Original Article

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Burden of Care Among Caregivers of Patients with Schizophrenia in Baghdad City

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ABSTRACT

Background: The family members of schizophrenic patients frequently report that caring for the patient imposes a great burden on them and hampers the typical structure and functioning of the family to the detriment of its members.

Objectives: To assess the level of the burden of care (objective and subjective) shouldered by the primary caregivers of schizophrenic patients and to determine the relationship between the objective and subjective level of such burdens.

Method: A descriptive analytical study was conducted on a purposive sample of 50 primary caregivers of schizophrenic patients who were hospitalized in Ibn-Rushd Psychiatric Teaching Hospital in Baghdad. The data were gathered utilizing self-administered questionnaires, namely, the objective burden questionnaire (OBQ), the subjective distress questionnaire (SDQ), and the self-reporting questionnaire (SRQ 20).

Results: It was revealed that the primary caregivers of schizophrenic patients experienced high levels of objective and subjective burdens. Significant differences were observed in the relationships between the objective and subjective burdens and between objective burdens and the SRQ 20 at $p \leq 0.05$ and $p \leq 0.01$, respectively.

Conclusions: Schizophrenia affects the interactions and routine among family members much more substantially than their income and leisure.

Keywords: caregiver burden, schizophrenia, OBQ, Objective and subjective burden.

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INTRODUCTION

“Schizophrenia is at the heartland of psychiatry and the core of its clinical practices.[1] It is variable but a strongly disruptive clinical syndrome”. Its psychopathology involves a study of the cognitive, emotional, and perceptual aspects of the brain. Further, bizarre and abnormal behaviors concomitant with the syndrome are also analyzed. The manifestation of the symptoms varies across patients and over time, but the overall effect of the illness is invariably severe and, usually, lifelong. The disorder typically presents before the age of 25, persists throughout life, and affects persons of all social classes.[2] Both patients and their families often suffer from poor care and social ostracism, owing to the widespread ignorance about the disorder.[2] It has gained more public prominence in recent years since patients who would have once spent their entire lives in asylums and mental hospitals now live in the community.[3]

The personal struggles of schizophrenic patients and the transfer of the burden of care from hospitals to families are reflective of the considerable adversity caused by the syndrome. Further, society’s stigmatized perception of schizophrenic patients and their families in addition to the significant direct and indirect costs, including frequent hospitalizations, utilization of long-term psychosocial and economic support, as well as lifetime lost productivity, aggravate their circumstances and complicate the lives of the people involved.[4] Many patients with schizophrenia rely on their relatives for emotional support, which is medical and economic assistance. The families of schizophrenic patients often extend considerable support to their ill relatives and bear exceptional levels of burden as a result. The demands of caregiving include the financial costs of life-long psychopharmacological treatment and psychological follow-ups, enduring the social stigmatization that comes with mental illness, and emotional distress and discomfort that may result from the symptoms of the patient’s disorder. The burden is associated with a reduced quality of life and the significant impact it has on the mental and physical well-being of the caregivers. The key caregiver is perceived as the person who provides the most support to the patient, often devoting a substantial number of hours each day toward providing basic care to the patient.[4]

'Burden of care' is a complicated concept and is frequently viewed as controversial for being too broad and generally negative. Frequently, burden of care is defined by the effect it has on care providers and its consequences. In addition to the emotional, psychological, physical, and economic impact, the concept of 'burden of care' involves subtle but distressing notions, such as feelings of shame, embarrassment, and general feelings of guilt and self-blame. The early conceptualization of 'burden of care', which is divided into two distinct components (objective and subjective), has guided researchers’ efforts till now. The objective burden of care is evident in its effects on the household, such as taking care of daily tasks, whereas subjective burden indicates the degree to which the caregivers conceive the burden of care, so by that objective burden can be noticed by the dysfunction on the daily life activities , while the subjective one is felt and experienced by the person on a personal level.[5]

A thorough review of literature that dealt with family interventions in schizophrenia has revealed the immense positive impact of various family interventions in improving the family environment, decreasing relapses, and facilitating the burden of care relief. Although the evidence of the positive impact of family interventions on schizophrenia is frequently observed, such interventions are neither pervasive nor appropriately integrated into care plans and are commonly underfunded and undersupported.[4]

Aims of the study

1) To assess the level of burnout and the burden of care (objective and subjective) on the primary care providers of schizophrenic patients.
2) To estimate the relationship between the objective and subjective levels of burdens.

