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Surrogate Decision-Making and Advance Care Planning in Long-Term Care

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Introduction

Many residents of nursing facilities and other long-term care settings are cognitively impaired and thus may be incapable of making decisions about their medical care. Clinicians providing care for these residents must rely on previously specified advance directives or on other designated decision-makers, usually called surrogates, for guidance in medical decision-making. Because advance directives can explicitly address only a limited number of situations, and because for each incapacitated patient there are usually many decisions to make over time, continuing communication between the medical providers and surrogates is often necessary. Understanding the nature of advance care planning and surrogate decision-making is thus crucial for both health care providers and surrogates.

The terminology and laws pertaining to all aspects of surrogate decision-making vary greatly from state to state, and people involved in such decision-making must become familiar with their own state's statutes and language. What follows here is a general guide to surrogate decision-making, including that by guardians, and to the principles underlying it, along with recommendations on the subject from the American Medical Directors Association (AMDA). It is an overview of the subject, written with the understanding that some of the words used below may not be exactly those used in any individual's state of residence.

Competence

Although health care providers often use the terms 'competence' and 'decision-making capacity' interchangeably in conversation, these terms actually have different meanings. Competence (or competency) defines a legal status. A person is legally either competent or incompetent, with no gray areas in between. An adult is assumed to be competent unless he or she is determined by a court to lack the ability to make the decisions required for living safely, at which time the court deems that person incompetent.

Laws in different states may specify domains of competence, such as competence to be a parent, be married, serve as a witness, stand trial, or make medical decisions. In determining a person's competence, courts may consider information provided by clinicians. The determination of incompetence changes a person's legal status, essentially removing the right to make decisions from him or her. The court transfers that right to someone else (termed a guardian in most states) whom it appoints. A guardian may be a family member, friend, or professional surrogate decision-maker.

Decision-Making Capacity

While courts alone determine competence, clinicians often assess what is usually termed the patient's decision-making capacity. Decision-making capacity implies the ability to understand the nature and consequences of different options, to make a choice among those options, and to communicate that choice. Decision-making capacity is thus required in order to give informed consent. When applied to medical decisions, this requires that a person understand a diagnostic or therapeutic intervention's significant benefits, risks, and alternatives.

A person unable to make and communicate medical decisions is deemed incapacitated. He or she may also be unable to provide for basic needs, including medical care, nutrition, clothing, shelter, or safety. Incapacity does not necessarily imply incompetence, as court proceedings are not undertaken for all incapacitated people. While competence denotes a legal status and is unambiguous, decision-making capacity, by contrast, can be partial and may have gray areas. Moreover, the standard for decision-making capacity varies with the complexity and consequences of the decision in question. The greater the complexity or the graver the consequences of the decision, the higher the standard, so that the same person may have the capacity to make one type of decision and not another. An individual's decision-making capacity may also fluctuate over time, as a result of transient changes in a person's ability to comprehend or communicate. For example, a person may lose the ability to communicate while under general anesthesia but regain that ability after recovering from anesthesia.

Incompetence does not necessarily mean that an individual lacks the capacity to make decisions. For example, an individual may be declared incompetent in one domain such as in handling financial matters, but may still retain the ability to make medical decisions.

A framework for assessing decision-making capacity

The capacity to make decisions implies the ability to communicate choices, to understand relevant information, to appreciate the idea of consequences, and to manipulate information rationally.^{1,2} To make medical decisions, a person must be able to understand the nature of the illness for which a particular treatment is offered, the probable course of the illness without the proposed treatment, and the nature and consequences of treatment options, including risks and benefits. This understanding need not be physiologically sophisticated, nor should cognitively impaired patients or surrogate decision-makers be held to a higher standard than cognitively unimpaired patients who make decisions about their own medical care. When determining decision-making capacity, one should attempt to understand how the patient arrived at a decision and to recognize the influence of the patient's personal values. (3)

The ability of a cognitively impaired person to make decisions may wax and wane because of the primary cognitive impairment or because of acute illness that may be superimposed upon underlying impairment. Decision-making capacity may be affected by medications, anxiety, or even time of day; it is often task-specific and situational and will depend on the complexity, as well as the risks and benefits, of the diagnostic procedure or treatment in question. A patient may possess the capacity to consent or refuse to have analgesics for pain, for example, yet may lack the capacity to consent to a complex chemotherapy regimen for cancer.

