41.

A score ranging from 6.00 to 18.00 and a mean score of  $14.06\pm3.41$ on the "community resources" subscale denoting a mean percent of  $67.17\pm28.43$ . A score ranging from 10.00 to 18.00 and a mean score of  $16.59\pm1.77$  on the "coping with stress and family problems" subscale reflecting a mean percent of  $88.28\pm14.71$ , and a score ranging from 3.00 to 9.00 and a mean score of  $7.07\pm1.60$  on the "miscellaneous" subscale expressing a mean percent of  $67.89\pm26.62$ .

Table (7) presents the ranking and mean scores of the studied caregivers' educational needs. The educational needs were illustrated in a descending arrangement from the most expressed interesting educational needs to the least interesting to the caregivers. It was observed that ways of managing stress more effectively (2.91±0.28), strategies for solving problems (2.86±0.35), managing "burn- out" (2.85±0.36), recent research on mental illness (2.77±0.44), early warning signs of illness and relapse

 $(2.77\pm0.45)$ , coping with stigma of mental illness  $(2.77\pm0.52)$ , getting what you need from the mental health system  $(2.73\pm0.49)$ , anger, violence and assaultive behavior  $(2.73\pm0.58)$ , biological theories  $(2.71\pm0.51)$ , and setting limits on patient's behavior  $(2.71\pm0.56)$  were the top ten most interesting educational needs from the caregivers' perspective.

On the other hand, the ten least interesting educational needs for the caregivers were drug/alcohol abuse (1.51±0.85), planning/coping with holidays  $(1.93\pm0.84),$ psychiatric hospitalization  $(1.96\pm0.81)$ , involuntary commitment to hospital (1.99±0.80), dealing with gain  $(1.99\pm0.90)$ , day (2.12±0.88), how psychiatric diagnosis are made  $(2.15\pm0.57)$ , how common is the illness and what tends to happen when a person has it  $(2.20\pm0.57)$ , vocational rehabilitation (2.21±0.88), and coping with depression and suicidal thoughts (2.22±0.91).

Table (1): Distribution of the studied caregivers according to their socio-demographic

characteristics (n = 150)		
Caregivers' socio-demographic characteristics	No.	%
Sex		
Male	58	38.7
Female	92	61.3
Age (in years)		
19 -	24	16.0
31 –	26	17.3
41 –	47	31.3
51 –	32	21.3
61 +	21	14.0
Min. – Max.	19.0 - 70	0.0 Years
Mean ± SD.	45.55	± 12.44
Kinship to the patient		
Mother/Father	63	42.0
Brother/Sister	62	41.3
Husband/Wife	18	12.0
Son/Daughter	4	2.7
Other (uncle and grandfather)	3	2.0
Marital status	3	2.0
Single	26	17.3
Married	94	62.7
Divorced/widower	30	20.0
Education Level	30	20.0
Illiterate/Read and write	87	58.0
Basic education	7	4.7
Secondary education	43	28.7
University education	13	8.7
Working status	13	0.7
Working Status	64	42.7
Housewife	56	37.3
Not working	15	10.0
Retired	15	10.0
Type of job $(n = 64)$	15	10.0
Free business	31	48.4
Employee	14	21.9
Worker / Farmer	10	15.6
Craft work	9	14.1
Income	Ź	- ''*
Not enough	57	38.0
Enough	91	60.7
More than enough	2	1.3

Table (2): Distribution of the studied caregivers according to clinical history and caring process (n = 150)

Family clinical history and caring process	No.	%
Family history of having mental illness		
Yes	56	37.3
No	94	62.7
Kinship of the sick person to the patient $(n = 56)$		
Father / mother	22	39.3
Brother / Sister	13	23.2
Grandmother / Grandfather	6	10.7
Uncle /Aunt	7	12.5
Other (Cousin, father's uncle)	8	14.3
Caregivers suffering from any diseases (mental/physical)		
Yes	37	24.7
No	113	75.3
Type of caregiver's disease $(n = 37)$		
Mental	6	16.2
Physical	31	83.8
The responsibility of patient's care is on		
The caregiver only	67	44.7
Others are helping too	83	55.3
Duration of caregiving (being only carer) (in years) (n=67)		
1-	20	29.9
5 –	32	47.8
10 +	15	22.4
Min. – Max.	1.0 - 20.0  Years	
Mean $\pm$ SD.	$7.67 \pm 4.96$	
Other helping carers (n = 83)		
Mother/Father	64	77.1
Brother/Sister	13	15.6
Husband/Wife	4	4.8
Other (Son or Daughter)	2	2.4

