

Examine Fatigue Levels And Mental Health Among Dementia Patients' Caregivers In Saudi Arabia

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ABSTRACT

Introduction: Since dementia has no treatment, its prevalence will strain healthcare systems. Dementia also impairs daily tasks, requiring long-term caregivers. Since dementia patients need 24-hour care, it can have a substantial impact on the caregivers' physical health and put a strain on their caregivers' mental health.

Aim: Evaluate the extent of fatigue and mental health indicators among dementia patients' caregivers in the eastern region.

Methods: A descriptive cross-sectional study was conducted from June 2023 to April 2024 at private hospitals, geriatric homes, and private homes in the eastern region of Saudi Arabia to collect data from dementia caregivers. The Fatigue Assessment Scale (FAS) and General Health Questionnaire (GHQ 12) collected data from 205 convenient dementia caregivers.

Results: 50% of the participants reported fatigue, while 72% reported mild mental exhaustion. The participants had a moderate level of fatigue ($M=23.8$, $SD=6.65$). There is no statistically significant difference in the overall fatigue scores among relative caregivers and nurses ($p=0.211$); however, there is a difference between males and females ($p<.001$). Specifically, the females experienced more fatigue. There is no significant difference in general mental health among the two caregiver groups ($p=0.211$) or between genders ($p=0.085$).

Conclusion: The majority of the participants suffered from mild mental exhaustion, while half reported fatigue. Still, there is a difference between males and females, with females reporting more fatigue than males. Family caregivers for people with dementia encounter challenges and require comprehensive assistance to meet their demands.

Key words: Dementia, caregiver, fatigue, mental health

Introduction

Dementia is a general term for the impaired capacity to remember, think, or make decisions that affect daily activities rather than a specific disease. It is progressive and leads to cognitive dysfunction (Alzheimer's Disease International and Karolinska Institute, 2018). In the United States, Alzheimer's disease, which is one cause of dementia, affects 5.8 million people (Gorostiaga et al., 2022). There are 130,000 dementia patients in Saudi Arabia. By 2050, the number will be doubled (Arvanitakis et al., 2019).). Around the world, every three seconds, one patient is diagnosed with dementia, and one out of three senior patients dies. As dementia has no cure, the increase in the number of people with dementia will have a significant impact on healthcare systems. Additionally, dementia makes it harder to do daily tasks, so people with dementia need long-term carers to take care of their physical needs. Since the care provided to dementia patients is around the clock, it can significantly affect the physical health and strain the mental health of the caregivers.

There is a lot of scientific research indicating that caring for older people with dementia is associated with increases in burden, distress, and decrements in mental health and well-being. More severe behavioral, cognitive, and functional impairments in a patient are associated with higher levels of burden and distress

among caregivers. Distress increased with care hours per week, number of tasks, and declining coping and support resources (Samy Atta, 2021). Caregivers often experience depressive and anxiety disorders, lower quality of life, and physical symptoms such as fatigue and insomnia. Additionally, caregivers may also be at risk for work-related musculoskeletal disorders. Caregivers such as those who are caring for dementia patients have higher rates of depressive and anxiety disorder, lower quality of life (QOL), higher risk of hypertension and heart disease, and decreased immunity than non-caregivers. Furthermore, work-related According to a study by Saikai et al., 2020, Musculoskeletal Disorders (WMSDs) can affect caregivers even more than a professional believed to be more prepared for caring activities. WMSDs encompass a range of inflammatory and degenerative illnesses that impact muscles, joints, ligaments, tendons, and peripheral nerves (Posner et al., 2015). A study by Vun et al. (2020) stated that caregivers may experience satisfaction and stress when providing care. When comparing a caregiver to a non-caregiver, more detrimental effects of caregiving were noted, including an increase in physical complaints (headaches and backaches), mental health consequences (stress or distress, depression, emotional), burden, cognitive issues, inadequate sleep and self-care, and financial burden (Erin & Andros, 2009). This, in turn, impacts caregivers' quality of life.

Increasing numbers of dementia patients in Saudi Arabia and worldwide call for attention to the well-being of caregivers and Dementia patients. Therefore, this study assesses physical exhaustion and mental health among caregivers of Dementia patients in Eastern Province, KSA. It becomes imperative to understand the factors that contribute to poorer physical and mental health among caregivers of Dementia patients and develop interventions that address their specific needs.

The Aim

Evaluate the extent of fatigue and mental health indicators among dementia patients' caregivers (caregivers) in the eastern region.

