

Burden of care on female caregivers and its relation to psychiatric morbidity

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Background

Recently, there have been increasing numbers of caregivers who provide care to their chronically ill family members. Care can represent a heavy burden and may put caregivers, who are mostly women (mother or wife), under a high level of stress. Culturally, such caregivers are expected to cope and not to complain.

Aim

To evaluate and compare the burden (objective and subjective) on female caregivers (mother or wife) who provide full-time care to family members who are suffering from either psychiatric or physical disorder.

Materials and methods

This study included 300 female caregivers (wife or mother) with 150 caring for patients suffering from a psychiatric illness and 150 looking after individuals suffering from a chronic physical illness. No male caregivers were included as culturally men are expected to be the breadwinners and if they have to provide care, this is likely to be as part time as most of their time would be dedicated for working outside home. This could provide men with an alternative time for ventilation or an outlet, which may bias the study results. Samples for the study were taken from the attendees of the outpatient clinics, University Hospital, Al-Azhar Faculty of Medicine, New Damietta, in the period 1 June 2007 to 31 May 2008. An approval was obtained from the ethics and scientific committee and informed consent was obtained from the individuals. All caregivers were assessed as follows: the Semistructured Clinical Interview using the diagnostic criteria of the Diagnostic and Statistical manual IV Text Revised (American Psychiatric Association), the Caregiver Strain Index, and Zarit Burden Interview (all these were translated, validated, culturally compatible, and doctor rated).

Results

The total sample included 300 female caregivers divided into two groups: the first group included 150 care providers of patients with psychiatric disorders, including 121 (80.7%) mothers and 29 (19.3%) wives, whereas the second group consisted of 150 female caregivers of individuals with chronic physical illness individuals, including 19 (12.7%) mothers and 131 (87.3%) wives. There was a significant difference between both groups with regard to distribution of nature of the relationship of female caregivers with the care recipients (mother or wife), their age, residence, and educational level. No significant difference regarding their job (the majority in both groups were unemployed) was observed. The objective burden was the highest in cases of poststroke disabilities, schizophrenia, chronic renal failure, chronic liver cell failure, and in those with bipolar disorder (<0.001). Similar distribution was observed in the subjective burden (<0.001). Caregivers suffered major depression in 102 cases (34.0%) and generalized anxiety disorders in 67 cases (22.3%). There was a statistically significant difference between mothers and wives regarding subjective burden and distribution of psychiatric disorders.

Conclusion

The study results may indicate that the burden (objective and subjective) of caregivers and the prevalence of psychiatric disorders in caregivers depend on the impact of the disease on the functional level of the patient. The level of subjective burden and prevalence of psychiatric disorders are higher in wives compared with mothers, which may be attributed to the difference in their appreciation of the caregiving situation and in their appreciation of their responsibility toward the individual needing care.

Keywords:

burden, caregivers, psychiatric morbidity

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Introduction

Providing care for a family member with mental illness is an overwhelming experience for the caregiver. On average, 250 000 patients with chronic mental illness discharge to the care of their families annually in USA [1].

Providing care for a patient with mental illness can be debilitating, stressful, and burdensome for the caregiver. In contrast, providing care to chronically ill or incapacitated family members may have an impact on family caregivers, such as increased self-respect or self-satisfaction from fulfilling a responsibility [2].

Previous studies have showed that caregivers have poor physical health and frequently experience social, emotional, and financial losses [3,4]. Interestingly, caregivers' stress and support are an integral element of an individual patient's assessment in most of the developed countries, for example, the UK [5].

Caregiver burden is defined as persistent hardship, stress, or negative experiences resulting from the provision of care by caregivers [6]. Caregiver burden is strongly related to sleep disturbances [7] and depressive symptoms [8]. It was reported that caregiver burden is negatively related to health-related quality of life, particularly mental health [9].

Researchers advanced the definition of burden when they distinguished between objective and subjective factors. Objective burden consisted of the concrete factors seen to disrupt family life and is subdivided according to specific effects on the family household, the health of other family members, family routine, and in particular, abnormal behavior likely to cause distress. Subjective burden refers to the subjective experience or psychological or emotional impact (i.e. feeling worried or strained) of caring for someone with a mental illness [10].

