

Impact of Palliative Care for Dementia Patients in Tertiary Hospitals among Saudi Arabia: A Systemic Review

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Abstract

Dementia has been considered an alarming disease that is characterized by cognitive decline. There are many etiological factors of dementia including neuropsychiatric, neurodegenerative, and many other medical conditions. In the advanced phase, people with dementia are completely dependent on their carers. The prevalence rate of dementia in Saudi Arabia and Gulf countries is poorly defined. Certain medications for dementia are available. However, palliative care is considered a better process to regulate dementia. The current study was designed to assess the palliative care of dementia patients in tertiary care hospitals and to evaluate the facilities for a plan of management (whether local or international). Further, the patient, the family satisfaction, and the corporation between the patient's family and the physician were assessed. Specific key search terms including Dementia and Saudi Arabia, Palliative care of dementia patients in tertiary care hospitals, and patient and family satisfaction were used for data retrieval to get precise literature. Results showed that very fewer data about palliative care is available in Saudi Arabia. Moreover, very little data was available for palliative care at tertiary hospitals. Furthermore, when patients' satisfaction with palliative care was observed, data from the literature showed that palliative care is satisfying for both patients and caregivers, due to the involvement of multiple healthcare staff.

Keywords: Dementia, Palliative care, Prevalence rate, Saudi Arabia

INTRODUCTION

Dementia is characterized by a decline in cognitive ability, which is associated with daily and independent functioning. Rather than called to be a disease, dementia is thought to be characterized as a syndrome. There are many etiological factors of dementia including neuropsychiatric, neurodegenerative, and many other medical conditions. Multiple diseases are seen to contribute to one of the patient's dementia syndrome. Dementias with neurodegeneration like the production of Lewy bodies and Alzheimer's disease are known to be more common in old age patients, whereas brain tumors and other brain injuries are commonly known to be more prevalent in young adults [1].

The number of chemical messengers implicated in decision-making, learning, and memory is known to increase in response to drugs like cholinesterase inhibitors like rivastigmine (Exelon), donepezil (Aricept), and galantamine (Razadyne). These medications were thought to be effective for Alzheimer's disease primarily but they can also be prescribed for other dementia-related disorders, including Parkinson's disease, vascular dementia, and Lewy bodies dementia. Side effects of these medications include vomiting, nausea, and diarrhea. Some other side effects can be a disturbance in sleep, low heart rate, and faintness [2].

The population of Saudi Arabia is now shifting towards old age. Back in 2016, the number of individuals who were above 60 years was 1.3 million, and now it is expected that this group of age will be extended by 10 million more, which only represents 25% of the population [3]. Another risk factor is associated with the expected increased life expectancy in Saudi Arabia. In the Gulf States, the average human life duration is set up at 72 to 82 years of age [3]. This is almost the age of elder citizens. At ages greater than 65, a person's brain is already facing some sort of

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deterioration and hence at such age, cognitive functions are naturally compromised. Accordingly, if the person faces the issue of dementia, it is very difficult for him to survive and thus, it is required all the time to be taken care of. One other risk factor for dementia is that the prevalence of dementia is increasing day by day, and in two decades it is expected to be increased by three times [4].

A stage between normal cognitive functioning and dementia, mild cognitive impairment (MCI) preserves everyday living skills [5]. The annual conversion rate to dementia reaches up to 20% [6]. The early detection of symptoms of dementia can help to reduce or to control the prevalence of the disorder which will be beneficial for both caregivers and patients [7]. Studies evaluating the prevalence of MCI and dementia are very less in Gulf countries and Saudi Arabia. Yet, no published studies are present to evaluate the incidence and prevalence rate.

In the advanced phase, people with dementia are completely dependent on caregivers [8]. Palliative care for those people who are at an advanced stage of dementia, can regulate the burden of symptoms, as well as forestalling the undertreatment of symptoms and unnecessary overtreatment. Moreover, it also lessens the burden of the caregivers and increases the quality of life of the caregivers [9, 10]. Unfortunately, persons with advanced-stage dementia receive very less palliative care and they are exposed to the burden of high symptoms [9]. Caring is more challenging or possesses different challenges for those individuals who are at the advanced stage of dementia rather than those who are having mild to moderate symptoms of dementia. Indeed, dementia research has reached advanced levels but there is still very less evidence about the interventions of palliative care [11]. ACP which is known as advanced care planning is often regarded and mentioned as an important element for better end-of-life care [12, 13]. ACP aims to implement the individual values and preferences of patients regarding possible therapeutic interventions for better health conditions in the future [14, 15]. The concerned persons showed their interests or wishes towards the treatment preferences, mindful aspects, and caregiving. It is an informative cycle going up against the individuals with dementia, family caregivers, and well-being experts with the conceivable course of dementia and death [8, 9].