Materials and Methods

Design and Setting

A descriptive cross-sectional study was conducted from June 2023 to April 2024 at private hospitals, geriatric homes, and private homes in the eastern region of Saudi Arabia to collect data from caregivers of dementia patients. According to a study conducted by Alsebayel et al. (2022), the prevalence of dementia is 16% - 11%. The study determined a 5% margin of error and a 95% confidence interval. We were using Kish L. formula (1965) $[n = z^2 \times p \hat{p} (1 - p \hat{p}) / e^2]$, $[n = 1.96^2 \times 0.16 (1 - 0.16) / 0.05^2]$. A sample size of 205 caregivers (caregivers) was required. A convenient sampling method was used to recruit caregivers from hospitals who worked as nurses and caregivers in geriatric homes. A purposeful sampling method was also utilized to reach family caregivers in their homes. The inclusion criteria include adult males and females, aged between 21 and 60, who have been providing care for dementia patients for at least three months. The exclusion criteria include those individuals under 21 or over 60 years of age who have been providing care for less than three months. In addition, to excluded caregivers for patients with other chronic diseases rather than dementia, such as neuromuscular or cognitive disorders.

Instrument

Demographic variables include age, gender, occupation, education, marital status, relationship with the patient, place of care, etc. Two questionnaires were used to assess the caregiver's fatigue and mental health:

The Fatigue Assessment Scale (FAS) was developed by De Vries et al. (2003), a 10-item self-report scale that evaluates symptoms of chronic fatigue. It measures physical Exhaustion and mental symptoms. The internal consistency of the FAS is 0.90. The measurement consists of two subscales: a) Mental fatigue (total of items 3, 6, 7, 8, and 9) – a measure of the cognitive impacts of fatigue for the client (e.g. lack of motivation, problems beginning tasks, problems thinking). b) Physical fatigue (total of items 1, 2, 4, 5 and 10) – refers to the physical impact of fatigue on the client (e.g. physical exhaustion, lack of energy). Available on the website.

The General Health Questionnaire (GHQ 12) was developed by Goldberg and Williams (1988). It assesses mental health. It consists of 12 items, each assessing the severity of a mental problem experienced in the preceding few weeks using a 4-point Likert-type scale ranging from 0 to 3. The tool is divided into three subcategories: social dysfunction (Q1,3,4,7,8,12), anxiety and disorders (Q2,5,6,9), and loss of confidence (Q10, 11). The score generated a total score ranging from 0 to 36. The positive items were corrected from 0 (always) to 3 (never) and the negative ones from 3 (always) to 0 (never). High scores indicate worse mental health, with a maximum of 36. The Cronbach's alpha coefficient test indicated a high level of internal consistency for the scale ($\alpha = 0.94$).

The tools are translated into English and Arabic to guarantee their content validity. First, the expert forwarded the translation from English to Arabic. Then, the Arabic translation was sent to a different translator, who took over and returned the translated text to its original English form. The researcher next performed a reconciliation by comparing the original and back-translated versions of the questionnaire.

Data collection

Researchers used a Google form (with a barcode added for simple scanning and access) to collect data from caregivers of dementia patients from Al Manaa hospitals, Geriatric care homes, and Homes, as described before. Before participants were asked to participate, the study's purpose and a summary were given to them. The consent form was included in the first part of the survey.

Statistical Analysis

The data analysis was performed via Jamovi. Demographic characteristics, fatigue levels, and mental health levels were subjected to descriptive statistical analysis, which involved calculating percentages and frequencies. Mean, standard deviation and mode were used to determine fatigue and mental health levels. The Man-Whitney test was also employed to compare the variables across different groups. A level of significance ($p < 0.05$) was used to define statistical significance.

Ethical approval

The MACHS IRB committee obtained the IRB (Reference number: SR/RP/130, Date 12/20/2023). Participants' involvement in the study was voluntary. They have the autonomy to abstain from completing the survey at any moment. All personal information was deleted prior to sharing the data with other researchers or publishing it, thus guaranteeing the anonymity, privacy, and confidentiality of the participant's data.

Results

Table 1 shows that out of the 205 participants who completed the questionnaire, the majority (77.5%) were family caregivers. These caregivers included spouses, children, siblings, grandchildren, and others. Most individuals (88.6%) were below 30 years, and 69% were married. Two-thirds of the sample consisted of females. Approximately 58.5% of the participants care for their relatives at home, whereas around 34.6% offer care in a hospital setting.