Living with the patient, patient behavior, demographic characteristics, and socioeconomic status have all been associated with different levels of burden [11]. One study found that caregivers of patients with dementia appeared more vulnerable to depression as a consequence of their experience [12]. White *et al.* [13] found that caregivers of people who had suffered a stroke had lower mental health-related quality of life compared with their counterparts who were not caregivers. Another study used the same questionnaire (SF-36) to measure caregivers' health-related quality of life and found that caregivers of people with cerebrovascular disease or diabetes had significantly negative mental health-related quality of life [14].

The physical consequences of caregiving have received less attention than psychiatric outcomes. One study indicated that caregivers often experience several physical problems, including back injuries, arthritis, high blood pressure, gastric ulcers, and headaches [15].

The aim of this study was to evaluate and compare the burden (objective and subjective) on female caregivers (mother or wife) who provide full-time care to family

members who are suffering from either psychiatric or physical disorders.

Patients and methods

This descriptive study included 300 women (either wife or mother, caring for patients with psychiatric disorders or patients with chronic physical illness), selected from the outpatient clinics of psychiatry and other specialties (University Hospital, Al-Azhar Faculty of Medicine; New Damietta) in the period 1 June 2007 to the end of March 2008.

Patients were classified into two groups. The first group included 150 women who are caring for patients with psychiatric disorders of at least 2 years or more and not suffering a chronic mental illness. Psychiatric disorders included schizophrenia, substance dependence, bipolar disorder, and attention-deficit hyperactivity disorder (ADHD). Patients with comorbid chronic physical disorders were excluded. The second group included 150 women who are caring for patients with chronic physical disorders of at least 2 years duration or more. Physical disorders included hepatic failure, renal failure, disabilities because of cerebrovascular strokes, and other neurological disorders. Any physically ill patient who has comorbid chronic psychiatric disorder was excluded.

The duration of illness for selected patients was two years or more for both groups depends on the results of Pim and Heleen [16] study, which indicated that the burden is more manifest after 2 years duration of illness.

In this study, psychiatric disorders include schizophrenia, bipolar disorder, substance dependence, and ADHD. In contrast, the chronic physical diseases include renal or hepatic failure and cerebrovascular stroke. Each subgroup of disorder was composed of at least 30 patients.

All included women were subjected to the following: Semistructured Clinical Interview using the diagnostic criteria of the DSM IV TR, Caregiver Strain Index [17], and Zarit Burden Interview [18]. These instruments were translated into Arabic language by translators who are not psychologists or psychiatrists and then retranslated into English. Face validity was judged by two Professors of Psychiatry (Al-Azhar University) who corrected some words and phrases. Reliability of the translated instruments was tested through application on 30 cases and then reapplication 2 weeks later and was found to be 0.97 for the Zarit Burden Interview and 0.87 for the Caregiver Strain Index. The scores of Zarit Burden Interview vary from 0 to 88, and the higher scores indicate higher burden. The Caregiver Strain Index is composed of 13 questions and positive responses for seven questions or more indicate a high level of burden.

Statistical analysis of data

The collected data were organized, tabulated, and statistically analyzed using the statistical package for social science (SPSS), version 13 (SPSS Inc., Chicago, Illinois, USA). For qualitative data, the number and

percentage distribution were calculated, and χ^2 was used for comparison between groups; and for quantitative data, the mean and standard deviation were calculated and for comparison between two means the Student's *t*-test was used. Tests were considered statistically significant when *P* value was less than or equal to 0.05.

Results

In this study, the caregivers of patients with psychiatric disorders were 150 women, 121 of them (80.7%) were mothers and 29 (19.3%) were wives. In contrast, the caregivers of nonpsychiatric patients were 150 women, 19 of them (12.7%) were mothers and 131 (87.3%) were wives. The mean age of women in group 1 (psychiatric) was 37.20 ± 10.17 years, whereas the mean age in group 2 was 47.36 ± 6.91 years. Fifty-two percent of women in group 1 lived in rural area compared with 65.3% who lived in rural area in group 2. In addition, the majority of women caring for patients with nonpsychiatric disorders were illiterate (66.7%) compared with 15.3% women caring for patients with psychiatric disorders, and there was a significant difference between both groups with regard to distribution of women (mother or wife), their age, residence, and educational level, whereas no significant difference with regard to their job (the majority in both groups were housewives) was observed (Table 1).