Talking about preferences and characteristics may feature the conflict between families' and patients' insight on treatment interventions [16]. There is a disagreement concerning the ideal time for starting ACP during the illness, e.g., to begin ahead of schedule after screening [17], and who should be answerable for [18]. In the advanced phase of dementia, frequent intermediary decisions are fundamental and proxies can be tested to settle on existential choices for the individual with dementia. Family caregivers don't feel set up to present choices in defense of the disintegration or moving toward death [16] and preferences

communicated earlier may negate current conduct. Surrogates and well-being experts actualize preferences of patients' values including the individual with dementia, however much as could be expected customized to the current limit [19]. Most family caregivers pick augmenting comfort as an essential objective of care [20]. Without ACP, individuals with dementia are in danger to get troublesome medications toward the end of life [21]. Despite the arrangement of palliative consideration components, a change of care objective to comfort generally happens shortly before death [15, 22]. Scientific research demonstrated a relationship between written ACP and the nature of care in the dying phase.

Aims and Objective

- To assess the palliative care of dementia patients in tertiary care hospitals;
- To evaluate the facilities for the plan of management (whether local or international);
- To assess the patient and the family satisfaction;
- To assess the corporation between the patient's family and the physician.
- To assess the adequacy of persons and skills involved in the care of dementia patients.

MATERIALS AND METHODS

Electronic Database

Scientific data was retrieved using the PubMed database.

Search Terms

Specific key search terms were used for data retrieval to get precise literature as follows:

- Dementia and Saudi Arabia;
- Palliative care of dementia patients in tertiary care hospitals;
- Facilities for a plan (whether local or international);
- Patient and family satisfaction;
- Adequacy of persons and skills involved in the care of dementia patients.

The Year 2000-2019

For each search term, ten papers were collected from many Google scholars. Additionally, the data was collected between the time duration of 2000 to 2022. Initially, 20 papers per search term were collected, and then a Second search filter was applied, where every fifth paper was analyzed for the search terms, which gave 4 papers.

Data Curation

Initially, without any filter, the search terms give out n=290 for "dementia and Saudi Arabia", n=23 for "Palliative care of dementia patients in tertiary care hospital", n=2 for "Facilities for a plan (whether local or international) in Saudi Arabia", n=6 for "palliative care and patient satisfaction in Saudi Arabia" and n=7 for "physician and

dementia in Saudi". All the data was then manually evaluated to remove irrelevant and out-of-context papers.

RESULTS AND DISCUSSION

Of all the used search terms, the maximum number of data was extracted from the term "dementia and Saudi Arabia" and all the other search terms showed very little data availability. It depicts that as we make the search term very precise, the number of available papers decreases. However, this fall is even greater than 90%, which depicts that there is lesser research data available for Saudi Arabia. Even the general term does not have sufficient data, which shows that not much research is conducted in the region of Saudi Arabia for dementia.

Database search for the prevalence of dementia in Saudi Arabia as well awareness of the Saudi general population of dementia and its associated risk factors (**Tables 1 and 2**).

Analysis revealed that out of 290 papers under the search term "Dementia and Saudi Arabia", most of the papers linked dementia to genetic predispositions, as was evident from several reviews, as well as case studies. The age factor was also important, as when the data was randomly curated. Through manual analysis, age appeared to be another important factor for dementia in KSA as shown in graph 1. When environmental factors were accessed, it was found

that data was also related to dementia. Another risk factor for dementia in KSA was found to be in combination with certain factors of age, environment as well as genes. The combination of age and environmental factors shows that there is a link between the development and the progression of dementia. Some other factors include genes and environment and a combination of all the factors i.e.; genes, environment as well as age, as shown in **Figure 1**.

