

Perspective of caregivers towards early signs of memory decline in their elderly relatives among the Saudi population

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Received: October 2022 Accepted: November 2022; Published: December 1, 2022.

Citation: Walid alkeridy et al. Perspective of caregivers towards early signs of memory decline in their elderly relatives among the Saudi population. World Family Medicine. 2022; 20(12): 114-121 DOI: 10.5742/MEWFM.2022.95251478

Abstract

Objectives: World aging poses a big challenge with the rise of people with cognitive impairment. We aim in this study to understand the perspective of the caregivers towards the early signs of memory decline and cognitive impairment in their elderly relatives; we also aim to understand the impact of culture on their perspective.

Methods: This is a cross-sectional, descriptive study with a quantitative approach. It was approved by the Institutional Review Board prior to data collection, using a survey containing 41 items of collected data from 101 caregivers. We obtained signed written informed consent from each subject.

Results: A sample of 101 participants enrolled in this study, of whom about 60.4% (n=61) were males and 39.6% (n=40) were females. The mean age of the elderly relatives of the caregivers was (73.5±10.0) years and mean years of education was (6.5±7.5) years. Significant differences between males and females were found in terms of driving and using public transportation as this might alert the caregiver about early signs of memory decline ($X^2=6.785$, $p=0.009$).

Conclusion: Some cultural perspective could be identified that could help earlier detection of cognitive impairment in elderly people who rely largely on their caregivers. Caregivers are the first people to encounter the early changes in the behavior of the demented elderly; understanding their perspective can help providing more efficient health care.

Key words: dementia, caregivers, perspective, memory decline, culture

Introduction

The percentage of the elderly population in Saudi Arabia is increasing. In 2016, the number of people over 60 years old was estimated to be 1.3 million and by the end of 2050 it is predicted to surge over 10 million, representing 25% of the total population of Saudi Arabia [1,2]. Besides, life expectancy in Saudi Arabia is expected to increase up to 82 years by 2050 [1]. With the rise in life expectancy, the risk of developing cognitive impairment is expected to increase accordingly [3]. In addition, the number of elderly with dementia worldwide is expected to become 63 million in 2030 and 114 million in 2050 [4]. The cultural diversity and the demographic changes in patient populations impact the provision of health care and diagnosing diseases earlier [5].

There are no studies in the literature about the perspective of the caregivers and the impact of their cultural differences in the early diagnosis of dementia in the Kingdom of Saudi Arabia. Knowing the perspective of caregivers and the cultural differences along with the demographic variables in the Kingdom may help us in detecting the very early stages of dementia contributing to a very good cost-effective screening [6].

Knowing that the first encounter with the early signs of cognitive impairment and dementia is mostly by the caregiver, it's important to understand their perspective and how culture impacts their understanding of the early signs of cognitive impairment and dementia. This is what we're trying to investigate in this study. We also hope to change these misconceptions to seek help once the caregivers recognize any abnormal change in their relatives. Conceptions of dementia, and the stigma and attributions that the society has may influence a range of illness behaviors, including self-care, help-seeking, and treatment compliance [6]. Understanding cultural conceptualizations of dementia and caregiving can help health providers work more effectively with elders and their caregivers. We argue that understanding the perspective of caregivers and their cultural differences will help us improve the quality of the health care provided to the elderly population and in diagnosing cognitive impairment and dementia earlier in the Kingdom of Saudi Arabia.

An American study that was published in September 2008 asked the participants to describe the earliest changes in the lives and relationships they noticed in their parents, or spouse, brought on by cognitive impairment. They reported taking on new responsibilities in an intense caregiving process [7]. Other research was done to help to understand cultural conceptualizations of dementia and caregiving among Vietnamese American caregivers so it can support health providers to work more effectively with elderly people and their caregivers [6].

A Palestinian study published in 2011 found that because of some cultural values, Palestinian women with cancer tend to keep their illness as a secret and thus remain undiagnosed, and this is due to the embarrassment and

the community stigma related to women exposing their bodies to strangers. This is how culture can impact the effectiveness of health care provided to the community as the gender preference and religious practice may build some cultural barriers. However the study also suggests that in some areas of the Middle East some of the population depend largely on herbal medications and use them rather than going to a doctor and this delays the diagnosis of the disease and reduces the effectiveness of the health care provided [8].

