



# Communication-related concerns of family caregivers of older adults living with dementia: A cross-sectional descriptive study

Patcharee Komjakraphan<sup>a,\*</sup>, Sirikul Karuncharernpanit<sup>b,†</sup>, Sasithon Kemsan<sup>c</sup>,  
Thanthip Kitphaiboonchai<sup>d</sup>, Suwanna Setthawatcharawanich<sup>e</sup>

<sup>a</sup> Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla 90110, Thailand

<sup>b</sup> Boromarajonani College of Nursing, Chakiraj, Prabormmarajchanok Institute, Ministry of Public Health, Rajchaburi 70110, Thailand

<sup>c</sup> Nursing department, Songkhla Rajanagarindra Psychiatric Hospital, Songkhla 90000, Thailand

<sup>d</sup> Nursing department, Hatyai Hospital, Hat Yai, Songkhla 90110, Thailand

<sup>e</sup> Department of Internal Medicine, Faculty of Medicine, Prince of Songkla University, Hat Yai, Songkhla 90110, Thailand

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## Abstract

The purpose of this study was to investigate the communication-related concerns of family caregivers of older adults living with dementia in Thailand. A cross-sectional study in which 115 caregivers from five outpatient clinics located in the central and southern regions of Thailand participated in a survey from May to October 2019. The survey questions spanned three topics: (1) communication problems and perceived communication difficulties; (2) communication strategies used and older adults' positive responses and; (3) communication training support. Data collected were analyzed by using descriptive statistics with focus on frequency ranking and correlation. In general, most of the caregivers were females with daughter-mother or daughter-father relationships, and had taken on the role of main caregivers of the older adults from one to five years. The older adults' ages ranged from 60–94 years with a mean age of 76.3 years ( $SD = 7.8$ ). The majority was female. TMSE scores ranged from 14–23 with the majority scoring 19 points ( $n = 78$ , 67.8%). The study results suggested that communication-related concerns among family caregivers of older adults living with dementia play a major role in their emotional burdens. Recognizing communication-related concerns should be utilized for designing an appropriate communication training program and implementing interventions for assisting family caregivers. A communication program assisting family caregivers to build a more open and positive relationships with older adults with dementia is recommended.

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\* Corresponding author.

E-mail address: [patcharee.ko@psu.ac.th](mailto:patcharee.ko@psu.ac.th) (P. Komjakraphan).

† Co-first authors.

E-mail address: [ksiriku@hotmail.com](mailto:ksiriku@hotmail.com) (S. Karuncharernpanit).

## Introduction

Communication-related concerns is an emotional strain for family caregivers, which is prevalent in daily communication between the older adults with dementia and family caregivers (Balkanska, 2012; Komjakraphan

& Karunchareonpanit, 2021). Several symptoms of dementia disturb the communications for example; semantic anomie aphasia such as word finding, discourse related difficulties (e.g., lack of conversation), repetitive question asking, and semantic difficulties such as the inability to communicate as they had done in the recent past (Byrne & Orange, 2005). These problems impact daily living activities and identified as high concern by family caregivers (Murray, Schneider, Banerjee, & Mann, 1999). In addition, previous study has shown that dysfunction in communication strategies of family caregivers of older adults with dementia correlate with their stress (Roberto, Richter, Bottenberg, & Campbell, 1998). Furthermore, a lack of knowledge of challenging behavior and its possible causes often leads to communication breakdown, fear, and misunderstanding.

Communication difficulties exhibited by family caregivers of older adults with dementia have been discussed in the literature (Balkanska, 2012; Komjakraphan & Karunchareonpanit, 2021, Savundranayagam & Orange, 2011) and have been identified as a factor contributing to caregiver stress (Balkanska, 2012) as well as caregiver burden (Watson, 2018). Poor communication between family caregivers and older adults with dementia can often lead to difficulties in managing the care and earlier placement of older adults (Egan, Berube, Racine, Leonard, & Rochon, 2010). In Thailand, research investigating the problems and needs of dementia caregivers indicated that the caregivers expressed that both basic ADL, including toilet hygiene, and instrument ADL, such as communication, created problems for their quality of life (Griffiths & Bunrayong, 2015). In addition, they described the experiences in communication with their care recipient as engaging in troublesome communication and inability to relate to each other (Komjakraphan & Karunchareonpanit, 2021).

