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A Study Protocol to Explore Dementia Care Needs and Preferences from the Perspectives of Persons with Dementia and Family Caregivers in Malaysia

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ABSTRACT

Background: Dementia is a growing public health issue in Malaysia, largely due to rapid population ageing. Despite this, the care needs and preferences of persons with dementia (PwD) and their family caregivers remain poorly documented. Existing care frameworks are often fragmented and lack coordination, limiting their effectiveness in supporting this population. This study protocol is to explore the needs and preferences of PwD and their family caregivers regarding dementia care, and develop the dementia care needs and preferences framework based on the perspectives of PwD and family caregivers.
Methods: This study employs a qualitative research design. A total of 40 participants, comprising 20 PwD and 20 family caregivers, will be selected through purposive sampling from tertiary hospitals and community clinics in Kuantan, Pahang. Data will be collected through semi-structured interviews and supplemented with field notes. All interviews will be audio-recorded, transcribed verbatim, and analysed thematically using NVivo software.
Results: The study will generate in-depth insights into the care needs and preferences of PwD and caregivers. The final findings are also intended to facilitate the development of a dementia care framework aligned with Malaysia's Dementia Action Plan, which emphasises early diagnosis, risk reduction, and support for family caregivers.
Conclusion: This research addresses a critical gap in dementia care in Malaysia. By incorporating the perspectives of both PwD and caregivers, the study aims to improve care delivery, and contribute to a more comprehensive dementia care framework.

Keywords: Dementia care; Person with dementia; Family caregiver; Needs; Preferences

INTRODUCTION

The global prevalence of dementia is projected to rise significantly in the coming decades due to population ageing. Presently, over 55 million persons are living with dementia, with nearly 10 million new cases each year, and the number is expected to increase to 152 million by 2050 (1). In 2018, the ageing population trend in Malaysia seems to be apparent, whereby approximately 260,000 individuals (8.5%) are estimated to be living with dementia (2). Specifically, dementia is not only characterised by cognitive decline but also involves emotional and social deterioration, requiring a deeper understanding of its multidimensional impacts (3). As such, it necessitates a comprehensive care approach that can accommodate the holistic care required by the person with dementia (PwD) and their family caregivers.

Addressing the needs of PwD is essential for enhancing their quality of life and reducing the burden on family caregivers (4). Persistent misconceptions of cognitive deterioration as a typical ageing feature can hinder early recognition and appropriate care for PwD. Evidence indicated that the presence of comorbidities and social vulnerabilities among PwD significantly affects their health trajectory and quality of life (4). As a consequence, they are susceptible to developing depressive symptoms (5), experienced abuse (6) and suffer from malnutrition (7). These vulnerabilities highlight the importance of coordinated, multi-sectoral strategies that focus on early identification, risk reduction, and the provision of integrated person-centred care (8,9).

In certain circumstances, the demands associated with caring for PwD among family caregivers can become particularly burdensome. They frequently encounter a range of challenges that may adversely affect their well-being, including physical, emotional, and psychological strain (10–12). In some cases, due to cultural demand, family caregivers are usually burdened with the responsibility to care for PwD, and these conditions often lead to deterioration of health and quality of life among family caregivers (13). It is reported that inadequate support for caregivers over time has been shown to elevate the risk for emotional exhaustion and mental health deterioration(14), highlighting systemic shortcomings in current dementia care approaches.

In Malaysia, the existing legal framework for dementia care remains fragmented and insufficient in addressing the broader spectrum needs of PwD and family caregivers, as well as faces significant challenges in delivering holistic care and coordinating support. This is primarily attributed to the lack of well-defined guidelines for early diagnosis, insufficient community awareness initiatives, inadequate training programs for healthcare practitioners and the support from the carers (15). Despite the official launch of the National Dementia Action Plan (NDAP) for 2020 – 2030, its implementation remains in the preliminary phase, with ongoing groundwork and limited substantial evidence of widespread successful execution reported.

The Mental Health Act of 2001, along with the Mental Health Regulations of 2010, provides the legislative basis for the treatment and care of individuals with mental disorders, including dementia (16). However, these legal frameworks are more explicitly addressing issues related to psychiatric care and legal procedure (16). Rather than the broader aspect of non-clinical care, particularly the long-term caregiving needs, support for family caregivers, and community-based interventions. As a result, family caregivers who play an essential role in the care of PwD often navigate care responsibilities without structured legal or institutional support.