Decision-making capacity can be assessed through open-ended questions that take into account the gravity of the situation, the patient's cognitive status, and the complexity of the decision to be made. One might begin by asking a patient to describe his or her illness and the likely result of specific treatments or treatment alternatives. Decision-making capacity is suggested by consistent responses to questions that are phrased in different ways. Patient's performance may be improved by delaying the capacity decision, enhancing the disclosure of information with

visual aids, addressing psychological issues, or facilitating family support. (*Grisso and Applebaum*) (Insert Table 1 here.)

Formal testing is not usually necessary to determine whether someone can understand the nature and consequences of a particular medical decision and to make and communicate that decision. No single test or instrument is adequate to determine decision-making capacity, and the results of any test need to be interpreted in the context of the whole clinical presentation. The mini-mental status exam (MMSE),⁴ for example, though helpful as a screening tool for detecting cognitive impairment, is neither sensitive nor specific for evaluating decision-making capacity, especially in the middle range of its scoring.⁵

Surrogate Decision-Making

A surrogate, one who makes decisions on behalf of another who is unable to make decisions for him- or herself, can be designated either informally or formally. State laws and terminology regarding surrogates, also called proxies or health care agents, and the scope of responsibilities and powers accorded to them, vary widely. Providers and surrogates working with incapacitated people should become familiar with their state's relevant laws and provisions.

In the most formal situations, surrogates are court-appointed; they are usually termed guardians or, in some states, conservators. Other formally designated surrogates, whose appointment does not require action by the courts, are those who have been named in advance directives prepared by the incapacitated person before becoming incapacitated. In situations in which there has been no court decision and when advance directives have not been specified, state laws may codify the order or hierarchy of people upon whom responsibility for surrogate decision-making devolves, usually family members or close friends of the incapacitated person; these surrogates are not court-appointed and are thus considered informal.

Advance Directives

Advance directives are instructions given by persons to direct their health care in the event that they lose the ability to make and communicate medical decisions for themselves. The purpose of an advance directive is to define the medical care desired and to specify whom to ask for decisions in the future, in order to make medical decisions that are consonant with the wishes and values of the person who has become incapacitated.

Formal written advance directives may take the form of a living will, a durable power of attorney for healthcare (DPOAHC), or some combination of the two. The terminology, statutes, and documents relating to advance directives vary from state to state. Nevertheless, an advance directive created in one state is valid in all other states and advance directives are thus portable from state to state. By law, health care facilities may not base admission on whether a person has or does not have an advance directive. (482 CRF section 489.102(a)(3)) In any health care facility, a copy of written advance directives should be placed in the patient's chart so that all caregivers are aware of its existence and contents.

A living will is a document in which a person specifies preferences for care or treatment in the event of future incapacity. A separate document designating a surrogate is called a durable power of attorney for health care (DPOAHC). Some states may require that a DPOAHC be separate from the living will; others may combine the provisions of a living will and a DPOAHC. A person completing a living will or DPOAHC may rescind or change it at any time, provided he or she still possesses the capacity to make decisions. Neither a living will nor a DPOAHC

becomes active unless the person becomes incapacitated. In some states, an individual may choose to activate a surrogate while he or she still has decision-making capacity.

Living wills may vary considerably in their degree of detail. They may simply specify general goals, comfort over aggressive treatment, for example, or discontinuation of treatment that appears to be futile. They may also specify types of care or treatment, such as attempted cardiopulmonary resuscitation, intubation, intravenous hydration or medication, hospitalization in the event of a serious illness, antibiotic therapy, or the use of feeding tubes.

A person completing an advance directive cannot foresee or address all the situations in which choices about treatment may be required. Choosing someone to make decisions on one's behalf provides additional flexibility in dealing with unforeseen circumstances.

Guardianship

The court appointment of a guardian to make decisions for someone who has been deemed incompetent typically requires substantial documentation, time, and expense. For medical decision-making, guardianship proceedings are unnecessary when the incapacitated person has completed an advance directive that formally designates a surrogate, or when the state recognizes the decision-making authority of informal surrogates, such as family members who appear to have the individual's best interests at heart.

