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Research Article

Long-term Care Nurses' Communication Difficulties with People Living with Dementia in Taiwan

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SUMMARY

Purpose: Impairments in word finding, language skills and memory in dementia patients increase the obstacles for health professionals to provide effective care. Although some research on communication with dementia patients has been done, no research that pre-assessed nurses' difficulties in communicating with dementia patients has been identified. This study aims to explore nurses' difficulties in communicating with patients who have dementia.
Methods: This was a qualitative research using the phenomenological approach. Data were collected through in-depth interviews. Fifteen nurses with at least 6 months of dementia care experience participated in this study. Each interview was audio-taped and transcribed within 48 hours after each interview. Participants were asked to respond to the question, "Please describe the difficulties in communicating with patients who have dementia."
Results: Through content analysis, two themes, each with two subthemes emerged: Different language, including repetitive responses and lack of language consensus; blocked messages, including difficulty in accessing emotions and in understanding needs. Ineffective language refers to a lack of agreement dialect between the nurse and the patient while blocked messages refer to the inability of nurses to understand the true underlying meaning of messages the patients send out through verbal or nonverbal behaviors or expression.
Conclusion: The results can serve as reference for planning dementia communication education for school curriculum to enhance student nurses' communication abilities and for junior nurses working in long-term or acute care settings to increase nurses' patient-centered communication abilities with the ultimate goal of improving quality of care for patients with dementia.
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Introduction

Like many countries, the elderly population in Taiwan comprises over 11% of the total population as of July 2012 (Ministry of Interior, 2012). According to the Taiwan Alzheimer Disease Association (2012), currently elders with dementia constituted 0.6% of the total elderly population with the number of such patients expected to double in 2026. In addition, people with dementia account for 26.8–64.5% of the residents in long-term care facilities, which includes all levels of elder care (Chen et al., 2007). Therefore, care providers in long-term care facilities must be equipped with adequate knowledge and skills to provide care for people with dementia.

People with dementia demonstrate a combination of language deficits and varying degrees of impairments, including memory loss, decreased attention span, and impairment in judgment, insight, and abstraction. The combination of deficits produces complicated communication which results in difficulty and the development of disruptive behaviors (Paquay et al., 2007). Although care attendants or nurse assistants are responsible for the majority of residents' physical care, nurses are the key health professional communicating with residents (Kao, 2004; McCabe, 2004). Effective communication strategies used by nurses are beneficial to patients' quality of life. Mayhew, Acton, Yauk, and Hopkins (2001) suggested that appropriate communication strategies help nurses understand the cognitive and emotional needs of patients and allow patients with dementia to retain their personality identity. On the other hand, poor communication is associated with relationship conflicts, patients' negative emotions, feeling of neglect and increased problem behaviors, all leading to decreased quality of life (Mayhew et al.). Mayhew et al. used videotaping to

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observe advanced dementia Alzheimer's type patients and found that even patients in later stages maintain a remnant of self-awareness of their cognitive decline. Therefore, appropriate communication strategies or skills can be useful for understanding patients' expressive clues. Dementia-related communication models or concepts have been developed by experts although very few have been empirically tested (Crawford, Bonham, & Brown, 2006; Feil & Klerk, 2002; Small, Gutman, Makela, & Hillhouse, 2003). It is believed that through communication education programs, nurses will be able to better handle patients' problems (Levy-Storms, 2008).

