#### 6. Ethical Issues in Long-Term Care

#### **Executive Summary**

Although there are many possible issues, we selected for detailed discussion in this report three areas of complex ethical issues that are unique to patient care in the long-term care setting. For the purposes of this report, long-term care includes inpatient units whose population is anticipated to reside there for more than three months, e.g., nursing homes, spinal cord injury units, psychiatric units. The committee intends its comments to be generalizable to any of these long-term care patient populations unless stated otherwise. Each of the three sections is followed by specific recommendations for health care providers. A bibliography is included to provide an overview of the literature in ethics in long-term care.

In the first section, we explore the definitions of competence and decision-making capacity, their use in everyday clinical parlance, ethical considerations in decision-making, and the impact of these considerations on issues of informed consent. Special concerns for cognitively-impaired patients are discussed and illustrated with case examples.

Next, this reports considers concerns in long-term care about appropriate use of mechanisms for advance care planning, issues of policy and patient preference for resuscitation and transfer, and the quality of dying, including relief of pain and suffering and demedicalization of the dying experience.

Finally, from the caregiver's perspective, we examine social and

institutional expectations surrounding the staff who care for the frail and elderly. A short case is used to demonstrate how long-term caregivers may find support in dealing with complex and emotion-laden clinical ethical issues. The analysis considers how sensitivity to cultural diversity affects patient/caregiver relationships and provides an overview of ethical principles and perspectives that may frame discussion of clinical ethical issues in long-term care.

#### **Summary of Recommendations**

- 1. Clinical evaluation of patients whose decision-making capacity is in question should include looking for a history of changes in emotional and cognitive states.
- 2. In the patient who exhibits recent memory loss, an earlier discussion with the provider about a treatment recommendation may not be remembered. The primary provider should determine whether inconsistencies are the result of caprice or cognitive impairment, versus inconsistencies that may be a result of truly altered preferences in a patient whose medical or social condition has changed.
- 3. Assessment of decision-making capacity should be carried out by the appropriate primary provider who is most familiar with the patient.
- 4. If the primary provider is uncertain whether the patient has adequate decision-making capacity, the appropriate specialist (e.g., psychiatrist, psychologist or behavioral neurologist) should be consulted to evaluate the patient.
- 5. Health care facilities should develop policies that promote advance care planning and decision-making while the patient is clinically stable and has decision-making capacity.
- Caregivers and facilities should work to solve the logistical problems regarding implementation of advance directives that have become apparent since these documents have received more widespread use.





- 7. Long-term care units should establish explicit policies or clinical guidelines regarding resuscitation and transfer to acute care facilities, pain management, and comfort care for patients who are near the end of life.
- 8. Long-term care facilities should provide adequate clinical training and ongoing educational, social, and emotional support for caregivers who work with dying patients.
- 9. Caregivers should develop the skills to alleviate or ameliorate both physical and psychological suffering at the end of life, utilizing hospice care teams when appropriate.
- Caregivers should be familiar with the cultural and spiritual aspects
  of dying that contribute to the overall quality of dying for
  individuals.
- 11. Ongoing education and training in ethical theory and moral decision-making should be provided for caregivers in long-term care settings.
- 12. Formal support groups for caregivers on long-term care units should be established to provide an opportunity for discussion of ethical issues that frequently arise in this setting.
- 13. A forum for discussion of ethical decisions should be provided for families of patients and caregivers in long-term care settings (family conferences or ethics advisory committee meetings).
- 14. A mechanism for resolution of ethical issues unique to the long-term care setting should be established at each VA facility.