Another American study found that cultural traditions and values affected the caregiving and help seeking in the immigrants of different nationalities, demonstrating their views of the early signs of dementia. Most of them see it as a natural part of aging rather than a sign of cognitive impairment and dementia [9].

In this study we aim to understand the perspective of Saudi caregivers on the early signs of memory decline in their elderly relatives and the impact of culture on their understanding of it by using a validated questionnaire.

Methods

This is a cross-sectional, descriptive study with a quantitative approach. It was approved by the Institutional Review Board at King Saud University (IRB number E-19-4418) prior to data collection. We obtained signed written informed consent from each subject after they had a chance to ask questions about the study. The survey collected data from 101 caregivers of elderly with cognitive impairment. The study took place in the geriatric outpatient clinic for elder care at King Khalid university hospital, Riyadh city, the Kingdom of Saudi Arabia. We started our study in September 2019 and it ended in May 2020. Collecting data started on the 22nd of February 2020 and was completed on the 6th of March 2020.

The participants were told that the study was designed to understand the perspective of the caregivers toward their elderly relatives' early signs of memory decline and understanding the effect of culture and demographic variations on the early diagnosis of the demented elderly. Inclusion criteria were being a caregiver for a 65 year old or above, from Saudi Arabia and receiving care at King Khalid University Hospital while participating in the study. All caregivers under the age of 18 years who didn't have a relative above 65 years old; were excluded from our study. We have used a validated, modified questionnaire (by modifying Bristol activities of daily living Arabic version scale which is used to assess cognitive impairment in elderly patients) in our modified questionnaire.

We aimed to measure the perspective of the caregivers of the early signs and alerting behaviors of memory decline and cognitive impairment in their elderly relatives. It consists of 41 items, and it includes the background and the demographic characteristics for the caregiver such as sex, age, relationship to the care recipient, formal education, and their occupation. For their relatives

it included questions about sex, age, the last job of the relative, history of volunteer work, type of residence and the average income. In order to detect culture and demographic variations of early cognitive impairment and dementia we have asked in our modified questionnaire about doing Muslim prayer 5 times a day, praying Muslim prayer Jumma (this variable was for males elderly only); attending weddings, social visits, preparing a complex meal for 4 people or more and mode of transportation.

The caregivers generally completed the questionnaire within 8-12 minutes and were given an oral debriefing, thanked for their participation, and were dismissed; there were no ethical considerations.

Data Analysis

The gathered data was analyzed using the Statistical Package of Social Sciences (SPSS) (v. 26, IBM Corp, IL, Chicago, USA). Descriptive statistics and Chi-square analysis were used to analyze participants' baseline characteristics and their responses to the study questionnaire. A significance level of ($\alpha \leq 0.05$) was used as a statistical significance threshold.

Results

In our study, we gave a questionnaire to 101 caregivers who live in Saudi Arabia and were 18 years or above, all of whom had to be a caregiver to a relative who is 65 years of age or above.

The results presented in Table (1) show the socio-demographic characteristics of the study participants. A sample of 101 participants enrolled in this study, of whom about 60.4% (n=61) were males. The mean age of the elderly relatives of the caregiver was (73.5±10.0) years and mean years of education was (6.5±7.5) years.

The results presented in Table (2) show the descriptive statistics of what caregivers think may alert them to their relatives' memory decline. The results showed that there

were no significant differences between male caregivers and female caregivers in feeding ($X^2=0.180$, $p=0.672$), dressing ($X^2=0.697$, $p=0.404$), going to the toilet by themselves ($X^2=0.068$, $p=0.694$), incontinence ($X^2=0.236$, $p=0.627$), bathing ($X^2=0.012$, $p=0.913$), ambulation ($X^2=0.048$, $p=0.827$), ability to use landline phone ($X^2=2.969$, $p=0.085$), shopping ($X^2=0.100$, $p=0.752$), food preparation ($X^2=0.000$, $p=0.997$), housekeeping ($X^2=0.021$, $p=0.884$), laundry ($X^2=0.398$, $p=0.528$), responsibility for own medication ($X^2=0.982$, $p=0.322$), and ability to handle finance ($X^2=2.669$, $p=0.102$). However, significant differences between males and females were found in terms of driving and using public transportation as it might alert the caregiver about early signs of memory decline ($X^2=6.785$, $p=0.009$).