Most of the research on dementia-related communication has been conducted in the United States and has focused on communicative or conversational strategies used by nurses, factors leading to ineffective communication, and assessment of language problems of the patients (Savundranayagam, Ryan, Anas, & Orange, 2007; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997; Williams, Herman, Gajewski, & Wilson, 2009 ; Yi & Yih, 2006). Tappen et al. pointed out that nurses could easily assist patients with dementia to increase their daily activities through the use of close-ended questions, while with open-ended questions, nurses could drive patients to share more information. Confusion about which of these communication strategies to implement in differing situations can decrease quality of care. Williams et al. found that nurses working in nursing homes tended to respond to residents with dementia in "Elderspeak," or infantilizing communication. Elderspeak was particularly evident when residents had pessimistic or negative behaviors, such as resisting, shouting, negative words or crying. Elderspeak probably increases the resistance to care among the patients with dementia compared to normal talk. In Korea, Yi and Yih used a conversation analysis to identify problems between nurses and patients with dementia. Directive and authoritative expressions, emotional and competitive expressions, evasive and on-looking expressions, and excessive use of title (such as calling them granny or grandpa without proper names) were only used by nurses. In addition, Savundranayagam et al. examined the impact of two communication-enhancing strategies used on patients with dementia. They found that personhood strategies had more positive effects on perceptions of staff and patients and their interactions than the directive conversations. Ferry used a range of conversational strategies in a nurse-led socialization group with demented residents in a long-term care facility and evaluated, through qualitative data analysis, that patients with advanced dementia are still able to engage in social conversation. On the other hand, Potkins et al. (2003) evaluated the impact of language problems on symptoms and socialization of patients with dementia and discovered that expressive language impairment was associated with presence of delusions, depression, and decreased social activities. Receptive language impairment was associated with aberrant motor behavior and decreased social activities.

Of the above mentioned studies, no study was found to address the content of communication difficulty with patients who have dementia from the nurses' perspective. There is a lack of culturally sensitive data for planning future communication education program for staff nurses in Taiwan. While a 2-hour lecture regarding dementia care is taught in the Taiwanese nursing curriculum, without continuous education training, graduated nurses lack the knowledge in caring for dementia patients particularly the skills in communicating with people with dementia.

Therefore, the purpose of this study was to identify nurses' difficulties in communicating with dementia patients. The results can serve as references for future development of dementia communication education in order to enhance the quality of care for patients with dementia.

Methods

Study design

Phenomenology is concerned with the experience from the individual's perspective. Phenomenological methods are applicable to the unfolding of the experiences and perceptions of individuals from their own perspectives (Lester, 1999). Therefore, a qualitative research adapting the phenomenological approach was used in this study to understand nurses' difficulty in communicating with patients who have dementia. Data were collected by in-depth interviews of 15 nurses from six long-term care facilities in southern Taiwan selected by purposive sampling.

Setting and samples

Nurses were invited to participate in the study if they had cared for patients with dementia at middle through end stage in long-term care facilities, including assisted living, residential care and nursing homes, for at least 6 months and were willing to share their experiences. The types of patients with dementia they had cared for were mainly Alzheimer's followed by the vascular type according to chart review. Each interview lasted approximately 1–1.5 hours. The interviews were audio-taped and transcribed in Chinese within 48 hours.

Ethical consideration

Upon approval of the university ethics committee (institutional review board), six facilities were invited to participate in the study and consent from the administrator of each facility was obtained. After referral by the supervisors, nurses were contacted in person; study purpose, risk and benefits of participation were explained and informed written consent was obtained upon the time scheduled for interview. The researcher also obtained written consents from certain patients or their guardians when there was a need to access their charts.

Procedure

The supervisors of the selected long-term care facilities in southern Taiwan referred nurses who met the study criteria. Interviews were scheduled outside of work hours at a convenient time and place. One female researcher (P.-F. H.) with a background in geriatrics and dementia conducted the interviews. A semi-structured interview guide was used. Participants were asked to respond to the principal question "Please describe any difficulty in communicating with patients who have dementia." Two probing questions were used by the interviewer when needed: "Please describe some difficult situations or problems you encountered when you communicate with residents who have dementia" and "Please recall any scenario you think is a difficult communication situation." If a specific patient was mentioned by an interviewee, the researcher learned about the phase and type of dementia of the patient from chart review afterwards.

