

***Dementia Care Users' Resistance to Long-Term Home Care Service:  
Taiwanese Care Workers Advised Communication Strategies***

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**Abstract**

Population of older people living with dementia is expected to rise in Taiwan due to the dramatically ageing trend. Long-term home care service becomes increasingly needed to help family with older people diagnosed with dementia cope. However, due to the health condition, older people with dementia can be difficult to reason given the changes in cognitive competence and personalities. It is also possible to encounter their resistance to long-term home care service which is mainly practiced by strangers, that is, care workers. Dementia care communication comes into the picture to help professional care workers to deal with such scenarios. 35 Taiwanese long-term home care workers with at least one year of dementia care experiences were interviewed. A number of communication strategies were identified for dealing with dementia care users' resistance to care service. They can be divided into two main groups, leading to two different communication outcomes: first, to postpone instruction without forcing dementia care users (with strategies used to show empathy and to avoid enhanced resistance) and second, immediate compliance to instruction (strategies used to help care users to accept service/instruction with light-hearted mood and to relate to what is concerned by them). The implication and potentially problematic nature of the advised communication strategies are also discussed in the conclusion.

Keywords: Long-Term Home Care, Older People With Dementia, Resistant Behavior, Dementia Care Communication

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## **Introduction**

Dementia is regarded as one of the most serious and worldwide health issue. In 2010, 35 million people were diagnosed with dementia in the world. It is expected to reach 65 million by 2030 and 113 million by 2050, of whom approximately two-thirds will live in developing countries (Brodaty et al, 2011).

Dementia is not a single disease. It is characterized by many behavioral syndromes, such as memory loss, language disorders, cognitive impairment, visual/spatial disorientation, decline in problem solving abilities, personality changes, and so on (van Der Flier & Scheltens, 2005). The most common types of dementia include Alzheimer's disease (60-70% of the dementia cases), Vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia (World Health Organization, 2017). Therefore, the syndromes for the elderly people with dementia of different types could vary.

According to Taiwan Alzheimer's Disease Association (2020), approximately 18% of Taiwanese people aged 65 and about 8% of the 85+ population in Taiwan suffer from dementia. Population with dementia in Taiwan grow dramatically. In addition, some epidemiological studies showed that the prevalence of dementia increases with age and was higher among women than among men (Fuh & Wang, 2008). It is also predicted that in the following 47 years, there will be a new individual diagnosed with dementia in every 40 minutes. Therefore, a huge demand of long-term care service for elderly people with dementia can be expected in Taiwan.

In the process of care services, long-term home caregivers may encounter resistances or uncooperative behaviors by elderly people with dementia who have mental disorder, cognitive deficits and physical restraint (Cadore et al, 2014; Smith & Buckwalter, 2005). Communication between long-term home caregivers and elderly people with dementia as care users can be frustrating and helpless. Furthermore, most studies (Small et al, 2003; James & Plerjert, 2014; James & Gibbons, 2019) about the communication strategies focused on how to establish the relationships between the two participants of dementia care communication. But it was less to discuss the solutions to the scenario when demented care users show denial of instructions. Therefore, this study is aimed to explore this issue. This aspect of discussion, arguably, could directly help long-term home caregivers tackle what can be the most difficult part of service delivery involving dementia elders.

## **Literature Review**

The statistics provided by Gender Equality Committee of Executive Yuan (2019) showed that people working as home caregivers have increased gradually to approximately 21 thousand in Taiwan. Long-term home care services include housework services and physical care services (Kane et al, 1998). Housework services involve cleaning services, meal preparation, and accompanying older care users to go to hospitals, whereas physical care services cover taking shower, wearing/taking off clothes, and helping with exercises. It seems to be easy to complete the above tasks, but when communication breakdown happens, the service operation can be terminated. This is why long-term home caregivers need to use certain strategies to interact with dementia individuals when they become difficult to reason and hence refuse service that should be delivered within certain period of time. What follows is the discussion.