The results shown in Table (3) represent the descriptive statistics of what caregivers think may have caused their relatives to not be able to do daily activities as they used to. The results revealed that there were no significant differences between males and females in ability to handle finance ($X^2=3.707$, $p=0.295$), responsibility for own medication ($X^2=4.843$, $p=0.184$), mode of transportation ($X^2=1.851$, $p=0.604$), housekeeping ($X^2=4.689$, $p=0.196$), food preparation ($X^2=4.156$, $p=0.245$), shopping ($X^2=0.798$, $p=0.850$), ability to use landline phone ($X^2=1.071$, $p=0.784$), actively supervise kitchen management or meal preparation ($X^2=3.525$, $p=0.318$), care for his/her appearance ($X^2=1.243$, $p=0.743$), social visits ($X^2=2.140$, $p=0.544$), weddings ($X^2=4.316$, $p=0.229$), pray five times a day ($X^2=2.634$, $p=0.452$), pray Juma ($X^2=5.259$, $p=0.154$), hobbies ($X^2=3.019$, $p=0.389$), volunteer ($X^2=1.683$, $p=0.641$), online shopping and bills ($X^2=4.494$, $p=0.213$), social media usage ($X^2=4.001$, $p=0.261$), knowing his/her disease ($X^2=1.318$, $p=0.725$), and appropriate medication to match disease ($X^2=2.149$, $p=0.542$). However, significant statistical differences were found in laundry ($X^2=9.065$, $p=0.028$) and preparing a complex meal for 4 people or more ($X^2=7.952$, $p=0.047$).

Table 1. Socio-demographic characteristics of the study participants (n= 101)

Variable	F (%)
Gender	
Male	61 (60.4)
Female	40 (39.6)
Age (M±SD)	73.5±10.0
Years of Education (M±SD)	6.5±7.5

Table 2. Descriptive statistics of what caregivers think that may alert them to their relatives' memory decline (n=101)

Variable	Male (n=61)	Female (n=40)	X ²	P
Feeding on their own Yes No	27 (44.3) 34 (55.7)	16 (40) 24 (60)	0.180	0.672
Dressing by themselves Yes No	28 (45.9) 33 (54.1)	15 (37.5) 25 (62.5)	0.697	0.404
Going to the toilet by themselves Yes No	26 (42.6) 35 (57.4)	16 (40) 24 (60)	0.068	0.794
Incontinence Yes No	28 (47.5) 31 (52.5)	17 (42.5) 23 (57.5)	0.236	0.627
Bathing by themselves Yes No	22 (36.1) 39 (63.9)	14 (35) 26 (65)	0.012	0.913
Ambulation Yes No	18 (29.5) 43 (70.5)	11 (27.5) 29 (72.5)	0.048	0.827
Ability to use landline phone Yes No	32 (52.5) 29 (47.5)	14 (35) 26 (65)	2.969	0.085
Shopping Yes No	21 (34.4) 40 (65.6)	15 (37.5) 25 (62.5)	0.100	0.752
Food Preparation Yes No	25 (41) 36 (59)	16 (41) 23 (59)	0.000	0.997
Housekeeping Yes No	22 (36.1) 39 (63.9)	15 (37.5) 25 (62.5)	0.021	0.884
Laundry Yes No	22 (36.1) 39 (63.9)	12 (30) 28 (70)	0.398	0.528
Using their own transportation or public transportation Yes No	39 (63.9) 22 (36.1)	15 (37.5) 25 (62.5)	6.785	0.009
Responsibility for their own medications Yes No	41 (67.2) 20 (32.8)	23 (57.5) 17 (42.5)	0.982	0.322
Ability to handle personal or family finance Yes No	39 (63.9) 22 (36.1)	19 (47.5) 21 (52.5)	2.669	0.102

Table 3. Descriptive statistics of what caregivers think may cause their relatives to not be able to do daily activities as they used to (n=101)