Table 1: description of the sample

Item	Category	Frequency	%
Age	18-22	84	41.6 %
	23-30	95	47.0 %
	above 30	23	11.4 %
Gender	Female	142	69.3 %
	Male	63	30.7 %
Caregivers	Relative Caregiver	158	77.5 %
	Nurse	46	22.5 %
Marital Status	Married	139	67.8 %
	Single	53	25.9 %
	Divorced	10	4.9 %
	Widowed	3	1.5 %
Level of education	University	158	77.1 %
	Secondary	32	15.6 %
	Intermediate	7	3.4 %
	Primary	6	2.9 %
	Illiterate	2	1.0 %
Having children	Yes	129	62.9 %
	No	76	37.1 %
Family Income	> 3000 SR	185	90.2 %
	< 3000 SR	20	9.8 %
Place of care	Home	120	58.5 %
	Hospital	71	34.6 %
	Care Center	14	6.8 %
Total Participants		205	

According to Table 2, the average score for the overall fatigue questionnaire indicated that the participants had a moderate level of fatigue ($M = 23.8$, $SD = 6.65$). Hendricks et al. (2018) found that a score ranging from 22 to 34 indicated exhaustion, whereas a score of 35 or higher suggests extreme fatigue. Furthermore, they were more physically exhausted ($M = 13.1$, $SD = 3.74$) than mentally exhausted ($M = 10.7$, $SD = 6.78$). Moreover, Table 2 displays that the respondents had mental well-being, as the average overall general mental health score was almost near the cut-off point of 12 ($M = 15$, $SD = 3.39$). Liang, Wang, & Yin (2016), a higher general mental

health score is indicative of poorer mental health, and cases could be regarded as such if they exceed the cut-off point of 12. The data shows that the highest average score was for social dysfunction, with a mean of 8.81 (SD= 1.85). The maximum score for this category was 18. The next highest average score was for anxiety, with a mean of 5.01 (SD= 2.32). Lastly, the average score for loss of confidence was 1.22 (SD= 1.62). The maximum score for this category was 6.

Table 2: Descriptive data for overall fatigue scores and general mental health (GMH) and their subcategories

	Mental Fatigue	Physical Fatigue	Total Fatigue Score	Social Dysfunction	Anxiety & Depression	Loss Of Confidence	Total GMH
N	205	205	205	205	205	205	205
Mean	10.7	13.1	23.8	8.81	5.01	1.22	15
Median	10	13	23	9	5	0	15
SD	3.78	3.74	6.65	1.85	2.32	1.62	3.39
Minimum	5	5	11	4	0	0	6
Maximum	25	25	50	13	11	6	26
Shapiro-Wilk p			< .001				0.085

Table 3 indicates that half of the sample had exhaustion, while the majority of the sample had mild mental exhaustion, specifically 72.7%.

Table 3 Frequency of fatigue and mental health level

fatigue category	Counts	% of Total
No fatigue	87	42.4 %
fatigue	103	50.2 %
extreme fatigue	15	7.3 %
General mental category	Counts	% of Total
Good Mental Health	55	26.8%
Mild Mental exhaustion	149	72.7
Severe Mental exhaustion	1	0.5%

Compare fatigue among groups. The Shapiro-Wilk test for normality revealed that the total fatigue score does not follow a normal distribution ($p = .001$), as Table 2 displays. Man-Whitney U was employed to compare the overall fatigue score and subcategories across various groups, including relative caregivers versus nurses and females against males. Based on the findings from Tables 4 & 5, the Man-Whitney U test revealed no statistically significant difference in the overall fatigue scores between the relative caregivers and nurses ($U = 3194$, $p = 0.211$) and their respective subcategories. Table 4 shows that relative caregivers ($Mdn = 23$) were more exhausted than nurses ($Mdn = 21$). However, a significant difference was observed between females and males in the overall fatigue scores ($U = 3037$, $p < .001$). Specifically, the females experienced more fatigue ($Mdn = 24$) than the males ($Mdn = 21$). Moreover, there is also a notable difference in the two subcategories of fatigue, mental fatigue ($U = 3341$, $p = 0.004$) and physical fatigue ($U = 3054$, $p < .001$).

Compare general mental health among groups. The total general mental health score exhibited a normal distribution ($p = 0.085$), as shown in Table 2. The overall general mental score and its subcategories were compared among the earlier groups using an independent samples t-test.

The t-test results showed no significant difference in overall general mental health between the relative caregivers and nurses' group ($t(202) = -0.676$, $p = 0.5$) or between both gender groups, males and females ($t(203) = 1.733$, $p = 0.085$), as seen in Table 5. Only two mental subcategories were significant among the groups. Social dysfunction was statistically significance between relative caregivers versus nurses ($p = 0.022$), and the loss of confidence was significant between females and males ($p = 0.018$).

