Meaning and practices of spiritual care for older people with dementia: experience of nurses and care workers

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Running Short: Meaning of spiritual care for dementia

ABSTRACT

Background: The aim of the present study was to comprehensively investigate the meaning and practices of spiritual care for older people with dementia from the perspective and experiences of nurses and care workers.

Methods: The study was designed to qualitative research strategies, using face-to-face interview data, with focus on nurses' and care workers' experience of caring elder persons with dementia. A total of five nurses and thirteen care workers of nine care facilities participated. We conducted ten interviews, each one to three participants, from April to August 2017. An open-ended questionnaire concerning the meaning and practices of spiritual care for older people with severe dementia was used to comprehensively and unintentionally capture the participants' experiences of caring for older people with dementia. Qualitative content analysis was used to systematically identify ideas and patterns emerging from the qualitative data.

Results: Three main themes were emerged through the qualitative analysis of what consisting of spiritual care of the older people with dementia: self-esteem; communication; and individual difference.

Conclusions: Nurses and care workers perceived that self-esteem was a core domain of spiritual care for older people with severe dementia.

Clinical implication: Reminiscing about important achievements and enjoying small pleasures in daily life enhance older people's self-esteem. Communication strategy involving active

listening and lying as therapeutic maintain older people's self-esteem and cognitive abilities. There is the difference in responses to standardized care procedures among their clients with dementia and the needs of a variety of skillful approaches by the care providers.

Key word: end-of-life care, spiritual care, dementia, therapeutic lying, team care

INTRODUCTION

End-of-life care targets the physical, psychological, social and spiritual needs in people's lives, and consequently their quality of life.[1] Spiritual care attends to a person's spiritual or religious needs as he or she copes with illness, loss, grief or pain, and can help him or her heal emotionally as well as physically and regain hope and meaning in life. [2-4]

Nurses and care workers stress the importance of developing a deeper knowledge about how people with dementia express their spiritual needs and how to perceive and interpret such needs.[5,6] However, people with dementia have trouble with understanding abstract concepts and expressing their own spiritual needs verbally.[7] Their memory and control of behavior and emotions is impaired, that may lead to a crisis-like state involving mental and spiritual pain and suffering with loneliness, grief and fear.[6,8,9] Therefore, it is difficult for nurses and care workers to properly assess their spiritual pain of the people with dementia.

Since researches on the experience of nurses and care workers with the spiritual care of older people with dementia is scarce, regardless of country and care setting, it remains unclear how the spirituality of people with dementia is perceived and how spiritual care is delivered by nurses and care workers. Ødbehr et al (2015)[6] outlined the following spiritual needs of Norwegian nursing home residents: need for serenity and inner peace, need for confirmation, and need to express faith and beliefs regardless of severity of cognitive impairment. The aim of the present study was to comprehensively investigate the meaning and practices of spiritual

care for older people with dementia from the perspective and experiences of nurses and care workers.

METHODS

Study design and setting

We used consolidated criteria for reporting qualitative research[10] to create the best study design possible through accurate and considerate planning based on existing circumstances by identifying available resources. This qualitative study was conducted in Aichi prefecture, located in the central Japan. The average household income of the prefecture was higher than the national average. Total population of the people older than 65 years were 23.8% of total population, and estimated 290,000 were with dementia.

We targeted nurses and care workers who had experience of caring elder persons with dementia, and worked in nine care facilities, including two home visiting care offices, a home visiting nurse office, three day service centers, a dementia-specific group home, a nursing home, and a psychiatric hospital.

Data collection

Five nurses and thirteen care workers were purposively selected by a snowball sampling from facilities with which we had a pre-established relationship. Participant details are listed in Table

1. We conducted ten interviews, each one to three participants, from April to August 2017. We used an open-ended questionnaire concerning the meaning and practices of spiritual care for older people with severe dementia, to comprehensively and unintentionally capture the participants' experiences of caring for older people with dementia. We also showed an illustrated assessment tool for dementia,[11] focusing on eight dimensions of emotional and spiritual pain often experienced by older people, ahead of the interviews to stimulate discussion. All the interviews were carried out in quiet meeting rooms by the first author, a geriatrician with ample qualitative research experience. Each interview which lasted about 60 minutes was audio-recorded and transcribed verbatim.

Data analysis

Qualitative content analysis[12] was used to systematically identify ideas and patterns emerging from the qualitative data on the meaning and practices of spiritual care for older people with severe dementia. We began the process by reading the transcriptions of the interviews several times to familiarize ourselves with the overall content of the data which we then arranged into meaning units in order to identify emerging topics. Subsequently, we grouped meaning units into common meaning groups in order to identify larger themes emerging from the data.