Despite the growing number of PwD in Malaysia, there remains a limited understanding of their specific care needs and preferences. Existing care, which is often fragmented and lacks coordination underscores the urgency of addressing this issue at both the policy and service delivery levels. A lack of comprehensive evidence related to PwD and family caregivers highlights the significance of the current study. To date, research on dementia care in Malaysia remains scarce, as most studies predominantly focus on the epidemiological aspect and laboratory-based investigations (17). Furthermore, the Ministry of Health Malaysia also supports it through the NDAP, which includes national strategies such as establishing a research data repository, integrating with clinical data registries, and capacity-building initiatives across research institutions (18). Thus, this study aims to explore the needs and preferences of PwD and their family caregivers regarding dementia care. Secondly, to develop the dementia care needs and preferences framework based on the perspectives of PwD and family caregivers.

METHODS

Study Design

A qualitative research design will be employed, as it enables the researcher to gain better insights and facilitates a deeper understanding of dementia care needs and preferences of PwD and their family caregivers (19). Such an approach is recommended for addressing the sensitive issues, especially within these vulnerable groups. The richness of the data enables the researcher to capture the complexity of lived experiences, as well as the dynamics of care (20).

Sample Size

A total of approximately 40 participants, comprising 20 PwD and 20 family caregivers, will be included in this study. This approach aligns with the existing literature, which indicates that at least 10 to 20 participants per subgroup are needed for enhancing the credibility and reliability of the research findings (21), thereby allowing for comparative insights across PwD as well as the family caregivers, and facilitating a better, holistic understanding of dementia-related care needs. Furthermore, the principle of data saturation will guide the recruitment of participants. Data collection will be concluded when thematic redundancy is evident, and the feasibility of identifying new themes is no longer observed (22).

Study Setting

The study will be conducted in tertiary hospitals and community clinics in Kuantan, Pahang, including the Sultan Ahmad Shah Medical Centre @ IIUM and Hospital Tengku Ampuan Afzan. Additionally, the IIUM Family Health Clinic and all ten community health clinics in Kuantan will also be included. The researcher will be actively involved in the recruitment process, and the decision to include participants will not rely solely on physicians but also involve direct researcher engagement to identify eligible participants.

Participants' Recruitment

Participants will be recruited using purposive sampling methods based on the inclusion and exclusion criteria. PwD who have received a formal diagnosis of dementia, either newly diagnosed or diagnosed for at least six months, and who can communicate effectively or have acceptable communication skills will be included in this study. They also must be able to converse in English and/or Malay. To capture the wide range of care needs and preferences, all dementia subtypes will be included, allowing for a more comprehensive exploration of the disease spectrum and thereby strengthening the generalizability of the findings. PwD who are concurrently diagnosed with substantial sensory deficits (such as severe hearing or speech impairments), severe underlying psychiatric illnesses (e.g., schizophrenia, bipolar disorder), or severe depression will be excluded, as it requires more complex intervention that may fall beyond the scope of the actual study. No specific instrument will be used to identify the exclusion criteria, as the researcher will solely refer to the patient's past medical records to confirm eligibility. The inclusion criteria for family caregivers must be over 18 years of age, able to converse in English and/or Malay, and have at least one year of continuous caregiving experience with PwD. Paid caregivers and those with underlying acute psychiatric illnesses that have been diagnosed by the medical personnel, including schizophrenia, anxiety disorders, or severe depression, that may influence participants' perspectives, will be excluded from the study.

Instruments

The topic guide will be used to facilitate the study. The relevant literature will guide the development of the topic guide. The topics include: (1) experiences and expectations in dementia care; (2) awareness of dementia and available services; (3) care pathways and access; and (4) the caregiving trajectory, including initial recognition, diagnosis, management, and associated challenges. Simultaneously, the researcher will document field notes to capture contextual and non-verbal information.

Data Collection

Once the ethical approval has been obtained, the data collection phase will commence. The recruitment of participants will depend on the suggestions made by medical personnel at the respective facilities, based on their professional judgment and medical diagnosis. All eligible participants will be approached and invited to participate in the study. They will receive a concise explanation of the research and be informed about the voluntary nature of their participation. Regarding the PwD, no special consideration will be undertaken in the written consent process. As in the early stages of dementia, symptoms are typically mild, which allows the PwD to retain a significant degree of autonomy. Thus, the researcher has decided to grant full autonomy to PwD in deciding whether to participate. Nonetheless, all potential participants are encouraged to seek input from trusted individuals before making their decision. The participants have the right to decline and prefer not to participate in this study, and they will be automatically excluded from the study. All potential participants who agree to participate in this study will be given a set of information sheets attached to the consent form, which will explain the purpose of the study, procedure, confidentiality, participants' rights, and the researcher's contact information.