In this study, there was a statistically significant increase in objective burden in group 2 (caring for nonpsychiatric patient; 146 cases had high objective burden) in comparison with group 1 (89 cases had high burden). Similarly, the subjective burden was statically high in women caring for nonpsychiatric disorders in comparison with those caring for psychiatric disorders (Table 2).

In this study, the objective burden was high in cases with poststroke disabilities, schizophrenia, chronic renal failure, chronic liver cell failure, and in those with bipolar disorder (Table 3). Similar distribution was observed in the subjective burden (Table 4).

Table 1 Characteristics of caregivers

Parameter	Group 1 (psychiatric)	Group 2 (physical)	<i>P</i> value
Who (<i>N</i> , %)			
Mother	121 (80.7%)	19 (12.7%)	<0.001(S)
Wife	29 (19.3%)	131 (87.3%)	
Age (mean \pm SD)	37.20 ± 10.17	47.36 ± 6.91	<0.001(S)
Residence			
Rural	79 (52.7%)	98 (65.3%)	0.026 (S)
Urban	71 (47.3%)	52 (34.7%)	
Educational level			
Illiterate	23 (15.3%)	100 (66.7%)	<0.001(S)
Middle	75 (50.0%)	36 (24.0%)	
Higher	52 (34.7%)	14 (9.3%)	
Job			
Employee	25 (16.7%)	17 (11.3%)	0.18 (NS)
Housewife	125 (83.3%)	133 (88.7%)	

NS, not significant.

Table 2 The objective and subjective burden exerted on caregivers

	Group 1 (psychiatric)	Group 2 (physical)	<i>P</i> value
Objective burden (<i>N</i> , %)			
Low	61 (41)	4 (0.03)	<0.001(S)
High	89 (59)	146 (0.97)	
Subjective burden (<i>N</i> , %)			
No or mild	16 (10.7)	0 (0.0)	<0.001(S)
Moderate	47 (31.3)	18 (12.0)	
Severe	56 (37.3)	71 (47.3)	
Extreme	31 (20.7)	61 (40.7)	

S, significant.

With regard to psychiatric disorders in caregivers, major depression was observed in 102 cases (34.0%), adjustment disorder with depressed mood in 32 cases (10.7%), adjustment disorder with anxious mood in 34 women (11.3%), adjustment disorder with mixed depressive and anxious mood in 15 women (5.0%), mixed anxiety and depression in 31 cases (10.3%), generalized anxiety disorders in 67 cases (22.3%), and no psychiatric disorders in 19 cases (6.3%). There was statistically significant difference between mothers and wives with regard to distribution of psychiatric disorders (Table 5).

Discussion

In this study, there is a significant statistical difference between the number of mothers and wives in the two groups ($P < 0.001$). The number of mothers in the first group was 121 (80.7%), whereas the number of wives in the same group was 29 (19.3%). These results are in accordance with other studies, for example, Pim and Heleen [16] who found that more than 50% of cases were mothers and only 25% were wives who are caring for patients with psychiatric disorders. In addition, Lakishika et al. [19] reported that 70% were mothers and only 5% were wives, whereas in the study of Eija et al. [20], mothers as caregivers were 49% and wives as caregivers were 15%. These differences could be explained by the fact that psychotic disorders (schizophrenia and bipolar) included in this study start at a younger age, drug abuse usually starts in adolescence, and ADHD in childhood, and thus, the original family (mothers) cares for their children.

In the second group, the number of wives caring for patients with nonpsychiatric disease (e.g. chronic kidney or liver failure) was 131 (87.3%) compared with 19 (12.7%) mothers, and these results are in agreement with the study of Lois [21] where most of the caregivers

Table 3 Objective burden according to the type of disorder

	Low (%)	High (%)	<i>P</i> value
Schizophrenia	0 (0.0)	38 (100.0)	<0.001(S)
Bipolar disorder	11 (28.9)	27 (71.1)	
ADHD	22 (59.5)	15 (40.5)	
Drug abuse	28 (75.7)	9 (24.3)	
Chronic liver cell failure	2 (4.0)	48 (96)	
Chronic renal failure	2 (4.0)	48 (96.0)	
Poststroke disabilities	0 (0.0)	50 (100.0)	

ADHD, attention-deficit hyperactivity disorder.

