Long-term Home Care Communication with Dementia Elders in Taiwan: A Focus on Nonverbal Communication Strategies

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Abstract

The population of older people living with dementia in Taiwan is growing dramatically. If seniors with dementia are to remain in their own homes, higher-quality long-term home care services are vital. One way to achieve this quality goal is to promote better communication between seniors and providers. Accordingly, this study addresses an aspect of communication behaviour that tends to be overlooked in studies on dementia-care communication: nonverbal communication accommodations. Specifically, it presents a typology of nonverbal communication strategies used in long-term home-care service in Taiwan, based on in-depth interviews with 30 long-term home-care workers with at least one year of dementia-care experience. Prominent among these strategies are constant smiling; using one's fingers to draw patients' attention to one's eyes to maintain eye contact; gentle touching to express concern or care; and firm holding of hands, as a means of gauging acceptance or refusal of instructions. However, nonverbal signs of patients' understanding also emerged as crucial to care workers' decision-making. In particular, eye movement, turning the face to the side, looking downward, and maintaining steady eye contact all were reported to have different meanings, knowledge of which was essential to successful care communication. These findings not only extend our understanding of social-care practices, but also have the potential to enhance the wellbeing of dementia patients.

Keywords: Nonverbal Communication, Dementia Care Communication, Long-term Home Care, Taiwan, Gerontological Sociolinguistics

Introduction

Increasing Demand for Long-term Home-care Services

Taiwan is ageing dramatically. According to the National Development Council, Taiwan (2019), people aged 65 and above comprise more than 15% of the total population, and by 2050, this proportion is expected to rise to 35.5%. It is therefore natural to expect increasing demand for care services among older people with serious physical and mental conditions. As a response, the government launched a ten-year long-term care programme in 2007, and the tax-financed long-term care service scheme launched at that time is still in place. As of 2012, this led to long-term home-care services being delivered to 27% of people aged 65 and above who had been classified as disabled using the Barthel Activities of Daily Living Index (ADL), the Instrumental Activities of Daily Living Index (IADL), and the Short Portable Mental Status Questionnaire (SPMSQ) (Ministry of Health and Welfare 2013).

Since long before the above-mentioned government programme was devised, care services in Taiwan had been delivered by specialist workers in seniors' own homes (Kane et al., 1998). The work in question includes peripheral services such as laundry, sewing, cleaning, meal preparation, and accompanying care users on necessary errands, as well as care *per se*, e.g., assistance when using the toilet, taking showers, putting on and taking off clothes, cleaning teeth, eating, taking medicine, turning to prevent bed sores, doing exercise, and getting into and out of bed.

Wu (2005) argued that Taiwan's long-term care should be further reformed to achieve the following four goals: 1) the development of multiple new types of home- and community-based services, 2) improvement of care-service quality via enhanced education and training for care workers and managers, 3) enhancement of support to local care services through the establishment of centralised care-management systems, and 4) sustainable financial resources. It is the second of these goals that the present study can make a contribution to, by raising important questions about what can be done to improve the quality of long-term home-care services, and more specifically, what can be done to enhance training programmes for long-term home-care providers to ensure service success.

Caregiver Training Programmes in Taiwan

Taiwan's existing caregiver training and licensing programme consists of two main parts. The first comprises 70 hours of classroom training on the relevant laws and regulations, long-term care resources, home-care services, stress management, professional image building, communication skills, care services for people with dementia, gender equality, psychology, nutrition, diseases and their diagnoses, physical care and fitness, how to handle emergencies, and hospice care. The second comprises at least 48 hours of practicum, including 10 hours of instruction and 38 hours of practice. Notably, training in communication takes up just 2 of the programme's 118 hours, and arguably produces only a vague or general understanding of what long-term home-care communication processes might be like. Hence, it is reasonable to expect that newly employed or inexperienced workers in this sector might find it challenging to communicate effectively with the physically and mentally ill people in their care.