Then, the data will be collected through face-to-face or online-based semi-structured interviews. The interview will be scheduled based on participants' availability and preferences, and each interview is expected to take approximately 30 to 60 minutes. If the participant decides to have the interview session in a clinic or hospital setting, a private and quiet room will be provided. Alternatively, when participants preferred home interviews or hybrid interviews, the researcher ensured minimal interruption to maintain privacy and confidentiality. To maintain transparency and minimise bias, each interview session will be held individually between the researcher and the participant, without the presence of others. Furthermore, all participants will be thoroughly informed about the presence and the purpose of the audio recording. They will also be reminded that all the audio files will be uploaded and stored on a password-protected computer that is only accessible to the researcher to maintain confidentiality. Recruitment of participants will continue until data saturation is achieved.

Data Analysis

Thematic analysis will be conducted using NVivo to systematically code and identify patterns within the data. It will be guided by the study's research questions, which focus on the experiences, needs, and preferences of PwD and family caregivers regarding dementia care. All audio recordings and accompanying field notes will be transcribed verbatim. A back-to-back translation will be performed for interviews conducted in Malay to maintain literature accuracy and consistency, thus enhancing the credibility and reliability of the analysis (23). The qualitative data will be analysed thematically in six steps: transcription and familiarization, keyword identification, coding, theme development, conceptualization, and the development of a conceptual model (24).

Trustworthiness

To enhance the rigour of the study findings, the concept of trustworthiness was adopted, which encompasses credibility, transferability, dependability, and confirmability (25). Credibility refers to the degree to which the data accurately represent the phenomenon under investigation and reflect the experiences of PwD and family caregivers. In the present study, triangulation was employed to enhance credibility. This involved the use of multiple data collection methods, including semi-structured interviews and field notes, to validate and cross-check the findings from different perspectives, transferability is described when the research findings can be generalised and applicable to the other context or situation, and it usually can be achieved through thick description and sampling strategies. In this element, the researcher has provided a detailed description of the research study to ensure it allows the reader to assess the transferability of findings, and the researcher also has clearly explained the sampling process and sampling criteria. Furthermore, dependability clarifies the consistency and stability of the research findings in producing a similar research study to demonstrate rigour. The researcher will maintain detailed information about the participants during the study to establish study dependability. Lastly, confirmability can be concluded when research findings are achieved to the extent in which the degree of naturality is defined and free from any form of bias by the researcher. The researcher will get validation from the expert to lessen the potential personal bias, therefore optimizing the accuracy of the findings.

Ethical Considerations

Ethical approval will be obtained from the Kulliyyah of Nursing Postgraduate Research

Committee (KNPGRC), the IIUM Research Ethics Committee (IREC), the SASMEC@IIUM Research Committee (SARC), and the Medical Research Ethics Committee (MREC).

Participants will be reminded that the conversation will be audio recorded. Pseudonyms will be used in all transcripts and reporting to maintain anonymity and ensure confidentiality. Each interview session will have the audio recorded with the prior knowledge and consent from the participants. The purpose of the recording will be clearly explained, and participants will be reminded that all recordings will be securely stored on a password-protected device accessible only to the researcher to uphold data confidentiality.

EXPECTED OUTCOMES

There remains a notable gap in the literature regarding the care needs and preferences of PwD and their family caregivers, which has been left underexplored, particularly in the Malaysian context. The absence of such data limits the ability of health systems to develop policies and practices that are both effective and culturally relevant. Thus, this study addresses this gap by exploring these perspectives in depth and contributing to the development of a framework designed to enhance the quality of dementia care.

CONFLICT OF INTEREST

There are no conflicts of interest to declare.

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AUTHORS CONTRIBUTIONS

NFSI: Contributed to the conceptualization, study design, literature review, methodology development, manuscript drafting, and preparation of the ethics application and study protocol documentation.

SMSE: Contributed to the conceptualization, critical revision of the manuscript, methodology development and supervision.

AM: Contributed critical revision of the manuscript, methodology refinement and co-supervision.

MAMA: Contributed to methodology refinement, co-supervision, and manuscript review.

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