



The Impact of Alzheimer's Disease on Family Caregivers in Saudi Arabia

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Abstract

Background: Providing care for a person with Alzheimer's disease is very difficult and may have a negative effect on the caregivers. The objectives of this study were to investigate the physical, psychological, social, financial, and religion impact of Alzheimer's disease on the family caregivers.

Methods: Cross-sectional study using self-administered online-based survey.

Main outcome measures: characteristics of the caring services and the burden of caring services on the family caregivers

Results: This study conducted on 172 family caregivers on Saudi Arabia (64%) of them were women, the majority (81.13%) were 21 to 50 years old, the caregiving services affected the sleeping hours of (59.89) of caregivers, (68%) felt frustrated, and the majority (82.56%) get social support from other family members. Most of the caregivers (90.12%) indicated that the caregiving is a religious duty, and (65.7%) did get financial support for giving services.

Conclusions: The caregiving services have negative physical and psychological impact on caregivers, they received social support but not received and financial support.

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Keywords: Alzheimer's disease; caregivers; physical, psychological, social, financial, religion, and impact

1. Introduction

Alzheimer's is a kind of dementia that causes problems with memory, thinking, and behavior. Manifestations, as a rule, grow gradually and deteriorate after some time, becoming severe enough to interfere with daily tasks. Alzheimer's is not a normal part of aging, the greatest known risk factor is increasing age, and the vast majority of Alzheimer's are 65 years and older. Approximately 200,000 Americans under the age of 65 have younger-onset Alzheimer's disease (also known as early-onset Alzheimer's). (1) By 2050, the number of people age 65 and older with Alzheimer's disease may almost triple, from 5.1 million to an anticipated 13.8 million, excepting the advancement of therapeutic achievements to avoid or cure the disease.(2)

As indicated by Saudi Alzheimer's Disease Association there are no official statistics on the spread of Alzheimer's disease in Saudi Arabia, yet experts appraise that there are no less than 50 thousand patients in the Kingdom, most of them are women. The Saudi Alzheimer's Disease Association demonstrate that the chances of getting the sickness twofold every 5 years

among people aging more than 65 years, while that half of those aging over 85 years were found infected with the disease. (3)

Dementia has a physical, psychological, social, and economic impact, not only on individuals with dementia, as well as on their carers, families, and society at large. (4) Given the high demands on caregivers of people with the AD, they may encounter negative impacts on physical, psychological, emotional, social, and monetary aspects of their life; some constructive outcomes have likewise been noted. About a third of family caregivers encounter symptoms of depression, and 61% rated the emotional stress of caregiving as high or very high, they described their own health as fair or poor and tended to report that serving as a caregiver worsens their health. Caregivers may also encounter higher levels of depression and stress hormones, reduced immune function, slow wound healing, and more new cases of hypertension and coronary heart disease compared to non-caregivers. (5)

Caregivers may progress toward becoming in danger of psychological and physical illness if they have a close relationship with the impaired person. Spouse caregivers of people who were hospitalized for dementia more probable than spouse caregivers of people who were hospitalized for other diseases to die in the following year, even after accounting for the age of the spouse caregiver. (6) Although 44% of caregivers reported being employed full- or part-time, many caregivers of people with AD and other dementias reported making major changes to their work schedules because of their caregiving responsibilities: 61% of women and 70% of men said they had to go in late, leave early, or take time off, whereas 21% of women and 18% of men had to take a leave of absence.(6)

The presented research aimed to examine the physical, psychological, social, financial, and religion impact of Alzheimer's disease on the family caregivers.

2. Methods

2.1 study sample and technique

To examine the impact of Alzheimer's Disease on family caregivers, the researchers conducted a cross-sectional study using self-administered online-based survey on a sample of 172 family caregivers, the online-based-survey was published in social media by Saudi Alzheimer association official account and the researchers' social media accounts.

2.2 The Study's Date Collection and Instrument

After reviewing the literature (7-11), we designed the questionnaire which consisted of four parts, the first part; the demographic data of the patients and their caregivers, the second part; the characteristics of the caring service, third part; identified the effects of AD on family caregivers in 5 aspects of their life (physical, social, psychological, financial and religion), the fourth part; contained one open-ended question ask about the suggestions to improve the services of the patients and their caregivers.

2.3 The Validity of the Study's Instrument

The final copy of the questionnaire has been collected and modified by the researchers and it was handed out (Pilot phase) for the definitive validation furthermore, the questionnaire was tested by well-known professors from Public Health Department, KSU.

2.4 The reliability of the study's instrument

The researchers used SPSS to calculate and report Cronbach's alpha coefficient for internal consistency reliability for all scales and subscales that used, an alpha of 0.712 is probably a reasonable goal, and high value for Cronbach's alpha indicates the good internal consistency of the items in the scale. The acceptable values of alpha ranging from 0.70 to 0.95. Descriptive and quantitative Statistical analysis was performed by SPSS 19.0 for windows.