Table 4 Subjective burden according to the type of disorder

	No or mild (%)	Moderate (%)	Severe (%)	Extreme (%)	P value
Schizophrenia	0 (0.0)	2 (5.3)	9 (23.6)	27 (71.1)	<0.001(S)
Bipolar disorder	1 (2.6)	12 (31.6)	22 (57.8)	3 (7.8)	
ADHD	14 (37.8)	12 (32.4)	11 (29.7)	0 (0.0)	
Drug abuse	1 (2.7)	21 (56.7)	14 (37.8)	1 (2.7)	
Chronic liver cell failure	0 (0.0)	9 (18.0)	25 (50.0)	16 (32.0)	
Chronic renal failure	0 (0.0)	6 (12.0)	22 (44.0)	22 (44.0)	
Poststroke disabilities	0 (0.0)	3 (6.0)	24 (48.0)	23 (46.0)	

ADHD, attention-deficit hyperactivity disorder.

were wives. These findings may be explained by the fact that these chronic diseases are most prominent in old age; thus, wives care for their husbands.

In this study, results show that the mean age of the caregivers in the first group (37.20 years) is significantly lesser than the mean age of the caregivers in the second group (47.36 years; $P < 0.001$), and this is attributed mainly to the younger age where psychotic disorders start to represent itself. These ages are slightly younger than those reported in the studies of Pim and Heleen [16] and Lakshika *et al.* [19] where it was 49.6 and 49.04 years, respectively, and this may be explained by the fact that these studies were carried out on caregivers for schizophrenia, bipolar disorders, and depression only, but this study included caregivers for ADHD who are cared for by younger mothers.

In addition, the mean age of mothers caring for patients with nonpsychiatric disorders was in agreement with that reported by Lois [21] where it was 48 years.

With regard to residency, there is no statistical difference between mothers and wives, whereas there is significant statistical difference between the caregivers in the two groups, as most of the caregivers in the psychiatric patients' group (52.7%) were living in urban areas, whereas most of the caregivers in the nonpsychiatric patients' group (65.3%) were living in rural areas.

These findings could be explained by the fact that nonpsychiatric disorders were prevalent in rural areas. In addition, the inhabitants of urban areas were more oriented by psychiatric disorders and asked for treatment, whereas the culture of rural inhabitants prevents them from asking treatment for their psychological suffering, or denies the disease at all [22].

With regard to the level of education, there is no significant statistical difference between mothers and wives as most of them are illiterate or have middle level

education. However, there is a significant statistical difference between the caregivers in the psychiatric and nonpsychiatric patients' groups, as the percentage of illiterates in the caregivers of the nonpsychiatric patients' group is 66.7%, whereas the percentage of illiterates in the caregivers of the psychiatric patients' groups is 15.3%. This may be explained by the increased prevalence of illiteracy in rural areas in comparison with urban areas.

In this study, there is no significant statistical difference between the caregivers in the study groups regarding occupation as most of the caregivers are housewives. These results are in contradiction to other studies that found that caregivers were working full time [23–25]. In contrast, these results are in agreement with Egyptian studies, for example, Abou El Magd *et al.* [26] who reported that 60% of caregivers for substance abusers were housewives. These results could be explained by the fact that the society in Damietta Governorate tends to keep women at home.

With regard to objective burden, there is no significant statistical difference in the level of the objective burden between mothers and wives, whereas the level of objective burden in the caregivers of patients with nonpsychiatric disorders is significantly higher when compared with the level of objective burden in the caregivers of patients with psychiatric disorders. However, when we study the level of objective burden in the caregivers for patients with each disease individually, we find that the level of objective burden does not depend on whether the disease is psychiatric or nonpsychiatric, but it depends on the level of disability caused by the care recipient's disease, where there is a high level of objective burden in all caregivers of patients with schizophrenia and patients with poststroke disabilities and most caregivers of patients with chronic liver disease, chronic renal disease, and patients with bipolar mood disorder, and the level of objective burden was low in most caregivers of children with ADHD and substance abuse patients.

