

Caregiver Perception in Supporting Communication for People with Dementia

Shahrulnizam SID^a, Muhammad Badri NH^b, Sokmum S^c, Rasli AF^c, Hassan FH^a

^aCenter for Rehabilitation and Special Needs Studies, Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia

^bKidsogenius Child Development Sdn Bhd, Kuala Lumpur, Malaysia

^cSpeech Therapy Unit, Department of Medical Rehabilitation Services, Hospital Canselor Tuanku Muhriz, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia

ABSTRACT

INTRODUCTION: Dementia progressively impairs cognitive abilities and negatively affecting communication between people with dementia (PWD) and their caregivers. This study explored caregivers' experiences in communicating with PWD. **MATERIALS AND METHODS:** This qualitative study received ethical approval from Universiti Kebangsaan Malaysia (JEP-2024-266). Sixteen family caregivers of PWD were purposively recruited from the Psychiatric Clinic, Occupational Therapy Unit, and Speech Therapy Unit at a public university hospital. Semi-structured face-to-face interviews were conducted individually, lasting 30–40 minutes, and were recorded via Microsoft Teams. The transcripts were analysed using thematic content analysis. Coding reliability achieved 81.33% agreement, and discrepancies were resolved through discussion. **RESULTS:** Two main themes were identified: Communication Challenges (CC) and Strategies to Support Communication (SSC). The CC theme comprised of four subthemes: cognitive deficits, other PWD-related factors, communication difficulties, and impacts on caregivers' personal lives. The SSC theme comprised of three subthemes: comprehensive support, active engagement, and the use of communication aids. Communication breakdowns, behavioural issues, coexisting health conditions, and limited family support contributed to caregiver stress, whereas memory support, emotional reassurance, cognitive stimulation, and multimodal communication strategies improved interaction. **CONCLUSION:** Caregivers' wellbeing is affected by the cognitive and behavioural challenges of PWD as well as the availability of family support. External support, engagement activities, and communication aids may enhance caregiver–PWD interaction and strengthen social connections. The findings highlight the need for culturally tailored interventions and caregiver training programs to improve communication experiences and overall quality of life for both caregivers and PWD.

Keywords

family caregivers, social perception, communication disorders, dementia, Alzheimer's disease

Corresponding Author

Dr. Fatimah Hani Hassan
Center for Rehabilitation and Special
Needs Studies, Faculty of Health
Sciences, Universiti Kebangsaan
Malaysia, Kuala Lumpur
E-mail: fatimahhani@ukm.edu.my

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INTRODUCTION

Dementia is a progressive neurological condition that affects cognitive and communication functions, posing significant challenges for people who are experiencing dementia and their caregivers.¹ Cognitive deficits affect communication abilities, including language, memory, and attention, making it more challenging to comprehend, process, and express oneself during communication.² Family caregivers play a central role in supporting people

with dementia (PWD) as the disorder progresses.³ The adaptation of communication strategies is essential to maintain the quality of interaction, relationships, and emotional connections.⁴ This study explored the perceptions of Malaysian family caregivers regarding their communication with PWD, the challenges they faced, and the strategies they employed to enhance interaction.

MATERIALS AND METHODS

Study Design

This study employed a qualitative approach involving individual face-to-face interviews with family caregivers of PWD. Ethical approval was granted by the Universiti Kebangsaan Malaysia's Research Ethics Committee (JEP-2024-266).

Participants

A total of 16 family caregivers were recruited based on predefined inclusion and exclusion criteria, namely individuals who: (a) have a family member diagnosed with dementia by a medical doctor, (b) serve as caregiver of the PWD, (c) able to communicate in Malay or English, and (d) have never been diagnosed with mental health disorders. Participants were recruited through purposive sampling at the Psychiatric Clinic, Occupational Therapy Unit, and Speech Therapy Unit of a public university hospital.⁴

Study Sites

All interviews were conducted in person at a public university hospital in a private consultation room to ensure confidentiality.