Understanding family caregivers' lives in terms of their communication concerns with their loved ones may help researchers provide family caregivers with culturally responsible education and training enabling them to develop communication skills for fostering positive communication. Regardless, for those looking after older adults with dementia at home, their communication-related concerns are poorly understood. In addition, few published studies have examined the nature and repair of communication problems in dementia dyads, especially among family caregivers (Savundranayagam & Orange, 2011).

Thus, this study investigated the family caregivers' perceptions of communication related-concerns in

Thailand to respond by developing and designing culturally responsible education and training services. The specific aims of this study were to (1) describe the communication problems of Thai older adults living with dementia; (2) evaluate the perceived communication difficulty of family caregivers; (3) describe communication strategies family caregivers use to facilitate communication; (4) determine how effective family caregivers feel the communication strategies are in facilitating communication and (5) explore the communication training needs of family caregivers.

## Literature Review

### *Communication Difficulties as a Result of Dementia*

Communication difficulties with speech and understanding are often referred to as aphasic syndromes (Samuelsson & Hyden, 2017) which are recognized as common characteristic features of neurodegenerative diseases causing dementia (Badarunisa, Sebastian, Rangasayee, & Kala, 2015; Banovic, Zunic, & Sinanovic, 2018). Aphasic syndrome in dementia affects both semantic and pragmatic levels of language processing (Kempler, 1991).

Semantic problems in dementia include word-finding and naming difficulties, word comprehension, semantic paraphasia, empty speech, neologisms and loss of verbal fluency (Bayles & Tomoeda, 2014). The pragmatic problems found in individuals living with dementia include digressing from the topic of a conversation, repeating ideas, speaking too loudly, using embarrassing words and talking at inappropriate times (Ferris & Farlow, 2013). It can be challenging to communicate effectively with individuals living with dementia and may lead to adverse behaviors such as agitation and aggression that can result in significant stress and burden for caregivers (Watson, 2018). Several studies have indicated that cause of communicative breakdown may result from caregivers' use of ineffective communication strategies (Orange, Lubinski, & Higginbotham, 1996; Small, Gutman, Makela, & Hillhouse, 2003).

Poor comprehension is one of the communication deficits in the individual living with dementia that causes communication difficulties. Their ability to sustain a topic and maintain its coherence is impaired. The individual living with dementia often shows decrease in vocabulary, anomia, and vague meanings. Pronouns may be used inappropriately, which affect the ability to have a conversation, and topic shifts disrupt the flow of conversation (Weirather, 2010).

## *Communication Strategies and Techniques in Dementia Care*

Based on literature reviewed, strategies aimed at compensating for dementia-related communication deficits are categorized as verbal and non-verbal techniques. The verbal technique can be grouped into two types; direct repair and indirect repair (Gentry & Fisher, 2007). For indirect repair, the caregiver paraphrases the speech of the person with dementia. In a direct repair response, the caregiver interjects with corrective feedback. Non-verbal responding to assist comprehension in dementia has been mentioned in several studies such as keeping sentences short, showing empathy and care, maintaining eye contact, remaining calm, and avoiding presenting the patient with too many choices at once (Mendes & Palmer, 2018; Weirather, 2010). One recent study demonstrated that the repair sequences frequently used in the interactions and interactional styles of conversational partners with older adult living with dementia are important (Samuelsson & Hyden, 2017).

## **Methodologies**

### *Study Design, Sample and Study Site*

This cross-sectional study was conducted from May to October 2019 in the central and southern regions of Thailand. The minimum sample size required as a result from Cochran's formula (Cochran, 1963) for infinite populations for proportion with a margin of error of 0.10, and a Z score of 1.96 for a 95 percent confidence interval was 96. In order to compensate for poor survey data, the researcher increased the sample size following the recommendation of at least 10 percent (Dolnicar, Grun, & Leisch, 2016). Therefore, the sample consisted of 115 representative main caregivers of older adults with dementia who had Thai Mental State Examination (TMSE) scores (Train the Brain Forum Committee, 1993) ranging from 14–23, respectively. The sample was recruited by using a stratified sampling technique from three different levels and specializations of Thai hospitals.