Though laws about guardianship vary from state to state, in general, a guardian is appointed by the courts to exercise all of the powers and duties necessary for the care of an incompetent person, who is usually termed the 'ward'. Courts can appoint someone to be a 'guardian of the person' to make medical or personal decisions, a 'guardian of the estate' to make financial decisions, or a 'plenary guardian' to make all necessary decisions on behalf of the ward.⁶

While the laws of many states grant guardians complete decision-making authority on behalf of their wards, other states specify limited forms of guardianship in which the ward retains some rights of self-determination or decision-making. Partial or limited guardianship is sometimes called 'conservatorship', and a limited guardian is then referred to as a conservator.

Courts often appoint as a guardian a family member or close friend of the ward. When an incompetent person is without family or friends, willing or able to serve as a guardian, or when there is unresolved conflict among family members, the court may appoint a 'public' guardian. Public guardians generally are expected to be familiar with the role and responsibilities of a guardian and willing to serve in that capacity. They are accountable both to the courts and to local administrative authorities.

The training, professional background, and scope of decision-making authority of public guardians varies. Some states require public guardians to undergo licensure, training, and supervision before their appointment, while others do not. Some states limits what a public guardian can decide on behalf of a ward. A public guardian may, for example, be prohibited from withholding or withdrawing specific treatments and from choosing that the ward forego attempted cardiopulmonary resuscitation without explicit court approval. Moreover, in some states, a public guardian is appointed to protect the specific interests of the state rather than of the ward.

An Ethical Framework for Surrogate Decision-Making

Because the health care of incapacitated people, including cognitively impaired residents of long-term care facilities, is medically and ethically complex, the decision-making required of surrogates can be conceptually and emotionally difficult.⁷ The following framework is intended to help surrogate decision-makers, including public guardians, and health care providers make ethical decisions on behalf of incapacitated nursing facility residents.

Autonomy

The principle of patient autonomy affirms the right of people to make decisions about their own medical treatment. Individuals have a constitutionally protected right to refuse treatment, including life-sustaining nutrition or hydration. Individual autonomy does not universally assume the primacy that it does in the United States, and a realization of this can help clinicians avert misunderstandings with people of different ethnic and cultural backgrounds. Autonomy may be far less valued than other factors, such as consensus, in more traditional cultures where decision-making may reside with the whole family or with the head of the family. Family members may be subject to powerful role expectations that pertain to pursuing medical treatment or providing care. Learning about the family's belief system and communicating respectfully about options can help the provider navigate these waters.⁸

Substituted Judgment

The principle of "substituted judgment" denotes for an incapacitated individual what he or she would have chosen had they been able to do so. It is difficult to know exactly what another person would have wanted, however, unless that person made his or her wishes known in advance, either by completing a written advance directive or by discussing preferences before becoming incapacitated.

Knowing what another person would want generally requires knowing that person well, though even that is often not sufficient. Public guardians, however, are often appointed specifically because no one else is available who knows the ward well. Without an advance directive, a public guardian has no clear information upon which to base substituted judgments on a ward's behalf. In some situations, public guardians and health care providers may try to ascertain what a person would have wanted by obtaining a "values history," which comprises examples of earlier decisions and statements a person has made and which may shed light on personal values and priorities.

Although substituted judgment is an important principle in ethical decision-making, many studies have shown that neither health care providers nor surrogates are generally very good at knowing or predicting patients' preferences about medical care.^{9,10,11,12,13,14} Doctors, nurses, and surrogates identify care preferences only moderately better than would be predicted by chance. Family members and health care providers tend to underestimate both self-perceived quality of life¹⁵ and the desire for aggressive care.¹⁰ Advance care planning is effective in that surrogates who have discussed end-of-life issues with patients more accurately represent their wishes than those who have not.¹⁶

Medical care is frequently inconsistent with patients' preferences and is determined by factors other than prognosis or stated preferences.¹² Given the relatively poor performance of family members, physicians, and nursing facility staff in making accurate substituted judgments, it is unrealistic to expect public guardians, who are often strangers to their wards, to do better.

Best Interest

The decision to carry out the previously stated wishes of the patient should be supported and is a manifestation of fidelity and respect for the individual. When an incapacitated patient has not indicated preferences about medical care, the surrogate's decisions should be based upon the "best interest" of the patient: the decisions should be the same as a reasonable adult would make if faced with the same circumstances. Reasonable adults may disagree about specific treatments, especially when no single treatment exists that is clearly superior to the others. To determine which treatment option among several is in the best interest of the patient, a surrogate needs information about the risks and benefits of each option. Physicians and other health care providers are often in the best position to provide this information.

