

Identifying the Family Experiences of Saudi's Alzheimer's Patients and Exploring the Nursing Perspectives Regarding the Experiences: A Qualitative Study

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ABSTRACT

Objective: This study aims to evaluate the experiences and support needs of family caregivers and nurses tending to Alzheimer's patients in Saudi Arabia.

Design: The study was based on a cross-sectional qualitative combined grounded theory approach,

Results: Six emerging themes have been reported in the study, which represent the influence of various factors, such as physical, spiritual, cultural background, health education, health care delivery and financial burden.

Conclusion: Providing care for patients with Alzheimer's disease presents diverse challenges for both family caregivers and nurses, underscoring the necessity of a comprehensive management system in Saudi Arabia to adequately support them.

Keywords: Alzheimer's, Dementia, Hearing Loss, Nursing, Saudi Arabia

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INTRODUCTION

Alzheimer's disease is a progressive, debilitating neurodegenerative disorder characterized by amyloid plaque deposition eventually leading to cognitive decline and impaired daily functioning^{1,2}. It aggravates with age and family history plays a significant role³⁻⁵. This incurable condition results in total dependency, and abnormal behavior, and burdens patients, caregivers, and the healthcare sector⁶. The symptoms of sight and hearing loss can be similar to some of the early signs of dementia.

Global statistics project a quadruple increase in Alzheimer's cases by 2050, with dementia care costs expected to reach US \$1.6 trillion^{7,8}. In Saudi Arabia, dementia prevalence is 6.4% and post-menopausal women aged 80-85 are at a higher risk due to reduced estrogen⁹⁻¹¹. Lack of effective medication intensifies public health concerns¹².

Considering the total reliance of Alzheimer's patients on their family members and nurses, it inadvertently places significant stress on caregivers, who witness their loved ones decline and may experience emotional turmoil¹³. Nurses, forming bonds with patients, also face emotional challenges. Therefore, understanding the perspectives of family caregivers and nurses is crucial for providing effective care and support. This study aims at improving the quality of nursing practice and aid healthcare planning for patients' families with respect to Alzheimer's disease. As it is impossible to gain information from patients with dementia, the attention should focus on the family's experiences and the experiences of a nurse, which will provide a more holistic picture. Accordingly, the researchers have set the following objectives:

1. To identify the support needs of family caregivers caring for patients with Alzheimer's in Saudi Arabia
2. To identify the nurses' perspectives and feedback regarding the family experiences with Alzheimer's in Saudi Arabia
3. Adapt this new nursing research framework to combine the family's and nurses' perspectives regarding the exploration of health problems.

METHODOLOGY

1. Research design

The study was based on a cross-sectional qualitative combined grounded theory approach, where the experiences of the nurses and family members of Alzheimer's patients are collected in a single encounter. The grounded theory approach utilizes the unconventional research methodology of drawing a theory from the study result. In this respect, perspectives of nurses and family caregivers seek development of novel research-backed framework for health systems within and outside Saudi Arabia to integrate into the Alzheimer's management framework.

2. Study Setting

The study was conducted in two hospitals in Jeddah,

Saudi Arabia namely King Fahad General Hospital and East Jeddah Hospital.

3. Study Population

Participants in the study mainly comprised of family members of patients with Alzheimer's disease and nurses working with Alzheimer's patients in Saudi Arabia. Only individuals consenting to the study were recruited and the researcher did not bias the study towards any sex, religion or cultural diversity.

4. Sample Size

Eighteen family caregivers aged 22 to 51, and 12 nurses aged 28 to 47, were recruited through purposive sampling for focused group interviews on Alzheimer's care. A higher female to male sex ratio for all the participants (family caregivers 13:5; nurses 2:1) was noted.

5. Data collection instrument

This study utilized a cross-sectional qualitative grounded theory approach, conducting interviews in two phases: Phase I, focused on family caregivers of Alzheimer's patients from Saudi Arabia, while Phase II targeted nurses' perspectives. Group interviews approximately lasted for 75 minutes, were audio-recorded, transcribed, and supplemented with field notes and journal entries for authenticity.

6. Trustworthiness of data

The trustworthiness of qualitative data was evaluated in terms of

credibility, confirmability, originality and transferability¹⁴.

6.1. Credibility

Credibility was upheld through peer review and translation by an Arabic nursing researcher.

6.2. Confirmability

Confirmability was ensured via methodological triangulation across different data collection methods and participant sources.

6.3. Transferability

The findings may find application in understanding similar chronic and terminal illnesses.

6.4. Originality

Originality lies in providing novel insights into nursing research regarding patient, family, and nurse dynamics in Saudi Arabia.

