Relationship between Knowledge, Attitude, and Burden among Alzheimer's Family Care Givers in Jeddah, Saudi Arabia

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Abstract

Background: According to Alzheimer's disease association. The prevalence of Alzheimer's patients will increase to reach 68% worldwide by 2050. More specifically according to Saudi Alzheimer's Association, the number of Alzheimer's patients was reported to be 130 thousand in Saudi Arabia. Therefore, this study looked at assessing the knowledge, attitudes, and level of burden among family care givers having Alzheimer patients. Methodology: A descriptive cross sectional correlational survey design was used to include 150 family care givers from Geriatric Society Association located in Almontazahat District, Jeddah, K.S.A. Three validated tools were used to assess the knowledge, attitudes and burden related to Alzheimer’s disease namely: Alzheimer’s disease Knowledge Scale, The Dementia Attitudes Scale, and Burden Scale for Family Caregivers. Findings: The majority (88.6 %) of the respondents were female, their mean age was (29.2 ± 12.5), and 55.6% had Bachelor level of education. Nearly three Quarter (72.5 %) of the respondents have moderate level (16-24 out of 30) of total knowledge of Alzheimer’s scale. Surprisingly, 78.5% of the respondents had a negative attitude, and 81.9% felt burden towards their Alzheimer's patients. Unexpectedly, a negative correlation was reported between participant's knowledge and their attitude at p ≥ 0.5 while, a positive correlation was conveyed between respondents’ knowledge and family burden scale at p ≥ 0.5. Conclusion and implications: It’s concluded that, the level of knowledge among study participants’ was moderate while their attitude was negative and felt burden toward having Alzheimer's patients. Therefore, it's recommended to conduct psychosocial interventions to improve family caregiver attitudes and reduce their burden toward their beloved Alzheimer patients. Comprehensive management of the Alzheimer patients includes building a partnership between health professionals and family caregivers, referral to Alzheimer’s Associations, and psychosocial interventions where indicated. Keywords: Alzheimer's, knowledge, attitude, burden, family caregiver.
ability of families to understand what is the factors can affect the behaviors of Alzheimer’s patient that will help the families and caregivers to managing AD [9]. However, the problem is when lacking in medical knowledge, social and emotional skills, therefore the care of the patients becomes harder [6] and can cause burden and Stress [10].

Actually, there is no available data that can assess the connection between the level of family caregivers attitude toward AD and burden [11]. Depend of the attitude toward Alzheimer's disease assumed the care giver may investment in the care which may increase the risk or protect against emotional distress and burden [11]. As reported in “learned helplessness” model the experiencing negative outcomes or failure to cope can determine by cognitive attribution or explanatory style [11]. According the caregivers’ stress model of Pearlin et al., [12] assumed the consequences of stress affected by cultural, socio-economic status, family network, and personal history in the first line. Furthermore, conflict with job, family, social life, financial problems and some intra-psychic strains such as self-esteem and sense of control. The family caregivers complains from that they didn’t find any medical support and community recourses for the management of AD [6]. Thus, they need more information about the disease, available treatments, nature and consequences of the disease, training strategies about coping, and how to manage with the stress. Beside, support in medical, financial, emotional, and legal [13]. The ability of families to understand what is the factors can affect the behaviors of Alzheimer’s patient that will help the families and caregivers to managing AD [9].

To the best of our knowledge, there is only one Alzheimer’s association which is nonprofit a charity nongovernmental, and only 18th consultant specialized in geriatric medicine in Saudi Arabia as reported by Dr. Basheikh [14].

The Problem Statement
There is a shortage of Alzheimer’s associations, health care providers, and number of care center for this destructive disease. Additionally, a limited source of knowledge about Alzheimer's disease which might leads to decrease family knowledge and improper attitudes toward Alzheimer's patients, and increased subjective burden over them. This problem is negatively affect the patients because they do not know how to take care of them physically and psychologically.