Surrogates may also ethically make the decision to withhold or withdraw treatment from an incapacitated person, though state laws about this vary.

The decision-making authority of surrogates is moderated by other ethical principles, such as 'beneficence' ('doing good') and non-maleficence ('doing no harm'). For example, surrogates are not automatically authorized, on the incapacitated person's behalf, to elect medical treatments that are considered by medical providers to be futile or harmful.⁶ In some situations, limitation of care may be preferable to further intervention. In the absence of other effective or desirable treatments, a palliative care approach, possibly including hospice care, may be appropriate for incapacitated or incompetent persons.

Decision-making by mentally incapacitated long-term care facility residents

Long-term care facility residents judged to be incompetent may still possess the capacity for making some decisions, particularly about such personally meaningful things as what to wear and what to eat. Thus, an incompetent person may possess the capacity to make meaningful personal decisions and yet lack the legal authority to do so.

Among the major losses experienced by people admitted to nursing facilities are loss of independence, loss of control over daily schedules, and often loss of the ability to perform basic activities of daily living. Consequently, the decisions that nursing home residents remain able to make loom large, representing the last vestiges of personal control. Thus it may be advantageous, for the sake of their quality of life, to ensure that even those residents who are incompetent, and those mentally incapacitated residents who simply lack the ability to make complex reasoned decisions, are encouraged to make those decisions they are able to make for themselves. The idea of providing choices to incapacitated people in the spirit of preserving and respecting their dignity has been described as part of 'everyday ethics.'¹⁷ The choices offered to mentally incapacitated people should not involve risks to their health if they make unwise choices. The goal is to balance the risks inherent in poor decisions against the loss of autonomy.¹

The hierarchy of medical decision-making for incapacitated nursing home residents

The Patient Self-Determination Act, enacted as federal law in 1991, grants all persons or their surrogates the right to refuse or discontinue treatment, and it makes advance directives completed in any state legal and portable. This law also requires all medical facilities receiving federal funds to ask, at the time of admission, whether a prospective patient has completed a written advance directive, which usually includes the naming of a surrogate decision-maker. Nursing facilities must document at regular intervals whether a resident has an advance directive or has designated a surrogate decision-maker.

In most states, the decisions of court-appointed guardians prevail over the directives of all others, except when the ward has executed an advance directive before losing decision-making capacity. Advance directives supersede decisions by a guardian or other surrogate. When guardians appear to be disregarding advance directives, the advance directives should prevail, and it may even be necessary for medical providers to petition the court to appoint a new guardian. For incapacitated patients without a guardian, written advance directives still prevail, even over the contrary wishes of family members or other surrogates.

Providers should discuss the provisions of advance directives with surrogates, particularly when the advance directives are vague, contain inconsistent instructions, or reflect misconceptions, in an effort to interpret the directive in the context of the patient's earlier decisions or preferences when those are available. In a medical emergency, emergency responders cannot be held responsible for failing to honor an advance directive of which they are unaware.

When there is neither a guardian nor an advance directive that specifies a surrogate, the right to make decisions falls to family members, generally in the following order: spouse, adult children, siblings, then other family members. The provisions of states differ: in some states, law specifies this order; in others, no order is specified. While some states recognize common-law spouses and grant them decision-making power, others do not; similarly, some recognize the category of "friend," which may apply to a longtime companion or partner. In some states, all adult children or siblings must unanimously make decisions as a "class". (Insert Table 2 here) Some states have rejected rigid hierarchies, recognizing instead that personal involvement and knowledge, as well as having the patient's best interests at heart supersedes such hierarchies.

When there is disagreement among family and friends about what a patient would have wanted or about which interventions are in the best interest of the patient, it is helpful for clinicians to spend the extra time required to reach consensus, even when only one person is technically authorized to make decisions. In rare cases, it may be necessary to petition the court for a guardian to act on the patient's behalf.

Many long-term care facility residents have no involved family members. The number of mentally incapacitated people in nursing homes for whom there is no designated surrogate decision-maker greatly outnumbers those for whom courts have appointed guardians. This puts health care providers in the circumstance of acting as *de facto* decision makers.¹⁸ Only a few states specify a procedure, which guides the care team's decision making on behalf of an incapacitated patient without a surrogate.