The results for the search term Palliative care of dementia patients in tertiary care hospitals came out to be 26 papers in total. Among these papers, a few papers were not related to palliative care and the remaining papers were discussing the implementation of palliative care as a plan to be applied in hospitals as illustrated in **Figure 2**.

In the context of the patient's and the family's satisfaction, appreciable data is available for palliative care, not only for dementia but also for other widely distributed and deadly diseases such as cancer. Cancer patients receiving palliative care in Saudi Arabia appear to have a very good association between their quality of life and their contentment with their treatment. Eight papers were observed in this section, in which patients, as well as their families' satisfaction, was discussed and after applying the filter of years, it was reduced to only six papers.

Table 1. Prevalence of dementia in Saudi Arabia

Author, Publishing Year	Study region	Methodology	Outcome
Alsebayel <i>et al.</i> (2022) [23].	Riyadh	Surveys with demographic data, the Arabic versions of the Patient Health Questionnaire (PHQ9) and the eight-item Alzheimer's Dementia (AD8) to screen for dementia and depression, respectively, were given to participants who were chosen from six primary healthcare facilities in Riyadh, Saudi Arabia.	Using the Arabic version of AD8, the study found that the prevalence of dementia was 16% and 11%, respectively, with depression and dyslipidemia serving as significant modifiable risk factors for dementia in the sample.
Albugami <i>et al.</i> (2018) [24].	Riyadh	An analysis of previous charts from 1995 to 2010. to outline the prevalence of various types of dementia, its demographic characteristics, its risk factors, and the current clinical practices of dementia in Saudi Arabia's tertiary care hospitals.	418 people with dementia in total (236 men and 182 women), with a mean age of 78.8. diabetes prevalence of 32%, hypertension of 71.53%, dyslipidemia of 30.5%, and depression of 24.41%. Clinically, memory impairment affected 64.37 percent of patients, confusion affected 54.25 percent, and personality change affected 34.63 percent. Mixed dementia (18.37%) and Alzheimer's disease (15.87%) were the two most prevalent types of dementia. The mortality rate was 779.99%. Infection was the most frequent cause of mortality (38.34%), followed by cardiovascular conditions such as stroke (23.34%) and cardiac illnesses (17.48%).
Alkhunizan <i>et al.</i> (2018) [25]	Riyadh	The cross-sectional study comprised patients 60 years of age or older who were seen in the Family Medicine Clinics connected to King Faisal Specialist Hospital and Research Center. A qualified doctor interviewed patients as part of their routine appointment to gather demographic information and administer the Montreal Cognitive Assessment (MoCA) exam in the validated Arabic language.	a sample size of 137 Saudi patients was determined. The included sample's average age was 67 ± 6 years. Cognitive impairment was present in 45% of cases. MCI was prevalent in 38.6% of cases, while dementia was prevalent in 6.4% of cases. Cognitive impairment was at risk from aging, inadequate education, hypertension, and cardiovascular disease.

Ogunniyi *et al.* (1998)
[26]

Riyadh

the study was conducted at a hospital using the DSM-IV and ICD-10 diagnostic criteria to reach a consensus on a case's diagnosis based on the clinical data and findings of the investigations. NINCDS-ADRDA, NINDS-AIREN, and ICD-10 criteria were utilized to create dementia subgroups, and CDR was used to grade the severity of the condition.

The study included 77 demented patients (49 men and 28 women). The facility saw 19.3/per 100,000 patients on average. The average patient's age at presentation was 74.6 years, whereas 17 patients had onset ages under 65. Alzheimer's disease accounted for 51.9% of dementia cases, followed by vascular dementia (18.2%), mixed cases (15.6%), dementia with Parkinson's disease (7.8%), and curable dementia (5.2%). There were only 3 individuals at the severe clinical stage, and infections were a major factor in their decline.