First, 160 government hospitals with medical clinics specializing in the assessment and diagnosis of memory were divided into the following three strata: (1) advanced-level hospitals, (2) middle-level and standard-level hospitals, and (3) mental health hospitals. Then a decision was made to fill the sample frame of five hospitals based on the proportions from each stratum. Next, two hospitals were randomly selected from each of the first and second

strata, and one hospital was randomly selected from the third stratum. At the second step, a purposive sampling was used to select samples from each of the five selected hospitals.

### *Data Collection*

Following ethical research approval, the research team contacted head nurses working at the five memory clinics/neuro-medical outpatient clinics in person, explained the study and asked for permission to look at the diagnostic and medical histories of the older adults who attended medical follow-up appointments. Once the candidates had agreed to participate, written informed consent for participation, including information about participation, anonymity, the purpose and objectives of the study, was obtained.

### *Instrumentation*

The questionnaire was divided into the following four sections: (1) socio-demographics; (2) perceived problems and difficulties in communication; (3) communication strategies used and perceived positive response and (4) communication training supports.

The socio-demographic section was composed of 11 items with 7 multiple-choice items and four open-ended items. Communication problem refers to interpersonal conflicts and less flexibility in communication style of the older adults and inability to relate to the older adults with dementia while providing care (Komjakraphan & Karuncharepanit, 2021). Inability to relate to each other portrayed feelings of difficulty in communication resulting from semantic, pragmatic, and comprehension problems such as speech errors, repeated words, repetitive storytelling, decrease in vocabulary and vague meaning (Bayles & Tomoeda, 2014; Ferris & Farlow, 2013). Perceived problems and difficulties in communication were composed of 25 items of communication problems. Beside each problem, there were five categories of responses requested from the caregiver. First, the caregiver was asked to indicate how often the older adults demonstrated the problem by checking one of five options: always, frequently, occasionally, rarely, or never. Then, they were asked to rate their perceived difficulties in communication on a 5-Likert scale, where a favorable response was given a lower score and the least favorable response was given a higher score. The summed score range was from 0–100.

Caregivers' self-reports on the frequency of communication strategies used and the older adults'

positive responses were used to determine the relationship between use and older adults' positive responses. A 17-item questionnaire was constructed into a verbal and non-verbal technique (Gentry & Fisher, 2007; Mendes & Palmer, 2018; Weirather, 2010) that listed the 17 communication strategies. Apart from communication strategies used, which had five options: always, frequently, occasionally, rarely, or never, were categories of positive responses perceived by the caregivers, and a 5-Likert scale was provided for rating their perception of positive response toward the communication strategy.

The section on communication training support was composed of 6 questions. The survey focused on dementia knowledge, information needs and current or potential communication training resources.

All of the instruments were developed by the research team. The content validity of the questionnaire was determined by three independent reviewers and experts in dementia care. The feedback from experts was then used to modify the questionnaire. Regarding reliability tests, the questionnaires were pilot tested before data collection with the use of 30 caregivers and Cronbach's coefficients alpha was obtained as shown in Table 1. Furthermore, based on data of all participants (115 participants), Cronbach's coefficients alpha of each subscale was recalculated and reported in Table 1. Most instrument tools had internal consistency with Cronbach's coefficients alpha range from 0.80–0.92; However, the communication training needs questionnaire that asked the caregiver's needs with different aspects was low. The training needs is required because this information will be used to develop a supportive program in the future.

### Data Analysis

Data were analyzed by using statistical software. Descriptive statistics were used to analyze the socio-demographic variables, frequency of encountering

communication problems, perceived difficulties in communication, communication strategies used and communication training supports. Bivariate analysis examined the relationships between use and efficacy of communication strategies by using spearman rank. An alpha level of .05 was set for a priori to determine statistical significance.