Guidance for guardians and other surrogates about medical decision-making

Guardians may come to their role from a variety of different backgrounds. A Public guardian is a government employee with experience in the role, but no prior knowledge of the individual. A private guardian may be a family member or friend knowledgeable about their ward but unfamiliar about the task assigned, a hired professional such as a social worker or geriatric care manager, an attorney familiar with legal and financial matters. Thus, guardians may differ with regard to their knowledge of the ward, as well as their knowledge of medical or legal affairs. Communication between the guardian and the attending physician is therefore necessary.

Guardianship can result in decision-making that is cumbersome and slow, which itself can have adverse consequences for patients. Laws affecting guardians' decision-making vary from state to state and may be ambiguous. Administrative policies of long-term care facilities may also affect or restrict the decisions that surrogates can make, especially those that involve withdrawing or

withholding life-sustaining treatment. It is helpful for the guardian or other surrogate, with the assistance of the health care provider, to plan for likely contingencies by making advance care plans on behalf of the patient. (Volicer JAGS 2002)

Perhaps the clearest way for surrogate decision-makers to begin formulating advance care plans is by thinking not about specific medical interventions but rather about the overall goals of care.^{19,3} These goals should be based both on the principle of best interest of the patient and on realistic assessment of the patient's medical, functional and cognitive status, life expectancy, and prognosis. Such goals of care might include prolonging life, maximizing function, or ensuring comfort. Because a medical intervention that would further one goal might compromise another, it is helpful to prioritize goals; that way, health care providers have a sense of which interventions would be most appropriate for a given patient. Prioritizing goals of care provides a framework that is highly flexible and can serve as a guideline in unanticipated situations.¹⁹ Setting goals of care in advance can help avoid delays in the initiation of desired treatment, prevent the initiation of treatment that is not consistent with the goals of care, and prevent miscommunication at times of crisis.

Advance care planning by the guardian or other surrogate should also, in states where it is legal, result in a written advance directive, signed by the surrogate. Some states have standardized forms-- such as Oregon's Physician's Order for Life-Sustaining Treatment (POLST)²⁰ and California's Physician Documentation of Preferred Intensity of Treatment-- that ensure portability from facility to facility, e.g., from long-term care facility to hospital, of specific advance directives such as DNR orders. Surrogates should be familiar with about the regulations in their particular state.

Clear decisions about whether to use or forego specific diagnostic and therapeutic interventions are crucial to advance care planning in long-term care facilities. Such interventions include cardiopulmonary resuscitation, mechanical ventilation, artificial feeding, intravenous fluids, antibiotics, hospitalization, and dialysis. Surrogates should decide in advance in the event of acute illness whether it is appropriate, given the goals of care, to use these interventions, or opt for other approaches such as palliative care in the long-term care facility.

Health care providers should notify surrogates when a patient has had a significant change in health status or is deemed terminally ill. Surrogates should also be informed that there may be no specific and recognizable turning-point in chronic conditions such as dementia, chronic obstructive pulmonary disease, or congestive heart failure. In the presence of these conditions, it is especially important to specify goals of care in advance and reevaluate these goals as a patient's condition worsens.

Although ethicists and courts have held that there is no difference between withholding and removing life support,⁷ there is often a perceived difference between these actions that can be especially painful for surrogates and caregivers. Advance care planning may help avoid the initiation of unwanted treatment, thus preventing the need to discontinue it later.

What surrogates and health care provider should expect from each other

Clinicians providing care for an incapacitated patient should discuss medical care with the patient's surrogate. Health care providers have responsibility for providing adequate information, as well as their own informed opinions, to surrogates. (Insert Table 3 here)

Surrogates who do not know what the patient would have wanted should be guided by the principle of best interest of the patient, which in turn is based upon clinical evidence, concern for the patient's comfort and dignity, and an understanding of the risks, benefits, and burdens of each option for treatment. Understanding the patient's prognosis, including his or her life expectancy, may help guide decisions about treatment.

Surrogates should expect health care providers to discuss the options for treatment, including the benefits and burdens of each. Discussion should include a description of the natural course of the illness if untreated. Providers should also describe the medical reasoning underlying their recommendations, which should take into account the patient's prognosis, cognitive function, comfort, and well-being. Provision of written materials can be especially helpful for surrogates. Some jurisdictions may require that guardians obtain written documentation from a clinician before granting a request to withhold or withdraw life-saving treatment.