Table (3): Distribution of studied subjects according to their results on Caregiver Burden Inventory (CBI) (n = 150)

Caregiver Burden Inventory (CBI) results	No.	%
No need for assistance (Score:0-17)	1	0.7
Need to seek some form of respite care (Score: 18-26)	9	6.0
Risk of burnout (Score: ≥27)	140	93.3
Total score (Score: 0-72)		
Min. – Max.	16.0 - 72.0	
Mean ± SD	$43.31 \pm 10.37$	
Mean %	$60.15 \pm 14.41$	

Table (4): Distribution of studied caregivers according to their scores on CBI dimensions (subscales) (n = 150)

CBI dimensions (subscales)	Range/Mean score	Mean percent
Time dependent burden (Score: 0-15)	0.0 - 15.0	
	$10.71 \pm 2.81$	$71.42 \pm 18.70$
Developmental burden (Score: 0-15)	0.0 - 12.0	
	$2.21 \pm 0.99$	$14.12 \pm 6.62$
Physical burden (Score: 0-12)	0.0 - 12.0	
	$6.23 \pm 2.75$	$51.89 \pm 22.91$
Social burden (Score: 0-15)	0.0 - 15.0	
	$7.05 \pm 3.17$	$46.98 \pm 21.16$
Emotional burden (Score: 0-15)	1.0 - 15.0	
	$9.05 \pm 3.23$	$60.31 \pm 21.51$
Total of caregiver burden inventory (Score: 0-72)	16.0 - 72.0	
	$43.31 \pm 10.37$	$60.15 \pm 14.41$

Table (5): Distribution of studied caregivers according to their total degree of interest in educational needs using ENQ (n = 150)

Total degree of interest in educational needs	No.	%	
<b>Low degree</b> (Score: 45-75 / <33.3%)	1	0.7	
<b>Moderate degree</b> (Score: 76-105 / 33.3% - 66.6%)	53	35.3	
High degree (Score: 106-135 / >66.6%)	96	64.0	
Subjects' total score (score: 45-135)			
Min. – Max.	71.0 - 135.0		
Mean ± SD	$110.12 \pm 16.17$		
Mean %	$72.36 \pm 17.97$		

Table (6): Distribution of studied caregivers according to their scores on the domains (subscales) of ENQ (n = 150)

Domains (subscales) of ENQ	Range/Mean scores	Mean percent
Basic facts about mental illness (Score: 1-39)	20.0 - 39.0	
	$30.28 \pm 4.67$	$66.46 \pm 17.95$
Coping with patient symptoms (Score: 1-33)	15.00-33.00	
	$27.09 \pm 5.24$	$73.12 \pm 23.80$
Enhancing social functioning (Score: 1-18)	7.00-18.00	
	$15.03 \pm 2.69$	$75.22 \pm 22.41$
Community resources (Score: 1-18)	6.00-18.00	
	$14.06 \pm 3.41$	$67.17 \pm 28.43$
Coping with stress and family problems (Score: 1-18)	10.00-18.00	
	$16.59 \pm 1.77$	$88.28 \pm 14.71$
Miscellaneous (Score: 1-9)	3.00-9.00	
	$7.07 \pm 1.60$	$67.89 \pm 26.62$
Total mean score of ENQ (Score: 45-135)	71.0 - 135.0	
	$110.12 \pm 16.17$	$72.36 \pm 17.97$

