

Depression Level and Burden of Care Among Family Caregivers of Older People With Physical and Mental Disability in Makkah City KSA

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Abstract

Aims: This study is aimed at examining the burden of care and depression level among the family caregivers of client diagnosed with physical or mental disability. In addition, this study purposed to test the relationship between socio-demographic factors and level of depression and burden of care.

Methods: Study design was a descriptive survey design. Study sample was 129 family caregivers of patients diagnosed with physical and mental disabilities in Makkah, Kingdom of Saudi Arabia. Data collected using a pre-designed structured interviewing questionnaire including the Beck Depression Inventory scale (Beck, Steer, & Brown, 1996) and Family Burden Interview Schedule.

Results: Percentage of depression level ranged from 63% among caregivers of physically disorder clients to 69% among caregivers of mentally disorder clients. Moreover, there were many factors that may increase risk of depression such as old age of caregivers, spouse and caregivers who cared for their charges four hours or more per day. There was significant difference in depression level and burden of care as regard to nature of relative illness ($p < 0.05$).

Conclusions: Policies and programs to alleviate the burden of care and to provide social support for these family caregivers are equally important for both family caregivers and their care receivers.

Keywords: depression, burden of care, older people, home care

1. Background

There is an increase in the numbers of older people. People worldwide and it is estimated that the proportion of the world's older adults will reach 22% in 2050. Older people individuals are at risk of developing mental disorders, neurological disorders or substance abuse problems as well as other health conditions such as diabetes, hearing loss, and osteoarthritis. Furthermore, some of older people may experience co-morbidity, being diagnosed with several diseases at the same time (WHO, 2016). As a result, older people frequently need support in daily life activities and/or help from others to cope with disabilities and make their life easier to perform activity of daily living (Mosqueda et al., 2004).

Few studies have examined the factors associated with depression among caregivers. Pirraglia et al. (2005), conducted a study to explore the relationship between depression and burden of care among informal caregivers of HIV-infected persons. Study design was cross-sectional; the study sample was 176 of HIV patients and their informal caregiver. A scale of 21-questions called Beck Depression Inventory (BDI) was used to measure caregiver's depression while the caregiver's burden was assessed using the Caregiver Strain Index (CSI). The study revealed that median age of caregivers was 42 years, 53% were females, 30% had an educational degree beyond high school, 47% were the patient's partner, friends were 18% and 35% were a family member. Caregivers who had a high caregiver burden were 27%, and 50% of them were depressed. In addition, 25% of informal caregivers

were themselves having HIV positive. Results revealed that the burden of caregiving was strongly and independently associated with depression in the informal caregiver of HIV-infected individuals. In addition, medical comorbidity besides HIV in the informal caregiver, illicit drug use by the informal caregiver, having others to help besides the HIV patient, spending all day together, and duration of the HIV patient's diagnosis were also associated with greater depression in the informal caregiver. Of all other characteristics of the informal caregiver, of the relationship between the informal caregiver and HIV patient, or of the HIV patient, none was independently associated with depression in the informal caregiver.

The study recommends the need for additional research to determine effective means to support caregivers and the older patients with depression and to identify their problems, which has significant implications not only for the health and well-being of caregivers but also for their ability to provide effective care for a susceptible group of older adults. Masakazu et al., (2014) investigated the factors led to depression among family caregivers of older people with physical disabilities who used Home Health Care in the Metropolitan City of Hokkaido, Northern Japan. The design was a cross sectional, using a self-administered questionnaire, including the Center for Epidemiologic Studies Depression Scale (CES-D) to evaluate the participant depression. The study showed that 45.5% of caregivers were depressed and the finding also revealed that there were many factors that may increase risk of depression such as old age of caregivers, spouse, caregivers who cared for their charges four hours or more per day and caregivers having chronic disease. The study recommends that care should be directed to family caregivers especially spouse or older caregivers in addition to the care given to disabled older people.