In addition, the part of the programme covering dementia care lasts only 4 hours, while other health problems that long-term home-care users commonly have are not specifically targeted at all. Obliquely, this discrepancy can be seen as an acknowledgement by the training system that dementia care is sufficiently unique as to require additional attention, and presumably, specialised communication techniques. Nevertheless, the content of its existing dementia-related training does not include any references to communication skills. This is concerning, because dementia-care communication is marked by levels of complexity and uncertainty that could make it unusually difficult, as further discussed in the Literature Review section, below.

Moreover, because dementia patients who receive long-term home care are mostly older, care workers drawn from younger age cohorts should be learning to attend to age-related issues in care communication. However, interrelated issues of language, communication and ageing have not been emphasised in the training either, despite Ripich et al.'s (2000) findings that appropriate communication training for the caregivers of Alzheimer's disease (AD) patients can result in more successful communication with them and thus, a better quality of life.

Taken together, the above critiques of the existing training programme suggest that the delivery of satisfactory long-term home-care service to dementia patients could be compromised. That possibility inspired the present sociolinguistic study, which aims to obtain practical, experience-based communication-related recommendations for long-term home care workers who would like to provide high-quality care services to seniors with dementia.

Literature Review

Dementia: Trends and Challenges

According to the Taiwan Alzheimer's Disease Association (2019), approximately 18% of Taiwan's 65+ age cohort, and about 8% of its 85+ cohort, suffer from dementia. Moreover, it is predicted that over the next half-century, one Taiwanese person will be diagnosed with dementia every 40 minutes, such that by 2065, dementia patients will account for more than 5% of the population. These figures imply huge growth in demand for care services for dementia patients, whether institutional/community-based or home-based, and all the difficulties in carer-patient communication that will come with it.

As the 2019 Taiwan ADA (Alzheimer Disease Association) pointed out, dementia does not refer to one particular disease, but is defined by a series of syndromes including memory loss, language disorders, cognitive impairment, visual/spatial disorientation, decline in problem-solving abilities, and personality changes, among others. Most types of dementia progress slowly. AD is one of the most common types of dementia, while some dementia is triggered by strokes.

People with dementia tend to experience progressive impairment in the acquisition and retention of new information, though their remote memory is generally intact, particularly in the early stages (Patterson et al., 2007). It has also been found that as dementia increases in severity, impairment in executive functions and attentional abilities becomes greater (Mahendra et al., 2017). This led van Halteren-van Tilborg et al. (2007) to argue that, during the performance of care-related tasks, multiple-task conditions should be avoided, and instructions given only after environmental distractions (e.g., the radio) have been reduced.

Dementia and Language Disorders

Dementia patients' abovementioned deficits also lead to language disturbances, which often manifest early. As noted in a review by Caramelli et al. (1998), early dementia of the AD type can be characterised by linguistic changes, including anomia and impairment during verbal-fluency tests; and when the disease progresses into the intermediate phrase, lexical and discourse deficits become marked, and manifested especially as semantic impairment amid the preservation of syntactic and phonological abilities. Other forms of deterioration in communication in such patients include unnecessary repetition and losses of relevancy or meaning (Tappen, 1991). When Ripich and Terrell (1988) compared the communication between an interviewer and six patients with senile dementia of Alzheimer type (SDAT) against the same interviewer's communication with six elderly people who were well, they found that the SDAT group used more turns and more words, and also showed greater inconsistency caused by one subtype of cohesion-disruption: missing elements. The authors concluded that SDAT results not only in impairment of linguistic abilities, but also of discourse abilities, such that the development of thematic structures in conversations with SDAT sufferers would tend to be more difficult than with others.

Mentis et al. (1995) subsequently reported that dementia patients also have reduced abilities to change conversational topic while still preserving the flow of discourse. Difficulties with active contribution to the propositional development of topics were also observed, and usually manifested as failure to consistently and clearly maintain topics. Because of these discourse-pragmatic, linguistic, and cognitive problems associated with AD, the authors highlighted the need for further exploration of verbal interactions among AD patients, and how these problems affect conversations with them.