Table (7): Ranking and mean scores of the studied caregivers' educational needs distributed by single items (n = 150)

single items	single items (n = 150)			
Number				
of	ENQ items	Ranking	$Mean \pm SD$	
item		C		
11	Ways of managing stress more effectively.	1	2.91±0.28	
13	Strategies for solving problems.	2	$2.86\pm0.35$	
40	Managing "burn- out".	3	$2.85\pm0.36$	
41	Recent research on mental illness.	4	$2.77\pm0.44$	
9	Early warning signs of illness and relapse.	5	2.77±0.45	
45	Coping with stigma of mental illness.	6	$2.77\pm0.52$	
35	Getting what you need from the mental health system.	7	$2.73 \pm 0.49$	
25	Anger, violence, assaultive behavior.	8	$2.73\pm0.58$	
5	Biological theories.	9	2.71±0.51	
14	Setting limits on patient's behavior.	10	2.71±0.56	
16	Improving social relationships.	11	2.69±0.54	
10	Stress and illness.	12	$2.65\pm0.51$	
20	Improving independent living skills.	13	2.65±0.60	
8	Side effect of medication.	14	$2.64\pm0.56$	
12	Improving communication with relatives.	15	$2.64\pm0.58$	
33	Alternatives treatment approaches.	16	2.61±0.61	
36	Applying for financial assistance.	17	$2.59\pm0.71$	
6	Genetics and vulnerability to illness.	18	$2.53\pm0.63$	
28	Sleeping problems.	19	2.55±0.64	
30	Loss of pleasure.	20	$2.49\pm0.73$	
32	Problems with concentration.	21	$2.48\pm0.65$	
31	Lack of interest and motivation.	22	2.48±0.74	
29	Social isolation, avoidance/withdrawal.	23	$2.46\pm0.69$	
24	Anxiety and panic attacks.	24	$2.45\pm0.72$	
26	Persistent hallucinations.	25	2.45±0.79	
27	Persistent delusions.	26	2.43±0.82	
15	Enhancing leisure and recreational activities.	27	$2.41\pm0.73$	
19	Alternative living situations.	28	$2.41\pm0.78$	
37	Relative support and advocacy organizations.	29	$2.39\pm0.78$	
4	What the illness is like for the person with it.	30	2.39±0.62	
21	Improving grooming and hygiene.	31	2.35±0.84	
3	Symptoms of illness.	32	2.33±0.65	
7	Psychiatric medications.	33	$2.33\pm0.54$	
38	Patient's self–help organizations.	34	$2.32\pm0.78$	
42	What happen when caregiver dies.	35	2.31±0.81	
22	Coping with depression and suicidal thoughts.	36	$2.22\pm0.91$	
18	Vocational rehabilitation.	37	2.21±0.88	
1	How common the illness and what tend to happen when a			
	person has it.	38	$2.20\pm0.57$	
2	How psychiatric diagnosis are made.	39	$2.15\pm0.57$	
17	Day treatment.	40	$2.12 \pm 0.88$	
43	Dealing with weight gain.	41	1.99±0.90	
34	Involuntary commitment to hospital.	42	$1.99\pm0.80$	
39	Psychiatric hospitalization.	43	1.96±0.81	
44	Planning / coping with holidays.	44	1.93±0.84	
23	Drug/alcohol abuse.	45	1.51±0.85	

### Discussion

Chronic psychotic illnesses are impact negatively on reality testing and social functioning in the affected individuals (Shamsaei et al., 2015), (Shamsaei et al., 2013). Individuals with these disorders are generally living with their families who become the major source of caregiving and form the basis of all caregiving activities for their patients (Abdul-Mulud & McCarthy 2017). Among patients' families, primary caregivers are central to their patient's daily lives. The caregiving relationship can become one-sided, dependent and intensive with long-term obligations that trouble the caregivers' lives (Bademli, 2015), (Kate et al., 2013), (Atagün et al., 2011).

Since the family members are the main support system and shoulder the responsibility for patient care in the community, it is important to analyze the various burdens placed on them as providers of care and to pay attention to their psycho-educational needs as caregivers for patients with psychotic disorders (Shamsaei et al., 2015). Therefore, the present study aimed to assess the degree of caregiving burden and to determine the psycho-educational needs among family caregivers of patients with psychotic disorders.

In the current study, the majority of the studied subjects showed a risk for burnout. Scoring a total mean of 60% on caregivers' burden inventory reflecting a high degree of burden. This refers to the negative impact of the individual's mental illness on the entire family. Good reasons for this result can be the patients' dependency, unexpected and unacceptable behaviors that sometimes become aggressive and violent which require that caregivers pay a great attention to the patient's behaviors and place their own needs and wishes after those of the patient. This imposes a lot of burden including-besides physical care burden- the fear and embarrassment about illness signs and symptoms, uncertainty about the course of the disease, and the stigma they are confronted with. Other causes for the family caregivers' burden may also include fears and anxiety about the

future, lack of social support, feeling of being isolated and lonely, the financial impact of mental illness, as well as changes in lifestyle and family functioning such as restricted social life and leisure activities (Shamsaei et al., 2015), (Singh & Prajapati, 2012).