A study conducted by (Toyoshima et al., 2014), aimed to evaluate the burden and depression among 78 pairs of psychiatric clients who were receiving services of nursing home visits and their caregivers. A cross sectional design was used to investigate the caregivers and their clients who were having psychiatric problems. The used questionnaire included self-administered Japanese version of Zarit Caregiver Burden Interview (ZBI) and a Japanese version of the Center for Epidemiologic Studies Depression (CES-D) Scale. The results showed that (50%) of caregivers were depressed and (57.7%) clients were diagnosed with schizophrenia. The results also revealed that depressed caregivers attend hospitals for treatment for their own chronic diseases and were significantly burdened. The study also mentioned that physically disabled clients might need physical care only while psychiatric clients needed both (physical and psychiatric care). In a study conducted by (washio, et al., 2015) in Japan to investigate factors that lead to depression among caregivers of frail clients who were using visiting nursing services, sample was 68 pairs of caregivers and their clients, and the design of the study was cross sectional. The questionnaire was used for measuring the burden of caregivers. Mental disability defines as any form of mental illness according to DSM-V and physical disability includes any form of somatic disorder, mainly neurological and cardiac problems (Khan et al., 2016).

The result revealed that 43.3% of the caregivers were depressed and significantly burdened and using public services more than non-depressed caregivers. Results also revealed that there were many factors that may increase risk of depression such as old age of caregivers or being a spouse. The study also showed a heavy burden among caregivers when spending more time with the clients; it is considered additional risk factor for them

Khan et al. (2016) conducted a study to examine burden and depression among caregivers of visually impaired patients in a Canadian population. It was a clinic-based, cross-sectional survey in a tertiary care hospital. Caregivers were considered unpaid family members for patients whose sole impairment was visual. Patients were stratified by vision in their better seeing eye into two groups: Group 1 had visual acuity between 6/18 and 6/60 and Group 2 were those who had 6/60 or worse. Burden was evaluated by the Burden Index of Caregivers and the prevalence of being at risk for depression was determined by the Center for Epidemiologic Studies Depression scale. Results revealed that total mean Burden Index of Caregivers scores were higher in Group 2. Female caregivers, caregivers providing greater hours of care, and caregivers of patients who have not completed vision rehabilitation programs were at higher risk for depression. The aim of the study was to assess the burden of care and level of depression among the family caregivers of older people patients. This study added to understand the Saudi caregivers psychosocial problems as a result of providing direct care for ill relatives.

2. Methods

2.1 Design

The study was employed descriptive survey design.

2.2 Study Setting & Recruitment

In the Kingdom of Saudi Arabia there are 209 hospitals implement the services of "Home Health Care". The number of service users are 27764 patients. In Makah where the study was conducted, there are 7 hospitals provide

home health care services to, 1749 patients. (Statistics from the home health care program administration, department of statistics, till the end of April 2017).

2.3 Sampling

2.3.1 Participants

Inclusion Criteria

Caregivers had to be free from any mental illness, they had to consent voluntarily to participate in the study and they had to be willing to participate. Caregivers needed to be able to read and understand either Arabic or English.

Sample Size

The target sample of this study was 300 family caregivers and the final sample consisted of 129 family caregivers (response rate 43%) of patients diagnosed with physical and psychiatric problems. The sample size was calculated based on power 80%, level of significance 0.05, then the required sample size is 270 with attrition rate 15%.

Data Collection Procedure

Ethical approval was obtained from the Institutional Review Board (IRB) committee in the Ministry of Health. Following the explanation phase of the initial approach, eligible potential participants were given written information about the study, including the electronic information sheet along with relevant consent forms that they could take home prior to deciding whether to participate in the study. These electronic information sheets were supported by text message explanation about the study's importance and the proposed effect on their life. They were told they had the freedom to withdraw from the study at any time without explanation.

Data Collection Method and Outcomes Measure

A pre-designed structured interviewing questionnaire including the following items:

Personal data: Age, sex, residence, marital status, level of education, economic status, occupation, relation of the caregiver to the patient, number of contact hours spent with the patient and duration of caring process.

Determination of the severity of depression symptoms among caregivers using Beck Depression Inventory scale. This scale was devised by Beck, Steer, and Brown (1996) and was used to assess the severity of affective, behavioral, cognitive and somatic symptoms of depression. It includes statements that cover items related to the basic symptoms of depression, such as hopelessness and irritability, feeling of guilt or feelings of being punished, as well as physical symptoms such as fatigue, weight loss, and lack of interest in sex. The translated version showed excellent reliability, Cronbach's Alpha coefficient of the scale as a whole amounted to (0.807), which is an acceptable reliability coefficient since it exceeds (0.70) as stated by (Malkawi and Odeh, 2014).

