

The Goals of Care Conversation: A tool to improve patient care in the nursing home at the end of life

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ABSTRACT

Patients residing in nursing homes may undergo burdensome transitions in care during the final months of life. They may get care they do not want and are unlikely to benefit from. Patients and families may not understand prognosis or the potential benefits of treatment. A “goals of care” conversation can be the critical first step in identifying a patient’s wishes and then developing a plan of care that honors those wishes. When the goal of care is to focus on comfort, hospice can be accessed. Hospice can help ensure that the patient’s final time is spent in comfort and that the family’s needs are attended to both before and after the patient dies.

KEYWORDS: end of life, hospice, communication, advance care planning

INTRODUCTION

Patients residing in nursing homes often undergo burdensome transitions in the final weeks and months of life.¹ Patients may return to the hospital for care they did not want and were not likely to benefit from. Identifying the patient’s goals, values and preferences and then developing a plan of care based on these can help to improve care in the final weeks of life. A goals of care discussion is the critical first step in determining what care is most likely to benefit the patient in achieving their goals, what care is not consistent with their goals, and what options, such as hospice, would help meet their goals. Common goals of care include: curing disease, avoiding premature death, maintaining or improving function, prolonging life, relieving pain, enhancing comfort, maintaining or improving function, and dying peacefully.

GOALS OF CARE MAY NOT BE STATIC

The goals of care will typically change as an illness progresses. A patient in the nursing home may have experienced a lifetime of medical care with goals that focused on curing illness and prolonging survival. Patients may have endured discomfort and, at times, suffering to achieve these goals. They may come to a point where cure is not possible and the goals of care may change to maintaining function

and independence. As an illness progresses, the goal may then shift to maintaining or improving quality of life and then finally to having a peaceful death. Discussion of goals of care should be held on admission to the nursing home and then repeated at regular intervals, particularly when there are changes in health status.

Before establishing goals of care, it is important that patient and family understand where the patient is in his/her illness. Goals may change significantly as the prognosis is better understood. Research has shown that many patients are unaware of their prognosis. Many patients with heart failure, for example, did not understand that their heart disease would limit their life expectancy.² Patients with renal disease on dialysis were much more optimistic about their prognosis than their physicians.³ Those patients who understood they had a poorer prognosis were less likely to want potentially life prolonging care. Families may not understand that dementia is a terminal illness.⁴ Honest discussion about prognosis can begin to address some of these misunderstandings. It is important when outlining prognosis that jargon be avoided. Also vague and evasive comments about prognosis like “only God knows” or “I don’t have a crystal ball” are not helpful, especially when it is clear the patient has a limited life expectancy and is seeking information to inform decision-making.

Concerns are sometimes raised by family or nursing home staff that discussing these issues may be upsetting to the patients. However, it has been shown that patients who have conversations about the kind of care they want at the end of life are not more likely to develop depression than those who do not engage in these types of conversations.⁵ They are, however, less likely to get aggressive care at the end of life.

DECISION-MAKING CAPACITY AND GOALS OF CARE

In the nursing home, many patients have dementia and it will be important to assess decision-making capacity. The patient must be able to understand the clinical information, use the information to make a decision and understand the consequences of the decision. If the patient is not able to make medical decisions, the surrogate named in the advance directive will need to be consulted. If a surrogate has not been designated, the family can assist in determining goals

and making decisions. In speaking to families it is important that they understand the role of surrogate. The family should not be asked what they want done for the patient but instead they should be asked to assist in determining what the patient wanted. This clarification can be critical to alleviate some of the burden that the family may feel. Some may feel that they are being asked to “play God” if they are solely responsible for the decision making process.

When the patient is unable to participate in the discussion, the family or others will need to assist in identifying the goals and values of the patient. Ideally the patient has left an advance directive. This serves two purposes. The document can identify the person the patient has designated to speak for them when they are unable to speak for themselves. It can also help in describing preferences for care in the setting of an advanced illness. The Rhode Island Durable Power of Attorney for Health Care form helps patients to note these preferences. The form presents three scenarios, one when actively dying, the second describing a persistent vegetative state and the third advanced dementia. Given those scenarios, patients are asked to note if they would want a feeding tube or life support. Patients also have the opportunity to describe other wishes or limits they want. This information can be very helpful in guiding the discussion.