Data analysis

Data were analyzed using the conventional approach of content analysis described by Hsieh and Shannon (2005). Conventional content analysis is used with a study designed to explore a phenomenon, in this study, the communication difficulties experienced by nurses. Data analysis began with reading each transcript repeatedly to gain a general sense of the data. Second, data were read line by line to highlight any meaningful text, which captured key concepts. Keywords or phrases where noted in the margin of the text. During this process, the researcher jotted impressions. As

the process continued, labels of codes emerged, were compared and an initial coding scheme developed. The codes were sorted into subthemes and combined into main theme.

Trustworthiness

Lincoln and Guba (1985) suggested four principles for ensuring trustworthiness of qualitative research: credibility, transferability, dependability, and confirmability. In credibility, we seek to ensure that our study measures what is actually intended. The interviewer had previous experience in long-term elder care. Participant-centered interviews were maintained by audio-tape recording and note-writing during each interview. The data and coding were discussed with research team members regularly throughout the analysis. Two transcripts and their codes were reviewed by two nurse experts in qualitative research for peer debriefing. Themes were verified by two nurses with dementia care experience for member check. In rransferability, we were concerned with the extent to which the findings of our work can be applied to other situations. This study presented the findings and conclusion clearly, so that the results of the work can be applied to a wider population such as nursing students and nurses working in acute and long-term care settings. In dependability, we expect that if the work were repeated, similar results would be obtained. This study described the research process, methodology, and findings in detail, thereby enabling a future researcher to repeat the work. In addition, after completing the data analysis, the researcher sampled one of the transcripts randomly, re-analyzed and coded. The consistency between the two codes on one sample was 82%. In confirmability, we were concerned with the objectivity of the researcher. The researcher acknowledged bias, maintained neutral, and objectively presented what methods and procedures the research used for enhancing the rigor of research findings in the research process, such as the use of member check.

Results

Participant characteristics

Data saturation was achieved with 14 female nurses but the interviewer continued to interview 1 more participant to ensure the data saturation. The participants' ages ranged from 24 to 35 years old; seven had a 4-year Bachelor of Science in Nursing (BSN) degree, six had a 2-year Associate Degree in Nursing (ADN) degree, and two received a vocational nursing diploma. In Taiwan, nurses are also classified by levels from N1 to N4, a higher N reflects greater experience and knowledge. In this study, nine nurses were at N1, three at N2, and three at N3. Their experiences of caring for dementia patients ranged from 6 months to 7 years. Eight nurses worked in residential care facilities, four worked in assisted living facilities, and three worked in nursing homes.

Two themes emerged: "Different language" with the subthemes of repetitive responses and lack of language consensus and "Blocked messages" with the subthemes of difficulty in accessing emotions and difficulty in understanding needs.

Theme 1 : Different language

Different language refers to a difference in dialect between the nurse and the patient. It is frequently described using a Chinese proverb "A chicken is talking to a duck", inferring that both parties are using different languages. In dementia care the difference in dialect occurs when the nurse does not understand the patients' meaning upon the delivery of a message, and the patient cannot recognize what the nurse is trying to convey. Two subthemes comprise "Different language".

Repetitive responses

Repetitive responses occur when both patients and nurses repeat their message. When patients express verbal or nonverbal behaviors, nurses often cannot comprehend what the patient is expressing. Nurses then attempt different responses to patients. However patients fail to respond to whatever efforts the nurse makes, so the patients' behaviors are repeated or sustained. Often times, because of memory and cognitive impairment, patients cannot remember or understand what nurses have said, thus, nurses continually repeat their responses or descriptions in a language the patient does not understand. A vicious cycle occurs:

> She always repeatedly asks questions about the time of day or when an event will occur. When I told her "you are repeating", she gets angry. (Alzheimer's type, middle stage; nurse A)

> He kept repeating something! I answered him over and over and it was no use, he would hold on to his own views. It's really troublesome. He would never listen to me! (Alzheimer's type, middle stage; nurse C)