## **Communication with older people with dementia**

A survey by Small et al (2003) identified and recommended ten strategies as used by caregivers for communicating with people with dementia. Through these techniques, home caregivers can have deeper understanding of the behavior and demand of those with dementia. The strategies include: (1) eliminating distractions, (2) approaching the person slowly and from the front; establishing and maintaining eye contact, (3) using short, simple sentences, (4) speaking slowly, (5) asking one question or give one instruction at a time, (6) using “yes/no” questions, (7) repeating messages using the same wording, (8) paraphrasing repeated messages, (9) avoiding interrupting the person; allowing plenty of time to respond, and (10) encouraging the person to “talk around” or describe the word he is searching for.

## **Challenges in dementia care communication**

Colling (1999) indicated that when people with dementia encounter communication disorder, their difficulty in expressing their feelings might be realized in terms of the forms of resisting or attacking others. In addition, Ripich (2000) suggested that having appropriate communication trainings for home caregivers can facilitate more successful communication with people with dementia and give them better care services and living quality. Challenges such as being rejected and aggressively attacked by people with dementia can be handled well if one knows how to communicate with them. What follows provides some insights.

Jansson and Plejert’s (2014) research investigated the conversational interactions for shower tasks between home caregivers and people with dementia in two nursing homes. The people with dementia initially rejected bathing service. But, when caregivers expressed concerns and showed negotiable manners to complete the tasks step by step, bathing tasks became less challenging. This implies that it is important to treat people with dementia as if they are normal individuals and hence also have rights to choose from options, needs of receiving care and respect. Only when those person-centered considerations are evident in the communication processes, rejection of service can be reduced and no longer becomes a problem.

James and Gibbons (2019) also examined communication involving people with dementia who have cognitive impairment. No matter how rude they were, the study showed that caregivers still remained kind and polite. However, it is noticed that people with dementia needed someone whom they could feel related to and hence have a sense of security or trust in the communication. Hence, to develop a relationship with those with dementia, home caregivers could try to position in the role to be trustworthy or reliable by changing the language tone, accent, body language, and appearance.

The review of the above studies indicated that it is likely to experience resistance of service by people with dementia in the process of delivering professional care services because they are puzzled or out of character or do not fit into the situation at hand (Smith & Buckwalter, 2005). This implies distress to people with dementia, their family and caregivers. Therefore, this study argues that it is necessary to explore how caregivers communicate with people with dementia with a focus on their resistance to care services in Taiwanese long-term home care contexts.

## **Methodology**

Interviews with a total of 35 long-term home care staff were conducted to elicit in-depth views on the research topic under study in this paper. All the participants were from Pingtung County in Taiwan, and their age ranges were from 41-60. The average years of the participants' experiences working as long-term home care workers are 7 years. They all had at least one-year experience of providing home care services to older people living with dementia. They were asked the following interview questions:

1. How many older dementia care receivers (who are over 65 years old) have you cared for? (Please inform their severity level of dementia)
2. How long have you been a long-term home care worker?
3. Do you have any experiences of taking care of older people with dementia who showed denial of intrusions? How do you perceive them when they do so?
4. What communication strategies did you demonstrate when older care users with dementia resisted your home care service?

## **Results**

### **Dementia care communication for resistant behaviors**

The suggestions on how to communicate with older care users who show denial of instructions or show resistant manners are divided into four main categories, illustrating four different kinds of communicative effects or functions, that is, "avoiding enhanced resistance", "showing empathy", "persuasion based on resisting care receivers' main concerns", and "persuasion with light-hearted tones".

As to "avoiding enhanced resistance" and "showing empathy", the communicative effects are to postpone dementia care users' acceptance to follow the given care-related instructions without making them feel forced. Successful delivery of the service hence is not the main priority.

On the contrary, the persuasion based on resisting care receiver's main concerns or with light-hearted moods aims to arrive at immediate compliance to the given instructions in care. Figure 1 shows the clear organization of the strategies in relation to the communication purpose/goals.

#### **1. Avoiding enhanced resistance**

When older care users with dementia show denial of instructions, their mood also becomes emotional and furious. To prevent older care users with dementia from getting out of control, the interviewed care workers provided four strategies to avoid enhancing resistant behaviors further, that is, "diverting the attention to calm down and step-by-step negotiation", "avoiding keywords", "ignoring until forgetting, and "using body languages to enhance comprehension". The details of each strategy are introduced below.