MATERIALS AND METHODS

A descriptive analytical study was conducted on the families of schizophrenic patients hospitalized at the Ibn-Rushd Psychiatric Teaching Hospital at the time when the present study was undertaken.

The researcher reviewed the hospitalized patients' charts with a definite diagnosis of schizophrenia. The patients were contacted after permission was obtained. They were informed about the study and asked to submit consent for the participation of their relative in this study. All patients who were contacted were living with their relatives and submitted consent.

The primary caregiver was the family member who had most contact with the patient and one who performed the major caregiving role in the family.

The sample: the study sample was the primary caregivers of 50 psychiatric patients who had been diagnosed with schizophrenia by a psychiatric specialist working at the Ibn-Rushd Psychiatric Teaching Hospital.

The duration of the study was 5 months, starting from 1 August, 2009 to 30 December, 2009.

All the caregivers were family members living at the same home as the patient for at least 2 consecutive years. Such caregivers were selected to make sure that they had been exposed to the stress of caring for the patient. They were the patients' parents, siblings, sons/daughters, or spouses.

The criteria to qualify the patients as eligible for participation in the study were as follows:

1) Being 20–60 years old.
2) Having been ill for at least 2 years.
3) At least one adult relative having lived with them.
4) Not having been away from home for more than six months.
5) Not having family members with disabling physical or psychiatric diseases or drug abuse living with them.

The criteria to disqualify the patients as eligible for participation in the study: Any criterion not in the inclusion criteria.

Study instruments

Section 1:

Part I: An introductory page invited the candidates to take part in the study and to express their feelings about the difficulties experienced by them and the subsequent hardships resulting from their requirements.

Part II: The demographic data sheet was formulated, which detailed the socio-demographic characteristics of the patient and the caregiver.

Part III: The objective burden questionnaire (OBQ) was constructed by Al-Juboori[6,7,8] to describe the four major aspects of objective burden:

1) The effect on family income (investigated by the first 9 items)
2) The effect on family routine (investigated by items 10–16)
3) The effect on family leisure (examined by items 17–21)
4) The effect on family interaction (investigated by items 22–28)

These items were rated on a 4-point Likert scale (no occurrence: 0; no effect: 1; mild effect: 2; and severe effect: 3)

Section 2:

The subjective distress questionnaire (SDQ) was constructed based on the extensive review of relevant literature and the objective burdens. It consisted of 40 items. Out of them, 20 were positive and the other 20 were negative. The scoring was on a 3-point Likert scale—never: 1; sometimes: 2; and always: 3 for the positive items, always: 1; sometimes: 2; and never: 3 for the negative items.[9] The 40 items of the SDQ reflected the caregivers' distress stemming from the four aspects of objective burden and the stigmatization of the mental illness endured by the family, which were considered as an essential part of the subjective burdens.

Section 3:

The shorter version of the Self-Reporting Questionnaire (SRQ 20) was utilized as a practical screening research instrument for the detection of psychiatric morbidity across different cultures. The SRQ 20 was developed by the World Health Organization (WHO) as part of the international project "Strategies for Extending Mental Health Care" (1975–1981) in 7 developing countries.[10]

The cut-off point identified for "cases" and "non-cases" in another study in Baghdad (2004) was 7. This cut-off can be utilized to categorize "potential psychiatric cases" and more generally, persons with significant psychological distress. The Arabic version of the SRQ was administered to adults (18+) randomly selected from the household roster by the means of a Kish grid.[11]

In the current study, the SRQ 20 was implemented to determine the physical and psychological distress experiences by the caregivers as an integral part of the subjective burdens, in addition to the aforementioned SDQ. This instrument was translated to

Arabic, tested for reliability and validity for its utilization in Iraq by Numan Ali and Mufeed Raoof (2001), and has been used as one of the research tools in the Iraq mental health survey which was conducted by the WHO in 2006.