Health care providers should expect surrogates to understand their role, to be available for discussions, to respond promptly to requests for decision-making, and to be willing to formulate goals of care to avoid delays in appropriate treatment and to prevent initiation of undesired procedures and treatments. Health care providers and surrogates should be willing to avail themselves as necessary of ethics committees, ombudsmen, and other community resources that may help them to arrive at the best possible decisions. Ideally, clinicians and guardians are expected to make and communicate decisions with the same care that they would bring to decisions about a close family member of their own. (Insert Table 4 here)

Some Important Clinical Issues

Understanding of the evidence about outcomes of specific treatments can help guardians to make decisions. A brief summary of research about some specific medical interventions in incapacitated long-term care facility residents here follows. It is important to note that in most instances the outcome data and other information presented is in the context of caring for incapacitated elderly long-term care facility residents, particularly those with dementia, and may or may not be applicable to children or younger adults in long-term care.

Cardiopulmonary Resuscitation (CPR)

Current federal law mandates that long-term care facilities must ask residents (or their surrogates) whether they wish to receive CPR in the event of a cardiac or respiratory arrest. Research on CPR performed on elderly nursing home residents consistently shows very poor outcomes. Survival following CPR is less than 5% in this population, with most studies showing 0% survival.^{21,22} The poor outcome of CPR in nursing home residents is more likely a result of the irreversibility of the underlying diseases that end in cardiopulmonary arrest in such patients.

The way in which treatments processes and outcomes are described strongly influences the decisions of patients and surrogates with regard to those treatments.²³ When presented with information about the actual likelihood of surviving CPR, for example, older patients who have previously expressed a wish to undergo CPR generally decide not to.^{23,24,25}

Despite consistent evidence of its ineffectiveness, CPR continues to be offered and performed in long-term care facilities, by either facility staff or emergency medical technicians.²⁶ Nursing facilities are prevented from implementing facility-wide "do not resuscitate" (DNR) policies and procedures,²⁷ and are required instead to ensure that decisions about resuscitation be expressed by individual residents or their surrogates.

In the case of CPR performed in the long-term care facility, the level of discordance between outcome data and national policy, or between evidence and practice, is extreme. This highlights the importance of educating patients, surrogates, and health care providers about the outcomes of specific medical interventions. The issue of CPR may also reflect our society's unrealistic expectations of technological interventions, even in situations in which they are likely to fail. Moreover, lawmakers and regulators may be averse to system-wide or facility-wide policies that might be viewed by some as denying choice or care to patients. Based on the best available evidence, however, it is recommended that CPR not be performed in mentally incapacitated elderly long-term care facility residents unless they have clearly indicated their desire for such treatment before becoming incapacitated.

Tube feeding

Enteral (nasogastric, gastrostomy or jejunostomy) tube feeding has recognized benefits in specific clinical situations, for example, in the treatment of acute stroke when swallowing is impaired. In the setting of severe dementia, however, its benefits are questionable.

The natural history of dementia often results in loss of ability to swallow without a significant risk of aspiration. At this stage of dementia, some clinicians initiate tube feeding in an attempt to prevent aspiration pneumonia, malnutrition and its consequences, pressure ulcers, provide comfort, or prolong life. The published research about tube feeding in nursing facility residents with advanced dementia has been extensively reviewed.^{28,29} There is no good evidence that tube feeding succeeds at avoiding or reversing any of these poor outcomes.²⁸ Specifically, there is no evidence that tube feeding reduces the risk of aspiration pneumonia. In fact, the risk of aspiration pneumonia may actually be increased by tube feeding.²⁸ Furthermore, the leading cause of death in tube-fed patients with dementia is aspiration pneumonia. (28) Nasogastric tubes violate the gastroesophageal sphincter and, like gastrostomy tubes, provide a ready source of material in the stomach for reflux and aspiration. Nor is jejunostomy associated with lower rates of pneumonia than gastrostomy, as neither procedure eliminates aspiration of nasopharyngeal secretions.