According to the data presented in Table 4, mental exhaustion was more prevalent among nurses ($M = 15.4$, $SD = 4.15$) than relative caregivers ($M = 14.97$, $SD = 3.86$), while men reported lower levels of mental fatigue ($M = 14.333$, $SD = 3.89$) than women ($M = 15.359$).

Table 4: Groups Descriptives data

	Group	N	Mean	Median	SD	SE
Total fatigue	Relative caregivers	158	24.01	23.00	6.50	0.517
	Nurse	46	23.04	21.00	7.25	1.069

	Female	142	24.923	24	6.71	0.563
	Male	63	21.254	21	5.80	0.731
Total General Mental Health	Relative caregivers	158	14.97	15.00	3.86	0.307
	Nurse	46	15.41	16.00	4.15	0.611
	Female	142	15.359	15	3.92	0.329
	Male	63	14.333	14	3.89	0.490

Table 5: compare overall fatigue scores and general mental health scores among groups.

	statistics	df	P
Mann-Whitney U test compares overall fatigue scores among groups.			
Relative caregivers Vs. Nurses			
Mental Fatigue	2986	202	0.065
Physical Fatigue	3606	202	0.936
Total Fatigue	3194	202	0.211
Females Vs Males			
Mental Fatigue	3341	203	0.004
Physical Fatigue	3054	203	< .001
Total Fatigue	3037	203	< .001
Independent Samples t-test compares overall general mental health scores among groups.			
Relative caregivers Vs. Nurses			
Social Dysfunction	-2.317	202	0.022
Anxiety & Depression	1.151 ^a	202	0.251
Loss Of Confidence	-0.660	202	0.510
Total General Mental Health	-0.676	202	0.500
Females Vs Males			
Social Dysfunction	-0.162	203	0.872
Anxiety & Depression	1.416	203	0.158
Loss Of Confidence	2.365	203	0.018
Total General Mental Health	1.733	203	0.085

Discussion

Caregivers of individuals with dementia may be less able to cope with stressors as they have high rates of financial, emotional and physical difficulties associated with caregiving. (Freedman & Spillman, 2014). Moreover, Caregivers of dementia patients have difficulty in maintaining social relationships with family and friends. They feel isolated and alone, lack familial and community support, and need social support (Grigorovich et al., 2016). Most involving family caregivers of persons living with chronic conditions (e.g., dementia, cancer), has identified that the stress of caregiving can affect physical and mental health outcomes (JiYeon Choi et al., 2014). Therefore, this work aims to assess fatigue and general health parameters among dementia caregivers in the eastern region of Saudi Arabia. Providing care for an individual with dementia is extremely stressful and has far-reaching consequences. Caregivers often sacrifice their own needs and well-being to provide care for their loved ones. The distress experienced by dementia caregivers is typically referred to as caregiver burden, which includes both physical and emotional aspects (Alzheimer's Disease International and Karolinska Institute, 2018). The current study revealed that half of the caregivers experienced mild fatigue levels and reported more physical tiredness than mental exhaustion.

Similarly, Teahan, Á. et al. (2021), the family caregivers of individuals with dementia showed a much higher likelihood of reporting moderate or high levels of burden. In their study, Srivastava et al. (2016) found also that all caregivers experienced a mild to moderate level of burden. They also observed low mean scores in the quality-of-life domains, such as physical, social, psychological, and environmental. The result was opposed to a study by Kang et al. (2020), which revealed high levels of physical and mental fatigue by caregivers of patients with cancer or other chronic, severe illnesses. The data analysis showed high scores of anxiety and depression among the studied group. Brenna et al. (2015) agreed with this conclusion. They mentioned that people who care for individuals with dementia tend to have much higher rates of depression, psychological illness, and stress than people who do not care for someone with dementia. Because of how dementia works, the stress on carers grows as symptoms get worse. Carers have been linked to chronic depression, anger, fatigue, and more mental health issues. Similar findings were reached by Gorostiaga et al. (2022), who concluded that the primary caregivers group tends to have poorer self-rated health, higher levels of depression and anxiety and poorer physical health than a secondary caregiver. Additionally, Kaddour and Kishita (2020) found that around one-

third of caregivers reported feelings of anxiety and depression. Moreover, our study's findings showed that almost three-quarters of the studied group were suffering from mild mental exhaustion. This result is similar to what Gorostiaga et al. (2022) found when they looked closely at secondary caregivers and found that some of them have mental health issues and may require specific support for their psychological well-being.