In the same line, numerous researches have shown that caregivers of patients with mental illness in different developed and developing countries experience moderate to high levels of caregiver burden (Shamsaei et al., 2015), (Singh & Prajapati, 2012), (Caqueo-Urízar et al., 2011). This was also emphasized by Shamsaei et al. (2015) who added that the burden of caregivers of patients with psychotic disorders is large, multifaceted, and constitutes direct and indirect costs. Headmost, were the direct costs of providing care for patients with schizophrenia and mood disorders. This was present in areas like finances, routine activities, family leisure and interaction. In support, Inogbo et al., (2017) also reported that threats, nuisances, time spent with the affected one, restricted social life and leisure activities may lead to caregivers' burden. The indirect costs encompass the loss of productivity through impairments, disability as well as some legal problems including violence Shamsaei et al., (2015).

Speaking of the dimensions of caregiving burden, the results of the present study show that "time dependent burden" came on the top of the dimensions with more than two-thirds of the studied caregivers having high level of burden, indicating that the care of the patient consumes a great deal of time and impacts negatively on the personal life and their social caregivers' commitment. Followed, was the "emotional burden" where about two thirds of caregivers scored high, indicating how much caregivers were living under psychological stress such as feeling embarrassed, ashamed, resent, angry and/or uncomfortable. This was proved to be true as they were most interested and scored the highest on "coping with stress and family problems" as a subscale of the educational needs. "Physical burden" was rated third which reflects the physical consequences of caregiving on the caregivers (e.g., not getting enough sleep, feeling physically sick and tired, or actually having health suffer). This was followed by "social burden" as ranked fourth which illustrates their interpersonal and social relationships conflicts within the family and

working environment, having problems in marriage, as well as lack of appropriation and support. This goes hand in hand with another piece of the results where "enhancing social functioning" as expressed educational need was ranked second by the present study caregivers pointing to their need to enhance their recreational activities, improving social relationships and communication, improving independent living skills and setting limits on patient's behaviors.

The least scored burden was the "developmental burden" which indicates the impact of caregiving on failing to catch the opportunities and pursue their goals in life due to the increased responsibilities and the countless caregiving activities leading to emotional drain and the feeling of "missing out life". It seems that the subjects in the present study had a tendency (being Egyptians and mostly females) to put this burden aside and rate it less. However, in the study of Bademli et al., (2017), the ranking of caregivers' burdens different was relatively where the "developmental burden" was ranked first, followed by "time-dependence burden" and "physical burden", whereas the "emotional burden" was ranked fourth and "social burden" was ranked fifth.

Regarding psycho-educational needs of family caregivers, the present study findings revealed that near to two-thirds of the caregivers showed high interest in educational needs. This result is consistent with previous international research's outcomes where patients' caregivers were most interested in learning information required to provide optimum patient's care (Bai et al. 2020). In the current study, the top ten educational needs perceived by the studied caregivers as most interested in included "ways managing stress more effectively". "strategies for solving problems", "managing burnout", "recent research on mental illness", "early warning signs of the illness and relapse". "coping with stigma of mental illness", "getting what you need from the mental health system", "anger/ violence/ assaultive behavior", "biological causations", and "setting limits on patient's behavior". These expressed needs reflect the high degree of suffering and burden of care on the family caregivers.

Trying to group these highly ranked educational needs, they mostly come under either "coping with stress and family problems" or "basic facts about mental illness" as areas of educational needs. Knowing this fact, it is fairly expected for these caregivers to look forward and to seek information that help them deal with their stress, find ways of managing it, searching for new strategies to solve their problems, and getting the utmost benefit from the health system in a trial to minimize or manage their burnout that is evident in the great majority of caregivers. This can be fairly accepted in the light of the low education prevailing in the present study subjects, the prevailing stigma about mental illness in the Egyptian culture as well as the absence of the community mental health services in the Egyptian health system with its many negative consequences. The latter include -among others- lack of support (social, psychological, and financial), very limited psycho-education, no rehabilitation and so on.