Trustworthiness

We contacted the participants after data analysis in order to validate the transcription and analysis. At each stage of the process, the findings were discussed with the other authors and the participants to make sure they were interpreted accurately. In case of differing opinions, theme identification was decided by consensus.

Ethical consideration

This study was approved by the Bioethics Review Committee of the Nagoya University School of Medicine prior to the investigation (approval number 2015-0444). Written and verbal informed consents were obtained from the care managers and their older male clients. Interviews of older men were conducted privately, and participants' transcripts were anonymized.

RESULTS

Three main themes were emerged through the qualitative analysis of what consisting of spiritual care of the older people with dementia: self-esteem; communication; and individual difference.

Self-esteem

Due to deteriorated cognitive function and subsequent decline in daily and social activities,

older people with severe dementia are worried about autonomy and independence. Older people generally want to remain independently up to the very end of their life. Some participants observed that a number of their older clients with severe dementia who had been committed to rehabilitation had subsequently managed to regain the ability to perform daily living activities independently.

> *They feel great when they succeed in defecating in the toilet without soiling their clothes.* (Participant 16, 35 year-old care worker)

The daily lives of older people with severe dementia are usually monotonous and spiritless due to lack of social activities and limited interaction. Some participants encourage their older clients with severe dementia to find something to enjoy on a daily basis.

> *I would like my clients to enjoy things they appreciate like recreation services, talking, eating, bathing.* (Participant 10, 49 year-old care worker)
>
> *They really enjoy special activities like excursions or cherry-blossom viewing.* (Participant 17, 59 year-old nurse)

Reminiscing about past achievements usually helps older people improve their self-esteem and appreciate the meaning of life. Participants acknowledged that talking about the past allows older people with severe dementia to enhance their self-esteem.

I am happy when my clients share information about something they are passionate about, and my clients appreciate the fact that I take the time to listen to them. (Participant 1, 58 year-old care worker)

When the wife of a former company president said to us "You are my employee", we played along. (Participant 19, 40 year-old nurse)

Communication

Short-term memory loss caused by dementia makes it impossible for older people with dementia to remember what they just said, so they repeatedly ask for the same information. Although this behavioral disorder is often irritating, caregivers are required to patiently listen to their patients to provide reassurance. Also, if they are genuinely disorientated by their surroundings at their nursing care institution, older people with dementia may repeatedly request to go home. Some participants felt that the appropriate course of action in this case was to twist the truth a little to provide reassurance and calm patients down.

Although listening to clients repeat the same thing endlessly can be exhausting, it is crucial to remain patient. (Participant 7, 80 year-old care worker)

When older clients with severe dementia mention that they are worried about the cost of their care, I simply respond that "It's free" to reassure them. (Participant 18, 50 year-old care worker)

Individual difference

Although ample literature on standardized dementia care procedures has been published so far, study participants reported experiencing vast difference in response to care according to individuals. Also, the participants agreed on the fact that nurses or care workers should play a complementary role in the dementia care team because each professional brings a unique set of skills and a distinctive approach.

> *My client's family explained that my client would not comply with their advice, so they asked me to try to persuade my client into cooperating.* (Participant 5, 50 year-old nurse.
>
> *On their own, care workers cannot provide perfect care for older people with dementia. However, by sharing know-how with the team members, the care we can provide will be very successful, close to perfection.* (Participant 20, 35 year-old care worker)

DISCUSSION

Nurses and care workers participated in the study perceived that self-esteem was a core domain of spiritual care for older people with severe dementia. To enhance their clients' self-esteem, they encouraged their clients to reminisce about important achievements and to enjoy small pleasures in their daily life. They also found that traditional basic communication skills, such as active listening of what their clients talked, helped maintain their self-esteem and cognitive

abilities. Through the interviews, they also realized the difference in responses to standardized care procedures among their clients with dementia and the needs of a variety of skillful approaches by the care providers.

Our findings indicated that self-esteem plays a central role in the spiritual life of older people with dementia. WHOQOL Group developing methods for assessing quality of life in different cultural settings, suggesting the close relationship between self-esteem and spiritual health.[4] Older people may feel insecure and lose confidence in themselves and their abilities, and those with dementia may feel they are no longer in control and may not trust their own judgment. Thus, dementia can have a negative impact on the people's self-esteem. The nurses and care workers in the present study used their clients' surroundings to try to unlock their clients' personal motivations and enhance their self-confidence by facilitating activities of daily life and providing small changes: recreation services, eating out, going out into nature and observing birds and flowers. The notion that self-esteem is positively affected by daily life activities corresponds with previous studies and literature.[5,7,13-15]