This scale consists of 21-items, each answer of the participants was scored on a Likert type scale ranging from 0 to 3, the highest score indicates that individual's experience of severe episode of depression.

Measurement of the burden of care among caregivers using the family burden interview schedule (FBIS). This scale was devised by Pai and Kapur (1981). The FBIS has 24 items and focuses on six domains of primary caregivers' burden: family finance, routine, leisure time, physical health, mental health and family interaction. Each item is rated on a three-point Likert scale (0: no burden, 1: moderate burden, 2: severe burden) scored from 0 to 48; a higher score indicates a higher level of burden. The scale has a (Cronbach's alpha of 0.87) and test-retest reliability of 0.83. The translated version showed excellent reliability (Cronbach's alpha, 0.86) and inter-rater reliability (ICC, 0.86).

2.4 Ethical Approval

Ethical approval was obtained from the Institutional Review Board (IRB) committee in the Ministry of Health. All participants were informed and a written consent was taken from every participant after explaining the aim of the study. No obligation of any kind for participating in the study, and every participant was free to withdraw from completing the study at any time.

2.5 Data Analysis

Data entry and statistical analysis were done by using the Statistical Package for the Social Sciences (SPSS) version 23. Statistical significance was set at $p < 0.05$. Descriptive and inferential statistical techniques were utilized to analyze the collected data. These techniques included (frequencies, percentages, mean value and standard deviations). In addition to Chi Square Test applied to examine differences among groups for most of the variables such as age, gender, marital status or level of education.

3. Results

3.1 Sociodemographic Characteristics of the Study Participants

Approximately 300 of electronic questionnaires were distributed, a Google Play link (Google Play link was used to prepare the questionnaire). The total number of returned questionnaire was 129 (response rate is 43 %).

Tables 1 and 2 summarize the sociodemographic characteristics of the study participants. The majority (47.3%) of the participants' age ranged from 31–40 years (17.1% caring for mentally disabled and 30.2% caring for physically disabled). In addition, the majority of the family caregivers were female in both groups. Over half of those who were caring for physically or mentally disabled were married, more than half (67%) were holding bachelor degree. In terms of economic status, most of the study participants had a monthly income of less than 9000 SR. Most of the family caregivers were son and daughter. Most of them caring for their relative more than one year they formed 35.7% and had more four contact hours daily.

Table 1. Sociodemographic Characteristics of the study participants

	Mental disability		Physical disability		Total	P value
	Frequency	%	Frequency	%		
Family Caregivers						
Gender of caregiver						
Male	24	18.6 %	36	27.9 %	60	0.92
Female	27	20.9 %	42	32.6 %	69	
Total	51	39.5%	78	60.5%	129	
Age						
20 or less	0	0 %	1	0.8 %	1	0.29
21-30	10	7.8 %	15	11.6 %	25	
31-40	22	17.1 %	39	30.2 %	61	
41-50	13	10.1 %	19	14.7 %	32	
>50	6	4.7 %	4	3.1 %	10	
Total	51	39.5%	78	60.5%	129	
Social status						
Single	11	8.5 %	20	15.5 %	31	0.92
Married	32	24.8 %	44	34.1 %	76	
Divorced	7	5.4 %	12	9.3 %	19	
Widow	1	0.8 %	2	1.6 %	3	
Total	51	39.5%	78	60.5%	129	
Educational status						
Can read and write	0	0 %	1	0.8 %	1	0.59
Primary level	0	0 %	3	2.3 %	3	
Secondary level	1	0.8 %	2	1.65 %	3	
High school level	16	12.4 %	17	13.2 %	33	
University level	34	26.4 %	54	41.9 %	88	
Postgraduate	0	0 %	1	0.8 %	1	
Total	51	39.5%	78	60.5%	129	