The medical history may also provide some clues as to what the patient might want. Family history in many cases simply reads “noncontributory.” It is certainly true that the cause of death of parents of the terminally ill patient is very unlikely to impact the care of the patient. How they died however, often provides important insight into what the patient might have wanted as their death is approaching. If, for example, a parent died after a prolonged hospital stay with multiple unwanted interventions, the patient may have commented on the kinds of things they wouldn’t have wanted in that situation. If a parent died at home among family and friends, this may also have elicited some comments by the patient.

The social history may also have some important information. The number of cigarettes smoked and the amount of alcohol consumed is unlikely to be of great benefit in establishing goals of care. Instead, an appreciation of the kinds of activities that brought quality to the patient’s life can be extremely helpful. The clinician may learn if the patient was someone who valued independence or if they were quite satisfied with a more sedentary and dependent role; these are clues that may help direct the discussion about patient goals and preferences.

DEVELOPING A PLAN OF CARE

Once the patient’s goals and values have been elicited, a plan of care can be developed. When the goal is to have comfort for the final weeks of life, the plan of care will be very different than when the goal is prolonged survival, even if it requires burdensome interventions. Strong physician or

practitioner input in developing the plan of care is critical.

One error that is sometimes made in discussing the plan of care is to focus solely on what will not be done (e.g., no intubation, no CPR, no hospitalization). This may leave the patient and family wondering what will happen as they are dying. They will need to be informed how pain, dyspnea, and suffering will be effectively managed and be reassured that care will not be withdrawn.

Patients and families may still have misconceptions about the benefits of various interventions. CPR in particular may be misunderstood. Patients and families may vastly overestimate the success of CPR and may make decisions based on that misinformation. Learning about the futility of this intervention in certain settings and conditions may change the likelihood of requesting it.⁶ Benefits of dialysis for nursing home patients may also be misunderstood. It has been shown that most patients residing in a nursing home who begin dialysis will die or have a significant decline in function in the year following initiation of dialysis.⁷ Patients receiving chemotherapy or radiation for advanced cancer often do not understand that the treatment is not likely to cure their cancer.^{8,9} Many families may assume that the placement of a feeding tube will benefit a patient with advanced dementia whose dietary intake has declined. Research has shown that the placement of a percutaneous endoscopic gastrostomy tube does not prolong survival.¹⁰ It is important to assess patient and family understanding of the benefits or the treatment options they are considering, or they may be opting for interventions that are unlikely to help them.

Patients, families, and nursing home staff may not understand the benefits of antibiotics in a dementia patient with pneumonia. Antibiotics are often viewed as a comfort measure by the staff; however, research has shown this is not the case. Patients with dementia who were given antibiotics were actually found to be more uncomfortable than patients who did not receive antibiotics.¹¹ Antibiotics did however prolong survival of patients with advanced dementia and pneumonia. Again, it is critical to determine what the goals of care are at that point.

THE ROLE OF HOSPICE

If it is determined that quality of life and comfort are the goals of care, then hospice may be helpful in achieving those goals. Research has shown that nursing home residents who receive hospice care are less likely to be hospitalized.¹² It has also been shown that management of pain is better for nursing home resident residents enrolled in hospice than for those not receiving hospice care.¹³ Many nursing home residents do access hospice care which can improve the quality of life. Unfortunately for many residents, it is only accessed for the final days of life, often after multiple hospitalizations.

Some dying patients may leave the hospital and go to the nursing home as skilled patients so that Medicare will pay for the room and board. If they go to the nursing home with

hospice care at the routine level, the family will be required to pay the daily room and board rate which can be up to \$300 a day or more. Medicaid may cover this cost for those patients who meet eligibility guidelines and established in that state. This creates a disincentive for patients to access their Medicare hospice benefit following a hospitalization. Research has shown that patients who receive skilled care are less likely to use hospice and are more likely to have a short hospice stay, and those patients without hospice in place are much more likely to return to the hospital.¹⁴

If decisions have been made to limit potentially life-prolonging interventions, the Medical Orders for Life Sustaining Treatment (MOLST) form can be completed. This document ensures that the patient's wishes for care will be honored if they leave the nursing home for another setting. It includes preferences for CPR, comfort care, feeding tubes, and hospitalization.

For many patients in the final weeks and months of life hospice can provide tremendous benefit not just to the patient but to the patient's family and caregivers. Hospice can help ensure that the patient final time is spent in comfort and that the family's needs are attended to both before and after the patient dies.

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