Data Collection Tools and Procedure

A participants' background questionnaire was constructed to gather sociodemographic data. A semi-structured interview guide was also developed to facilitate the exploration of the caregivers' roles, challenges, and communication strategies. Individual face-to-face interviews were conducted, each lasting approximately 30 to 40 minutes. All sessions were audio-recorded using the Microsoft Teams application and securely stored in password-protected cloud storage. Before participation, caregivers were screened to ensure they met the inclusion criteria. Written informed consent was obtained from each participant.

Data Analysis

Interview recordings were transcribed verbatim and analysed using a thematic content analysis approach to identify the main ideas that addressed the study

objectives. In the analysis, each transcript was segmented into meaningful units. A specific code was given to each segment. A list of initial codes was generated. The codes were grouped into categories, which were then used to identify themes and subthemes. To ensure reliability, an independent coder conducted coding on two transcripts based on the initial code list. The codes between the two coders were evaluated for agreement.

RESULTS

The age of participants ranged from 20 to 77 years, with a mean of 54.25 and a standard deviation of 14.7. The participants included spouses (31.25%), children (62.5%), and other family members (6.25%). The sample included caregivers of Chinese (68.75%), Malay (18.75%), and Indian (12.5%) ethnicities. The duration of providing care to PWD ranged from 10 months to 14 years, with a mean of 4.86 and a standard deviation of 4.07. The sociodemographic data are summarised in Table I.

Table I: Sociodemographic Characteristics of Participants (n=16)

Participant	Age	Ethnicity	Relationship with PWD	Occupation	Duration of Caregiving
1	72	Chinese	Husband	Retired	2 years
2	47	Indian	Daughter	Assistant editor	2 years
3	60	Indian	Son	Retired	2 years
4	50	Chinese	Daughter	Pediatrician	3 years
5	77	Malay	Husband	Retired	3 years
6	75	Chinese	Wife	Retired	6 years
7	20	Chinese	Grandson	Student	14 years
8	50	Chinese	Daughter	Housewife	14 years
9	52	Chinese	Daughter	Housewife	9 years
10	50	Chinese	Daughter	Finance manager	3 years
11	43	Chinese	Daughter	Beautician	2 years
12	44	Chinese	Daughter	Accountant	5 years
13	65	Malay	Wife	Retired	4 years
14	54	Chinese	Daughter	Company secretary	5 years
15	42	Chinese	Daughter	Housewife	3 years
16	67	Malay	Wife	Retired	10 months

In qualitative analysis, a list of codes was generated based on the analysis of the transcriptions. The codes were evaluated through coding reliability, resulting in 81.33% agreement. Discrepancies were resolved through discussions between the coders.

Key Themes

Thematic analysis of the interviews revealed two major themes: "Challenges in Communication with PWD" (CC) and "Strategies to Support Communication with PWD" (SSC). For the first theme (CC), four subthemes

were identified: the impact of dementia on communication, cognitive deficits, other PWD factors and the impacts on caregivers' personal life. For the second theme (SSC), three subthemes were identified: comprehensive support, active engagement, and the use of communication aids. These themes are outlined in Figure 1.

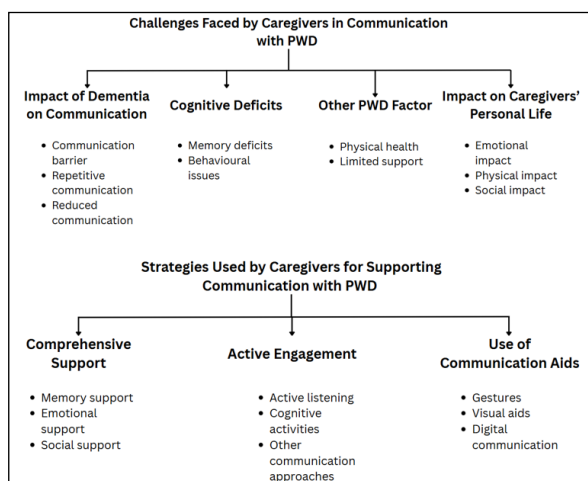


Figure 1: Overview of the themes and subthemes

Challenges Faced by Caregivers in Communication with PWD (CC)

Caregivers of PWD reported four key challenges in communication (CC). Participants' quotes and subthemes are presented in Table II. Firstly, they experienced significant impacts of dementia on communication, including barriers to understanding, repetitive speech, and reduced verbal interaction. Secondly, cognitive deficits such as memory loss and behavioural disturbances further hinder effective communication. Thirdly, other PWD factors such as hearing loss, coexisting medical conditions (e.g., stroke), and limited family support compounded these challenges. Lastly, the impact on caregivers personal lives were considerable, with many experiencing emotional stress, physical exhaustion, and social isolation due to their caregiving responsibilities.