Significance of The study
The increasing prevalence of Alzheimer disease in Saudi Arabia are fast-becoming well-known issues, despite the greater efforts and attention from Saudi officials and decision makers. According to Saudi Alzheimer association 2014 located in Riyadh, the number of Alzheimer’s was increasing to reach more than 130 thousand patients and the percentage of dead patients who had not treated properly due to lack of rehabilitations and treatment centers all over the kingdom. Additionally, lack of number of consultants and physician specialized in geriatrics and their illness as well stigma regarding people and their families. To the best of our knowledge, the family care givers didn’t attend any awareness program because there is no awareness program conducted in Saudi Arabia despite the annual conference of Alzheimer that held either nationally or internationally therefore, they feel burden of caring with their family member having Alzheimer patient. Therefore, we looked at assessing knowledge, attitudes and burden among family caregivers having Alzheimer patients.

Aim of The study
This study was conducted to assess family knowledge and attitude toward Alzheimer's patients and explore to what extent this improved knowledge and attitudes of caregivers will help in decreasing the subjective burden on them.

Research Questions
- What are the family caregiver knowledge, attitudes, and burden level of Alzheimer’s disease?
- What are the effects of participant’s demographic data on their knowledge, attitudes and burden level of Alzheimer’s disease?
- What are the correlation between outcomes in relation to knowledge, attitudes and level of burden among study participants?

RESEARCH METHODOLOGY
RESEARCH DESIGN
A descriptive cross sectional correlational survey design was used to achieve the objectives of the current study. The design is considered appropriate since it can assess the knowledge, attitudes, and burden level among family care givers having Alzheimer patients.

Research Setting
The current study was conducted in the Geriatric Society Association located in Almontazahat District, Jeddah, K.S.A. This institution is the only center present in Jeddah to manage elderly people in general and Alzheimer's patient in specific. Accordingly, this association is providing services for 300 old age patients and their family caregivers’ The role of this association is directed toward protecting elderly health from deterioration, assisting with their geriatric diseases, providing all necessary support for their health, and providing activities and programs for
psychotherapy for them, and conducting educational programs for their families caregivers.

**Sampling and Sampling Techniques**

150 families was contacted at Geriatric Society Association located in Almontazahat District, Jeddah, KSA. A convenient sampling technique was used to recruit minimum of 150 to maximum 200 family caregivers.

**Data Collection Process**

- Once the official permission to conduct the study was obtained from research unit at CONJ, KAIMRC, and IRB, the data collection process was started.
- All family caregivers who were enrolled to geriatric association, Jeddah, KSA were invited to participate in the study through leaflet and brief discussion and/or explanation at the time of getting approval from the association.
- The participants were asked to signs informed consent before filling the questionnaires of the survey.

**DATA COLLECTION INSTRUMENTS**

**A. Tools of the study**

To achieve the objectives of the current study 4 tools was used as following:

1. Demographic background tool: This tool was used to question the participants about their age, marital status, and level of education, did they attend workshops before, and what are the relative relationship between them and their patients.

2. The second instrument is Alzheimer’s disease Knowledge Scale (ADKS) which was used to assess AD knowledge. The tool was developed by Carpenter BD [15]. ADKS includes 30 true/false items and a total score is 30, thus, the higher scores represent greater AD knowledge. According to the original author, the ADKS tool is consisted of five main items including: risk factors, assessment and diagnosis, symptoms, life impact, caregiving, and treatment and, management of Alzheimer patients.

3. The third instrument is the Dementia Attitudes Scale which was developed by O’Connor & McFadden [16]. This tool was used to assess a family care givers’ general perception of persons with Alzheimer Disease and Related Dementias (ADRD) and their feelings toward those population. (ADRD). The tool is self-administered including 20-item in a likert scale from strongly agree to strongly disagree. A total score is ranged between 20-40, and when the score is more than 27 ,it indicates the positive attitudes toward Alzheimer patients.

4. The forth instrument is the Burden Scale for Family Caregivers (BSFC-s) designed by Graessel and colleagues 2014. A short version was used to assess the level of burden among family members who are caring with the Alzheimer patient’s. The scale was included 10 items to measure subjective burden, each item was rated on a 4-point scale starting from “strongly disagree” (0), “disagree” (1), “agree” (2), and “strongly agree” (3). A high degree of agreement indicates higher subjective burden for the caregiver.