Table 5 Psychiatric disorders in caregivers (mother and wife)

	Mother (%)	Wife (%)	Total (%)	P value
Major depression	33 (23.6)	69 (43.1)	102 (34.0)	<0.001(S)
Adjustment disorder with depressed mood	20 (14.3)	12 (7.5)	32 (10.7)	
Adjustment disorder with anxious mood	20 (14.3)	14 (8.8)	34 (11.3)	
Adjustment disorder with mixed anxious and depressed mood	12 (8.6)	3 (1.9)	15 (5.0)	
Mixed anxiety and depression	13 (9.3)	18 (11.3)	31 (10.3)	
Generalized anxiety disorder	26 (18.6)	41 (25.6)	67 (22.3)	
No psych disorder	16 (11.4)	3 (1.9)	19 (6.3)	

The poststroke disabilities interfere with the patients' ability to walk and care for themselves, and these facts are true for patients with chronic liver cell failure and chronic renal failure as they lead to several disabilities that represent a major burden on the caregiver; besides, these diseases have poor prognosis and continuously deteriorate, and the patients' need for caregiving increases day by day [27].

In contrast, the bipolar disorder is accompanied by free periods where the patient can care for his or her self, thus leading to a decrease of the burden of caregiving [16]. These facts are also true for ADHD as it needs slight adaptation and the nature of the Damietta governorate provides the child with a wide place to play and thus the burden on the family is less in comparison with other diseases.

In this study, the level of subjective burden was significantly higher in the wives when compared with the mothers. In addition, the level of subjective burden was significantly higher in the caregivers of patients with nonpsychiatric disorders when compared with the caregivers of patients with psychiatric disorders. But as in objective burden, the level of subjective burden does not depend on whether the disease of the care recipient is psychiatric or nonpsychiatric because when we study the subjective burden caused by each disease separately we find that the subjective burden was significantly high in the caregivers for patients with schizophrenia than the caregivers of patients with poststroke disabilities, and it was significantly low in the caregivers of children with ADHD and substance abuse patients.

In fact, no sufficient studies were found comparing wives with mothers as caregivers, but Lois [21] reported that the relation between the subjective burden and the degree of relativity is unclear. Some studies reported that the level of subjective burden is higher in wives in comparison with any other relative [28,16]. Other studies have not found any difference in the level of subjective burden between wives and other female caregivers [29], whereas other studies found that the levels of subjective burden were higher in other women compared with wives [30].

The increased level of subjective burden in wives in comparison with mothers may be explained by the difference between both wives and mothers in their understanding of caregiving; for example, Kurz and Cavanaugh [31] reported that the fundamental characters of a marriage relationship are that it is optional and it can be ended at any time, whereas the relation between the mother and her child is more powerful. In addition, it is noted that the majority of wives in this study care for patients with chronic nonpsychological disorders that need higher level of caring and that affects the husband's sexual power, thus, increasing the burden on wives [27].

The results of this study showed that there is a significant statistical difference between mothers and wives with regard to the prevalence of psychiatric disorders, which are more prevalent in the wives compared with mothers, especially major depressive disorder, generalized anxiety disorder, and mixed anxiety and depression,

whereas adjustment disorders are more prevalent in the mothers compared with wives. The results also showed that there is a significant statistical difference between caregivers of patients with psychiatric and nonpsychiatric disorders with regard to the prevalence of psychiatric disorders, which are more prevalent in the caregivers of patients with nonpsychiatric disorders compared with caregivers of patients with psychiatric disorders. However, when we study the prevalence of psychiatric disorders in the caregivers for patients with each disease, we find that the prevalence of psychiatric disorders does not depend on whether the disease is psychiatric or nonpsychiatric but it depends on the nature of the disease of the care recipient and its impact on the functional level of the patient, as the depressive disorders were more prevalent in the caregivers of patients with schizophrenia and patients with poststroke disabilities. However, anxiety disorders are more prevalent in the caregivers of substance abuse patients, and psychiatric disorders are less prevalent in the caregivers of children with ADHD.

These results are compared with that of Beason *et al.* [32] and Berg *et al.* [33] who reported that depression is more prevalent in wives caring for their husband in comparison with other relatives (sons).