The current study revealed no statistically significant difference in the overall fatigue scores and total general mental health between relative caregivers and nurses. This could be attributed to the fact that most of the studied caregivers were under 30 years old. Younger individuals tend to be more tolerant when caring for their relatives than older caregivers, who may have chronic illnesses that increase their burden. This is incongruent with Kang et al. (2020), who cited that the caregiver's fatigue got worse with age, sleepiness, anxiety, and depression, as well as with the patient's illness lasting longer. Similarly, Tsai et al. (2021) reported that older caregivers felt difficult or poorer experiences related to family care. Phillips et al. (2023) supported the idea that older personal health issues may make it difficult for them to carry out their caregiver responsibilities, reducing their social support system. An additional reason is related to the culture where most Arab families have elderly relatives residing with their sons and families to receive care, resulting in a customary expectation for family members to provide caregiving, as it is typically practiced within their families. The current study revealed that more than half of the participants care for their relatives at home. This finding was supported by Kang et al. (2020), who reported 97% of caregivers were living with the patients. Additionally, in Arab culture, it is considered obligatory to provide care for parents and sick family members, and it is deemed inappropriate to express dissatisfaction with this responsibility.

Not surprisingly, the greater part of the literature on gender differences in caregiving has been devoted to caregiver burden. The current finding showed that 70% of caregivers were females. In the same vein, Almugti and colleagues (2023) mentioned that females were the primary caregivers in Saudi families, and the majority of individuals with dementia were males. Additionally, the data analysis revealed a significant difference between females and males in the overall fatigue and general mental health scores, where the females reported more fatigue and less mental health. Lirn et al. (2013) also found that female spousal carers had more negative experiences with caregiving than male spousal carers. For example, they reported worse mental and physical health, a lower quality of life related to their health, less life satisfaction, and less marital satisfaction. In consensus, Phillips et al., 2023 supported that women experience a greater sense of responsibility in caregiving, which leads to them having to juggle various conflicting responsibilities. They were associated with the fact that most females take responsibility for caregiving for the older people in the family. Specifically, the females experienced more fatigue than the males. This result is similar to what Kim and Woo (2022) found in their meta-analysis, which said there is proof that the health effects of informal caregiving are different for men and women. Also, they said that female carers, like wives, daughters, and daughters-in-law, are more likely to be sick than male carers. Additionally, several additional research have indicated that female family caregivers encounter elevated levels of psychological distress, humiliation, and caregiver load (Gresswell et al., 2018; Avdikou et al., 2019; Brites et al., 2020; Phillips et al., 2023). Women are more prone to experiencing a decline in their sense of self and feelings of isolation when taking care of a family member, which increases their vulnerability to caregiver depression. In contrast, men are more at ease with delegating the caregiving role to others and rely more on themselves and their social network for support (Ruisoto et al., 2020).

Lastly, despite notable variations in spousal status, all caregiving groups self-reported similar health, energy, weariness, and sleep levels. Healthcare professionals can help senior caregivers keep an eye on their health and identify when they require services to support their position as caregivers. Therefore, future prospective studies should look into ways to lessen the symptoms of depression and weariness experienced by caregivers of patients whose conditions are unlikely to get better (Jeste, Mautsach, & Lee, 2021). Additionally, it might be required to determine whether treating anxiety and depression can alleviate weariness, at least in part, mentally.

Conclusions

The majority of the participants suffered from mild mental exhaustion, while half reported fatigue. Nurses and relative caregivers have no significant difference regarding fatigue and mental health. Still, there is a difference between males and females, with females reporting more fatigue than males. Family caregivers for people with dementia encounter challenges and require comprehensive assistance to meet their demands.

Recommendation and Implication:

Family caregivers of individuals with dementia may necessitate customized social assistance to uphold their well-being. Specific interventions for caregivers, such as exercise, relaxation techniques, a health promotion program, and remote social contact, can effectively reduce caregiver strain and distress, particularly among women. Assessing the requirements of family caregivers is crucial in developing social and healthcare services. Greater emphasis should be placed on recognizing caregiver fatigue, stressors, and mental exhaustion since this can lead to potential improvements in the adverse health effects commonly linked with caregiving. More

research with a large sample is needed to identify possible factors related to fatigue and poor general health of caregivers.

Limitation

One of the study's limitations was using convenient sampling in the sample selection process. Another is that there is no dementia patient registry which facilitates access to all the data about those patients in the eastern region.

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Competing Interests

The researcher declares there is no conflict of interest.

Data Availability Statement

The datasets are available from the corresponding author upon reasonable request.

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