#### **Competence and Decision-Making Capacity**

Competence is a legal term denoting the capacity to act on one's own behalf and to make decisions relevant to one's interests and welfare for which one can be legitimately judged accountable. The issue of an individual's competence may arise in regard to the capacity to manage one's own financial affairs, to stand trial, or to make health care decisions. An individual's competence may become compromised in certain clinical situations, either temporarily or permanently.<sup>1</sup>



#### Judicial Determinations of Competence

The law presumes that all adults are competent until specific evidence indicates otherwise. Determination that an individual is not competent is made only by a court or appropriate judicial authority. Most frequently, judicial assessment of competence arises in civil situations involving contractual agreements: disposal of property by sale, gift, or will; marriage; adoption; and divorce. In criminal matters, the issue of competence may arise with regard to one's capacities at the time a crime was committed, and whether one should be required to stand trial or be permitted to assist in one's own defense. A court may also determine that an individual lacks the capacity to make health care decisions and may, as part of that determination, appoint a legal guardian or a special guardian for health care to act as a surrogate if necessary.<sup>2</sup>

#### Decision-Making Capacity

For patients<sup>3</sup> in long-term care facilities, questions regarding decision-making capacity may arise and complicate many clinical situations.<sup>4</sup> In the everyday practice of medicine, the term decision-making capacity is often misused synonymously with the term competence.<sup>5</sup> In 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research issued a report entitled "Making Health-Care Decisions." Based on the findings of the President's Commission and the consensus of the clinical ethics literature, an adult who can meet the following criteria may be said to have decision-making capacity. Such an individual should be able to demonstrate:

- 1. the ability to understand the information presented,
- 2. the ability to appreciate the consequences of acting (or not acting) on that information with reference to one's own values and goals,
- 3. the ability to understand that choices are being offered and to deliberate among the choices,



- 4. the ability to make a consistent or stable choice which is not revoked or altered capriciously, and
- 5. the ability to communicate that choice.

#### The President's Commission noted the following:

- "...society seeks to enhance their (those with limited capacity) well-being by protecting them from substantial harms (or loss of benefits) that could result from serious defects in their decision-making abilities."
- "...a conclusion about a patient's decision-making capacity necessarily reflects a balancing of two important, sometimes competing objectives: to enhance a patient's well-being and to respect the person as a self-determining individual. Commentators have sometimes failed to recognize this balancing element, viewing 'capacity' or 'competence' as having intrinsic meaning apart from consideration of particular circumstances or situations..."
- "...determinations of incapacity to participate in medical decision-making should reflect the balance of possibly competing interests." 7

In the clinical setting, heath care providers make determinations regularly regarding the capacity of a given patient to make health care decisions. Most often, if the patient is deemed unable to make that type of decision, the appropriate surrogate decision-maker is consulted. If the primary provider is uncertain about the patient's capacity, he/she may seek consultation by an appropriate professional who is qualified to evaluate decision-making capacity. Such consultation may be useful to the primary provider who has ultimate responsibility for the patient's care. A judicial determination of incompetence and appointment of a guardian to make health care decisions is not required unless that patient has no designated or otherwise authorized surrogate. 10

#### Ethical Considerations in Decision-Making

Informed, patient-centered decision-making is based on the ethical principles of autonomy and beneficence.<sup>11</sup> To make autonomous decisions, an individual must be able to develop a personal value

structure and use it to guide and evaluate his or her own decisions and those of others. <sup>12</sup> Health care providers respect autonomy by accepting the patient's ultimate decisional authority and working to promote autonomous decision-making. To that end, they should provide appropriate and relevant information, try to assure that the patient understands the information, avoid coercion, and implement the patient's choice.

Providers also have a professional obligation to act beneficently to promote and to protect the well-being of their patients. However, the patient is best qualified to identify what counts as good or beneficial in his/her individual circumstances. The provider is best qualified to identify options for the patient that may help him/her to achieve his/her goals.

A patient's refusal of recommended treatment is a commonly cited reason for questioning that patient's capacity for decision-making. <sup>13</sup> Conscientious providers may believe they are acting to promote the patient's well-being by protecting the patient against the consequences of a "poor" choice. However, this beneficent "protection" comes at the expense of the patient's autonomy or right to make a determination of what counts as "good" for oneself. The patient is entitled to choose from among the options presented and is not under an obligation to agree with the provider's recommendation.