### Results and Discussion

Family caregivers' ages ranged from 17–75 years with a mean age of 48.4 years ( $SD = 13.1$ ). The majority was female ( $n = 93$ , 80.9%) with daughter-mother or daughter-father relationships ( $n = 71$ , 61.7%) and completion of secondary education ( $n = 67$ , 58.3%). The caregivers were mostly Buddhists ( $n = 105$ , 91.3%), married ( $n = 76$ , 66.1%) and had taken on the role of main caregiver for the older adults from one to five ( $n = 95$ , 82.6%) years. The older adults' ages ranged from 60–94 years with a mean age of 76.3 years ( $SD = 7.8$ ). The majority was female ( $n = 73$ , 63.4%). TMSE scores ranged from 14–23 points with the majority earning scores of 19 points ( $n = 78$ , 67.8%).

Overall, the mean score for perceived communication difficulty was mostly at the difficult level with a mean of 50.6 ( $SD = 9.9$ ). Table 1 shows the frequency scores of communication problems in rank order. It is clear that the top five communication problems in this study were as follows: (1) asking repeatedly; (2) repeating the same story; (3) initiating conversation; (4) naming familiar persons and (5) answering or talking back. However, many communication problems were reported by caregivers with the same median scores as shown in Table 2. The five least common communication problems were as follows: (1) self-talk; (2) constantly interrupting or using meaningless words; (3) talking non-stop; (4) hesitant speech and (5) repetition of meaningless phases/words, as shown in Table 2.

Table 2 demonstrates the communication problems such as a certain type of speech and language disorder commonly found in people with Alzheimer's disease, vascular dementia and mixed dementia (Klimova & Semradova, 2016). The majority the older adults in this study had TMSE scores of 19, which were considered mild or early stage of dementia. Since repetitive questioning is a prominent feature in the early stages of Alzheimer's dementia (Hamdy et al., 2018), the most frequently encountered communication problem perceived by caregivers in this study was asking repeatedly. In accordance with previous studies (Reeve, Molin, Hui, & Rockwood, 2017), it was found that repetitive questioning

**Table 1** The Cronbach coefficients alpha of each questionnaire and subscales

Instruments	Cronbach Alpha coefficients	
	Pilot test ( $n = 30$ )	This study ( $n = 115$ )
Communication problem	0.80	0.83
Perceived communication difficulties	0.88	0.91
Communication strategies used	0.88	0.86
Positive response of older adults	0.88	0.92
Communication training needs	0.66	0.54

**Table 2** Rank order of communication problem

<i>n</i> = 115			
No.	Communication problems	Median	IQR
1	Asking repeatedly	3.00	2.00
2	Repeating the same story	3.00	2.00
3	Inability to initiate conversations	2.00	2.00
4	Answering or talking back	2.00	2.00
5	Taking a long time to answer	2.00	2.00
6	Stop talking in the middle of conversation	2.00	1.00
7	Carry on a conversation	2.00	3.00
8	Making decision	2.00	2.00
9	Naming familiar persons	2.00	2.00
10	Naming objects	2.00	3.00
11	Accusing others	2.00	3.00
12	Lying (not tell the truth)	2.00	2.00
13	Understanding sign, label	2.00	3.00
14	Refusal, Resistance	2.00	2.00
15	No Responses	1.00	2.00
16	Expressing needs or feelings	1.00	2.00
17	Using bad words	1.00	3.00
18	Writing to express needs	1.00	3.00
19	Using substitutes, related words	1.00	3.00
20	Understanding what others say	1.00	1.00
21	Repetition of meaningless phrases/words	1.00	2.00
22	Hesitant speech	1.00	2.00
23	Talking non-stop	1.00	2.00
24	Constantly interrupting or using meaningless words	1.00	2.00
25	Self-talk	1.00	2.00

was the most frequent type of verbal repetition, while self-talk, constantly interrupting and talking non-stop were reported less frequently, possibly because later communication problems were associated with “problem or challenging behaviors” and neuropsychiatric symptoms such as delusion, hallucination and aggressive behavior (Watson, 2018). Furthermore, these problems seem to occur more frequently in advanced stages of dementia (Teipel et al., 2017). The finding that community-dwelling subjects with dementia and neuropsychiatric symptoms are generally less frequent and severe than in patients recruited in hospital or long-term care facilities was also reported by Cerejeira, Lagato, and Mukaetova-Ladinska (2012).