Economic status						
Less than 3000 SR	6	4.7 %	13	10.1 %	19	
3000 - Less than 6000 SR	13	10.1 %	16	12.4 %	29	0.83
6000 - Less than 9000 SR	20	15.5 %	30	23.3 %	50	
9000 SR or more	12	9.3 %	19	14.7 %	31	
Total	51	39.5%	78	60.5%	129	
Relationship to patient						
Parent	4	3.1%	8	6.2%	12	
Spouse	6	4.7%	6	4.7%	12	0.97
Patients brother and sister	7	5.4%	11	8.5%	18	
Offspring	34	26.4%	53	41.1%	87	
Total	51	39.5%	78	60.5%	129	
The number of hours spent with the patient per day						
Less than four hours	42	32.6%	64	49.6%	106	0.96
Four hours or more	9	7.0 %	14	10.9 %	23	
Total	51	39.5%	78	60.5%	129	
How long have you been caring?						
Less than 6 months	11	8.5%	12	9.3%	23	
6 months or more	40	31.0%	66	51.2%	106	0.37
Total	51	39.5%	78	60.5%	129	
Are you a primary caregiver?	39.5%		60.5%		100%	
Are you occupied with other issues?						
No	11	8.5%	19	14.7%	30	
Yes	40	31.0%	59	45.7%	99	0.71
Total	51	39.5%	78	60.5%	129	
Gender of Patients						
Male	33	25.6%	56	43.4%	89	
Female	18	14.0%	22	17.1%	40	0.39
Total	51	39.5%	78	60.5%	129	
Age of Patients						
≤20	1	0.8%	3	2.3%	4	
21 and 30	1	0.8%	4	3.1%	5	
31 and 40	5	3.9%	2	1.6%	7	0.96
41 and 50	5	3.9%	5	3.9%	10	
>50	39	30.2%	64	49.6%	103	
Total	51	39.5%	78	60.5%	129	

The mean score of depression among caregivers of clients diagnosed with mental disability was higher than caregivers of clients diagnosed with physical disability (17.43 and 17.03 respectively), as indicated in Table 3. Independent sample t-test was used to compare the depression score between family caregivers of clients diagnosed with mental or physical disability. There was no significant difference in depression level as regard to nature of relative illness ($p < 0.05$).

Table 3. Depression Scores amongst the caregivers

	Type of Patients disability	N	Mean	Std. Deviation	P value
Depression Score	Mental disability	51	17.43	10.743	0.84
	Physical disability	78	17.03	12.360	

The mean score of depression among caregivers of clients diagnosed with mental disability was higher than caregivers of clients diagnosed with physical disability (18.62 and 13.84 respectively), as indicated in Table 4. Independent sample t-test was used to compare the depression score between family caregivers of clients diagnosed with mental or physical disability. There was no significant difference in depression level as regard to nature of relative illness ($p < 0.05$).

Table 4. Burden of Care Scores amongst the caregivers

	Type of Clients disability	N	Mean	Std. Deviation	P value
Burden of care score	Mental disability	51	18.6275	11.05796	0.03
	Physical disability	78	13.8462	7.60884	

4. Discussion

Caring of elder people with disabilities is often associated with mentally and physically burdened of caregiver (Maeda, 2003). The psychological health of the family caregiver is negatively affected by providing care to elder people with disabilities. Higher levels of depressive symptoms and mental health problems among caregivers than among their non-caregiving peers (Pinquart et al., 2003).

The result of the study showed that percentage of depression ranged from 63% among caregivers of physically disorder clients to 69% among caregivers of mental disorder clients. This finding agreed with (National Alliance for Caregiving [NAC], 2008, 2009) which stated that between 40 and 70% of caregivers have clinically significant symptoms of depression, with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression.

On the other hand, level of depression among caregivers in the present study was higher than the previous studies of (Washio et al., 2003; Oura et al., 2007; Hashimoto et al., 2013; Washio et al., 2014; Masakazu et al., 2014) and (Pirraglia et al. 2005) who stated that percentage of depression among caregivers ranged from (43%–50%). This result can be explained that the caregivers in the present study were married (54.8%) with multiple social responsibilities, university students (31%) and offspring (12%) forming large sector of the sample. Moreover, percentage of caregivers in the present study who were caring their clients for a period of six months or more was (76.2%) and those who were occupied with other issues were (79.8%). These factors led to higher percentage of depression among caregivers in the present study than the previous studies.