It is the provider's responsibility to ensure that the patient is capable of making a choice and to provide an atmosphere for decision-making that promotes patient autonomy and well-being. A truly beneficent provider allows the patient to make decisions based on the patient's own value structure and to determine what counts as beneficial personally. This tension between respecting autonomy and acting beneficently is heightened when the patient may have limited or compromised capacity to make such decisions. An important challenge for the provider is to maintain an appropriate, morally justified balance between autonomy and beneficence.



#### Cognitive Impairment and Decision-Making Capacity

Mental disability alone should not disqualify a patient from health care decision-making unless there is specific evidence that decisionmaking capacity has been lost. 14 A person whose decision-making capacity is impaired may have a psychiatric (e.g., psychosis, neurosis, personality, or behavior), neurobehavioral (e.g. Alzheimer's or multiinfarct dementia), metabolic (e.g., endocrine encephalopathy) or developmental (e.g., mental retardation) disorder that affects cognitive or emotional functions to the extent that capacity for reasoning and judgment is significantly diminished. While capacity for decisionmaking may be impaired, these individuals may still be capable of making many decisions for themselves. 15 In addition, patients who have intermittent intervals of lucidity may be able to make some types of decisions in those lucid intervals and should not necessarily be considered incapable of making any decisions. For all cognitively impaired patients, the health care provider should carefully assess the patient's capacity and promote autonomous decision-making whenever possible.

Because of the complexity of cognitive and emotional deficiencies, and the waxing and waning nature of many of these disorders, careful assessment of capacity to make decisions requires expertise and a significant time investment on the part of the provider making the evaluation. <sup>16</sup> There is no simple, agreed-upon algorithm for quick assessment of a patient's decision-making capacity. In some cases, consultation should be sought from an appropriate specialist (e.g., psychiatrist, psychologist, behavioral neurologist). Particularly for patients whose cognitive or emotional state may vary considerably over time, an ongoing assessment by the consulting provider may identify periods of lucidity during which the patient may have the capacity to make decisions to guide treatment and indicate future preferences.



#### **Case Example**

A young schizophrenic, long estranged from his family with no guardian or conservator, is hospitalized for treatment of an acute psychotic episode. During that hospitalization, he develops symptoms of acute appendicitis. A surgeon is consulted and recommends an immediate operation, but refuses to operate on the patient until his family comes in to provide consent. The patient becomes angry, says his family hasn't seen him in years and would not care whether he lived or died. The patient also states that he understands he is very ill and may die if he does not have the surgery. He wants to sign the consent form for the procedure. He also believes the clinical staff are Martian and are wearing rubber masks to conceal their true origins. One might argue successfully that he is not competent for some tasks in the legal sense, but he does meet the criteria for having decision-making capacity in this particular clinical setting.

#### Sliding Scale of Decision-Making Capacity

Some authors have suggested that the criteria for determining decision-making capacity be flexible, tying the assessment of decisionmaking capacity to the patient's comprehension of the balance of risks and benefits associated with the decision. Drane and others have argued for a "sliding scale" as a reasonable way to enhance both the patient's liberty and well-being. 17 Using a sliding scale, stricter tests of capacity are employed when the risks of the proposed treatment or procedure pose serious dangers to the patient or when a refusal of recommended treatment may result in significant harm to the patient. While decision-making capacity is generally agreed to be a threshold determination, that threshold may slide up or down. As Drane says "...when the consequences flowing from patient decisions become more serious, competency standards for valid consent or refusal become more stringent." One potential weakness of this approach is that it may be misused in certain clinical situations as a justification for undermining respect for autonomy and promoting paternalism.



#### **Case Example**

Mrs. D., a WWII army nurse lived a fulfilling life until she was 60 years old when, in a single traumatic year, her husband died of lung cancer, her only grandchild was killed in a drive-by shooting, and her daughter committed suicide. Now at age 73, she presents with a history of several months of cough and blood-tinged sputum, which is diagnosed as bronchogenic carcinoma. Her thoracic surgeon recommends removal of the cancerous lung, but is concerned about whether Mrs. D. has adequate decision-making capacity to give consent.