##### **Strategy 1: Diverting the attention to calm down and step-by-step negotiation**

The attention of resistant demented care users could be diverted away from the current arguments surrounding their rejection of care services. One way is to change the topics to those preferred by older care receivers (see Extract 1) until the denial of the instruction is forgotten.

After that, home care workers can try to negotiate with them. Therefore, observing what topics are considered interesting by demented care users is important while having daily conversation with them so that when the denial of service appears, care workers know what topics can be raised to divert attention away. It is hence advised to know the personal history of demented care users and what preferred topics could be raised appropriately. This is a rather individualized approach of topic selection in dementia care communication.

Extract 1: I chose a topic related to picking up beautiful clothes instead of taking a shower to divert a demented elderly lady's attention. She was very happy because she loves pretty clothes. As a result, she forgot that she refused to go to the bathroom for shower. (C3, 2020.09.13/ 57-year-old/ Female)

#### Strategy 2: Avoiding keywords

Some home care workers avoid keywords regarding the rejected service or instructions when older dementia clients show resistance. By not to say any words which the dementia people dislike, care workers could avoid making them angry or provoking their bad temper. Also, it is advised to refer to the topics in daily conversation in case the denial of service appears. In order to do so at the needed moment, care workers need to know the personal history of the clients so that the preferred topics can be raised appropriately. This is a rather individualized way of topic selection in care communication.

Extract 2: At first, I would say "Let's go to take a shower", but the older care user would reject. So now, I say "Let's go" directly instead of "Let's go to take a shower", and he is willing to go with me and take a shower. (C15, 2020.10.19/ 50-year-old/ Female)

#### Strategy 3: Ignoring until forgetting

It is mentioned that ignoring older care receivers can be one communication strategy when they resist home care services and do so until they forget. Some interviewed home care workers would stop the home care services that annoy older care users who are resistant and demented. Moreover, being out of their sight is one way to calm their resisting attitude down.

Extract 3: Sometimes, the older care user is not willing to let me cook and ask me to go out. Hence, I follow her requirement and stop cooking because you cannot have a quarrel with older people with dementia if they get angry, because they will become angrier due to the quarrel. (C9, 2020.10.05/ 53-year-old/ Female)

#### Strategy 4: Using body languages to control

Body languages are also useful way to prevent the older care users from out of control. Many Taiwanese home care workers interact with their older care receivers with dementia through body languages, such as touch their bodies or smile. The interviewed home care workers mentioned that this strategy is able to make care clients follow their instructions and make them feel comfortable.

Extract 4: Sometimes, the older male care user with dementia can be quite moody and can act quite aggressively when showing resistance to my service. I sometimes need to hold his hands to prevent him from being out of control and try to make eye-contact with him to calm him down. (C11, 2020.10.17 / 30-year-old / Male)

## **2. Showing empathy**

According to the interviewed home care workers, there must be a reason to explain why older care receivers with dementia reject the home care services. If home care workers could not find the reason, the older care users with dementia would refuse the care service every time. Therefore, “standing in resisting care receivers’ shoes” (Strategy 5) was advised by the interviewed home care workers. They suggested that home care workers should see or understand things from the older dementia care user’s feeling or perspective so as to provide appropriate care services to older care receivers with dementia even when they show refusing manners.

Strategy 5: Standing in resisting care receivers’ shoes

Extract 5: I have provided home care services with an older female who usually rejected to be fed by me. After I observed her in attempt to understand her, I find that she considers me as a visitor, so she has to have meals with me for curtesy. In other words, if I do not have meals with her, she would wait. (C6, 2020.09.20/ 45-year-old/ Female)

## **3. Persuasion based on resisting care receiver’s main concerns**

Persuading resisting care receivers by giving them a reason to accept service or by referring to the person they like or care. Such as strategy is to enhance persuasion based on resisting care receiver’ s main concerns, and the main approaches or communicative tactics could include pretending to threat (Strategy 6), highlighting service free of charge (Strategy 7), changing roles (Strategy 8).