As to language and communication disorders observed in non-Alzheimer's dementias (for a review, see Cherrier et al., 1998), vascular dementia (VaD) patients exhibit aphasias and complain of word-finding problems. Also, as compared to AD patients, VaD patients experience more of the motor aspects of speech abnormalities, such as poor articulation and slower rates of speaking (Powell et al., 1988).

Dijkstra et al. (2004) conducted interviews aimed at eliciting details of family and life stories with 30 older adults who had dementia and 30 without dementia. The authors quantitatively coded the occurrences of discourse-building features, reflecting coherence and cohesion, and discourse-impairing ones such as disruptive topic shifts and empty phrases, and concluded that the healthy subjects exhibited more of the former, and the dementia patients more of the latter.

Based on experimentally elicited descriptive discourse and narratives by 30 persons with AD and a control group of 30 non-AD seniors in Taiwan, Lai and Lin (2012) identified key conceptual markers that could significantly differentiate between these two groups of Chinese speakers. Specifically, their findings indicated that the participants with AD used discourse markers less frequently, and also with less variation, than the controls did. They further identified some particular conceptual markers (e.g., *dagai* 'probably', *cai* 'only, just') and non-conceptual ones (e.g., *danshi* 'but', *haiyou* 'and', *suiran* 'though', *suoyi* 'so') of which usage varied the most sharply between the two groups.

In a subsequent study, Lai and Lin (2013) assigned their AD and non-AD participants a category-fluency task and a picture-naming task, and sought to identify the nature of the AD patients' action-object semantic impairment. They noted that the content of information given by the Chinese-speaking AD participants was seriously compromised by the significantly smaller number of semantic-lexical items that they produced.

Another study conducted in Taiwan by Lai (2014) assessed the predictive power of discourse features for the severity of AD. Based on analysis of the discourse-building and discourse-impairing features in interview-style conversations with 20 AD and 20 non-AD elderly Mandarin speakers, Lai confirmed that the AD group's conversations included fewer discourse-building features and more discourse-impairing features than those of their non-AD counterparts; and established that – considered as variables – the discourse-impairing features had significantly stronger power to predict a person's degree of dementia than the discourse-building ones.

Dementia-care Communication: Perceptions and Strategies

Ekman et al. (1991) reported that difficulty of communicating with patients suffering from severe dementia often makes caregivers feel hopeless, and that their work lacks meaning. The existing literature has proposed a variety of communication techniques for care workers in this situation, not only from the perspective of linguistics, but also nursing, communication sciences, psychiatry, public health, health/primary care, medical science, audiology/speech science, and psychology. Accordingly, its research paradigms and approaches have been quite varied. For instance, Tappen (1991) proposed some special techniques for nurses aimed at facilitating perioperative care communication with AD patients. Specifically, to help individuals with AD to comprehend surgery, Tappen advised that nurses' communication be slow-paced, simple, concrete, and repetitive, and that their nonverbal communication be positive and supportive, such as by smiling steadily, touching, and maintaining eye contact. Acquiring knowledge of each patient's past was also encouraged, as a basis for understanding what the patient is talking about and a foundation for further conversations. Lastly, Tappen recommended that nurses build greater awareness of how individual AD patients signal that they are being overwhelmed by information: for instance, through facial expressions, raised voices, and confusing verbalisations.

To gain a clearer understanding of how to improve therapeutic communication with AD patients, Tappen et al. (1997) invited advanced practice nurses to interview such patients in nursing homes as part of a treatment approach, under observation by the researchers. The interview- and observation data were subjected to content analysis aimed at establishing whether particular AD communication strategies were as effective as prior literature had claimed. The authors concluded that AD subjects could respond to open-ended questions as well as close-ended ones, but that nurses used more closed-ended questions in the treatment interviews. Thus, the authors recommended that closed-ended questions can be used for assisting AD sufferers to complete daily-living activities, but that for the purpose of developing a relationship or expressing feelings/concerns, open-ended questions were preferable.