A number of clinical specialists are consulted to evaluate Mrs. D.'s complex medical condition (emphysema, angina, hypertension, mild clinical depression, mild multi-infarct dementia) and the impact on her decision-making capacity. Mrs. D.'s decision-making capacity is threatened by a combination of clinical factors including depression, a sense of demoralization, mild dementia, and the adverse effects of polypharmacy on her cognitive function. Despite her cognitive impairment, the clinical staff believe she has a good understanding of the seriousness of her prognosis, the risks of the surgery, and the possible consequences of treatment versus no treatment. They feel she is capable of making an informed decision.

A clinical ethicist reviews the case, talks with Mrs. D., and concurs with the impression held by the clinical staff. After lengthy discussion with a supportive childhood friend, she tells her surgeon she would like to undergo surgery to have her lung removed.

#### Modified or Limited Guardianship

Modified or limited guardianship was originally devised to assist with the medical care needs of cognitively impaired adults who could often understand certain illnesses and the discomfort they caused, but could not comprehend the nature and/or consequences of particular treatment options. When such a patient needed diagnostic studies or treatment, the provider discussed the options with him/her in the presence of a "limited guardian," who would work with the patient by

going over the details in very simplified terms and by assisting the patient in making his/her own decision when the patient was capable of doing so.

On the occasions when the patient is unable to make the decision for himself/herself, the limited guardian provides consent based on knowledge of the patient acquired over time: his/her values, goals, abilities and the nature of the particular clinical problem. In VHA, only an authorized surrogate may make health care decisions for a patient who does not have the capacity to make decisions for himself/herself. It may be helpful in cognitively impaired patients to have the authorized surrogate decision-maker act as a "limited guardian" to help preserve and maximize patient autonomy.

#### Recommendations

- 1. Clinical evaluation of patients whose decision-making capacity is in question should especially include looking for a history of changes in emotional and cognitive states. With advances in understanding of brain-behavior relations, neurobehavioral as well as psychiatric examinations may be conducted. Evaluation should include analysis of the five critical concepts regarding patients abilities, as noted earlier in this report. A thorough clinical interview with the patient, including a complete mental status examination, is an essential part of the evaluation process. For patients who have intermittent periods of lucidity, repeated evaluations over time may be necessary to capture their greatest decision-making capacities.
- 2. When the patient exhibits recent memory loss, he/she may not recall an earlier discussion with the provider about a treatment recommendation. In this case, repeated discussions may reveal that the patient's preferences remain consistent with the original treatment plan. If the patient's preferences are now inconsistent with previous decisions, careful evaluation of decision-making capacity should be undertaken. While some inconsistencies may be the result of caprice or cognitive impairment, others may be a result of truly altered preferences in a patient whose medical or social condition has changed.





- 3. Ideally in the long-term care setting, assessment of decision-making capacity should include the participation of the appropriate primary provider who is familiar with the patient. Assessments should be made in a quiet room with as few distractions as possible, paying careful attention to the patient's level of alertness, level of attention, attention span, eye contact, and body language. The provider should speak the patient's native language (vernacular) and avoid the use of medical jargon.
  - In many cases, the patient may be made more comfortable or be reassured by the presence of a trusted friend or the individual he/she has named a surrogate decision-maker. (The latter would not be acting as surrogate since the patient still has decision-making capacity.) Caution should be exercised lest there be an element of implied or subtle coercion by having the surrogate present.
- 4. If the primary provider is uncertain whether the patient has adequate decision-making capacity, the appropriate specialist (e.g., psychiatrist, psychologist, or behavioral neurologist) should be consulted to evaluate the patient.