DATA ANALYSIS

Analysis of data involved translating Arabic interviews to English and peer-reviewing for accuracy. Following data preparation and familiarization, key subjects were coded and categorized. Patterns and standpoints were observed, leading to interpretation and presentation through tables, charts, and diagrams. A grounded theory was developed to create a health belief framework aimed at enhancing

nursing care for ESRD patients, reducing family burdens, and ultimately improving patient outcomes and quality of life.

ETHICAL CONSIDERATIONS

The research proposal was approved by the institutional review boards of participating hospitals. Consent forms were signed by all ESRD patients, family members, and nursing staff, ensuring confidentiality and ongoing informed consent throughout the study, with opportunities for questions.

RESULTS

1. Demographic characteristics of respondents

The study recruited 18 family caregivers and 12 nurses involved in taking care of patients having Alzheimer's disease, with participants ranging from 22 to 51 years of age (family caregivers: 22-51 years; nurses: 28-47 years). The researcher found higher participation of female family members and nurses as compared to males. With respect to educational qualification, 10 family caregivers had secondary education and 8 had university education. Amongst the nurses, 7 had a Bachelor's degree in Nursing whereas 5 had a diploma course. The family caregivers had a common background with respect to nationality, religion and race. However, the nurses' group did not necessarily belong to a shared community, where only 4 of them belonged to Saudi Arabia and were of the Muslim community. All the participants in the family cohort were either the patient's siblings or children.

2. Emerging themes

The primary aim of the study was identification of support needs of family caregivers and nurses for patients suffering from Alzheimer's disease. Based on their experiences and perspectives, the researchers have generated 6 specific themes from the data. These were later translated into narrative passages, with findings corresponding to participant's responses.

2.1 Influence of physical factors

Participants, including family members and nurses tending to Alzheimer's patients found common physical factors influencing their daily lives. Overburdened with the responsibility of patients along with maintaining the balance of daily lives deeply affected the family caregivers. On the other hand, nurses found a lack of manpower and thus were exhausted and were overloaded with work, in general.

An example family caregivers expressing their grief can be followed by this expression:

"Accompanying my father during his treatment in Jeddah is exhausting, especially after my mother passed away last year. I have a sister who lives far from Jeddah, thus putting me as a sole attendant. Unable to manage my duties, I have recently recruited a home health nurse as a helping hand."

Nurses caring for Alzheimer's patients encounter physical strain due to language barriers, particularly with Arabic dialects, complicating their duties and contributing to mental exhaustion alongside workload pressures. One of the nurses expressed in the following words:

"As a non-Arabic speaker, understanding the needs of family members caring for Saudi patients with Alzheimer's can be frustrating at times. Further, lonesome patients become aggressive and violent with us at times. All of this, becomes depressing."

2.2 Influence of Psychological factors

Along with the physical factors, family caregivers and nurses face psychological and emotional challenges daily, witnessing the suffering of Alzheimer's patients, which significantly impacts their emotional well-being. The family members struggle with painful emotions upon seeing their dear ones suffering with dementia, unable to remember them. Nurses tend to harbour negative emotions of frustration and helplessness because of their inadequacy in meeting with the complex needs of patients having Alzheimer's, as has also been shown previously¹⁵.

An excerpt from an Alzheimer's patient's family member can be followed as:

"I am stressed out seeing my 75-year-old father, who does not remember me and only remembers my mother. He keeps asking about her and calling for her. It is depressing to see him in this state and I often cry thinking about the same."

An example of nurses' plight can be followed from the expression:

"Witnessing Alzheimer's patients suffer and observing their families endure alongside them can be deeply distressing. This is not only depressing, but I also feel powerless as I cannot do anything to ease their pain. At times, a sense of hopelessness overpowers me and I wish to leave the profession, but I gather strength in order to tend to them."

2.3 Influences of cultural background

The physical and emotional health of the patients as well their caregivers is largely dependent on their cultural background. Most of the patients' family members show their gratitude to the Islamic origin and find it to be a good support system for their well-being. Nurses, while not necessarily being Islamic, have a deep sense of respect for the Islamic culture and find that the Muslim communities have deep-rooted bonds within their families, aiding in sharing the responsibilities of tending to Alzheimer's patients .

Family caregivers' express their gratitude through the following words:

In one of the versions:

"I thank God for having a supportive life partner, who is sharing my responsibilities at home and life. My biggest

support is my family, who take care of everything and make sure that I'm not overburdened."