The caregivers in this study perceived mostly difficult problems in communication with the older adults living

with dementia. This also corresponds with our earlier observation showing that asking repeatedly and repeating the same story can fluctuate and has been reported as a marker of a “bad day” as described by caregivers (Rockwood, Fay, Hamilton, Roos, & Moorhouse, 2014).

Table 3 shows the ranking of communication strategies used by the family caregivers. The seven most common communication strategies used by family caregivers were as follows: (1) drawing the attention of the elderly by calling his/her name before starting a conversation; (2) reading the facial expressions of the elderly while talking to them; (3) acting in a manner that shows the elderly you care; (4) speaking slowly; (5) asking one question at a time; (6) repeating message and (7) speaking in a soft tone.

**Table 3** Rank order of communication strategies used by the family caregivers

*n* = 115

Order	Communication strategies	Median	IQR
1	Drawing attention of the elderly by calling his/her name before starting a conversation	3.00	2
2	Reading facial expression of the elderly while talking to them	3.00	2
3	Acting in a manner that shows the elderly you care	3.00	2
4	Speaking slowly	3.00	3
5	Asking one question at a time	3.00	2
6	Repeating message	3.00	1
7	Speaking in a soft tone	3.00	3
8	Allowing the elderly plenty of time to respond	2.00	1
9	Encouraging circumlocution	2.00	3
10	Offering “yes/no” or “like/dislike” answer	2.00	2
11	Asking general questions about the elders’ distant past	2.00	1
12	Using comforting gestures such as gently touching a hand or back while talking to the elders	2.00	2
13	Keeping sentence short	1.00	2
14	Reducing noise disturbances before speaking to the elderly	1.00	2
15	Using picture or symbol to communicate	1.00	2
16	Using a written message as a constant reminder	1.00	2
17	Using another language (if the elderly is bilingual or multilingual)	1.00	1

The communication strategies appearing as the most highly recommended in Western literature included keeping sentences short and speaking slowly (Mendes & Palmer, 2018; Small & Gutman, 2002), but these did not appear to be the first rank or most frequently used communication strategies by caregivers in this study. Attitudes towards older people are influenced by cultural values, norms and social structures. Thai society is deeply embedded in eastern collectivistic cultures as evidenced by a sense of long-term responsibility to the group, the family, the extended family or other extended social groupings (Buriyameathagul, 2013). Eastern collectivistic cultures place a stronger emphasis on honoring and supporting older people, committing oneself to family obligations, social interdependence, and self-sacrifice. Moreover, children are obligated to care for their parents based on Buddhist customs (Rittirong, Prasrtkul, & Rindfuss, 2014; Sasat & Bowers, 2013) and they have been taught to be cautious and considerate towards elderly parents. Therefore, most of the communication strategies frequently used are non-verbal and body language reflecting children’s attitudes toward their elderly parents.

Table 4 shows the correlation between overall communication strategy used and response of the older adults. The overall correlation between combined strategy use and the older adults’ positive responses was significant ( $r_s = .39, p < .01$ ), which indicates that all strategies patterned together. The strongest correlations were observed for strategies 11 (offering “yes/no” or “like/dislike” answer) ( $r_s = .73, p < .01$ ), 10 (encouraging circumlocution) ( $r_s = .69, p < .01$ ), and 17 (using another language) ( $r_s = .67, p < .01$ ). The weakest correlations were observed for strategies 9 (allowing the elderly plenty of time to respond) ( $r_s = .25, p < .01$ ), 8 (repeating message) ( $r_s = .31, p < .01$ ), and 7 (asking one question at a time) ( $r_s = .47, p < .01$ ).

As shown in Table 5, when asked about dementia knowledge and information needs, most of the caregivers ( $n = 82, 71.1\%$ ) were extremely likely to have knowledge and information about the disease. However, when asked about communication knowledge and practice, most of the caregivers ( $n = 94, 81.8\%$ ) had not been taught or practiced how to communicate with the older adults with dementia. In addition, most of the caregivers ( $n = 71, 61.7\%$ ) had not found the right communication training resources to meet their needs.