### Advance Care Planning, Resuscitation, and Quality of Dying

#### Advance Care Planning

Advance care planning is a deliberative process that permits individuals to indicate their preferences for future medical care in the event that they are unable to make decisions for themselves at that time. In this planning process, individuals clarify their personal health care goals and evaluate the benefits and burdens of future treatment. They should try to choose treatments most consistent with their values and goals. In the long-term care setting, the responsibility of health care providers to assist patients in evaluating their treatment options often includes advance care planning, e.g., completion of advance directives, designation of surrogate decision-makers, and

consideration of issues surrounding dying and resuscitation. The obligations of the providers to respect patient autonomy and act beneficently are particularly important in helping patients make decisions about lifesustaining treatments. <sup>19</sup>

Many patients in long-term care facilities are able to work with their providers and families to make thoughtful advance care plans and execute written advance directives. However, a number of long-term care patients are admitted with compromised mental or communication abilities. Some of these individuals, after careful evaluation, may be found to be capable of making some or all health care decisions for themselves, e.g., patients having spinal cord injuries. certain psychiatric disorders, or mild dementia. Health care staff and families should work with these patients to engage them in the planning process and encourage them to make advance care plans when possible. Other patients may have fluctuating capacity to engage in this process and providers must work especially hard with this group to engage them as far as possible in planning for their own care. 20 Still another group of patients may have insufficient decision-making capacity to participate meaningfully in advance care planning or in the consent process required to execute written advance directives. Their authorized surrogate decision-maker will make their health care decisions 21

The Role of Surrogates for Patients Without Decision-Making Capacity and Who Have Not Executed an Advance Directive

Patients who lack decision-making capacity and who have no written advance directive must have their health care decisions made by an authorized surrogate. The health care staff needs to identify the appropriate person to act as surrogate for the patient and ascertain whether the surrogate is familiar with the patient's values and goals. If the patient has not discussed preferences with the surrogate, but has shared them informally with the health care staff, it is important to share that information with the surrogate as well. Surrogates participate in the decision-making process at the time particular care plans or diagnostic or therapeutic treatments are recommended by the



provider. VHA policy does not currently permit surrogates to execute written advance directives for patients without decision-making capacity.  $^{23}$ 

The decision-making process for the surrogate will reflect his/her familiarity with the patient's preferences. As in all health care decision-making, the process should promote and preserve the patient's autonomy. When possible, the authorized surrogate should use "substituted judgment" – i.e., the surrogate should attempt to make the decision that the patient would have made if he/she still had the capacity to do so. Without knowledge of the patient's preferences or values, the ability of a surrogate to make decisions using substituted judgment is compromised. In that event, the surrogate has to make decisions based on his opinion of what would be in the patient's best interests in the context of the patient's current quality of life.<sup>24</sup>

#### Reviewing Patients' Preferences and Advance Directives

When residents of long-term care facilities have executed written advance directives, health care providers should not assume that these are necessarily fixed preferences. Health care staff should initiate discussions with each patient to explore whether his/her preferences or health care goals have altered whenever there are significant changes in the patient's health or social circumstances. If appropriate, any previously executed advance directives should be updated to reflect any changes in the patient's preferences. When the patient's course has been stable, advance directives should be re-examined with the patient at regular intervals in a routine review and recorded in the patient's medical record. One important goal of advance planning is to promote the patient's participation in decision-making. The responsibility for periodic re-evaluation of the patient's preferences and advance directives is an important one and should be a regular part of the primary care of the patient.

Health care facilities should determine as a matter of policy which health care staff member(s) will be responsible for this periodic review of advance directives, as well as ensure appropriate and accessible documentation of the review. Regardless of which staff member is responsible for the review, the primary care physician should be familiar with the patient's current directive. Mechanisms should be developed for communicating the existence and content of the patient's advance directive to all providers in the long-term care facility, as well as the providers in acute care settings for those patients who are transferred.

#### Logistical Issues

Finally, the logistics of having a properly executed advance directive in the location where it is needed and when it is needed are often complex. This logistical challenge requires effective, consistently followed, administrative procedures and careful education and planning for the staff, patient, and family.