However, the ten educational need statements ranked as most important in the present study were different from findings of other studies. For example, while "biological theories" and "coping with stigma of mental illness" were ranked more highly by family members in the present study, they were ranked low in other study (Dastan & Kilic, 2014). Moreover, in the United States family caregivers placed priority on information regarding "medication effects and side effects", and "maximizing use of available mental health services" (Gasque-Carter & Curlee, 1999). Such variations clearly reflect the differences from one country to another in levels of education, culture, and the availability of community health services with all its components.

Speaking of the sub-domains of educational needs, "coping with stress and family problems" came first which expresses how much burden they are suffering and their severe lack of knowledge about ways of dealing with and managing their burnout and the strategies to be used. Such a result goes hand in hand with the results previously discussed under "burden". Second, came "enhancing social functioning" which shows having interactional

and relational problems with their patients, within and outside the family members. This is probably a reflection of lack of support, and psycho-education from the community and health services. "Coping with patients symptoms" came third in the hierarchy of caregivers' educational needs. Patients' behavior can be very strange, odd, and dangerous. Without appropriate support and psycho-education, caregivers can feel helpless, threatened or at risk which adds to their caregiving burden. Fourth, was the educational need "community resources" something that is still very deficient in the Egyptian health system. Unfortunately, the absence of community mental health services impacts negatively all over the whole situation (caregiving burden and the educational needs). In fact, all the present study results can be explained and traced back to the lack of the community mental health services in Egypt's health system. Striking enough, the domain "facts about mental illness" was the least scored. This is probably due to the low level of education of the studied subjects and consequently lack of interest in the scientific aspects of psychotic illnesses. It seems that caregivers are more concerned with "what to do" rather than "what to know". On the same line, study conducted by Sharif et al., (2012) found that family caregivers need to increase their awareness about different strategies for dealing with daily problematic situations, orientation to the patient's symptoms and behavior, and the skills of coping with them. On the contrary, El-Sayeh & Khedr, (1998) found that their studied caregivers were most interested in learning "basic information about mental illness".

On the other hand, the least expressed educational needs in the present study were related to "drug/alcohol abuse", "planning/coping with holidays", "psychiatric hospitalization", "involuntary commitment to hospital", "dealing with weight gain", "day treatment", "how psychiatric diagnoses are made", "how common the illness" and "what tend to happen when a person has it", "vocational rehabilitation", and "coping with depression and suicidal thoughts". Looking at these "least" expressed educational needs, one can see that most of them come under either "basic facts about mental illness" or

"community resources" as sub-domains of educational needs. The researcher believes that two factors probably contributed to this result. First, illiteracy and the low educational level prevailing among the studied caregivers kept them away or not interested in the basic facts about mental illness. Second, the lack or unavailability of community resources in the field of mental health in the Egyptian health system made such items vague to the caregivers and thus were ranked the least. In addition, an item like "dealing with weight gain" looks out of context for this level of caregivers.

### Conclusion

Based on the results of the present study, it can be concluded that caring for a patient with psychotic disorder within a family can put a great burden on whoever is providing the care to the extent of exposing them to the risk of burnout. In response, the need for psycho-education is expected and highly expressed by the caregivers, especially in the areas of coping with stress, patient's social functioning, patient's symptoms and the resources available to help and support them.

### Recommendations

In the light of the results of the present study, the following recommendations are suggested:

- A routine assessment of the psychoeducational needs and caregiving burden of families of both in and outpatients with psychotic disorders may be carefully considered while developing family-centered interventions.
- Psycho-educational interventions should be tailored based on the assessed caregivers' needs. Such interventions would be delivered individually or in a group, through face-to-face method, and/or using written and web-based materials.
- Designing family counseling programs for caregivers who are at risk for burnout, i.e., those with a high degree of burden, on how to improve their coping strategies in the patient's caregiving process.

• Workshops should be delivered for psychiatric nurses about the different psychoeducational needs and caregiving burden of families caring for patients with psychotic disorders. The training should also emphasize the importance of assessing families' caregiving process, their educational needs and caregiving burden.

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