3. Results

3.1 Demographic Characteristics of the caregivers.

This study conducted on 172 family caregivers in Saudi Arabia (64%) of them were women, the majority (81.13%) were 21 to 50 years old. Half of them (51.7% and 51.1% respectively) had low income "less than 9000 Saudi Riyal" and were unemployed. There was a different relationship between caregivers and patients, (45.3% and 32%, respectively) of the caregivers were daughters and sons. (Table 1)

3.2 Demographic Characteristics of Alzheimer's Patients.

More than half (57%) of Alzheimer's patients were women, more than third (39%) of them were in age from 76 to 85 years old. The majority (66.9%) of patients their family caregiver did not know about the Alzheimer's disease stage. (Table 2)

3.3 characteristics of the caring services

Three quarter (75%) of the caregivers live with the patients in the same house, and almost (91%) of them were seeking help a nurse or housekeeper on caring of the patients. The main source of the information of (80%) caregivers was the doctor while only (1.2%) of them stated the health educators. (Table 3)

3.4 The burden of caring services on the family caregivers

Regarding the physical burden; (38.4%, 35.47%, and 18%, respectively) of caregivers feel sometimes they haven't enough time for their self, their health and sleeping hours were affected by caring service. For psychological burden, more than two-third (78.5% and 68%, respectively) of them sometimes, frequently or always feel stressed because of trying to balance between the caring services and other responsibilities, and afraid about the future of their patients. (Table 4)

Moreover, half (51.2%) of caregivers' social relationships never affected, (82.56% and 72.67%, respectively) get help and supported by the family members while more than half (54.65%) never communicated with people who have a patient with Alzheimer's disease. Around two-third (74.42%) considered the caring service as a religious duty, and (52.95) fell that they did not have enough money for caring, (table 4). In overall, (43%) of caregivers feel that they had a mild burden (69.8%, 45%, and 32.8%, respectively) of them stated that they always feel caring services are a religious duty, the patients were always dependant on them, and get help from family members, (table 5).

3.5 The caregivers' suggestions

3.6 More than half (59.4%) of caregivers gave suggestions for improving the caring services, (15.7% and 11.6%, respectively) of caregivers need educational courses and health education program. (Table 6)

Table 1: General characteristics of family caregivers.

	n=172 (100%)
The caregivers' gender:	
- Male	62 (36)
- Female	110 (64)
The caregivers' age:	
- less than 20	7 (4.07)
- 21-30	40 (23.26)
- 31-40	53 (30.81)
- 41-50	50 (29.06)
- 51-60	15 (8.72)
- More than 60	7 (4.07)
Marital status:	
- Widower	6 (3.50)
- Single	50 (29.10)
- Married	108 (62.80)
- Divorce	8 (4.70)
Income:	
- 1000-3000 SR	47 (27.30)
- 3001-9000 SR	42 (24.40)
- 9001-1500 SR	29 (16.90)
- More than 15000 SR	54 (31.40)
Employment:	
- Student:	15 (8.70)
- Employed	69 (40.10)
- Unemployed	88 (51.20)
Level of education:	
- Uneducated	7 (4.10)
- Elementary	14 (8.10)
- Intermediate	9 (5.20)
- Secondary	30 (17.40)
- University and above	112 (65.10)
The relationship with Alzheimer's patient:	
- Son	55 (32.00)
- Daughter	78 (45.30)
- others	39 (22.67)

Table 2: General characteristics Alzheimer patients.

n=172(100%)			
The patients' gender:			
- Male			74 (43)
- Female			98 (57)
The patients' age:			
- less than 45			2(1.2)
- 45-55			6(3.5)
- 56-65			11(6.4)
- 66-75			55(32)
- 76-85			67(39)
- More than 85			31(18)
Stage of the AD:			
- First stage	Female	Male	Total
- Second stage	8	2	10
- Third stage	5	5	10
- Fourth stage	3	3	6
- Fifth stage	5	2	7
- Sixth stage	6	3	9
- Seventh stage	3	4	7
- I don't know	6	2	8
	62	53	115

Table 3: The characteristics of the caring services provided by the caregivers

		n(%)
Living with the patient in the same home:		
- Yes		81 (47.15)
- No		91 (52.9)
caregivers seeking the help of a nurse or housekeeper on caring of the patient:		
- Yes		43 (25.0)
- No		129 (75.0)
Caregivers main source of information:		
- Internet		61 (35.5)
- TV		7 (4.1)
- Radio		1 (0.6)
- Doctor		80 (46.5)
- Books		4 (2.3)
- Health educator		2 (1.2)
- Magazines & newspapers		3 (1.7)
- Social media		14 (8.1)
• Twitter		4 (2.3)
• WhatsApp		7 (4.1)
• YouTube		3 (1.7)
Caring duration per week:		
- 1-3 day		20 (11.6)
- 4-6 days		14 (8.1)
- Working days		4 (2.3)
- All the week		123 (71.5)
- Weekend		11 (6.4)

Table 4: The burden of caring services on the caregivers.