#### Resuscitation and Transfer

All long-term care facilities should strive to provide the best possible comfort care to all patients regardless of the resuscitation or transfer status of the patient. As part of their mission statement, long-term care facilities ought to establish and make explicit clear policies regarding resuscitation and transfer of patients who have become acutely ill. All parties who have a stake in these policies should participate in their development. In addition, resuscitation and transfer policies should articulate fair mechanisms to manage disagreements between patients and their families and health care staff. Since individuals admitted to long-term care facilities may be experiencing an adjustment reaction to loss of function and independence, their expressed preferences should be carefully assessed and any evidence of clinical depression should be thoroughly evaluated, particularly if their preference is for no resuscitation or transfer. As with all advance care planning, preferences should be regularly reviewed.<sup>25</sup>

Two major issues that may arise in long-term care facilities are 1) whether cardiopulmonary resuscitation (CPR) should be attempted in the event of a cardiac arrest, and 2) whether the resident should be transferred to an acute care facility for an acute deterioration in health status. Optimally, these issues should be discussed with the patient and



his/her family in the context of advance care planning when the patient is clinically stable. It is important not to delay discussing issues of resuscitation with patients unless there is good cause to do so. Due to the frailty of many patients in long-term care facilities, delay may result in a lost opportunity for patient input and the health care staff must then rely on the judgment of surrogates who are often uncomfortable with this type of decision or unfamiliar with the patient's preferences.

#### Use of CPR in Long-Term Care Facilities

Long-term care facility policies should consider the appropriateness of CPR under specific clinical conditions. CPR was developed originally to reverse intra-operative cardiac arrest or sudden, unexpected arrest in young healthy individuals, and in victims of drowning and electrocution. Over time, the use of CPR has been extended to many other clinical situations. There is a growing literature that characterizes the circumstances under which CPR is considered to be medically inappropriate or futile (e.g., when patients are dying of a terminal condition, multi-organ failure, when CPR is initiated too late.)<sup>26</sup> Thus, for many patients in long-term care facilities, initiation of CPR may be inappropriate because the likelihood of success or restoration to a good state of health is very low or non-existent.<sup>27</sup>

CPR may not be compatible with the goals of care for some patients in a long-term care facility. Maintaining quality of life and maximal independence in a safe environment is different from instituting advanced cardiac life support efforts to simply prolong life. <sup>28</sup> In some circumstances, such as with spinal cord injury patients or patients with psychiatric diagnoses, CPR may be an appropriate treatment option. For older, frail nursing home patients, the philosophy of care of the facility and the health care goals of the patient may not include CPR, as it connotes acceptance of "rescue medicine." While it is commonplace for CPR to be the default option on all patients without a do-not-resuscitate order who have a cardiopulmonary arrest, long-term care facilities may wish to reassess their policies on resuscitation to see if this is appropriate and consistent with both the facilities'

philosophy of care and patient preferences. If a facility considers CPR to be an inappropriate treatment option for some patients (i.e., it is not the default option), this should be made explicit to all patients and their families prior to or at the time of admission. This offers patients and their families an opportunity to discuss the facility's philosophy of care and indicate their preferences regarding care at the outset.

#### Do-Not-Hospitalize (Transfer) Orders

While most health care providers are familiar with Do-Not-Resuscitate orders, few facilities provide an option of Do-Not-Hospitalize or have as an explicit policy that patients may choose in advance not to be transferred to an acute care facility and have an order written to that effect. Offering this as an option to patients may provide a means of respecting patient values and more appropriately assist them in achieving their health care goals. For example, consider the patient who has a DNR order, becomes febrile and obtunded with labored breathing, and is transferred to an acute care facility with a probable diagnosis of pneumonia. In the intensive care unit the pneumonia is aggressively treated, but unfortunately the patient arrests and is not resuscitated (DNR order). This patient might have preferred the option of choosing to reside in a facility that would agree in advance not to transfer for acute deteriorations. Of course, facilities that offer Do-Not-Hospitalize orders as an option must be able to provide adequate care to patients to preserve their comfort and dignity in the event of an acute deterioration.

