



## Letter to the Editor

### Advanced Directives in Older Adults with Dementia: Ethical Challenges and Advocacy Role of Nurses

Mehrnoosh Partovirad<sup>1</sup>, Amin Hosseini<sup>2</sup>, Elham Navab<sup>\*3</sup> 

<sup>1</sup> Department of Community Health and Geriatric Nursing , School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

<sup>2</sup> Department of Medical-Surgical, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

<sup>3</sup> Department of Critical Care, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

\* **Corresponding Author:** Department of Critical Care, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran. **Tel:** +989173110323, **Email address:** elhamnavab2@gmail.com

Received 20 June 2023

**Citation:** Partovirad M, Hosseini A, Navab E. Advanced directives in older adults with dementia: ethical challenges and advocacy role of nurses. *Elderly Health Journal*. 2023; 9(2): 55-56.

The world population is aging at a fast rate. This issue has caused an increase in the number of people with progressive, debilitating and incurable neurodegenerative diseases such as dementia (1). According to recent studies, the number of older adults with dementia is estimated to be around 7 million in the United States in 2002 and the number of people with dementia is estimated to increase from 57.4 million cases globally in 2019 to 152.8 million cases in 2050. Dementia is the fifth leading cause of death among the elderly, and the number of people living with dementia will triple in the coming years (2, 3). With the progress of the disease, patients gradually lose the ability to make decisions and interact with the surrounding environment, becoming increasingly dependent on others for self-care (4).

However, medical advances have created tools, such as advanced directives, to bridge the gap between the principles of medical ethics (autonomy, beneficence, justice, and non-emergency) and clinical practices in situations where vital decisions need to be made for the elderly (5). Advance directive is an official document for making decisions about future treatment based on the patient's preferences, and it is used when an elderly person is unable to make medical decisions about his health due to illness or injury (6). Adherence to the principle of autonomy is one of the main pillars of this document. Here, autonomy refers to the basic capacity of people to make decisions about their own health (7). Although the completion of advanced directives is not limited to a specific disease or health status, in elderly people with dementia, features such as autonomy, beliefs, priorities and even identity are subject to change due to the non-linear pattern of disease progression.

At this time, formal and informal caregivers take the responsibility of making decisions on behalf of these patients. This issue has made it a challenge to refer to the past wishes and preferences of elderly people with dementia when making important health decisions about them. It has also created a challenge for physicians, nurses and family caregivers in regard to the true wishes of patients when it comes to health. For example, in people with mild dementia, the decision about treatment and health care in the advanced stages of the disease may be contrary to their previous wishes and desires (5). In this situation, the completion of advanced directive, which refers to "instructions for the future", cannot fulfill the expected goals of this document in patients with dementia. It seems that the completion of advance directive will be useful for elderly people with dementia only when it seeks to give meaning and orientation to the future of these people through a flexible and evolving approach, and also when it encompasses their life story, as well as their past and present experiences. This problem brings about a great deal of mental burden and causes high levels of anxiety and depression for the caregivers of people with dementia and also fuels conflicts between their family members. For this reason, nurses, as the closest member of health care team to patients and their caregivers, play a significant role in diagnosis, care and management of dementia, and also in patient advocacy. Defending patient is a moral duty of nurses and one of the essential aspects of nursing profession (8). The nurse's support of patient is manifested through processes or actions such as informing and learning, honoring and respecting, and physically and emotionally supporting patient and his/her family. By continuously assessing the condition of elderly patients

in different stages of the disease, providing various trainings on the clinical course of the disease, and establishing regular communication and dialogue with their main supporters and caregivers, nurses can determine the priorities, goals and preferences of patients with dementia, even though they may go through changes with the passage of time. In situations where patients are not able to make decision about their health due to disease deterioration, nurses would help their caregivers to interpret future developments according to the learned experiences and make decisions that are based on the independence and autonomy of patients (9, 10).

#### Funding

None

#### Conflict of interest

None

#### References

- Burlá C, Rego G, Nunes R. Alzheimer, dementia and the living will: A proposal. *Medicine, Health Care and Philosophy*. 2014; 17(3): 389–95.
- Nichols E, Steinmetz JD, Vollset SE, Fukutaki K, Chalek J, Abd-Allah F, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*. 2022; 7(2): 105–25.
- Evripidou M, Charalambous A, Middleton N, Papastavrou E. Nurses' knowledge and attitudes about dementia care: Systematic literature review. *Perspectives in Psychiatric Care*. 2019; 55(1): 48–60.
- Merel SE, Gaster B. Advance directives for dementia can elicit preferences to improve patient care. *Journal of the American Geriatrics Society*. 2020; 68(7): 1606–8.
- Lyreskog DM, Karlawish J, Nagel SK. Where do you end, and i begin? how relationships confound advance directives in the care of persons living with dementia. *The American Journal of Bioethics*. 2020; 20(8): 83–5.
- Widdershoven G, Janssens R, Voskes Y. Beyond precedent autonomy and current preferences: a narrative perspective on advance directives in dementia care. *The American Journal of Bioethics*. 2020; 20(8): 104–6.
- Choi WJ. Ethics of care challenge to advance directives for dementia patients. *Journal of Medical Ethics*. 2022; 2022: 108475
- Gadow S. Clinical subjectivity. advocacy with silent patients. *Nursing Clinics of North America*. 1989; 24(2): 535–41.
- Pan J, Wang P, Wang Y. Expanding role of nurses in management of dementia in geriatrics: improving well-being of geriatric patients through quality nursing care. *Psychology, Health & Medicine*. 2022; 27(3): 707–14.
- Shepherd-Banigan M, Ford CB, DePasquale N, Smith VA, Belanger E, Lippmann SJ, et al. Making the informal formal: discussing and completing advance care plans in care dyads with cognitive impairment. *Journal of Palliative Care*. 2022; 37(3): 289–97.