	Never	Rarely	Sometim es	Frequen tly	Always	
Physical impact	Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	35(20.3 %)	29(16.9 %)	66 (38.4%)	29 (16.9%)	13 (7.6%)
	Does your sleeping hours affect by caregiving to the patient?	28 (16.28)	41 (23.84)	61 (35.47)	19 (11.05)	23 (13.37)
	Do you feel your health has suffered because of your involvement with your relative?	66 (38.4%)	44 (25.6%)	31 (18.0%)	18 (10.5%)	13 (7.6%)
Psychological impact	Do you feel sadness and frustration because of caring for the patient?	36 (20.93)	65 (37.79)	43 (25.0)	11 (6.4)	17 (9.88)
	Does your job or school performance affected by caregiving to the patient?	92 (53.44)	25 (14.53)	27 (15.7)	19 (11.05)	9 (5.23)
	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	30 (17.4%)	25 (14.5%)	51 (29.7%)	36 (20.9%)	30 (17.4%)
	Do you feel embarrassed over your relative's behavior?	88 (51.2%)	26 (15.1%)	43 (25.0%)	8 (4.7%)	7 (4.1%)
	Do you feel strained when you are around your relative?	47 (27.3%)	31 (18.0%)	57 (33.1%)	20 (11.6%)	17 (9.9%)
	Do you feel angry when you are around your relative?	87 (50.6%)	41 (23.8%)	34 (19.8%)	9 (5.2%)	1 (0.6%)
	Do you feel you have lost control of your life since your relative's illness?	78 (45.3%)	34 (19.8%)	39 (22.7%)	11 (6.4%)	10 (5.8%)
	Do you feel that you do not have as much privacy as you would like, because of your relative?	66 (38.4%)	30 (17.4%)	46 (26.7%)	20 (11.6%)	10 (5.8%)
	Are you afraid about what the future holds for your relative?	23 (13.4%)	14 (8.1%)	40 (23.3%)	36 (20.9%)	59 (34.3%)
	Social impact	Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	88 (51.2%)	28 (16.3%)	33 (19.2%)	17 (9.9%)
Do you feel that your social life has suffered because you are caring for your relative?		60 (34.9%)	38 (22.1%)	35 (20.3%)	30 (17.4%)	9 (5.2%)
Do you feel uncomfortable about having friends over, because of your relative?		95 (55.2%)	22 (12.8%)	27 (15.7%)	16 (9.3%)	1 (7.0%)

	Does one of your family members help you in caregiving to the patient?	11 (6.4%)	19 (11.05%)	44 (25.58%)	42 (24.42%)	56 (32.56%)
	Do you get moral support from community members who surround you?	26 (15.12%)	21 (12.21%)	35 (20.35%)	37 (21.51%)	53 (30.81%)
	Do you communicate with people who have patient with Alzheimer disease to exchange expertise?	94 (54.65%)	32 (18.6%)	26 (15.12%)	9 (5.23%)	9 (5.23%)
Religion impact	Do you feel that caregiving of the patient with Alzheimer disease is a religious duty?	12 (6.98%)	5 (2.9%)	16 (9.3%)	11 (6.4%)	128 (74.42%)
	Is caring for the patient with Alzheimer disease effect on your performance to the worship?	90 (52.33%)	32 (18.6%)	37 (21.51%)	7 (4.07%)	6 (3.49%)
Financial	Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	91 (52.9%)	22 (12.8%)	25 (14.5%)	13 (7.6%)	21 (12.2%)
	Do you feel your relative is dependent on you?	25 (14.5%)	30 (17.4%)	33 (19.2%)	36 (20.9%)	48 (27.9%)
	Do you feel that your relative seems to expect you to take care of him or her as if you were the only one he or she could depend on?	36 (20.9%)	35 (20.3%)	44 (25.6%)	30 (17.4%)	27 (15.7%)
	Do you feel that you will be unable to take care of your relative much longer?	89 (51.7%)	33 (19.2%)	25 (14.5%)	12 (7.0%)	13 (7.6%)
Others	Do you wish you could just leave the care of your relative to someone else?	120 (69.8%)	20 (11.6%)	17 (9.9%)	5 (2.9%)	10 (5.8%)
	Do you feel uncertain about what to do about your relative?	42 (24.4%)	39 (22.7%)	60 (34.9%)	17 (9.9%)	14 (8.1%)
	Do you feel you should be doing more for your relative?	19 (11.0%)	32 (18.6%)	51 (29.7%)	29 (16.9%)	41 (23.8%)
	Do you feel you could do a better job in caring for your relative?	18 (10.5%)	31 (18.0%)	67 (39.0%)	32 (18.6%)	24 (14.0%)
	Do you feel that your relative asks for more help than he/she needs?	51 (29.7%)	36 (20.9%)	40 (23.3%)	16 (9.3%)	29 (16.9%)