The increased prevalence of psychiatric disorders in wives can be explained by the increased subjective burden in wives in comparison with mothers. Previous studies showed that the relation between subjective burden and the prevalence of psychiatric disorders is proportional [34,35]. In addition, wives are younger than mothers, and some studies found that depression is less in older caregivers in comparison with younger caregivers [33,36]. Increased prevalence of psychiatric disorders in caregivers of nonpsychiatric disorders in this study is in agreement with Dennis *et al.* [37] and with Kotila *et al.* [38] who reported that the degree of depression in caregivers of patients with poststroke disabilities increased significantly with the degree of disability.

Conclusion

The study results may indicate that caregiver burden (objective and subjective) and prevalence of psychiatric disorders in caregivers do not seem to depend on whether the disease of the care recipient is psychiatric or physical, but seem to depend on the impact of the disease on the functional level of the patient. No difference exists between mothers and wives in the level of objective burden, which does not depend on the relation between the caregiver and the care recipient; however, the level of subjective burden and prevalence of psychiatric disorders are higher in wives compared with mothers, which could be attributed to the difference in their view and appreciation of the caregiving situation.

Limitations of the study

- (1) There was a significant difference between both groups 1 and 2 with regard to age and relation to the patient, which may cause bias for the study, but this factor

could not be avoided because of the uneven distribution of mothers and wives as caregivers in both groups.

- (2) Age of the patients, level of education, residence (rural or urban), and occupation were not considered as factors, which could affect the burden level.

There is no conflict of interest to declare.

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المخلص العربي

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الخلفية : هناك أعداد متزايدة من مقدمات الرعاية لذوي الأمراض المزمنة . وتقديم الرعاية يمثل عبئا , وهو يقع غالبا على النساء (أمهات أو زوجات) . ولا تعرف على وجه التحديد مدى وتأثير ذلك العبء .

هدف البحث: دراسة العبء الذي تتعرض له مآحات الرعاية(أمهات ، زوجات) للمرضى المزمنين (نفسيين أو غير نفسيين) ، وأثر ذلك على حالتهم النفسية.

العينة وأدوات البحث: تمت هذه الدراسة على عينة مكونة من 300 سيدة (أمهات ، زوجات) ممن يتردد أزواجهن أو أبناؤهم على عيادة الطب النفسي وبعض التخصصات الأخرى بالمستشفى الجامعي بمدينة دمياط الجديدة التابع لجامعة الأزهر في الفترة من يونيو 2007 م إلى مارس 2008 م ، وذلك من خلال استخدام المقابلة الإكلينيكية شبيهة المقتنة حسب الخصائص التشخيصية للدليل الأمريكي الرابع المراجع نصيا (DSM IV- TR) ، ودليل انضغاط مآحات الرعاية (C.S.I) ، ومقابلة زاريت للعبء (Zarit burden interview) .

النتائج: مآحات الرعاية للمرضى النفسيين كن أمهات في 121 حالة (80,7%) وزوجات في 29 حالة (19,3%) بينما العكس في الاضطرابات العضوية حيث مثلت الزوجات 131 (87,3%) بينما الأمهات مثلن 19 فقط (12,7%) . ووجدت فروق ذات دلالة احصائية كبيرة في السن والبيئة الجغرافية والمستوي التعليمي بين السيدات في المجموعتين ، بينما لم تجد الدراسة فروقا ذات دلالة احصائية في وظيفة السيدات (الغالبية ربات منازل) ، كما وجدت الدراسة أن العبء (الذاتي والموضوعي) كان ذا دلالة احصائية كبيرة في مآحات الرعاية لمرضى عجز ما بعد الجلطة المخية ، الفصام ، الاضطراب الوجداني ثنائي القطب ، فشل الكلى والكبد المزمنين (0,001) . كما وجدت الدراسة أن 102 (34%) من مآحات الرعاية لديهن اضطراب الاكتئاب الجسيم ، وعانت 67 (22,3%) منهن اضطراب القلق العام ، كما وجدت اضطرابات نفسية أخرى حسب نوع وشدة مرض من يرعونهم.

الخلاصة : يعتمد الشعور بعبء رعاية المرضى (الذاتي والموضوعي) ومعدل انتشار الاضطرابات النفسية بين مآحات الرعاية على طبيعة المرض ومدى تأثيره على كفاءة المريض الشخصية والوظيفية ، كما أن العبء الذاتي ووجود الاضطرابات النفسية كان أعلى بين الزوجات مقارنة بالأمهات اعتمادا على إدراك كل منهن لموقف الرعاية .