Strategy 6: Pretending to threat

Humans tend to be afraid of someone or something in their life, and the elderly people with dementia are no exception. Home care workers would observe and understand what the elderly people with dementia are afraid of or care the most. Hence, when they refuse to accept care services, long-term home care workers would negotiate with them by pretending to threat.

Extract 6: An older woman who is 72 years older and suffers from dementia. She usually refused to take the medicine. Trough observation, I found that she cannot stand to skipping meals. Therefore, I would pretend to threat that if she does not have the medicine, I would not provide her meals. She is afraid, so she would follow my instruction and take the medicine. (C16, 2020.10.24/64-year-old/ Male)

Strategy 7: Highlighting service free of charge

When care users with dementia are highly concerned about money, highlighting service free of charge could persuade them to accept.

Extract 7: An older woman with dementia refused me to accompany her to go to the hospital because she thought she would be charged for the service. Therefore, I told her that I had free time and what I did was only to offer help. Hence, she accepted the service as a result. (C4, 2020.09.15/ 33-year-old/ Female)

## Strategy 8: Changing roles

People tend to be easily persuaded by the authorities who are experts or people working on behalf of the government and this is employed by long-term home care workers to deal with resistance of service from their demented care receivers. For instance, when they are refused to enter the homes of demented care users who perceive them as strangers, it might be useful to declare their identities as staff working in the government to assist the older dementia clients and usually successful entry can be obtained (see Extract 8). Other options of useful identities claimed for this situation include pretending to be friends or relatives so as to gain trust from those demented care users who do not perceive the reality well due to cognitive decline (see Extract 9).

Extract 8: R: How do you get permission to enter home care users' houses when they regard you as a stranger? C7: I would say, "I am sent by the government to assist you with bathing. (C7, 2020.09.20/ 55-year-old/ Female)

Extract 9: I have provided home care services for an older man with dementia. Every time I arrived his home, he would not let me in because he forgot who I am again. In this case, I would pretend to be his friend to remove his alert and said "I am your friend, and we often chat away." (C16, 2020.01.24/ 64-year-old/ Female)

## 4. Persuasion with light-hearted moods

To complete the assignments immediately, the interviewed home care workers would make older care users with dementia feel light-hearted and in a pleasant mood. It is believed that if older care receivers with dementia are joyful or happy, home care workers could persuade older dementia clients easily. There are four strategies employed for this communicative purpose, including giving compliments (Strategy 9), humorous persuasion (Strategy 10), and begging (Strategy 11).

### Strategy 9: Giving compliments

Compliment is like candy which makes people happy. The interviewed home care workers would express approval, admiration, or respect to make older care users with dementia delighted when they refuse home care services, such as having a meal or taking the medicine. To encourage care receivers to follow instructions, giving compliments would be a good choice.

Extract 10: I have encountered an older care user with dementia who did not want to have meals. So, after she started to a bite of the provided food, I immediately said, "WOW! You are so great!" Upon the compliment, she decided to eat up by herself. (C3, 2020.09.12/ 57-year-old/ Female)

### Strategy 10: Humorous persuasion

Being humorous is another useful strategy to persuade older care receivers to accept given service or instructions. Making them laugh is one way to reduce their resisting manner and to create a relaxed atmosphere for the communication (see Extract 11).

Extract 11: An older client with dementia who I take care of usually refuses to take medicine as instructed. So I would persuade him by saying, “Let’s take the elixir” instead of “Let’s take the medicine”. The older client with dementia would laugh and feel amused so later he would be willing to taking the elixir (medicine). (C3, 2020.09.12/ 57-year-old/ Female)

### Strategy 11: Begging

Sometimes, begging older clients with dementia to follow the instructions is also a useful way to persuade them because they would feel respected and needed or they feel empowered to give consent. As a consequence, they are more willing to accept instruction or service (see Extract 12).