Influence of health education

As a critical viewpoint, it must be noted that most of the participants appreciate the importance of proper health awareness programmes and look forward to having awareness camps for proper precautionary measures. They urge the government to school the population about the implications, treatment and diagnosis of neurological disorders, especially in Saudi Arabia. Alongside, the nurses also advocate the proper training amongst nursing staff for personalized treatment and holistic care of these patients.

The patients' family members were quoted as:

"I wish there were resources available to educate myself and my family about Alzheimer's disease and its prevention. I'm concerned because both my father and grandfather had Alzheimer's, suggesting a possible genetic link. Therefore, I look forward to having services for its early screening and detection."

Nurses had a more practical approach to the same, and expressed themselves as:

"It would be an advantage if the nursing colleges could provide specialized courses for palliative, hospice, home health care, geriatric care. It would aid dealing with chronic cases such as Alzheimer's."

The effect of health care delivery system

The study found that all the participants, including the family caregivers and nurses stress on the importance of having specialized Centres dedicated to Alzheimer's treatment in Saudi Arabia. Such specialized centres are essential for several reasons. Firstly, they provide a focused environment where individuals with Alzheimer's disease can receive tailored care and support that addresses their specific needs. This includes specialized medical interventions, cognitive therapies, and assistance with daily living activities, all delivered by healthcare professionals with expertise in managing Alzheimer's disease. Moreover, specialized Alzheimer's treatment centres can serve as hubs for research and innovation in the field of dementia care. In addition, these centres can play a crucial role in providing education and support for family caregivers.

To quote the expression of nurses:

"I really hope that the government or ministry of health can provide more centres dedicated to Alzheimer's patients and they construct health care units capable of providing special services to palliative patients, geriatric care."

Influence of financial burden

Amongst the participant cohorts, it is primarily the patient's family who are burdened with the financial requisite for the treatment. Prolonged treatment regime adds financial load to the families, especially when they do not belong

to a rich community. Expressing their angst, one of the family members said:

"I'm not rich and I barely manage supporting my own family. So, I find it difficult to bear the charges for home health nursing for my father. Luckily, he has his own retirement money, which aids with the additional expenses. Also, I am grateful to the Government for providing free medication, which further compensates for the expenses".

DISCUSSION

This study comprising of 30 participants essentially dictated 6 emerging themes which emphasized on the experiences and support needs of family caregivers and nurses tending to Alzheimer's patients. The researchers found that caregivers' perceptions of caring for Alzheimer's patients are influenced by their individual challenges, as documented previously¹⁶. This finding aligns with previous reports from other regions, indicating that factors such as the progressive decline in cognitive function among patients, extensive caregiving hours, and inadequate support directly burden both family caregivers and nurses¹⁷.

In addition to the physical challenges inherent in Alzheimer's caregiving, there is a significant impact of financial burdens and the pressing need to address spiritual and psychological needs. The caregiving experience is multifaceted, with caregivers often facing emotional distress, social isolation, and financial strain due to the demands of providing care for Alzheimer's patients. These challenges are well-documented in the literature and underscore the complex nature of Alzheimer's caregiving¹⁸.

Furthermore, there is a clear imperative for a robust healthcare delivery system that caters to the specific needs of Alzheimer's patients and their families, as well as the healthcare professionals involved in their care. This includes access to specialized medical services, comprehensive support programs, and caregiver education initiatives. A well-functioning healthcare system is essential for ensuring optimal outcomes and improving the quality of life for individuals affected by Alzheimer's disease^{19, 20}.

Although our study gives a comprehensive account of the experiences of family caregivers and nurses associated with Alzheimer's patients and their support needs, we also understand that this study has certain limitations, the most important being dearth of information. There are limited similar studies exploring the caregivers' experiences in Alzheimer's disease. However, this study would provide a framework for adapting to new ways for nursing research, especially considering that it is provide a combined assessment of experiences and perspectives from the family caregivers and nurses²¹.

Altogether, this research highlights the caregivers' perceptions of care for older adults having Alzheimer's

disease are influenced by individual, social, and cultural factors. While some studies have explored associations with demographics, illness duration, and caregiver characteristics, the qualitative nature of this study precluded such analysis. Future research should delve into these relationships for a comprehensive understanding of caregiver experiences^{22, 23}.

CONCLUSION

Altogether our studies delineating caregiving needs for Alzheimer's patients in Saudi Arabia reveals challenges in spiritual, physical, and financial realms, alongside factors contributing to satisfaction. Caregivers and nursing staff stress the importance of financial aid and better access to specialized treatment centres. Collaboration between healthcare and government is crucial for effective care, as affirmed by all participants. Ongoing counselling and support from nurses, friends, and family significantly contribute to patient well-being.

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