**Reliability and Validity**

The structural validity of the English version of the scales are confirmed by original authors in their studies. The instruments were translated into Arabic language and back translated into English language. Back translation aimed at verifying whether the translation covers all aspects of the original English version of the questionnaires or not. Then to ensure the face validity and reliability of the final translated Arabic version of the questionnaire was evaluated by a panel of experts who were selected based on their qualifications and experience in nursing research and education. The validity of the questionnaires were calculated and reported 0.81 for ADKS, 0.79 for ADRD and 0.78 for Burden Scale for Family Caregivers (BSFC-s)

**Pilot Study**

After the validity was confirmed for the Arabic version of questionnaires, the tools were piloted and tested by 10 of the Alzheimer’s patients family members to identify ambiguities in questions, time required for completing the questionnaire, and any difficulties that might be encountered by the participants in reading or understanding the questionnaires. Those 10 members were included within the actual sample due to the limited number of studied population. In the present study, the Cronbach’s alpha coefficient for the ADKS total scale was 0.78, 0.87 for ADRD and 0.77 for (BSFC-s) which represents good reliability.

**Ethical considerations**

The study was submitted for official approval from the research unit at the College of Nursing, Jeddah, KAIMRC, and IRB. Then the approval letter was submitted to the Geriatric Society association for approval. After that, study subjects were approached for explaining the purposes and the procedure of the study. Subjects were informed that participation in the study is voluntary and they can withdraw without any penalty at any time. All participants were assured that their answers will be kept anonymous during the study and that their data will be kept confidential.

**Data Analysis**

The data were coded and analyzed using SPSS version 21.0. Data were presented using descriptive
statistics for discrete variables in the form of frequencies and percentages, and for interval and ratio variables in the form of means and standard deviations. Appropriate statistical tests were used to find the association of the participants’ demographic background and their knowledge, attitude, and the significance level was tested at p<0.05.

FINDINGS

Demographic Details of Respondents

Table-1 showed the distribution of studied respondents according to their Socio-demographic background. Majority (68.5%) of participants was single, (88.6%) were females, (55.7%) had bachelor degree, and (74.5%) of them didn’t not attend a support group or educational program related to Alzheimer’s disease. Also (55%) of participants was not responsible for Alzheimer’s patient in either on their job or volunteer, and (43.6%) perceived themselves as knowledgeable about Alzheimer’s disease.

Table-2 presented the distribution of studied respondents on their Alzheimer’s disease Knowledge scale. As regard to risk factors included in the knowledge scale which were reflected on statements no. 13,27,26, and 18, the majority (83%) correctly answered item number 27 reported that” Genes can only partially account for the development of Alzheimer’s disease compared with only (36.9%), and (51.7%) correctly identify that “People age and having high cholesterol can be at risk of Alzheimer’s disease respectively.

As regard to symptoms identification among respondents, majority (85.2%) correctly identify that” A person with Alzheimer’s disease becomes increasingly likely to fall down as the disease gets worse. Compared with only 44.3% correctly identified that Symptoms of severe depression can be mistaken for symptoms of Alzheimer’s disease

Concerning treatment and managements of Alzheimer disease, it was reflected on items number 5, 8,9,15,16,25,28, and 29. The majority (88.9%) of the respondents correctly identified that People whose Alzheimer’s disease is not yet severe can benefit from psychotherapy for depression and anxiety. Compare with only (31.5%) correctly answered that” It is safe for people with Alzheimer’s disease to drive, as long as they have a companion in the car at all times”.

While the items number 6, 17, and 24 are used to assess knowledge of caregiving, the majority (91.3%) recognized that “When people with Alzheimer’s disease begin to have difficulty taking care of themselves, caregivers should take over right away” compared to (78.5%) identified that “When a person has Alzheimer’s disease, using reminder notes is a crutch that can contribute to decline”.

Table-3 the distribution of studied respondents according to the Dementia Attitude scale. (N=150) this table showed the only 43% of respondents are strongly agree that It is important to know the past history of people with ADRD and (60.4%) agree that “Difficult behaviors may be a form of communication for people with ADRD. On other hand, the two third (60%) of the respondents strongly disagree that people with ADRD are fearful. While, (48.3%) was disagree on that they can’t imagine their self-caring with someone with Alzheimer’s.