Statistical analysis: The data were analyzed through the application of statistical approaches to assess the results of the study. These approaches had included:

1. **Descriptive statistics:** Frequencies, percentages, and means, standard deviations, and statistical tables
2. **Inferential statistics:** Correlation coefficient was computed to identify the relation between the objective burdens' total scores and the subjective burdens' scores (SDQ & SRQ 20 scores).

RESULTS

Table 1: The socio-demographic characteristics of the patients.

	Patients' characteristics	F	%
1	Age(years):		
	20–29	21	42
	30–39	14	28
	40–49	9	18
	50–60	6	12
2	Gender:		
	Male	31	62
	Female	19	38
3	Marital Status:		
	Single	39	78
	Married	8	16
	Divorced	3	6
4	Duration of Illness (years):		
	2–6	24	48
	7–11	9	18
	12–16	6	12
	17–21	3	6
	≥22	8	16

Table. At the time of the study, the majority of the patients (42%) were 20–29 years old, 62% were males, and 78% were single. The duration of illness for most of the patients (48%) ranged from 2–6 years.

Table 2: The socio-demographic characteristics of the primary caregivers.

	The caregivers' characteristics	F	%
1	Age(years):		
	20–29	3	6
	30–39	6	12
	40–49	9	18
	≥50	32	64
2	Gender:		
	Male	17	34
	Female	33	66
3	Occupation:		
	Officer	13	26
	Student	1	2
	General business	2	4
	Housewife	24	48
	Unemployed	10	20
4	Kinship:		
	Father	10	20
	Mother	21	42
	Sibling	12	24
	Spouse	7	14
5	Residence:		
	Urban	47	94
	Rural	3	6

The findings revealed that the majority of the caregivers (64%) were ≥ 50 years old, were females (66%), mothers (42%), housewives (48%), and from the urban areas (94%).

Table 3: Objective burdens analysis among primary caregivers**.**

Objective burdens	**N=50** **Mean**	 **SD**	**Mean differences from hypothesized mean**
1. The effect on family income	14.82	3.06188	1.32
2. The disruption of family routine	12.2	1.70234	1.7
3. The disruption of family leisure	8.72	1.26233	1.22
4. The disruption of family interaction	11.98	1.92184	1.48
* Total objective burdens (TOB)	47.72	4.37544	5.72

The results demonstrated that the level of the caregivers' objective burdens was considerably high (total means of scores=5.72). The level of distress caused by the disruption of family routine activities and family interaction (1.7, 1.48, respectively) was higher than the distress caused by other aspects of the burdens.

Table 4: Analysis of the subjective burdens among primary caregivers.

Subjective burdens	**N=50** **Mean**	 **SD**	**Mean differences from hypothesized mean**
The self-reporting questionnaire (SRQ 20)	8.86	2.5794	1.86
The subjective distress questionnaire (SDQ)	83.20	8.5547	3.2

This table exhibits the high level of SRQ 20 scores (mean 8.86) representing the physical aspects of the subjective burdens. Further, the high level of SDQ scores (83.20) representing the physical and psychological distress caused by the subjective burdens was observed.

Table 5: *Pearson's* correlation for the relationship between the objective and subjective burdens.

	Mean	**SD**	**SRQ20**	**SDQ**	**TOB**
SRQ 20	8.86	2.5794	1	0.426**	0.298*
SDQ	83.20	8.5547	0.426**	1	0.592**
TOB	47.72	8.5547	0.298*	0.592**	1

**Correlation is significant at the 0.01 level
*Correlation is significant at the 0.05 level

This table presents the established relationship between the objective burden and the subjective distress. It was found that the total objective burden (TOB) had a more substantial effect upon primary caregivers than subjective distress (SRQ 20, SDQ), at p≤0.05 and p≤0.01, respectively.