#### Quality of Dying

Quality of dying issues are a common concern in long-term care facilities providing care to elderly or dying patients. <sup>29</sup> The issues surrounding quality of dying may emerge gradually as a patient inexorably nears the end of life, allowing ample time for providers, patients, and families to plan for and participate in the dying process. Occasionally these issues may present themselves unexpectedly as a patient suddenly deteriorates. To promote a quality of dying that fosters peacefulness and dignity for all patients, long-term care units should work to articulate their mission or philosophy of care. <sup>30</sup>



Nursing Home Care Units (NHCUs) should develop explicit policies regarding care options for dying patients based on their philosophy of care and also within the context of the overall mission of the health care facility in which the NHCU is located. Occasionally, limits may have to be placed on patient and family autonomy when the patient's individual health care preferences or requests for specific treatments are outside the scope of the health care facility's mission. However, every effort should be made to develop care plans for dying patients that reflect and respect the values and preferences of the individual patient. In the NHCU, as in any other health care setting, providers should allow the patient to determine what counts as beneficial for himself/herself and to respect his/her choices.

In consideration of quality of dying issues, providers, other caregivers, and health care facilities may draw upon several ethical approaches for insight.<sup>31</sup> The justice or fairness of broad allocation decisions generally forms the framework of operationalizing the facility's overall health care mission.<sup>32</sup> On an individual level, the ethical principles of autonomy and beneficence form the basis of most personal health care decision-making in the United States. If health care decisions for individuals are made in the setting of a facility that has already reached broad operational decisions about the limits of patient autonomy and what constitutes beneficial care for some patients, then providers need not serve as health care resource gatekeepers and may function primarily as patients' advocates. Health care providers may utilize an ethic of care to view the concerns surrounding the dying patient from the perspective of the patient and his/her personal relationships, providing a highly individualized framework for the dying process. Virtue theory, for example, reminds providers that compassion and prudence can come together in a common sense approach to patient care. 33 Providers and other caregivers should draw on these ethical theories or perspectives to assist them in de-medicalizing the dying process and promoting a dignified, respectful, comfortable death.



#### Pain and Suffering

When caring for patients who are near the end of their lives, a primary concern is attention to comfort measures in order to relieve pain and suffering, to maintain personal functioning whenever possible, and to emphasize quality of life over quantity of life. Some NHCUs may choose to utilize a hospice care team as consultants whose main function is support of the patient through the dying process, attending to both physical and psychological needs. In VHA, these teams also provide pain management consultation to deal with specific issues of physical pain.<sup>34</sup> Clinical guidelines for "comfort measures only" may assist caregivers in appropriately caring for dying patients. For example, promotion of the patient's comfort might include limits on the use of artificial feeding devices, treatment of fevers with antipyretics rather than aggressive medical care, and maintaining cleanliness and moisture of the patient's skin. Caregivers should encourage family members to assist the patient through this difficult process.

Some caregivers find it useful to distinguish the more general concept of suffering from physical pain. Suffering may refer to physical, emotional, or spiritual symptoms. In the vast majority of dying patients, pain control is achievable using a full complement of pain control agents. Other physical symptoms that may cause suffering might include shortness of breath, weakness, gastrointestinal discomfort, and sleep disturbances. Psychological issues affecting the quality of dying may also need specific recognition and attention by caregivers to assist the patient in coping with his/her approaching death. Dying patients may be anxious or depressed, and they may be dealing with feelings of hopelessness, worthlessness, fear and apprehension. They may need help in coping with the enormous task of saying goodbye to family and friends and dealing with an overwhelming sense of loss. The long-term care facility should provide adequate training to its staff to recognize and manage these symptoms to ensure a high quality of support and care for the dying patient. Caregivers will also benefit from ongoing support for themselves in dealing with the emotional toll and special stresses inherent in caring for the dying patient.