Table 2. Awareness of dementia in Saudi Arabia

Author, Publishing Year	Study region	Methodology	Outcome
Alshammari <i>et al.</i> (2022) [27]	Riyadh	A questionnaire was provided to the study sample between May and June 2020 by email and Whatsapp, with participation completely voluntary.	Increasing age resulted in a higher level of awareness. Age and level of consciousness were found to positively correlate. Comparing healthcare professionals to college students, the study's findings revealed that they were much more aware of the preventable risk of dementia.
Algethami <i>et al.</i> (2019) [28].		An online survey was used to perform this study on the general public. The research was carried out between May and August of 2019. The statistical package for the social sciences software version 21 was used to analyze the collected data.	32.5% of the total study sample knew about dementia, compared to 67.5% who had little to no awareness. Only 18% of participants believed that caring for someone with dementia might be highly satisfying. 47.5% of participants believed that dementia patients could live alone in the early stages, while 75% of participants believed that patients could be managed by medication in the late stages. The level of knowledge was influenced by gender, age, and education.

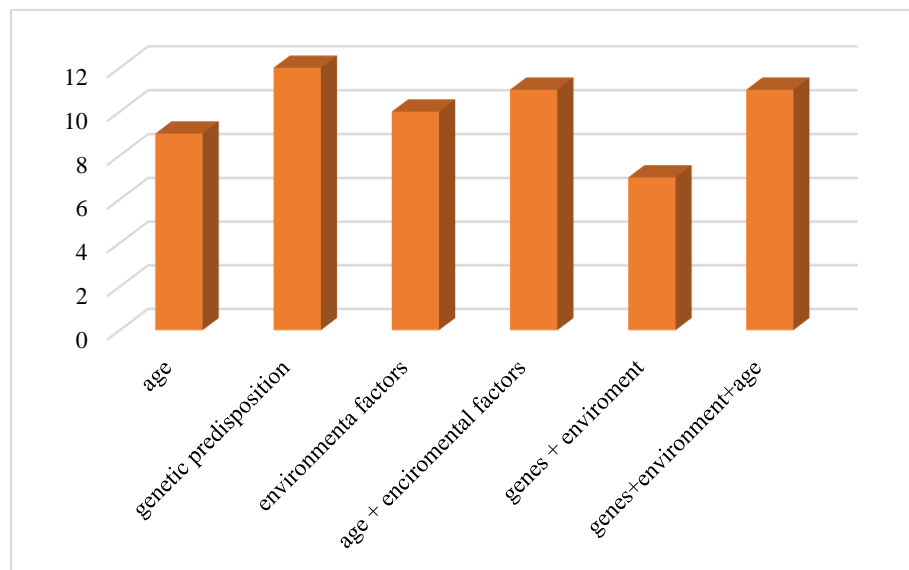


Figure 1. The association of different factors with dementia in Saudi Arabia

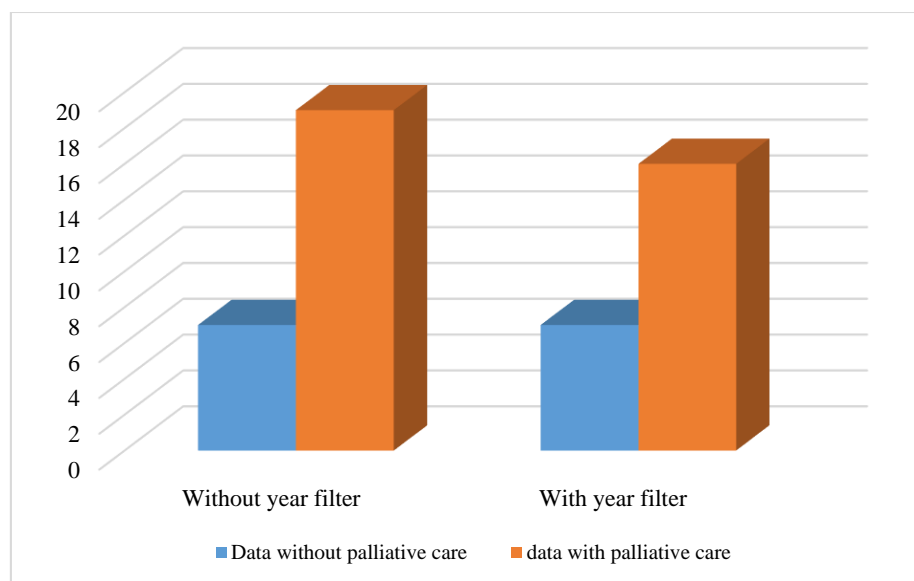


Figure 2. The availability of data for palliative care for both with and without year filter

Dementia is not a simple disease but a multifactorial disease with which certain risk factors are associated. Some of the major risk factors are age, environment, genes, and the presence of other disorders such as diabetes, hypertension, or cardiovascular diseases [29]. Data showed that the most widely present risk factor for dementia is genetic predisposition and second comes environmental agents. Certain environmental agents such as alcohol consumption are directly linked to dementia. Metals-contaminated water is also reported to be linked to dementia. Among these metals, the most dangerous ones include aluminum, arsenic, cadmium as well as lead. The consumption of food with high fats is also one major factor in the progression of dementia [25, 30-32].