Strategies to Support Communication with PWD (SSC)

Caregivers employed a range of strategies to support communication with PWD, which were categorised into three main areas. Participants' quotes and subthemes are presented in Table III. “Comprehensive support” involved reinforcing memory through repeated reminders,

providing emotional reassurance, and fostering social interaction to enhance engagement. “Active engagement” strategies included active listening, cognitive stimulation through games or structured activities, and, when necessary, more assertive communication methods to gain the attention or cooperation of the PWD. Additionally, caregivers utilised various communication aids such as gestures, visual tools like whiteboards, and digital platforms including smartphones and messaging apps, to facilitate clearer and more consistent communication. These strategies reflect caregivers' adaptability in addressing the evolving challenges of dementia care.

Table II: Challenges Faced by Caregivers in Communication with PWD

Subthemes	Categories	Quotes
Impacts of Communication on Dementia	Communication barrier	“...right now, when you speak to her, she will find it difficult to receive what you're going to tell her” (P01) “...they want something, but you couldn't figure out what they want.” (P09)
	Repetitive communication	“Yes, she always tell story. She will repeat, repeat and repeat” (P12) “Every five minutes after that, he will ask again what time is it” (P16)
	Reduced communication	“He is quite afraid to talk because he is afraid, he will talk nonsense, so he talks less now.” (P08) “It's just previously she talks alot and now I think maybe reduce to 20% to 30%.” (P12)
Cognitive Deficits	Memory deficits	“She keeps on saying she wants to go home but she can't remember that this is actually her house” (P05) “My mother-in-law, she cannot remember us. If we ask her who she was living with, she said she is with her sister, when in fact, she lives with my husband, which is her son.” (P08)
	Behavioural issues	“Nowadays, it is more difficult, he would always say no and be aggressive.” (P02) “...she have emotion problem and then so she was sometimes certainly will very sad or very angry.” (P15)
Other PWD factor	Physical health	“And then, she also used to tell me she can't hear exactly what I want to tell, maybe because of the ear” (P01) “...officially diagnosed by doctor premier HUKM with minor brain stroke. So, he seems forgetting since then.” (P16)
	Limited support	“His siblings also do not want to take care of him.” (P16)
	Emotional Impact	“...because you don't understand, and you tend to be very impatient and get angry and also very stress” (P06) “...quite stressful to take care of someone who is forgetting.” (P14)
Impacts on Caregivers' Personal Life	Physical Impact	“It's very tiring and frustrating in a sense” (P02) “...now I am stressed, because lack of sleep to take care of him” (P16)
	Social Impact	“We talk only when it is necessary. Even if we talk many times, he will forget.” (P16)

Table III: Strategies Used for Supporting Communication with PWD

Subthemes	Categories	Quotes
Comprehensive care	Memory support	“..we ask what date? Then she says can't remember. Then, we remind her again” (P03) “So you need to repeat two three times, then he will understand” (P07) “I just repeat and repeat when she was asking about my pet. I already told her many times, but she still asks” (P11)
	Emotional support	“..to comfort, to say it is okay if you have forgotten.” (P13)
	Social support	“She is very happy about little children. So, there is bonding for my mother and her grandchildren. She got the initiative to communicate with them” (P09) “..he still want to go back to the same restaurant to see whether his friend is there so that he can talk around.” (P10)
	Active listening	“..need to always listen to him..” (P10)
Active Engagement	Cognitive activities	“..they sort of do guessing game, try to guess what he trying to say” (P02) “Then, we prepare a menu to help in memory” (P03)
	Other communication approaches	“We just do whatever method. I will be louder and force her.” (P08) “Sometimes, I need to shout to him. I guess that's the most effective which is to shout” (P16)
Use of communication aids	Gestures	“..my mom and I sometimes will get irritated and point to what we are trying to say” (P02)
	Visual aids	“..only the whiteboard where I put what he is supposed to do.” (P13)
	Digital communication	“But it was a good thing she actually started using phone and there was one time I think we chat about two minutes” (P04) “If he goes outside, I will always check on him via Whatsapp, which is another form of communication.” (P13)