To date, there is no evidence that tube feeding prolongs survival among older nursing home residents. One-year mortality among tube-fed older nursing home residents with severe cognitive impairment is significantly higher than that of those not treated with tube feeding.^{30,31,28} There is no published evidence to indicate that tube feeding improves the outcomes of pressure sores in this older population.²⁸

The decision to initiate tube feeding in severely demented or terminally ill long-term care facility residents is generally based on a desire to provide adequate nutrition and to prevent suffering and inexorable deterioration. Many people consider it unethical to do otherwise. Unfortunately, the use of feeding tubes in the terminally ill (such as those with end-stage malignancies) may prolong suffering, and their use in the severely demented may be counterproductive. Initiation of tube feeding in a cognitively-impaired long-term care facility resident often has adverse outcomes aside from aspiration pneumonia. Placement of the feeding tube itself has associated morbidity. Cognitively impaired residents may inadvertently or intentionally remove feeding tubes, requiring subsequent reinsertion. Physical and chemical restraints are sometimes used under such circumstances to prevent patients from removing their feeding tubes, however, physical and chemical restraints have their own adverse consequences, including discomfort, aspiration, pressure sores, and reduced quality of life. Tube feeding deprives patients the enjoyment of tasting food as well as contact with caregivers during the feeding process.

Tube feeding is not necessary to prevent suffering during the dying process. Terminally ill patients often stop eating or drinking in the days or weeks before death. Those who are cognitively intact and able to communicate frequently indicate that they do not experience hunger, thirst, or discomfort as a result of having stopped eating or drinking. Symptoms related to dry mouth can effectively be relieved with sips of water or periodic swabbing of the mouth. While patients with severe dementia may be unable to report whether they experience pain, hunger or thirst from not eating or drinking, observational studies have not shown any physical or physiologic signs of distress among those in whom tube feeding is not provided. There is no evidence that voluntary cessation of eating and drinking makes terminally ill persons physically uncomfortable.²⁹

Based on the best available evidence, therefore, it is recommended that tube feeding not be initiated in severely demented patients unless they have clearly indicated their desire for such treatment before becoming incapacitated.

Hospitalization

In patients with severe dementia, hospitalization for the treatment of acute illness entails serious risks. Even cognitively intact elders when hospitalized have an increased incidence of confusion, anorexia, incontinence, falls, deconditioning and inactivity.³² These conditions can result in such medical interventions as the use of psychotropic medications, restraints, nasogastric tubes and urinary catheters, all of which carry their own risks such as thrombophlebitis, pulmonary embolus, aspiration pneumonia, urinary tract infection, falls and sepsis.

Hospitalization is not always the best method for managing infections or other acute conditions in nursing home residents.³⁵ For example, hospitalization is not always necessary for optimal treatment of nursing home-acquired pneumonia. Immediate survival and mortality rates are comparable between patients treated in the long-term care facility and those treated in the hospital.^{36, 37, 38}, and 2-month survival is higher in patients treated in the nursing home compared with those treated in hospital (Fried JAGS 1997)

Hospitalization itself is associated with additional loss some functional ability, such as the ability to transfer, toilet, feed or self-groom. These functional losses do not improve significantly by discharge, and they resolve more slowly than the acute illness that precipitated the hospitalization.³³ A large percentage of long-term care facility residents are older adults with preexisting pressure sores, cognitive impairment, decreased physical or social activity, and are thus at added risk for these complications.³⁴ Hospitalization of many long-term care facility residents thus exposes them to substantial risks that require important consideration before deciding upon hospital transfer. Emergency room or hospital transfer should be used only when it is consistent with the overall goals of care, and not as a default option when an unexpected acute illness arises.

Antibiotic Therapy

In older patients with acute infections such as pneumonia, treatment with antibiotics administered orally is often just as effective as antibiotics administered parenterally.⁴⁰ Intravenous therapy is difficult to administer to cognitively impaired patients, as they may not understand its rationale but may experience discomfort from it and try to remove the intravenous access catheter. In patients for whom parenteral antibiotics are indicated by the severity of the illness, once-daily cephalosporin therapy administered intramuscularly may offer a reasonable alternative to intravenous therapy for many infections.

In patients with advanced dementia, the effectiveness of antibiotic therapy may be limited by the recurrent nature of their infections, because the underlying causes of the infections, such as impaired swallowing, aspiration, and decreased immune function, persist after treatment of each acute episode.⁴¹ Use of antibiotic therapy for infections does not prolong survival in patients whose cognitive impairment is advanced, in those who are unable to walk unassisted, or in those who are mute as a result of severe dementia.⁴² Antibiotics do not prolong survival in patients with advanced dementia and fever.⁴² Antibiotics may not necessarily even provide comfort in patients with dementia who develop acute infection. In a study of patients with dementia treated with antibiotics for acute infection, no difference was found in patient discomfort compared to similar patients not receiving antibiotic therapy.^{43,44} Analgesics, antipyretics, and oxygen can provide adequate comfort in the absence of antibiotics.