> Just a few seconds after I finally put him on the bed, it happened again…he kept repeating the same old thing. (Alzheimer's type, late stage; nurse E)

> During meal, she would keep saying, "Why I don't have enough rice, I don't have enough rice." I would reply, "Yes, you do, yes you do. (Alzheimer's type, late stage; nurse J)

Lack of language consensus

When different languages are used for communication the parties must agree on a common language for the message to be effectively communicated. If both sides maintain their own intention and views, there is no language consensus. For example, when patients with dementia exhibited problem behaviors (such as wandering around, aggressive behavior, hoarding, or rejecting food as a way of expressing their underlying needs), nurses tried to persuade or advise patients as a way of modifying behaviors. However, the behavior continued despite nurses' efforts. In addition, when patients became disoriented, confused, or delusional, nurses tended to clarify the reality regardless of patients' ability to comprehend their communication. Nurses often use reasoning skills with patients who have lost the ability to reason:

> We try all kinds of measures to persuade some patients to eat a meal but they are still in vain! They keep saying "No! I don't want to eat!" (nurse C)

> Before the Lunar New Year, she kept worrying about steaming rice cake! She said that she had ordered the sweet rice, which was downstairs, and she had to go get it! We explained to her again and again that there was no such thing… It is difficult since she's really stubborn! (Alzheimer's type, middle stage; nurse B)

> No matter what I said to him, he wouldn't stop his behavior, he just wondered around and continuously made noise. (Alzheimer's type, end stage; nurse F)

> It is just like I see an American crossing the street in danger and I shout to him in Chinese and…still something happened! (nurse N)

Theme 2 : Blocked messages

Blocked messages refers to the inability of nurses to understand the true underlying meaning of the information. Nurses fail to recognize the patients' real needs, fail to perceive their emotional state or have difficulty knowing the patients' inner world. For instance, many nurses feel quite helpless when patients are in tears because the nurse cannot interpret the meaning behind the emotional behavior.

Difficulty in accessing emotions

People with dementia, especially those in the severe stage, often lose their verbal language skills completely and cannot clearly deliver emotional messages to others. The loss makes it difficult for nurses to have a perspective on the patient's state of emotional health:

> We have to try to make them smile and talk to us. It is difficult! We must help them open their hearts. (nurse A)

> He would not tell you anything, whenever he looks sad, I asked him "What happened?" He always says "Nothing, don't bother me." (Vascular type, middle stage; nurse H)

> What sentences can I say to open her heart? It seems like she hides a lot of emotions deep inside from me! (Alzheimer's type, late stage; nurse I)

> I never get to know her feelings from her face… She always appears apathetic! (nurse K)

Difficulty in understanding needs

When people with dementia have impaired verbal expression, they can exhibit problem behaviors when communicating their needs or occasionally use nonsensical words or meaningless sentences. Often nurses cannot comprehend and respond to dementia patients' behavioral messages, which leave patients' needs unmet. For example, when patients are in physical pain, they may present with anger or refuse to get out of bed.

> I don't understand what he means, don't know what he needs. He makes some noise but…I cannot help him. (Alzheimer's type, end stage; nurse D)

> He says he has a stomachache every day! After a while, he says he has no pain at all and another area hurts! We are confused! (Alzheimer's type, late stage; nurse F)

> Sometimes I wonder what are the meanings of their postures or behavior? (nurse I)

> Sometimes I said to myself "Oh, my goodness, what does this mean!" I really have no idea what they tried to express their needs. (nurse J)