DISCUSSION

Communication breakdowns between caregivers and people with dementia (PWD) were prominently reported as major challenges in caregiving. Several participants described instances where PWD were unable to comprehend or respond appropriately, repeatedly asked the same questions, retold the same stories, forgot familiar people or surroundings, and made inappropriate requests such as asking to "go home" despite already being at home. These communication difficulties often led to frustration, reduced quality of interaction, and increased stress among caregivers.^{5,6} These findings are consistent with previous research, which indicates that cognitive decline disrupts communication and is a major contributor to caregiver emotional strain.^{7,8}

Interestingly, unlike past research,⁹ reduced verbal interaction between caregivers and PWD was minimally reported in this study. Behavioural challenges, such as aggression and emotional instability, were also highlighted

as significant stressors, adding unpredictability to caregiving situations.¹⁰ Coexisting medical conditions, including hearing impairment or the after-effects of stroke, further complicated interactions, echoing prior findings that multimorbidity increases the complexity of dementia caregiving.¹¹ A lack of family support was also reported as a contributing factor to caregiver strain and social isolation.^{12,13} Emotional exhaustion, frustration, and burnout were recurrent subthemes, which align with previous studies identifying communication-related stress as a core issue for caregivers.⁸ Physical consequences, such as tiredness and disrupted sleep, were also described and are consistent with findings on the health impact of long-term caregiving.¹⁴ However, social withdrawal was less frequently reported in this study compared to its recognised risk in the literature.^{15,16}

In addressing these challenges, caregivers described a range of communication strategies that could be grouped into three subthemes: comprehensive care, active engagement, and the use of communication aids. Memory support strategies, such as frequent reminders and repetition, were widely used to reduce confusion among PWD, which is consistent with past studies indicating that prompting supports memory retention.⁸ Emotional reassurance and fostering social interactions were also highlighted as beneficial, providing both cognitive and emotional support.^{17,18} Active engagement strategies, including attentive listening and cognitive stimulation through games or tasks, were employed by several participants and are supported by previous findings showing their positive effects on communication and mental functioning.⁹

A few caregivers reported using more forceful communication methods, such as raising their voices when necessary. Although sometimes effective, such strategies must be used cautiously, as they risk increasing distress or confusion in PWD if delivered without empathy.⁸ The reported use of communication aids such as gestures, whiteboards, and digital tools like messaging apps, illustrates a shift toward multimodal communication. These tools can provide structure and continuity, reflecting broader trends in the integration of technology into dementia care.^{15,18}

This study has several limitations. The sample size was small and context-specific, with all participants recruited from a single university hospital in an urban area. Therefore, the findings may not be generalisable to caregivers in rural areas, where lifestyle and resources may differ. Furthermore, the data were based on self-reported experiences, which may be subject to recall bias or individual interpretation. Future studies should consider recruiting more diverse samples and triangulating caregiver narratives with observational data or professional perspectives.

CONCLUSION

This study highlights the significant communication challenges faced by caregivers of PWD, including cognitive, behavioural, and medical-related barriers. Despite these challenges, caregivers employ a variety of strategies ranging from memory support and emotional reassurance to active engagement and the use of communication aids to improve interactions with PWD. Addressing these communication challenges through culturally appropriate caregiver training programs in Malaysia is crucial. Such programs should include practical communication strategies, emotional support, and guidance on utilising digital communication tools in home care. Additionally, respite services and peer support networks can help alleviate the emotional and physical burdens faced by caregivers. Ultimately, improving communication between caregivers and PWD has the potential to enhance not only the quality of interaction but also the overall quality of life for both caregivers and PWD.

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