Table-4 exhibited the distribution of studied respondents according to Burden Scale for Family Care Givers. This table showed that (57%) feel physically exhausted, and an equal number (53.7%) of the respondents indicated that the care takes a lot of their strength, and they worried about their future because of the care we give Moreover, (45%) of respondents agree about that, their life satisfaction has suffered because of the care, 44.3% agree that since they have been a caregiver their financial situation has decreased and an equal number of the participants (41.6%) indicated that sometimes they don’t really feel like “themselves” as before and they feel torn between the demands of their environment (such as family) and the demands of the care respectively.

On the other hand, 40.3% of respondents disagree about they could to run away from the situation they in followed by (39.6%) disagree that their relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care, and (38.3%) didn’t indicate that their health is affected by the care situation.

Figure-1 displayed the study respondents according to their level of knowledge, attitude, and burden. This figure reported that, 72.5 % had moderate level of knowledge compared by 78.5 had moderate favorable attitudes, while more than half (53.7%) felt moderate burden toward their beloved one.

Figure-2 this figure presented the total mean and standard deviation of knowledge (18.389±3.9175), attitude (53.523± 8.071), and burden (14.288±6.022)

Table-5 showed that there is no significant correlation between knowledge (18.39± 3.918) and attitude (53.52± 8.071) and burden at P≥ 0.05 On the other hand, there is significant correlation between knowledge studied group and their burden caregiver scale at P≤0.003

Table-6 displayed that marital status, level of education, responsibility about Alzheimer patients and their agreement level of having knowledge about dementia had significant association with the respondent’s level of ASD knowledge scale at P = 0.001, 0.001, 0.049 and 0.036 respectively. While,
gender has no significant correlation with the knowledge scale at p ≥0.05.

Table-7 showed the correlation between attitudes and burden scale with the respondents’ demographic background as there was no significant correlation between all their basic characteristics, attitudes and burden care giver scale at P=≥0.05.

DISCUSSION

This correlational cross sectional study was looked at assessing the knowledge, attitudes, and level of burden among family caregivers having Alzheimer patients. To the best of our knowledge and overtime, the current study might be the first one to be conducted in the Alzheimer topic in Jeddah, Saudi Arabia. The results revealed that (72.5%) of the respondents had a moderate level of knowledge as it was measured by AD knowledge scale. Similarly [15], assessed knowledge of AD among professional, senior center staff, caregivers, undergraduate students, and older adult without cognitive impairment, and reported adequate level of knowledge among professional, less comprehensive among older adult and Caregivers, and they know more than senior center staff and undergraduate students. They indicated that medical and professional staff hold more knowledge than lay or public. Moreover, Rawlins et al., [17] who conducted their study among undergraduate students and pre-health care students, they reported 40.01% had great knowledge of Alzheimer’s disease because maybe they had previous exposure to information related to AD compared to non-medical students who had a less knowledge about AD.

On the other hand, the result of this study is contradicted the results obtained by Sullivan et al., [18] who assessed knowledge of AD among caregiver, AD patients, and non-caregivers showed that the caregiver had the highest mean level of knowledge they correctly answering 50% of questions, that is related to prevalence of AD causes, progression of symptoms, role of memory loss, diagnosis, aluminum in causing of AD, role of support serves, response of AD patients to their illness, cause of personality change, and the impact of orienting information or note provision on AD patients compared to AD patients and non-caregivers answered 25% of questions with poor level of knowledge. In the same vein, a study done by Hicks and Miller [19], reported low level of knowledge, related to the prevalence, causes, and symptoms of the disease, which contrarily with the results of current study.

Furthermore, as regard to the attitude among family caregivers the current study findings was reported moderate favorable attitudes toward caring with Alzheimer patients. This results were contradicted by the work of Rawlins et al., [17] who found a positive attitude toward Alzheimer's disease patients among pre-health care and non-medical students. Actually, the complexity in caring for people with dementia could be one reason why family care givers generally have negative attitudes toward their beloved one [20]. Another reason for caregivers’ negative experiences in caring for people with dementia could originate from their lack of knowledge about the Alzheimer disease [21].