In the current study, level of depression among caregivers was higher in females than males. Moreover, level of depression was higher among caregivers > 50 years old, and among caregivers with spousal relationship with the disabled client. These findings were in agreed with (Mc Grath et al., 2002; Vitaliano et al., 2003; Masakazu et al., 2014; Khan et al., 2016; Pinquart, 2003) who stated that greater degrees of depression and low ratings of subjective well-being among caregivers are consistently associated with old age of caregiving, a spouse relationship with the clients and being a female who have higher rates of depression than men in the care-giving role.

However, a study by Khare et al., (2016) stated that aunts, nieces, and cousins were as depressed and burdened as spouses, parents, and children.

The result of the present study revealed that long period of caregiving every day was associated with higher level of depression among caregivers. Percentage of depression among caregivers who were caring for disabled clients for four hours or more per day was higher than those who were caring for their clients less than four hours per day. This result is in consistent with the study of (Washio et al., 2014) which showed that the spending more hours in caring of disabled clients was associated with higher percentage of depression among caregivers. This can be explained that spending longtime in caring or doing same duties routinely and necessarily every day is logically

leading to depression. More time spent by the caregiver may be a risk factor for stress, caregivers is heavily stressed when spending more time for caring for older people, with mental and physical disability.

The present study showed that the duration of caregiving (>6 months) is significantly correlated to caregiver depression and is a predictor of caregiver burden. This is consistent with the findings of a study that was carried out on caregivers of Alzheimer's dementia patients (García-Alberca et al., 2011). This may be because of the nature of organ failure patients and the unexpected fluctuating course of disease, which places more burden on caregivers.

However, a study by Razali et al. (2011) shows that caregiver's depression is not significantly related to the duration of caregiving. In contrast, McConaghy and Caltabiano (2005), found that caring for a patient with dementia over a long period of time was associated with decreased levels of caregiver's depression and increased well-being. In the current study, the mean score of burden of care level among caregivers of clients diagnosed with mental disability was higher than caregivers of clients diagnosed with physical disability (18.84 and 18.62 respectively), as indicated in Table 3. In addition, the mean score of depression among caregivers of clients diagnosed with mental disability was higher than caregivers of clients diagnosed with physical disability (17.43 and 17.03 respectively), as indicated in Table 4. Moreover, there was no significant difference in depression level and burden of care as regard to nature of relative illness ($p < 0.05$). This finding agreed with Scultz & Martire (2004) who stated that caregivers of an older people. With psychological illness such as dementia were associated with higher levels of mental health problems compared to caregivers of a relative with a physical illness. This can be explained that most patients with mental disabilities have been living in close contact with their families, which have often represented the primary resource for their social integration. Fluctuation of symptoms is more prevalent among mentally disabled clients creating additional source of burden and depression among their caregivers. Numerous studies have demonstrated that family caregivers of clients with severe mental illness suffer from significant stresses, experience moderately high levels of burden, and often receive inadequate assistance from mental health professionals. For families who are already confronted with a range of day-to-day problems that affect all aspects of their lives, a member with a severe mental illness may have a significant impact on the entire family system (Saunders, 2003). The main limitation of the study is that small sample size and participants were recruited from one site which jeopardies the generalizability of the study findings.

Conclusion and Recommendation

The study concluded that providing care for clients diagnosed with mental disability posits higher level of burden on family caregivers compared with caregivers of clients diagnosed with physical disability. This negative consequence was linked with high level of depression among those caregivers. As a result, the main recommendation based on the study findings is

- 1) Implementation of programs in each healthcare unit to educate caregivers how to deal with care stressors and their negative effects as well as enhance caregivers' abilities regarding coping strategies and problem solving.
- 2) There is a need to adopt effective strategy to lower burden of caregiving and to prevent adverse outcomes for disabled clients and their caregivers.

Authors' Contributions

The authors had equal contribution into the manuscript

AAH Design the study

AAH Collected data

AAH – Analyse and Report the Result

Ethics Approval and Consent to Participate

Ethical approval was obtained from FCMS and from all the study participants

Consent to Publish

"Not applicable" in this section as no personal information is provided in your manuscript.

Availability of Data and Materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request

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Competing Interests Statement

The authors declare that there are no competing or potential conflicts of interest.

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