To achieve the aim of identifying the role and the availability of palliative care strategy in tertiary hospitals for the management of people suffering from dementia, data was collected. Surprisingly, very little data was available for palliative care at tertiary hospitals [33]. Palliative care is a very crucial treatment strategy for patients with dementia, as dementia is widely prevalent in elderly persons and at such age, a person's self-care diminishes [34-37]. As a result, caregivers provide help for patients, and the availability of little data on palliative care suggests that it still needs to improve the conditions for dementia patients at tertiary hospitals. Another aspect concerns when the year filter was adjusted, then there was no change in the number of scientific papers within palliative care. The results also depicted that although dementia cases are distributed in the state of Saudi Arabia, yet, palliative care is not promoted. The urgent need is to maintain the palliative care treatment for dementia, as most of the dementia patients in the Gulf region are aged 60 and more [37-39].

Results suggested that there were no facilities or treatment plans concerning palliative care in Saudi Arabia [40, 41]. It suggests an alarming situation in two ways. Firstly, not enough data is available for the treatment plans or proper strategies against diseases in KSA. Secondly, for dementia, no proper strategic plan was identified. Dementia patients are at a loss of memory and the self-care process is compromised, although, in other similar developed countries, official plans are available for palliative care to improve the lifestyle of both the patients dying with dementia as well as the families of the patients. However, one reason for the scarcity of the data may be the lack of agreed outcomes measures as well as the inability of dementia patients to get used to existing tools, due to the lack of memory and the difficulties of verbal communication. It should be realized that in the case of dementia or the case of end-stage dementia, a person is somehow entirely dependent upon the person who is taking care of him. So, under such circumstances, palliative care can very clearly play its role. When talking specifically about the state of Saudi Arabia, data shows that more than half of the dementia patients in KSA are of age greater than 60 years, so this puts more emphasis on the need for a proper and authentic tool and plan for facilitating the palliative plans in Saudi Arabia for dementia patients [42, 43]. Since palliative care can be carried out regardless of the age factor, so for dementia, can prove to be one of the best strategies for taking care of and managing dementia patients' cases as already discussed.

Patients show a positive attitude towards the palliative care plan, as the end stage of patients in more than 80% of cases is in one way or the other linked to nursing care and personal care, and hence, palliative care plays a crucial role [44]. Another important thing to be discussed here is the efficiency and adequacy of the persons who are involved in

palliative care [45] since, in the palliative care of dementia patients, a lot of persons are involved such as multiple doctors, nurses, and physicians. It shows a sort of teamwork where everyone is actively participating for the better lifestyle of patients, regardless of the prognosis of the disease, while the patient can hardly remember any one of these persons. This is the reason why the adequacy and efficiency of the persons who are involved in palliative care are important [46, 47]. The persons who will be taking care of the patients for 24 hours need to have a basic knowledge of the disease. One should provide appropriate assistance with basic physical care tasks. In order to maximise comfort, sense of well-being, and independence, he should take into account the person's abilities, needs, and preferences. He should also learn about the person's personal history, personal, religious, and spiritual preferences, as well as the individual's cultural and ethnic background [48, 49].

CONCLUSION

Dementia is one of the most widely distributed diseases across the world. In the population of Saudi Arabia, the prevalence of dementia is increasing at an alarming rate, which is mainly associated with different factors involved in pathophysiology, including the high intake of a high-fat diet and some associated genetic factors. Palliative care is thought to be an emerging medicating intervention to control dementia but the concept of Palliative care is not much-taken care of and considered in Saudi Arabia. The patient's satisfaction with palliative care is more than 80%. It has been regarded as the best strategy to control dementia, because of the involvement of multiple individuals including doctors, nurses, and other caregivers.

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