Variable	Male (n=61)	Female (n=40)	χ^2	p
Ability to handle personal or family finance			3.707	0.295
1. Age	28 (45.9)	25 (62.5)		
2. Mood change or depression	3 (4.9)	3 (7.5)		
3. Memory decline or Alzheimer	28 (45.9)	11 (27.5)		
4. Other	2 (3.3)	1 (2.5)		
Responsibility for own medications			4.843	0.184
1. Age	23 (37.7)	23 (57.5)		
2. Mood change or depression	2 (3.3)	2 (5)		
3. Memory decline or Alzheimer	35 (57.4)	14 (35)		
4. Other	1 (1.6)	1 (2.5)		
Using own transportation or public transportation			1.851	0.604
1. Age	33 (54.1)	24 (60)		
2. Mood change or depression	3 (4.9)	4 (10)		
3. Memory decline or Alzheimer	17 (27.9)	8 (20)		
4. Other	8 (13.1)	4 (10)		
Laundry			9.065	0.028
1. Age	40 (65.6)	29 (72.5)		
2. Mood change or depression	1 (1.6)	3 (7.5)		
3. Memory decline or Alzheimer	7 (11.5)	7 (17.5)		
4. Other	13 (21.3)	1 (2.5)		
Housekeeping			4.689	0.196
1. Age	38 (62.3)	31 (77.5)		
2. Mood change or depression	1 (1.6)	1 (2.5)		
3. Memory decline or Alzheimer	10 (16.4)	6 (15)		
4. Other	12 (19.7)	2 (5)		
Food preparation			4.156	0.245
1. Age	39 (63.9)	30 (75)		
2. Mood change or depression	3 (4.9)	4 (10)		
3. Memory decline or Alzheimer	10 (16.4)	4 (10)		
4. Other	9 (14.8)	2 (5)		
Shopping			0.798	0.850
1. Age	42 (68.9)	29 (72.5)		
2. Mood change or depression	3 (4.9)	3 (7.5)		
3. Memory decline or Alzheimer	11 (18)	5 (12.5)		
4. Other	5 (8.2)	3 (7.5)		

Table 3. Descriptive statistics of what caregivers think may cause their relatives to not be able to do daily activities as they used to (n=101) ...continued

Ability to use landline phone			1.071	0.784
1. Age	34 (55.7)	24 (60)		
2. Mood change or depression	4 (6.6)	4 (10)		
3. Memory decline or Alzheimer	22 (36.1)	11 (27.5)		
4. Other	1 (1.6)	1 (2.5)		
Preparing a complex meal for 4 people or more	42 (68.9)	30 (75)	7.952	0.047
1. Age	2 (3.3)	4 (10)		
2. Mood change or depression	5 (8.2)	5 (12.5)		
3. Memory decline or Alzheimer	12 (19.7)	1 (2.5)		
4. Other				
Actively supervise kitchen management or meal preparation			3.525	0.318
1. Age	37 (60.7)	29 (72.5)		
2. Mood change or depression	5 (8.2)	5 (12.5)		
3. Memory decline or Alzheimer	9 (14.8)	3 (7.5)		
4. Other	10 (16.4)	3 (7.5)		
Care for his/her appearance			1.243	0.743
1. Age	33 (54.1)	23 (57.5)		
2. Mood change or depression	14 (23)	8 (20)		
3. Memory decline or Alzheimer	13 (21.3)	7 (17.5)		
4. Other	1 (1.6)	2 (5)		
Social visits			2.140	0.544
1. Age	30 (49.2)	21 (52.5)		
2. Mood change or depression	15 (24.6)	13 (32.5)		
3. Memory decline or Alzheimer	12 (19.7)	5 (12.5)		
4. Other	4 (6.6)	1 (2.5)		
Attending weddings			4.316	0.229
1. Age	30 (49.2)	23 (57.5)		
2. Mood change or depression	19 (31.1)	9 (22.5)		
3. Memory decline or Alzheimer	8 (13.1)	2 (5)		
4. Other	4 (6.6)	6 (15)		
Pray 5 times a day			2.634	0.452
1. Age	19 (31.1)	14 (35)		
2. Mood change or depression	2 (3.3)	3 (7.5)		
3. Memory decline or Alzheimer	37 (60.7)	19 (47.5)		
4. Other	3 (4.9)	4 (10)		
Jumah prayer			5.259	0.154
1. Age	24 (39.3)	16 (45.7)		
2. Mood change or depression	2 (3.3)	1 (2.9)		
3. Memory decline or Alzheimer	33 (54.1)	13 (37.1)		
4. Other	2 (3.3)	5 (14.3)		

Table 3. Descriptive statistics of what caregivers think may cause their relatives to not be able to do daily activities as they used to (n=101) ...continued