DISCUSSION

It has been observed from the sociodemographic data of the schizophrenic patients that most of these patients are single, males, with age ranging 20–29 years old, and living in urban areas (Table 1). This is consistent with the findings of Mangen.[12] A logically derived rationale approves that the families of such individuals can experience episodes of burdens greater than others due to the intensive nature of caregiving demanded by the disorder. The findings from the data analysis of sociodemographic characteristics of the primary caregivers illustrated that the majority of the caregivers were housewives and females, most of whom were also the patients' mothers. This is consistent with the findings of Cook,[13] in which mothers as caregivers were found to assume better primary caregiving roles, due to their substantial responsibilities. The discussion of findings related to the analysis of data of the objective burdens regarding proportions that represent the distribution of means relative to the four major aspects of objective burdens (the effect of the patient on the family income, the disruption of family routine, the disruption of family leisure, the disruption of family interaction) revealed that patients had a consequential impact upon family income and resulted in further disruption on family routine (Table 3). Such findings agree with those of Karanci[14] who reported that caregivers stated a financial cost due to the patient, which involved attending the hospital and compensating for the patients' entertainment expenses, as a difficulty.

Concerning the subjective burdens (Table 4), the results consistent with other studies indicated that the subjective distress was higher among female relatives like those of Grad. J and Sainsbury,[15] Magliano and his colleagues,[16] and Ali A. and his colleagues,[16] these contrasting the findings of Tennakoon. L & his colleagues,[17] and Letley,[18] which revealed that the patients' mothers had experienced a significantly lower level of subjective distress, which can be explained by the fact that mothers are responsible for the caregiving in a vast majority of cases and they tackle significant responsibility.

Concerning the relationship between objective and subjective distress and SRQ 20 (Table 5). The significant relationships between most aspects of objective burdens, subjective distress scores are consistent with the findings of Plat & his colleagues,[19] who reported a significant correlation between caregivers scores and the" total subjective burdens, which is predicted situation regarding the caregiver stress amount which is presumably high.

In addition, Pereira and de-Almeide,[20] indicated that 41% of the caregivers experienced minor psychiatric morbidity. Further, measures of the objective and subjective burdens were moderately correlated. These results were supported by the findings of Greenbery and his colleagues,[9] in which subjective burden of care was significantly related to higher levels of objective burden. Provided that, it is observed that caregivers not only suffer from caregiving stress but also struggle with psychiatric morbidity, which has a genetic basis in most cases.

Furthermore, Steketee[21] found that there is a considerable burden inflicted on families, which reduces their social activities and increases their isolation and subjective distress. This might be explained by the social distancing and the stigmatization they grapple with. To add to this, Karanci,[14] revealed that the most frequently reported difficulties experienced by the caregivers were family conflicts and disruption of family life (57%), and financial cost due to patient (27%).

CONCLUSION

The primary caregivers of schizophrenic patients experienced a high level of objective and subjective burdens. Schizophrenic patients have a more significant impact on family interaction and routine than their income and leisure. All aspects of objective burden positively affect the level of subjective burden that is experienced by caregivers.

We recommend conducting more research addressing the same topic in other cities of Iraq to understand the struggles of caregivers and contribute to the available data on them.

This will lead to decreased caregiver stress and lower risks of depression. Further, addressing the symptoms of schizophrenic patients directly through a biopsychosocial approach should be an important aim, since it leads to better behavioral symptom management.

Limitations

The sample size considered in this study was limited. There was a lack of diversity, due to which significant generalizability couldn't be established. The demographic subgroups, like men over 29 years of age, minority populations, rural populations, patients with multiple caretakers, etc. were underrepresented.

Conflict of Interest Statement

The author(s) declared that they have no conflict of interest.

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