As regard to the burden of family care givers the results revealed that, more than half (53.7%) of the family caregiver felt a moderate burden toward the beloved one. In the same vein, this finding is similar with [22] who reported a high level of burden in physical, emotional, and social among caregivers because they spend a lot of time in care. Andas reported by [11] that caregiver burden was relative with a a negative attitude also, other study [23] found significant correlation of burden with appearance of neuropsychiatric symptoms like hallucination, unusual behavior, and abnormal behavior in night. Meanwhile, Norbergh et al., [24] emphasized the importance of maintaining a positive attitude toward people with dementia to promote the patient’s psychological well-being.

As reported by Warner [25], who found low level of knowledge among caregivers of Alzheimer’s disease especially regarding the prevalence, causes and symptoms of AD which is correlate with low level of education. In addition, other study Ko, Han & Kim [26], which contrarily with the results of current study was conducted among nurses in dementia center in Korea and found there is a significant correlation between burden and dementia attitude (r=.25, p<.05) and dementia knowledge (r=-.32, p<.001). Moreover, a study done by Scerri & Scerri [27], which, assessed knowledge and attitude among nursing students, reported that the nursing students had adequate knowledge about Alzheimer's disease with a positive attitude toward the patients who are affected by AD or dementia.

According to Alzheimer’s Disease International, 95% of the public worldwide they believe that they will get dementia in the future, and 54% of them think the part of developing dementia is lifestyle factors, and below 70% think that there is enough competent physicians specialist in AD globally. Unfortunately, a lot of challenges that faced people in the Middle East countries including an increasing number of elderly, delay in developing services for geriatrics or seniors, community services are not professional for geriatric, geographic variations can affect the delivery and accessibility to services, and the nursing school under-trained for geriatric care. Moreover, there is a lack of rehabilitation center for the elderly, shortage in local geriatricians or physicians trained in geriatrics, and imperfection in curriculum regarding geriatric at medical schools [28]. However, in
Saudi Arabia there is only one association for Alzheimer's disease located in Riyadh, the capital city and there are only 18th consultants specialized in geriatric medicine as reported by Basheikh [14]. Saudi Alzheimer's association reported that the number of Alzheimer's patients is 130 thousand, but there is no specific prevalence of Alzheimer's patients in Jeddah. Also, according to the Saudi commission for health specialties Alzheimer's disease is one of the most causes of premature mortality in Saudi Arabia, and 394 years of life lost per 100,000 due to this cause [29].

Another interpretation for the obtained results could be given in relation to culture and religion in Saudi Arabia. In Islam, Allah and Prophet Mohammed gave guidance and principals toward taking care of the elderly, and emphasizing taking care of parents with love, sympathy, support, and patience that present in the Quran and Sunnah. In addition, respecting elders is a part of respecting (Allah) so those who do not respect elder’s parents or take care of them considered as a disobedience to parents [30]. Therefore, there is no enough association in Saudi Arabia related to AD because the caregiver considers the caring of elder parents as great performer and they obey the worship of God and they do not want to be disabled for their parents.

Concerning the correlation between demographic background of the respondents was the age were ranged between 18 to 76, Majority (68.5%) of participants was single, female (88.6%), had bachelor degree (55.7%), and (74.5%) of them didn’t attend a support group or educational program related to Alzheimer’s disease. Also, (55%) of participants was not responsible for Alzheimer’s patient in either on their job or volunteer, and 43.6% perceive them is knowledgeable about Alzheimer’s disease. Similarly [23], showed that the mean age of caregivers was 59.6 ± 14.8 years, and the majority were female (81.5%), but contradicted with the present study in level of education which is the majority had a primary school (mean 9.3 years of education). On the other hand, the result of demographic data in this study is contradicted the results obtained by Yuri Jang et al., [31] the adults aged range between 60 and 96 years, and majority (70%) of the participants had high school education, also similar to our study more than half (58.8%) of the participants were female, and (23.4%) of them were single.