Table 5: the relationship between the caregiving burden and other variables

	Burden				Total
	No or little	Mild	Moderate	Sever	
Patient dependence on the caregiver:					
- Never	1				
- Rarely	3	9	5	0	15
- Sometimes	13	4	6	0	13
- Frequently	7	18	11	5	47
- Always	17	9	7	1	24
- Total	41 (24%)	33	18	5	73
		73 (43%)	47 (27%)	11 (6%)	172
Get help from family members:					
- Never					
- Rarely	1	8	2	0	11
- Sometimes	5	9	4	1	19
- Frequently	12	14	14	4	44
- Always	6	18	16	2	42
- Total	17	24	11	4	56
	41 (24%)	73 (43%)	47 (27%)	11 (6%)	172
Feel caring of the patient is a religious duty:					
- Never	7	5	0	0	12
- Rarely	0	4	0	0	4
- Sometimes	4	9	2	1	16
- Frequently	2	4	5	0	11
- Always	28	51	40	10	129
- Total	41 (24%)	73 (43%)	47 (27%)	11 (6%)	172

Table 6: Demonstrates the Caregivers' suggestions

Suggestions	n(%)
Courses for caregivers	27 (15.7)
Health education program	20 (11.6)
Center for the patient	19 (11)
financial support	10 (5.8)
Support for caregivers	9 (5.2)
Nurses	9 (5.2)
Home healthcare	4 (2.3)
permissions and allowances from the work	4 (2.3)
Did not give suggestions	70 (40.6)

Discussion

The objectives of this study were to investigate the physical, psychological, social, financial, and religion impact of Alzheimer's disease on the family caregivers. This study revealed that the majority (64% and 62.8%, respectively) of family caregivers were women and married these results are similar the 2013 Alzheimer's disease fact sheet which indicated 62% of caregivers of people with AD and other dementias were women and 70% were married(12) and the 2017 Alzheimer's disease fact sheet said that The responsibilities of caring for someone with dementia often fall to women where approximately two-thirds of caregivers are women(13). However, this study found (59.9%) of caregivers are not living with the patient, the majority (75%) did not ask for the help of a nurse or housekeeper on caring of the patient. The caregivers' main sources of information were clinicians and internet (46.5%, and 35.5%, respectively).

Although, (38.4%, and 35.47%, respectively) of caregivers indicated that they did not find a time for themselves and feel their hours of sleeping affected by caregiving, (38.4%) of them did not feel that their health affected by their caring services. Furthermore, (78.5%, 68%, and 41.28%, respectively) of caregivers were afraid about the future of their patients, feel stressed between caring for their patients and trying to meet other responsibilities and feel with sadness and frustration because of caregiving. A study done by Mahoney et al was interested in discovering what makes certain caregivers more susceptible to developing anxiety and depression, concluding results showed that roughly a quarter of the caregivers were shown to be affected by anxiety and ten percent of these individuals were depressed. (14)

Previous researcher demonstrated that Caregiver burden was likely to be higher when the caregivers had lower levels of family function and social support (15), this study found that around two-third of the caregivers (72.67%, and 82.56%, respectively) said that they got moral support from community members who surrounding them, and one of their family members helped them in caregiving. Where, the impact of caregiving stress can be reduced by the social support this support may provide a sense of embeddedness within a helping network, which suppress stress appraisal(16).

Most caregivers (90.12%, and 70.93%, respectively) indicated that they fell the caregiving of the patient is a religious duty, and the caring services did not affect on their performance to the worship. Heo G suggested developing and maintaining religiosity plays an important role in enhancing positive aspects of caregiving (17).

The limitations of the study: the questionnaire is online based survey which may not reach to the caregivers who cannot access the internet.

Conclusions

The most family caregivers are women, the frequent relationship between the patient and caregivers with daughters and sons. they feel frustrated and depressed, they received help from family members and get moral support from community members who surrounding, they believed that the caring services are a religious duty.

This study recommends that: There is a need for providing emotional and financial support for family caregivers, establish centers for Alzheimer's patients for specific hours during working of family caregivers that equipped with all the necessary requirements.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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