Antibiotic therapy is associated with numerous adverse effects, such as gastrointestinal upset, *c. difficile* infection, diarrhea, allergic reactions, hyperkalemia and agranulocytosis. While diarrhea may be a temporary annoyance to younger patients, in immobile patients and those with dementia, it can result in fecal incontinence that may lead to problematic skin breakdown. In addition, procedures that are often performed in order to diagnose or treat infections (i.e. blood-drawing, sputum suctioning) are associated with at least moderate discomfort. These procedures may also increase agitation in cognitively impaired patients who cannot understand or remember the reasons for them. Moreover, diagnostic procedures frequently fail to indicate the source of fever in these patients.⁴² Treatment is therefore often empiric. The decision to use antibiotics in long-term care facility residents with advanced dementia should take into account the recurrent nature of these infections in such patients, the adverse effects of antibiotics, the discomfort produced by accompanying diagnostic and therapeutic procedures, and the absence of evidence that these measures enhance some patients' comfort.

Summary and Conclusions

Surrogate decision-making for long-term care facility residents will increase in frequency as the population ages. Decisions made by guardians and other surrogates should be ethically sound and based upon the best available clinical evidence. Health care providers have a responsibility to keep surrogates informed, to communicate information about prognosis and changes in condition, to provide guidance, and to work closely together with surrogates to foster decision-making in the best interest of the patient. Using all the available information from all involved persons, surrogates should be available to make decisions promptly, be willing to accept that treatment of some conditions may be ineffective or futile, be willing to forego ineffective treatments, and engage in advance care planning. Advance care planning may help to prevent delays in decision-making, and prevent undesired or futile treatments. Health care providers should familiarize themselves with the statutes and regulations pertaining to surrogate decision-making in their states.

Before patients become incapacitated, health care providers should encourage the completion of advance directives, including a living will and the naming of a surrogate decision maker (as in a DPOAHC), and should encourage patients to discuss their preferences and goals of care with whomever they have designated as surrogates. Health care providers, regulatory agencies, and public guardians should work together to clarify these issues and sponsor joint educational efforts. Because the legal framework for surrogate decision-making varies state by state, state-specific collaborations will be necessary to improve decision-making and outcomes for these vulnerable populations.

Table 1

A Framework for Assessing Capacity to Make Medical Decisions ^{1,6}

Can the person make and express personal preferences at all?

Can the person give reasons for the alternatives selected?

Are the supporting reasons rational in the sense that the person begins with a plausible idea and reasons logically from that premise to a result?

Can the person comprehend the personal implications, namely the probable risks and benefits, of the various choices presented and selected?

Table 2

Hierarchy of Medical Decision-Making for Incapacitated Patients

Advance directives specified by the patient before (s)he became incapacitated prevail, even over the contrary wishes of guardians and other surrogate decision-makers

The decisions of the guardian or of a surrogate designated in an advance directive prevail over all others except in the presence of a written advance directive

Decisions of surrogates, including guardians, should be guided by:

Substituted judgment (if the incapacitated person's wishes were known but not formalized in an advance directive)

Best interest of the patient, based on clinical evidence, prognosis, life expectancy, risk and benefit of proposed treatments, comfort and dignity

Family members and friends take precedence next, usually in the following order

Spouse

Adult children

Siblings

Other family members

Friend

Health care providers follow, in the absence of other decision-makers (not optimal)

Table 3**What Surrogates Should Expect From Health Care Providers**

Accessibility

Communication about diagnosis, prognosis, available treatment options, and life expectancy

Description of the benefits and burdens of each treatment

Recommendations for treatment and discussion of the reasoning underlying the recommendations

Access to pertinent written education materials or journal articles

Written communication of recommendations about treatment and their justification, when requested

Access to ethics committees

Emotional support

Table 4**What Health Care Providers Should Expect of Surrogates**

Basic comprehension of the surrogate's role

Availability for discussion

Prompt response to requests for decision-making

Willingness to discuss overall goals of care

Willingness to collaborate in care planning

Willingness to make use of available community resources including ethics committees and ombudsmen when necessary.

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