

Advance Care Planning in Early Stage Dementia

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ABSTRACT

Dementia is a chronic illness that involves progressive loss of cognitive and functional abilities. In the early stages, persons with dementia actively face their cognitive decline, adjust to cognitive loss, and are able to take an active role in discussing values and preferences for future care. Preparing patients and families for what to expect in the course of dementia is vital in ascertaining an individual's wishes regarding supportive and life-sustaining interventions. Nurse practitioners in primary care have a responsibility to initiate advance care planning conversations with persons in the early stages of dementia.

Keywords: advance care planning, dementia, palliative care, primary health care

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Dementia is a chronic illness that involves progressive loss of cognitive and functional abilities. The most common cause of dementia is Alzheimer disease (AD), and most people affected are 65 years old and older.¹ The average survival ranges from 7 to 10 years.² In the early stages, persons with dementia (PWD) actively face their cognitive decline, adjust to cognitive loss,^{3,4} and are able to take an active role in discussing values and preferences for future care.^{5,6} Primary care nurse practitioners (NPs) have a responsibility to initiate advance care planning (ACP) conversations with PWD and facilitate the discussion in the early stages.

“Advance care planning is defined as conversations which cover the patient's specific health conditions, their options for care and what care best fits their personal wishes, including at the end of life (EOL), and the importance of sharing those wishes in the form of a written document.”^{7(p15)} There is consensus in recommending that ACP in AD and other progressive dementias should begin at the time of diagnosis to engage the PWD in making future choices and decisions.⁸⁻¹⁰ Livingston et al¹¹ identified the following common difficult decisions made by family caregivers (CGs) for PWD: 1) accessing health and social services; 2) considering care home placement; 3) legal matters, such as finances and driving; 4) deciding on

non—dementia-related health care, such as surgery, EOL care, and resuscitation; and 5) making plans for the PWD if the CG becomes too ill to care for him or her.

The first definition of optimal palliative care (PC) in dementia included person-centered care, communication, and shared decision making¹² and that is only possible in early and moderate dementia. Some experts have expressed concerns about bringing up EOL issues in the early stages and fear of undertreatment or being abandoned when dementia care is labeled as PC.¹³

Persons with dementia may not have the opportunity to express their health care values and preferences for future care because they are often diagnosed too late in the disease process. In 2016, the Centers for Medicare and Medicaid Services (CMS) provided further incentives to primary care providers and hospitals with additional payments for ACP as a medically necessary service, in addition to screening for cognitive impairment and discussion of ACP in the Medicare Annual Wellness Visit. However, a recent study found that only 14% of primary care physicians had ACP conversations and billed Medicare, and few (29%) were trained to talk with patients and families about EOL issues.⁷

In primary care, in which most patients engage in care, missed or delayed dementia diagnosis is

significant¹⁴ and undermines the ability to plan and provide PC. Persons with dementia and CGs report not being told of the diagnosis.¹⁵ Yet, PWD prefer to be informed of the diagnosis¹⁶ and participate in decision making for as long as possible.¹⁷ CG surrogate decision makers are more confident in knowing preferences for EOL in dementia when formal advance directives or informal discussions are completed in the earlier stages.¹⁸ Primary care providers are well positioned to discuss difficult issues in dementia with patients and CGs and should provide basic elements of PC including ACP.¹⁹ However they may not feel well equipped to communicate ACP in the early stages.²⁰

DEMENTIA AND ACP

The course of dementia varies for each type of dementia and for each individual and family. Loss of cognition and function may occur rapidly or in a more insidious manner over the course of many years and often with periods of acute decompensation caused by secondary illness such as infection.^{21,22} Preparing patients and families for what to expect in the course of dementia is vital in ascertaining an individual's wishes regarding supportive and life-sustaining interventions. Establishing trust and a sense of team is key to helping patients and families establish advanced care plans.

Specific discussions regarding resuscitation, artificial nutrition and hydration, and advanced level care such as intensive care should occur early in the course of dementia. Decisions regarding these interventions are deeply rooted in cultural and religious beliefs as well as personal previous experiences.^{23,24} NPs should guide these discussions with that in mind.

It is expected that over the course of the disease individuals will experience acute decompensations related to cognitive and functional decline. Falls, pneumonia (particularly aspiration), urinary tract infections, and dehydration are all common occurrences in the later stages of dementia. It is helpful to describe particular clinical scenarios that patients may face. For example, if a patient develops acute sepsis related to aspiration pneumonia would they want intubation and, if so, is there a limit to the length of intubation. In this clinical scenario, it would also be helpful to discuss the complications related to

aspiration, the likelihood of recurrent infections, and opinions regarding artificial nutrition and hydration.

It may also be helpful to provide patients and families with statistics and current scientific evidence regarding the success rates of these interventions as well as discussing the potential burden of suffering. For example, survival rates of in-hospital cardiopulmonary resuscitation (CPR) in older adults is low to moderate (11.6%–18.7%) and decreases with age.²⁵ Percutaneous feeding tubes are not recommended in advanced dementia because they are associated with agitation, greater use of physical and chemical restraints, greater health care use because of tube-related complications, and development of new pressure ulcers.²⁶

Eliciting an individual's definition of what constitutes quality of life (QOL) for them is critical in illustrating a patient's wishes regarding interventions. Loss of independence and concern for family burden often play a role in patients' thoughts regarding EOL care. Multiple tools exist to assist in assessment of QOL. The brief Older People's Quality of Life questionnaire is a highly reliable and valid short measure of QOL in older age.²⁷

Unfortunately, in some situations, it is challenging to develop consensus among patients and family members. In these situations, a family meeting to include all vested parties is most effective. The NP may be called to act as a mediator between and among family members. The role of patient advocate comes into play here, ensuring that the patient's wishes are expressed and heard.²⁸

ADVANCE DIRECTIVES AND PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT

An advance directive is a legal document used to provide guidance about what types of medical treatments a person would want to receive in case of a future, unknown medical emergency.²⁹ It designates a surrogate health care decision maker, a living will, or both. A Provider Order for Life-Sustaining Treatment (POLST) or other similar state form (ie, Maryland Order for Life-Sustaining Treatment [MOLST]) is an ACP process that emphasizes conversation between the patient and health care providers and documents medical orders about treatment decisions such as CPR and medical interventions or treatments.³⁰ The POLST exists at some level in all 50 states and Washington, DC.

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