Extract 12: One of my older care user with dementia does not want to take a shower, so I would try to persuade him by saying, “Could you go with me to the bathroom? Please. I need you.” It always worked and he would agree to go to the bathroom with me. (C15, 2020.10.19/ 50-year-old/ Female)

## **Discussion and Conclusion**

This study revealed a number of widely advised and useful communication strategies by experienced long-term home care workers for communicating with demented care users who show resistance to their service. This situation can be problematic since no delivery of service means no payment. These strategies can help long-term home care workers accomplish the home care services by strategically communicating, negotiating and persuading their demented clients to accept the care service they need.

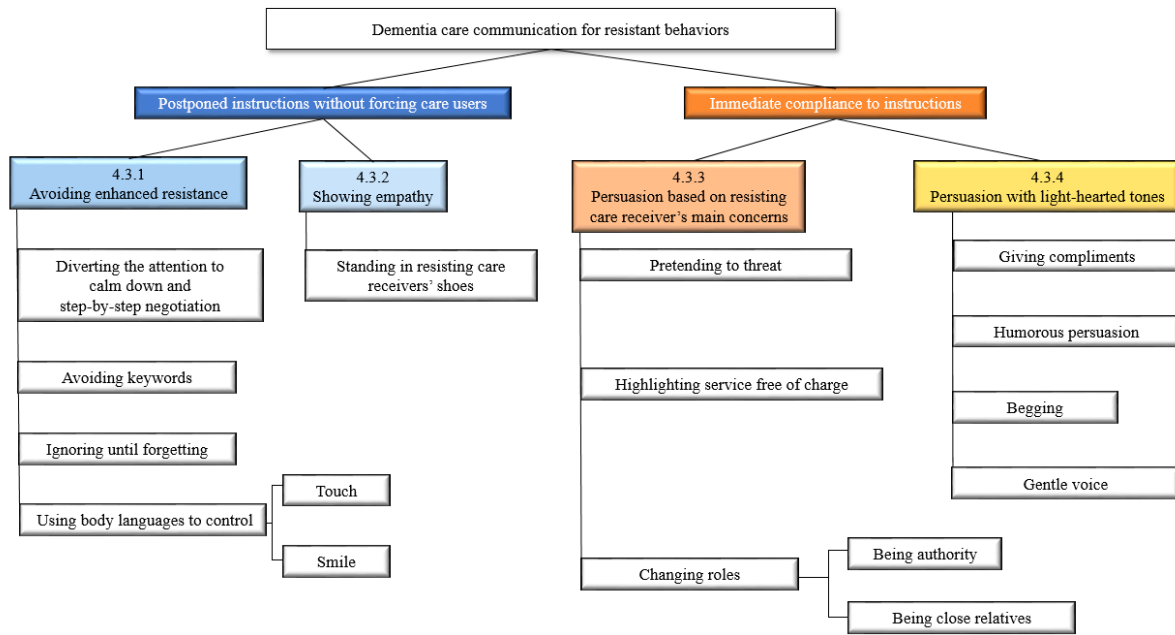
However, it should be noted that this study has only examined the viewpoints of the long-term care works. The previous studies indicated that long-term home care services should show person-centered consideration and treat elderly people with dementia as if they are normal individuals who can choose from their needs of receiving care services. Based on this consideration, we assume that some caregivers in this study might overlook the dementia clients’ real needs and demands since some of the interviewed home caregivers used the strategy of a pretending threat (strategy 11) to communicate when their service was resisted. Although eventually, the service can be delivered, this strategy, feasible based on demented clients’ fear, could compromise their well-being and future opportunities to engage in social interactions with the caregivers.

However, it is comforting to know that the strategy of showing respect to the individuals’ rights to make decision (including resisting service) in the care communication processes is acknowledged and this, even though, from service provider’s point of view, may not be an effective strategy, can actually be the most person-centered approach to take.

The results of this study have to be seen in the light of some limitations. First, it only depended on the perceptions of home caregivers as the accounts to the topic under study. Therefore, the effect of these communication strategies on dementia clients’ attitudes or evaluation to the service may be examined in the future. Second, there are many other scenarios which could also be noteworthy and require specific communication accommodations. They should be explored in the future as well.



Figure 1. Dementia care communication strategies for resistant behaviors



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