Doing hobbies			3.019	0.389
1. Age	37 (60.7)	22 (55)		
2. Mood change or depression	9 (14.8)	8 (20)		
3. Memory decline or Alzheimer	12 (19.7)	5 (12.5)		
4. Other	3 (4.9)	5 (12.5)		
Volunteering			1.683	0.641
1. Age	45 (73.8)	27 (67.5)		
2. Mood change or depression	5 (8.2)	5 (12.5)		
3. Memory decline or Alzheimer	8 (13.1)	4 (10)		
4. Other	3 (4.9)	4 (10)		
Shopping and paying online			4.494	0.213
1. Age	34 (55.7)	25 (62.5)		
2. Mood change or depression	3 (4.9)	2 (5)		
3. Memory decline or Alzheimer	19 (31.1)	6 (15)		
4. Other	5 (8.2)	7 (17.5)		
Social media usage			4.001	0.261
1. Age	36 (59)	27 (67.5)		
2. Mood change or depression	4 (6.6)	4 (4)		
3. Memory decline or Alzheimer	15 (24.6)	22 (21.8)		
4. Other	6 (9.8)	12 (11.9)		
Knowing his/her diseases			1.318	0.725
1. Age	28 (45.9)	14 (35)		
2. Mood change or depression	2 (3.3)	2 (5)		
3. Memory decline or Alzheimer	29 (47.5)	22 (55)		
4. Other	2 (3.3)	2 (5)		
Medications for disease match			2.149	0.542
1. Age	25 (41.7)	19 (47.5)		
2. Mood change or depression	0 (0)	1 (2.5)		
3. Memory decline or Alzheimer	34 (56.7)	19 (47.5)		
4. Other	1 (1.7)	1 (2.5)		

Discussion

The results indicate that the cultural differences in the Kingdom of Saudi Arabia impact the perspective of the caregivers towards the early signs of cognitive decline in their elderly relatives. Our findings show that the caregivers think that their relatives inability to pray 5 times a day (55.5%) is due to memory decline rather than aging. This can help us in understanding that the inability to perform daily religious activities is an alerting behavior to the caregivers towards their elderly relative's cognitive function.

The findings also demonstrate that the gender of the relative has an effect on the perspective of the caregiver towards the early signs and alerting behavior of cognitive impairment and dementia. The analysis shows that the caregivers consider not being able to drive or use public transportation as an alerting behavior in their elderly male relatives (63.9%) but they don't consider it as an alerting behavior in their elderly female relatives (37.5%) and we think this is largely to the fact that females haven't started driving until recently in the Kingdom of Saudi Arabia (Table 2). This suggests that the perspective of the caregivers differs due to the cultural and geographic variations in the Kingdom of Saudi Arabia between the two genders.

It is clear that culture has a significant effect when it comes to early diagnosis and providing more effective health care [6]. Also, knowing what may alert the caregiver to any early sign of memory decline is crucial as an early diagnosis may be fundamental in maximizing the impact of the intervention and treatment [10]. Demographic and background characteristics of the caregivers themselves may also affect the diagnosis and treatment of patients with signs of memory decline [11].

We believe that the findings suggest a relation between the culture and the way the caregiver thinks about their elderly's habits and their alerting behaviors and how that may alert the caregiver that there is something wrong. This can help in understanding how to use the perspective of the caregiver to provide more effective health care to the elderly. This could be by designing scales that are culturally based and that would help in earlier diagnosis of cognitive impairment and dementia in the Kingdom of Saudi Arabia.

However, some limitations should be noted; the primary limitation to the generalization of these results is the limited sample size. This is probably due to the limited geographic area that we covered. Another limitation was the lack of enough literature about the impact of Arabic culture and religion on the perspective of the caregivers and their impact on the effectiveness of the health care provided. Finally, respondent fatigue was one of the earliest limitations that we had and this was largely due to the 41 item questionnaire that we used.

We recommend that the health care system develop a scale or tool that is culturally based to improve the health care of the elderly populations of the Kingdom of Saudi Arabia. It would help in reaching a better outcome and high-quality care for the elderly patients. Having a scale that is designed according to the perspective of caregivers themselves can help us provide more efficient health care and improve the screening process for cognitive impairment and dementia.

Conclusion

Some cultural perspective could be identified that could help earlier detection of cognitive impairment in elderly people who rely largely on their caregivers.

Caregivers are the first people to encounter the early changes in the behavior of the demented elderly; understanding their perspective can help provide more efficient health care.

Our recommendation is to conduct more research about the nature of daily activities of the elderly population in the Kingdom of Saudi Arabia and the perspective of their caregivers since there are many differences in our culture than other cultures.

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