Several other strategies for establishing rapport or encouraging AD patients' participation in discussions have also been recommended (Tappen et al., 1997). To facilitate the expression of feelings and concerns, for example, it has been deemed better to use broad openings, to speak as an equal, to establish commonalities, and to share about oneself. Other scholars have likewise argued that AD subjects feel more able to determine the directions of conversations and talk about topics that are salient to them if broad openings and speaking as equals are employed (e.g., Peplau, 1952; Ramanathan-Abbott, 1994). The use of verbal and nonverbal encouragers to reflect, paraphrase and summarise each discussion is also important to helping AD patients maintain conversations and follow themes through them when they have difficulties expressing their thoughts in a coherent manner (Carkhuff, 1993; Tappen et al., 1997).

Beach and Kramer (1999) studied caregivers' perceptions of communication with dementia patients in nursing homes. Analysis of their interview data using the grounded-theory method identified two core categories: 'compliance-gaining strategies' and 'learning the language'. The former highlights the need to confirm and accept the AD-suffering residents' reality, i.e., to enter their world, as well as to avoid 'no response' scenarios by creatively using a 'changing faces' strategy: i.e., calling upon another staff member to intervene in the communication process to stimulate the patient's response. The 'learning the language' category, on the other hand, refers to the effective employment of nonverbal messages to facilitate communication with AD patients, and the importance of knowing what they mean when they use particular types of nonverbal language themselves.

An expert team from neuropsychology, nursing, psychogeriatrics and speech pathology (Smith et al., 2011) integrated prior research findings on dementia patients' memory, cognition, and communication into two communication mnemonics: RECAPS, aimed at professional caregivers, and MESSAGE, for family members providing care. RECAPS stands for reminders (spoken prompts; written words and picture reminders), environment (have a permanent place for objects; don't change surroundings), consistent routines (keep up familiar routines and create new ones when needed), attention (avoid distractions; focus on attention), practice (maintain skills through use; practise new skills), and simple steps (break tasks into small, discrete steps; allow extra time). MESSAGE stands for maximize attention, watch your expression and body language, keep it simple, support their conversation, assist with visual aids, get their message and encourage/engage in communication. Crucially, both the communication models implicit in these mnemonics provide, in addition to knowledge-based communication strategies for dementia care, syntheses of practical insights into what content should be included in an effective caregiver-education programme. That research goal is shared by the present project.

Gap in the Literature

In light of the above review, it can be concluded that few prior studies have specifically addressed nonverbal aspects of communication as a means of enhancing interaction with dementia patients. This present study therefore aims to fill that gap by eliciting long-term home-care providers' views on how best to interact with their clients with dementia using nonverbal communication strategies.

Methodology

The 30 participants in this study (26 female) were all Taiwanese long-term home-care workers with at least one year of experience of caring for elderly dementia patients. They agreed to be interviewed by the researcher to share the communication strategies they utilised to deal with dementia patients' various communication behaviours. The researcher also conducted field observations to examine one of these 30 individuals' actual practices when taking care of dementia patients who were unable to express their thoughts verbally, due to being in the final, severe stage of the disease. This field study enabled the researcher to take notes on the interaction and mutual communication between these nonverbal patient-carer dyads.

Findings

Each of the four main identified nonverbal communication strategies for dementia-care communication in long-term home-care contexts is dealt with in detail in its own subsection below.

Steady Smiling

Two of interviewees recommended smiles as an effective device for building rapport and good relationships with their clients.

Extract 1: I smile a lot because I want to build a good relationship with the client. (Interviewee 1, Female [F])
Extract 2: Every time I see them, I smile at them because they like our smiling. They don't like our unpleasant face because their children would not look at them with such a face. (Interviewee 3, F)

Using Fingers When Giving Instructions

Three of the participants advised the use of fingers to direct patients' attention to instructions they were being given, and deemed this especially useful when communicating with those who refused to talk or maintain eye contact.