Discussion

Different language including repetitive responses and lack of language consensus is the first theme identified in describing nurses' communication difficulty with dementia patients. A person with dementia may use repetitive phrases because of their memory and verbal communication skills deficit. At the middle stage of dementia, some patients have difficulty finding the appropriate word when describing an object. The study found that nurses are more task-oriented, their intentions are to convince patients to a certain extent of cooperation upon communication in order to finish their work. However, many residents with dementia cannot understand the nurses' language. For instance, nurses expected that patients would immediately stop their repetitive questions upon receiving the answer from nurses to their questions. However, patients do not because of their short-term memory problems. Nurses attempt to use their own language to clarify and argue about the reality to dementia patients who have lost reasoning skills as a part of their disease course. Therefore, when nurses focus their communication efforts toward self-perspective and routine care, and patients fail to cooperate, ineffective communication occurs. This phenomenon can be explained by Nichols (1995), who suggested that when senders of a message focus only on their own needs, they are not listening to others or realizing others' problems, which results in poor communication. While no previous studies on communication difficulties experienced by nurses are available for comparison, in the current study, the different language used by nurses can contribute to poor communication strategies. Yi and Yih (2006) and Savundranayagam et al. (2007) also found that use of inappropriate communication strategies or expressions such as directive and authoritative expressions results in less effective communication with dementia patients. During interviews with nurses, lack of patient-centered communication appears to be a major cause of the difficulties nurses experienced. It is understandable that with only 2 hours of formal education spent on dementia care in formal nursing programs in Taiwan, nurses would not be expected to have knowledge and skills required to communicate effectively.

Blocked messages, including difficulty in accessing emotions and difficulty in understanding needs of people with dementia, was the second theme to emerge. Every message delivered by patients with dementia may be meaningful but challenges nurses because such messages are blocked. Patients with dementia may show a blunted affect, an apathetic face with poor expression of emotion. Nurses need to learn strategies for assessing patients' emotional or psychological status. Potkins et al. (2003) who studied a group of British people with dementia found that patients had difficulty in expressing themselves through language and thus had few psychological interactions with nurses. Behavioral messages may also symbolize needs of an individual and may manifest differently in patients based on their sociocultural background. In Australia, Wu, Low, Xiao, and Brodaty (2009) who studied emotions, problem behaviors, and the mental status of dementia patients, found that patients with different social and cultural backgrounds would manifest different forms of problems. Understanding patients' needs became a problem for nurses, since similar behaviors may have different meanings across cultures (Wang, Hu, & Cheng, 2011).

Findings of this study provide insight in developing dementia communication programs for nurses and other health professionals. Education should guide nurses on patient-centered not task-oriented communication strategies, as well as ways to avoid use of directive or instructive communication strategies that might be misunderstood. Instructions on ways to assess patients' affect and underlying needs from a sociocultural basis would be important to include in staff education.

Limitation

The participants in this study were relatively young and inexperienced. Older nurses expressed less difficulty in communication and declined to participate. The homogeneity of participants in this study may have limited the findings. Next, this study collected data by in-depth interview, and the researcher could only learn of the communication problems from the nurses' perspectives. However, communication is a complicated interaction between two parties. Thus, the researcher cannot infer dementia patients' difficulties in

communication. In addition, a few nurses were interviewed for more than 1 hour, where fatigue may have influenced the accuracy of data.

Future research can include both nurses and mild stage dementia patients, and the clinical scenario related to communication problems can be recorded through video recordings. Obstacles to effective communication between nurses and people with dementia may include environmental and contextual factors. Additional study is needed on the influence of these factors. Experienced dementia care nurses may be able to suggest effective strategies and their experiences could be explored. Nurses' communication difficulties in other countries and cultures may differ and could be investigated.

Conclusion

A preliminary study explored communication difficulties between nurses and patients with dementia from a nurse's point of view. Different language and Blocked messages are communication difficulties experienced by nurses. Learning to comprehend dementia patients' expressive and receptive messages and avoiding specific task-oriented communication is the first step to reach a common language. To be able to recognize patients' underlying needs through their manifestation of problem behaviors, patient-centered communication should be implemented. Given the young age of nurses caring for patients with dementia, dementia communication programs must be included in nursing curricula.

Conflict of interest

The authors declare no conflict of interest.

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