Study participants also perceived that reminiscing about the past helped older people with severe dementia boost their self-esteem and find meaning in life. Dementia aside, older people often feel that they have become useless because of infirmities due to old age and they often feel nostalgic. Our results coincide with the concepts of reminiscence and life review.[13,16] Increasing evidence of the merits of dignity therapy,[17,18] a widespread psychotherapeutic

intervention, has led to its gradual acceptance in palliative care settings. [19] The therapy aims to bolster psychosocial, emotional, and spiritual well-being through the process of life review and creating a lasting legacy document that typically contains important or meaningful memories, values, words of wisdom, and special messages to loved ones. Also, advance care planning requires life review communication between patients, their family, and their health care providers, and is best done through understanding and sharing of their personal values, life goals, and preferences unrelated to future medical care.[20] A Norwegian case study suggested that life storytelling is an important way of preserving dignity for people with dementia, and that health care professionals should be open and attentive to the life stories their patients tell.[21]

Our results confirmed that active listening of what their clients talked was a key element that facilitated communication between caregivers and their clients. Furthermore, participating nurses and care workers perceived lies and deception as acceptable in the context of certain interactions with older people with severe dementia. Although the acceptability and ethicality of deception in dementia care remains an area of heated debate,[22-24] because lying is viewed as therapeutic whereby the care provider's intent is to eliminate harm, control behavior disorder and reassure, deceptive practice has been shown to be endemic and prevalent in long-term care settings.

Our findings indicated that there was the difference in responses to standardized care procedures among their clients with dementia and the needs of team-based personalized care.

Although multidisciplinary collaborative care models incorporating neurologist, physician, nurse, social and care worker have been used to provide a system-level explanation of community-based integrated dementia care,[25-27] there have been no patient-level care models to explain how to provide team care that best meets the needs of patients with dementia and their family caregivers. The nurses and care workers perceived that by joining skills, they could provide ideal team-based personalized care while also tailoring the standardized dementia care procedures in accordance to the personal characteristics of their patients, such as gender, type or severity of dementia, presence of behavioral or mental health problems, and living situation.[28]

The strength of the study was that the interviewer was a geriatrician with ample clinical and research experience in dementia care. An additional strength of the study is that we used an illustration focusing on emotional and spiritual pain of older people with dementia, ahead of the interviews to stimulate discussion. However, there were several limitations to our study. First, although we used illustrations to facilitate the interviews, it was still difficult for the interviewees to make sense of spirituality and its care. Second, none of the participants discussed their clients' religious needs. This might have something to do with the fact that Japanese culture is not overtly open to religious expressions in general. Third, there may be local characteristics in the way of thinking about spirituality. Our study settings were limited to one specific area. Finally, we tried to recruit nurses or care workers in general working at

geriatric hospital and geriatric health services facilities where many older people with dementia spend the last days of their life, but we were unsuccessful.

In conclusion, we investigate the meaning and practices of spiritual care for older people with dementia from the perspective and experiences of nurses and care workers. As the results, self-esteem proved to be a core domain of spiritual care for older people with dementia. The results revealed that reminiscing about important achievements and enjoying small pleasures in daily life enhanced older people's self-esteem. The results also revealed that communication strategy involving active listening and lying as therapeutic maintained older people's self-esteem and cognitive abilities, and confirmed that there was the difference in responses to standardized care procedures among their clients with dementia and the needs of team-based personalized care.

Clinical Implication

- Self-esteem is a core domain of spiritual care for older people with severe dementia.
- Reminiscing about important achievements and enjoying small pleasures in daily life enhance older people's self-esteem.
- Communication strategy involving active listening and lying as therapeutic maintain older people's self-esteem and cognitive abilities.
- There is the difference in responses to standardized care procedures among their clients with

dementia and the needs of a variety of skillful approaches by the care providers.

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Conflict of Interest

The authors have no conflict of interest to declare.

Conflict of Interest and Source of Funding

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Table 1. Participants' characteristics.

Participant	Facility type	Age (year)	Sex	Licence
1	Home visiting care office	58	F	Care worker
2	Home visiting care office	58	F	Care worker
3	Home visiting care office	45	F	Care worker
4	Home visiting care office	42	F	Care worker
5	Home visiting nurse office	50	F	Nurse
6	Home visiting nurse office	45	F	Nurse
7	Day service center	80	F	Care worker
8	Day service center	55	F	Care worker
9	Day service center	50	F	Care worker
10	Day service center	49	M	Care worker
11	Day service center	46	F	Care worker
12	Day service center	38	M	Care worker
13	Day service center	35	M	Care worker
14	Day service center	30	F	Care worker
15	Group home	55	F	Care worker
16	Group home	35	M	Care worker

17	Nursing home	59	F	Nurse
18	Psychiatric hospital	50	F	Care worker
19	Psychiatric hospital	40	M	Nurse
20	Psychiatric hospital	35	M	Care worker