Additionally, two studies were conducted in Saudi Arabia, the first study was done by Amoajel et al., 2019 and the other by Al-Qahtani et al., [32] which are similar to the current study results that, the majority (64%, 53.8%) of family caregivers were females, but (81.13%) of their age was between 21 to 50 years which is different than the age of the participants in the present study. On the other hand, Al-Qahtani et al., [32] contradicted to this study in that, the majority of participants’ age were 40 years or less, majority (68.5%) of participants were married, most of them (40%) had secondary school and (39%) had bachelor degree.

Moreover, the findings of the current study demonstrated that demographic background of the respondent such as care responsibility about Alzheimer patients and their agreement level of having knowledge about dementia had significant association with the respondent’s level of ASD knowledge scale at P = 0.001, 0.001 respectively. This remarkable finding could be related to their continuous exposure and personal experience in handling AD among their family members due to the greater prevalence of AD [33-35]. Unlike developed countries where residential care is provided to older people especially those with AD, certain Asian countries, such as Saudi Arabia and Malaysia, still rely on family members on their daily living [36]. This finding is contradicting the results obtained by Rosato et al., [37] who stated that, Knowledge about Alzheimer and personal contact with someone who has Alzheimer do not always engender sympathetic responses.

While, gender has no significant correlation with the knowledge scale at p ≥0.05. The interpretation of this result may be due to the majority (88.6%), of studied respondents were female, this limitation couldn’t be avoided as the setting of the study handled female only and culturally male are very restrictive to participate under certain environmental organizations.

Furthermore, the current study reported that the age group (i.e., age <18) was found to be a significant independent predictor of higher ADKS score. This is consistent with an Australian study that surveyed the nursing, medical, support, and allied health staff, which revealed that age bracket of <30 years old scored 1.0 point ADKS higher than other age groups [38]. These findings highlight the complexity of social and personal responses to Alzheimer. Perhaps more in keeping with evidence from elsewhere, older age, lower education and limited knowledge are associated with perceptions of the need to exert high levels of control over people with Alzheimer, even at early stages [37].

LIMITATIONS

The present study has some limitations that should be acknowledged, including its small sample size. Despite the small size, the participants included were almost half the number of family caregivers served by the Geriatric Society Association which served 300 family caregiver’s. To our knowledge, this is the first study to describe the knowledge and attitudes toward Alzheimer among family caregivers in Saudi Arabia. Further, the majority of the present sample were women, which made it difficult to compare possible gender differences.
CONCLUSION

The findings of the current study revealed that respondents had limited knowledge of Alzheimer’s, their attitudes toward people living with dementia are negative. In addition to positive correlation between knowledge and burden of family care givers as the more the knowledge, the more the increasing the burden of responsibility of must caring toward their Alzheimer beloved one. Surprisingly, negative correlation was reported between knowledge and attitudes of the care givers. Similarly, negative correlation was reported among participants’ demographic back ground and knowledge, attitudes and burden scales.

The majority of family caregivers were women. This study revealed that had a negative correlation between attitude and burden, but positive correlation between knowledge and burden. Moreover, in this chapter discuss the finding and show more details.

RECOMMENDATIONS

Based on the obtained results, it is important to improve knowledge about Alzheimer among care givers to enable them to provide high-quality care for their Alzheimer patients. Therefore, the following is recommended:

- Continuation of this line of research to a larger sample in order to improve knowledge and attitudes surrounding dementia in Saudi Arabia.
- Conducting psychosocial interventions to improve family caregiver attitudes and reduce their burden toward their beloved one who is suffered with Alzheimer’ disease.
- Applying comprehensive management of the Alzheimer patients includes building a partnership between health professionals and family caregivers, referral to Alzheimer’s Associations, and psychosocial interventions where indicated.
- Establishing an awareness campaigns and in-service training program for family caregivers about what is Alzheimer’s disease, how to deal with Alzheimer’s patients, and management of burden that can affect the caregivers.
- Incorporating geriatrics courses within medical and nursing schools curriculum that can increase number of nurses and physicians who they can help in managements of Alzheimer’s patients and other diseases affecting elderly consequently, decreasing family care givers burden.

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