

Advocating for Older Adults with Dementia in Acute Care Hospitals

Japan Academy of Gerontological Nursing 2016 Position Paper (Short version)

Today, due to increased life expectancy, dementia is becoming a part of life that everyone, including one's own parents, grandparents, or even oneself, is likely to experience. For the people of Japan, dementia is no longer simply a difficulty faced by "other people."

Older adults with dementia admitted to acute care hospitals are confused and become easily agitated in these unfamiliar environments. Family members providing support during this period also experience difficulty when dealing with the exigencies of hospitalization. In this context, nurses in acute care hospitals are confronted with difficult issues when caring for older adults with dementia. One such problem is that current training methods are often unable to dispel the stigma associated with dementia among nurses, ultimately impacting the quality of care they provide. Another challenge is that despite the challenges faced by these patients, including the hospital environment detached from the rhythms of daily life, and a nursing system that does not encourage the acquisition of practical knowledge to address the individuality of older adults with dementia, the required level of care should be the same as that provided in the context of long-term care facilities. Furthermore, because nurses have not acquired the communication skills required to decipher the intentions of older adults with dementia, it is difficult for them to envision their patients' lifestyle or life after recovery, hence the tendency to distance themselves from their patients and the patients' families. Moreover, underlying these challenges is the major premise of "medical treatment that prioritizes speed and efficiency."

Family-related factors also exist in tandem with the abovementioned medical care-related factors. Specifically, older patients with dementia may experience unreasonable treatment yet family members under the pressure and responsibility of making life and death decisions on the patient's behalf, may keep silent in the face of such treatment by those providing therapy or medical treatment, because they feel that the recovery of their loved one is most important. Thus, these patients are placed in vulnerable situations.

The major challenge is that this results in situations where patients in acute care hospitals are advocated for by neither their families nor those responsible for their medical treatment, and that older adults with dementia are often left in isolation.

The Japan Academy of Gerontological Nursing considers these factors as the most pressing challenge facing nurses caring for older adults with dementia, and in providing practice guidelines for nurses and allied professionals in acute care hospitals, states the following eight "positions" for facilitating collaboration between medical treatment and care teams, and for promoting nursing practice that guarantees a sense of security and peace of mind for older adults with dementia receiving acute medical treatment as well as for their family members.

- Position 1 Eliminating negative attitudes and stigma toward older adults with dementia.
- Position 2 Protecting older adults with dementia within an environment that prioritizes medical treatment.
- Position 3 Promoting safe and early discharge fostered by sharing a lifestyle vision based on prospects of post-treatment recovery with patients' families and caregivers.
- Position 4 Presenting an overview of means that promote patient-centered medical treatment and care while taking into consideration the constraints faced by acute care hospitals:
 - ① Medical treatment and care that discourages the use of physical restraints
 - ② Medical treatment and care that identifies practices that worsen the confusion of elderly patients and strain the patience of family members
 - ③ Medical treatment and care that has a lifestyle vision for older adults with dementia.
 - ④ Medical treatment and care that promotes team-based personal care based on patients' prognosis and lifestyle.
 - ⑤ Improving aspects of the medical treatment and care environment and customs that are ill-suited to older adults with dementia.
- Position 5 Understanding the endurance and burden faced by families of older adults with dementia.
- Position 6 Updating our knowledge of dementia and dementia care regularly and consistently.
- Position 7 Gathering and presenting evidence as a basis for formulating guidelines and revising medical payments for medical care.
- Position 8 Systematizing dementia nursing by concerted efforts to amass academic knowledge.

To realize these propositions, in addition to supporting and educating nurses, the Japan Academy of Gerontological Nursing also will provide guidance to entire acute care hospitals through interdisciplinary collaboration and cooperation with families, caregivers, and the public. We will also undertake regular reviews of this position paper to remain current with the situation in acute care hospitals and to respond to future changes in the medical system and requests from the public.

*This position paper can be accessed at the website of the Japan Academy of Gerontological Nursing

<http://www.rounenkango.com/>

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Japan Academy of Gerontological Nursing 2016 Position Paper

Purpose of Issuing a Position Paper

People have the right to receive the best acute medical treatment according to their wishes. The Japan Academy of Gerontological Nursing hereby states its position on acute care nursing for older adults with dementia, in light of the principles of dementia care and in upholding this right, seeking to promote a nursing practice that guarantees a sense of security and peace of mind for older adults with dementia as well as their families, and to facilitate collaboration with medical treatment teams, in addition to providing practice guidelines for nurses and allied professionals in acute care hospitals.

Definition of Terms Used in the Position Paper

◆ **Acute care hospitals:** General or specialized hospitals that provide medical treatment for initial stabilization of patients presenting with various symptoms for set periods or whose physical health is suddenly compromised due to accident, illness, or injury.

◆ **Older adults with dementia:** Elderly individuals who have some capability and strength and attempt to live independently, despite age- or illness-related cognitive decline causing difficulty in daily life, regardless of whether proper diagnosis of dementia has been made, and who make their intention known even when unable to express themselves well due to communication disorders. Note that the term “older adult” does not refer to a specific chronological age range. This is in line with the view of the Japan Geriatrics Society as expressed in a position paper on end-of-life medical treatment and care of elderly patients: “Given that mental and physical changes that occur with age are highly individualized, it would be inappropriate to define the term according to age.”