Extract 3: Sometimes my client does not want to talk and I would use some gestures to help her engage in communication, or invite her to talk to me. I would also use fingers to draw her attention to me by saying 'look at me' while waving my finger in front of her eyes. (Interviewee 2, F)

Gentle Touch to Show Concern or Care

Six of the caregivers advised touching dementia patients when providing service, as a means of nonverbally showing concern and care, and thus stabilising their emotions by providing a greater sense of security.

Extract 4: In the process of taking care of clients with dementia, it is important to touch their foreheads, and then their faces. Skin touch can make them feel secure and cared about. They know people are showing care to them. (Interviewee 3, F)

Extract 5: My client sometimes scratches his swollen hands and feet. I touch his wounds to show concerns. He will then reply by saying ‘I am okay’. (Interviewee 5, F)

Extract 6: I think hugging is the best body language to show in the world, so sometimes when I am ready to go home, I hug my client to show her my care and to give her a sense of security by promising her that I will come back again tomorrow. When she feels upset, I also hug her. (Interviewee 6, F)

Extract 7: Seniors with dementia sometimes have hearing problems, so even though they can see you speaking, they can’t comprehend well. This is especially problematic when the clients also have eyesight problems. Their abilities to speak, hear and see decline to the extent that they can have problems interacting with others. In such cases, I touch their back while talking with them. Touching while speaking can help them get used to your presence, and can also help them pay attention to you when you are giving them instructions. (Interviewee 7, M).

Firm Holding of Hands to Check Acceptance or Refusal of Instructions

One of the caregivers also said she had encountered situations in which their clients refused to accept service or displayed aggression, and that the signs of such refusal or negative emotions were not always evident from their verbal expressions. Accordingly, they recommended that caregivers use their hands to detect or confirm such attitudes.

Extract 8: I would use body language to detect whether my clients with dementia are willing to follow my instructions. For example, I would hold their hands to make sure they do not shake my hands off, because that means they agree. (Interviewee 8, F)

It is clear from the above data that nonverbal signs given by dementia patients are important clues to their unspoken thought, to which long-term home-care providers should pay due attention. It is arguably even more important to attend to such clues when caring for those patients who suffer from aphasia to the point of not being able to talk at all.

During the field-observation phase of this research, the caregiver explained while delivering her service that she relied on the patient’s eye movements to comprehend her acceptance or refusal of instructions, which she would then verbally acknowledge. Specifically, when the patient pointed her eyes sideways, it indicated that wanted something to be given to her, whereas pointing them downward indicated refusal, and maintaining steady eye contact, that she was listening. In the absence of these signs, according to the caregiver’s observations, any attempt to communicate with this client would be interpreted as pressure, and it was better to wait for a while before giving either any further instructions, or services such as feeding that require the client’s cooperation.

Discussion and Conclusion

The four nonverbal communication strategies identified in this research were said by those long-term home-care givers who used them to effectively convey concern and affection; to enable the more effective giving of instructions; and to stabilize patients' emotions so as to enhance their psychological wellbeing while care was being delivered. Most importantly, by means of nonverbal communication strategies, especially the observation of eye movement, caregivers were able to perceive seniors with severe dementia and aphasia as individuals, and as still capable of exchanging their thoughts and personal preferences with others. Even though on a surface level, such a communication process appears to consist simply of carers' monologues, it in fact can reflect mutual understanding by means of silent nonverbal messages. This finding could help others to interact more effectively with dementia patients suffering from aphasia, by enabling them to be seen as still having a need to be understood, a desire to form connections with others, and the ability to make decisions: in short, personhood.

The field observations conducted as part of this study appear to complement the understanding, arrived at via the interview data, of how long-term home-care workers communicate nonverbally with dementia patients. However, because these observations were only conducted with one carer-patient dyad. Future research could therefore usefully focus on observing more individuals in similar situations, as a means of identifying and exploring further nonverbal practices that might enhance dementia-care communication in long-term home-care contexts.

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