

# PERTANIKA PROCEEDINGS

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# Perhatian in Practice: Dementia Care in Kuantan, Pahang

# Matthew Kuiper<sup>1\*</sup>, Rahimah Ibrahim<sup>1</sup>, Sarjit S. Gill<sup>2</sup>, and Amirah Fatin Ibrahim<sup>3</sup>

<sup>1</sup>Malaysian Research Institute on Ageing, University Putra Malaysia, 43400 Serdang, Selangor, Malaysia <sup>2</sup>Department of Social and Developmental Science, Faculty of Human Ecology, University Putra Malaysia, 43400 Serdang, Selangor, Malaysia

<sup>3</sup>Kulliyyah of Nursing, International Islamic University Malaysia, Jalan Sultan Ahmad Shah, Bandar Indera Mahkota, 25200 Kuantan, Pahang, Malaysia

#### **ABSTRACT**

As the world's population ages, social and cultural aspects of dementia care must be considered. This ethnographic study explores perceptions of dementia care among Malay and Chinese Malaysians living in Kuantan, Pahang. Two years of field work, 18 semi-formal and informal interviews, and archival research led to the results of this study. Areas for participant observation included visits to qigong courts, religious centres, and community organizations. Cultural values, familial responsibilities, and community dynamics impact the care of people experiencing dementia and influence the effectiveness of interventions. "Perhatian" (attention) is a key theme found in the community's perception of dementia care. This theme points to the importance of a community-wide desire for attention, compassion, and pampering in formal and informal care. Cultural awareness is essential in dementia care, and initiatives should be developed to support people experiencing dementia and their caregivers. Medical professionals should collaborate with communities to ensure that dementia is understood. "Perhatian" found in the community of qigong practitioners, demonstrates cultural values combined with caring for each other and the body. Community engagement must come from locals caring for people in Kuantan, Pahang. Medical professionals must advocate, educate, and equip patients and families using community-based tools.

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E-mail addresses: gs63334@student.upm.edu.my (Matthew Robert Kuiper) imahibrahim@upm.edu.my (Rahimah Ibrahim) sarjit@upm.edu.my (Sarjit S. Gill) ami.fatin@gmail.com (Amirah Fatin Ibrahim)

\* Corresponding author

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### INTRODUCTION

Communities worldwide are increasingly challenged by the ageing population and the rising prevalence of dementia and Alzheimer's disease. Dementia, often identified by progressive memory loss, behavioural disturbances, and communication difficulties (Emmady et al., 2024), demands not only medical, but also social responses to support patients and caregivers. Kuantan, Pahang, is missing key support structures to care for people experiencing dementia. Johor, Penang, Ipoh, Taiping, Malacca, and Kuala Lumpur, all have vibrant societies that provide support, but Kuantan, Pahang, is far behind. This ethnographic study attempts to understand how the community in Kuantan, Pahang, cares for individuals experiencing dementia.

#### **METHODS**

This study explored the perceptions of dementia within the community of Malay and Chinese Malaysians in Kuantan, Pahang. Eighteen caregivers were recruited through community outreach and advocacy programs. Data was collected through semi-structured interviews and informal conversations based on caregiving experiences. Reflexive thematic analysis was used on over 200 hours of fieldwork.

## **RESULTS**

Informal care in Kuantan is vital due to limited formal care services for people experiencing dementia. The care provided is influenced by social, cultural, and religious factors. Families are the primary caregivers but are always struggling with the complexities of dementia such as emotional outbursts, aggression, or wandering off. In Kuantan, Pahang, informal care networks have developed, where care responsibilities are shared among a wider community rather than being shouldered solely by families. This "care innovativeness" allows families to delegate care responsibilities, differing from the Philippines, where family members are judged for not providing direct care (Yeo et al., 2019). The theory of care convoys, which describes fluid networks of caregivers and those needing care throughout life, can be applied to the community dynamic in Kuantan, Pahang (Plath, 1980). Insights from caregivers strengthen this theme as they emphasize the importance of "perhatian", or paying attention, in caring for their loved ones. Care in Kuantan, Pahang, then looks like a collective, attentive approach rather than the establishment of a hierarchical formal system.

## **DISCUSSION**

Key themes to explore to improve care for people experiencing dementia and reduction of caregiver burnout are to improve community education programs. Advocacy event attendance is already strong, but the support group participation remains non-existent. The Bougainvillea City Dementia Café in Ipoh is a successful model for a positive and culturally informed structure. Medical community involvement is also a key to the success of health initiatives. Without clear guidance or referrals, people in Kuantan are lost, feeling

uncertain about the next steps to take. The cultural contrast between Western individualistic care systems and the Asian collectivist system was also made apparent during the research project asthe tools and care strategies brought in from the West must be culturally adapted and informed.

# CONCLUSION

The research highlights the importance of community involvement, education, and sensitivity in dementia care in Kuantan, Pahang.

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