**Table 4** Spearman rank correlation coefficient between overall communication strategy used and response of the older adults  
*n* = 115

Communication strategies	Response of the older adults	
	<i>r<sub>s</sub></i>	<i>p</i>
Overall communication strategy used	.39	.000
1. Drawing attention of the elderly by calling his/her name before starting a conversation	.48	.000
2. Keeping sentence short	.55	.000
3. Reducing noise disturbances before speaking to the elderly	.60	.000
4. Reading facial expression of the elderly while talking to them	.54	.000
5. Acting in a manner that shows the elderly that you care about what they are saying	.45	.000
6. Speaking slowly	.59	.000
7. Asking one question at a time	.47	.000
8. Repeating message	.31	.001
9. Allowing the elderly plenty of time to respond	.25	.005
10. Encouraging circumlocution	.69	.000
11. Offering “yes/no” or “like/dislike” answer	.73	.000
12. Asking general questions about the elders’ distant past	.64	.000
13. Speaking in a soft tone	.59	.000
14. Using comforting gestures such as gently touching a hand or back while talking to the elders	.48	.000
15. Using picture or symbol to communicate	.66	.000
16. Using a written message as a constant reminder	.55	.000
17. Using another language (if the elderly is bilingual or multilingual)	.67	.000

**Table 5** Communication training support*n* = 115

Question	Level of agreement				
	No comment 0	Totally disagree 1	Disagree 2	Agree 3	Totally agree 4
Being able to access to knowledge and information about dementia	-	3.5% ( <i>n</i> = 4)	25.2% ( <i>n</i> = 29)	45.2% ( <i>n</i> = 52)	26.1% ( <i>n</i> = 30)
Having someone to consult about dementia related communication problems	1.7% ( <i>n</i> = 2)	32.2% ( <i>n</i> = 37)	41.7% ( <i>n</i> = 48)	18.3% ( <i>n</i> = 21)	-
Having been taught about dementia communication technique	6.1% ( <i>n</i> = 7)	9.6% ( <i>n</i> = 11)	72.2% ( <i>n</i> = 83)	17.4% ( <i>n</i> = 20)	-
Having been trained about dementia communication skill	0.9% ( <i>n</i> = 1)	-	68.7% ( <i>n</i> = 79)	31.3% ( <i>n</i> = 36)	-
Having enough communication related dementia education resources	1.7% ( <i>n</i> = 2)	16.5% ( <i>n</i> = 19)	45.2% ( <i>n</i> = 52)	36.5% ( <i>n</i> = 42)	-
Having enough knowledge to care for older adults with dementia	3.5% ( <i>n</i> = 4)	7.8% ( <i>n</i> = 9)	33.9% ( <i>n</i> = 39)	54.8% ( <i>n</i> = 63)	-

## Conclusion and Recommendation

The communication-related concerns of the family caregivers of older adults living with dementia in Thailand were addressed by this study. The greatest communication problem of older adults living with dementia as perceived by family caregivers was their verbal repetition, while the most frequently applied communication strategy used by family caregivers were acting in a manner that shows the elderly that you care. Although the communication strategies the caregivers used and to which the older adults positively responded patterned together, the overall correlations were not strong. In addition, the caregiver's perceived difficulty in communication with their relatives was quite high since the elderly's verbal repetition could create a sense of tension, atmosphere and emotion. The unprepared family caregivers, therefore, might become irritated or frustrated and angry by the behavior, which might lead to their emotional distress and burden.

Therefore, the results of this study highlight the need to develop evidence-based communication strategies in educational programs to assist family caregivers in improving their moods and building positive relationships with older adults. It is imperative to teach communication skills to family caregivers since closeness and loss of closeness in the care dyad due to communication may be associated with both positive and adverse outcomes for caregivers (Fauth, Hess, Pierce, & Norton, 2012).

## Conflicts of Interest

There is no conflict of interest.

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