◆ **A sense of security and peace of mind for family members:** A condition in which the typical challenges associated with acute care are alleviated through easy and efficient access to acute treatment for older adults with dementia in a way that preserves their dignity, and in which family members, as the stakeholders who best understand these patients, receive trust and consideration from medical providers, and are allowed to participate in caregiving as much as they wish.

◆ **A sense of security and peace of mind for older adults with dementia:** A condition of being able to receive treatment and lead a tranquil life without any slight to personal dignity, even in acute care hospitals.

Basic Position

The objective of the Japan Academy of Gerontological Nursing is “to contribute to improving the quality of nursing practice while seeking to advance the field of gerontological nursing.” The association’s Code of Ethics states, “As experts in gerontological nursing, we will fulfill our duty to contribute to the happiness and welfare of people through nursing practice, education, research and social activities.” Specifically, this duty includes “placing the utmost priority on respect for human rights, considering individual capabilities, and striving to advocate for the rights of elderly patients,” “in our activities, striving not to impose behavioral restrictions or other undue physical or mental burden on our patients and their families, nor to cause any pain or discomfort,” “maintaining confidentiality and protecting the privacy of elderly patients and their families,” and “endeavoring to respect the rights and skills of professionals in other fields and to foster interdisciplinary collaboration.”

According to the Japanese Guidelines for the Management of Dementia 2010, the principles of dementia care are (1) dignity and patient-centered; (2) peace of mind and a fulfilled life; (3) support to achieve independence and rehabilitation; (4) safety, health, and preventive care; and (5) care in partnership with the family and the community.

The basic position of the Japan Academy of Gerontological Nursing in this paper is to contribute to people’s happiness and welfare through adherence to the association’s Code of Ethics and to improve nursing practice based on the principles of dementia care.

Members Involved in this Study

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Preparation Process

The following three-stage process was undertaken to prepare a draft position paper; the final draft was arrived at after soliciting public comments from members of the Board of Directors, employee representatives, and membership.

- (1) Identifying the issues facing nursing practice for older adults with dementia in medical treatment facilities
- (2) Clarifying the current state of nursing practice for older adults with dementia in medical treatment facilities via the following:
 - a. Interviews with nurses with experience in dementia nursing
 - b. Interview with the family members of older adults with dementia who have experienced hospitalization
- (3) Outlining the fundamental characteristics of nursing practice for older adults with dementia in acute care hospitals

(3) Outlining the fundamental characteristics of nursing practice for older adults with dementia in acute care hospitals

Family-related factors associated with patients being exposed and unprotected: Tolerating unethical treatment based on the notion that a cure is most important, and completely relying on medical professionals so as to avoid the burden of being entrusted with life and death decisions.

Even if unacceptable treatment is provided to their loved one, family members persevere and choose to exercise restraint in the face of this unethical treatment. This is because under pressure of being entrusted with a person’s life, family members think that “getting better is the most important thing.”

Working in conjunction with

However Patients are isolated in the space between

Factors associated with nurses’ desire to keep patients and their families at a distance: Not having a lifestyle vision or positive recovery vision for their patients based on shared information.

Nurses tend to view patients with dementia as “people who are a nuisance to themselves.” Hence, they want to keep a distance between themselves and the patients and the patients’ family members. This is because nurses are unaware of how having a vision of patients’ lifestyles or information from family members or other nurses can help to prevent accidents or reduce complaints, and so they cannot effectively discuss post-treatment recovery with the patients’ family members.

However

The reality of dementia as a disease: An age-related disease that can affect anyone, including the nurses themselves.

In combination with

For many nurses, dementia in old age is no longer a plight that befalls others, but one likely to befall their own parents or grandparents, or even themselves as well.

In combination with

However

Therefore

Nurses’ belief that “patients with dementia are special cases” does not change: Learning methods currently used do not dispel negative attitudes toward the disease and its symptoms.

Aspects of care that nurses perceive as unreasonable tasks: Welfare facility-based nursing care methods requested under the constraints of the hospital environment

Nurses’ perception of patients with dementia as “special cases” does not change because even when taught about disease and symptoms using current teaching methods, they are unable to dispel the negative connotations of dementia as “scary,” “an undesirable prospect,” “an illness from which there is no recovery,” and “an illness with a heavy burden of care.”

Nurses consider certain tasks as unreasonable, and this negatively impacts the quality of care they provide. However, within the context of the constraints imposed by the hospital environment and under an institutionalized medical model and nursing system that do not encourage the acquisition of practical knowledge with which to address patients individually, nurses are called on for ideas and nursing care practices regarded as “possible” in the context of facility-based care.

Therefore

Therefore

Measures to promote patient-centered medical treatment and care: Nursing guidelines that will guarantee certain outcomes, and revisions to medical fee payments that will motivate organizations

Evidence-based guidelines and methods of engagement that present techniques and methods to nurses who are already very busy, showing how to achieve certain tangible outcomes without conscious effort, and revisions to medical fees that will spur organizations to proactively engage with dementia care will be effective in promoting a model of medical treatment and care focused on older adults with dementia.

Therefore

Medical care-related factors associated with patients remaining unprotected: The underlying premise of medical treatment that prioritizes speed and efficiency.

In acute care hospitals, the purely rote checking of patient intentions, the practice of excluding family members from diagnostic and treatment settings, absence of a patient advocacy team, lack of humane interaction by professionals with elderly people or their family members which serves to obviate any agency or complaint on the part of patients, and the widespread use of physical restraints are caused by the demand for speed and efficiency, nurses being so busy that they have little time to think, and the outcome of paying unquestioning lip service to “giving priority to treatment.”

Underlying influence