For most patients, dying is a process. The care team should develop its care plan with regard to the overall dying process and not be inappropriately diverted from this plan by isolated medical events that may occur during or as part of the process. Prolongation of the process through some medical treatment options may not be beneficial to a patient. For example, a patient may fail to feed oneself or refuse feeding because he/she is far along in the dying process. This may be an event which could be anticipated and does not necessarily require intervention with artificial feeding devices. It may require, however, initiation of additional specific comfort measures. The care team should refer back to the health care goals as indicated in the care plan for the individual patient before making decisions about specific medical events in the course of care.<sup>35</sup>

#### A Caring Perspective

Until fairly recently in most Western societies, people have died at home either from a recognizable medical cause or from an unrecognizable but natural cause linked to the frailties of advanced age. <sup>36</sup> The experience of many caregivers is that most patients would still express a preference for dying at home if given the choice.<sup>37</sup> However, this is not possible for many patients. The nature of illness and related treatment or care may make it difficult for patients to remain at home and be cared for appropriately. The societal trend from extended to nuclear to single parent families and the geographic dispersion of family members may leave the patient with no family member(s) available to assist in his/her daily care. It may also be the case that otherwise available family members may not wish to care for a dying relative in their home. For example, many family members may have no previous close experience with death and may fear the actual circumstances surrounding the death itself or may not wish to have memories of a death occurring in a setting where they will continue to reside.

When patients die at home, the process may be accompanied by meaningful ritual and social interactions as friends and relatives gather around to say goodbye and perhaps to share memories or reflect on the

life of the one who is passing. These important rituals surrounding the dying person are often attenuated or may be missing in long-term care facilities. The NHCU can promote attention to these rituals by providing, for example, patient and family support groups. Such support groups may be able to offer some of the missing interactions necessary to bring social meaning to the remaining life and the death of these patients. Caregivers in any long-term care facility, and especially those taking care of dying patients, may develop a closer, more family-like relationship with the patient and the care plan may reflect this changed perspective. Care plans may be developed from a caring perspective. Caring or the care perspective is an emerging ethical perspective that provides a useful context for describing these complex caregiver/patient issues and has been discussed primarily in the nursing literature. <sup>38</sup>

Spiritual and pastoral caregivers are essential partners in the care of dying patients and are part of VHA hospice care teams. Caregivers should take the time to explore with the patient his/her perspective on spirituality and afterlife as part of the initial assessment. Often patients who have not been active members of an organized religion become interested in spiritual issues as they approach the end of their life. Pastoral caregivers may enhance the quality of the dying process and increase the comfort, both temporal and spiritual, provided the patient. They also may be a valuable resource to other members of the facility staff and the patient's family.<sup>39</sup>

#### Recommendations

- Health care facilities should develop policies that promote advance care planning and decision-making while the patient has decisionmaking capacity and is in stable clinical circumstances. Care plans should promote patient autonomy and enhancement of the quality of life for all patients, especially those who are dying. Family members should be involved in the planning process whenever possible.
- Caregivers and facilities should work to solve the logistical problems regarding implementation of advance directives that have become apparent since these documents have received more





- widespread use. This is particularly important for patients who are transferred from a long-term to an acute care facility. Facilities in VHA should strive to share their experiences with these problems and innovative solutions which they have developed.
- 3. Long-term care units should establish explicit policies or clinical guidelines regarding resuscitation and transfer to acute care facilities, pain management, and comfort care for patients who are near the end of life. These policies should be carefully explained and discussed with patients and their families. Care plans for individual patients should reflect thoughtful consideration of their health care goals, as well as a realistic assessment of their clinical condition. Long-term care facilities should consider a Do-Not-Hospitalize option for some patients when appropriate.
- 4. Caregivers should become keen student-observers of the dying process and ask patients, their own family members, and fellow staff about their own personal and clinical experiences. This open discussion may help caregivers become more comfortable with the dying process and more empathetic to the needs of dying patients and their families. Long-term care facilities should provide adequate clinical training and ongoing educational, social, and emotional support for caregivers who work with dying patients.
- 5. Caregivers should develop the skills to alleviate or ameliorate both physical and psychological suffering at the end of life. Consultation with appropriate specialists or comfort care teams should be utilized to maximize patient comfort and the quality of dying.
- 6. Caregivers should be familiar with the social and spiritual aspects of dying that contribute to the overall quality of dying for individuals. They should strive to appreciate the cultural and religious backgrounds of their patients to better promote a peaceful, comfortable, and respectful death.



#### The Caregiver's Perspective

#### Caregiver Support: Introduction to the Concept

Caregivers in long-term care may include the patient's family and significant others, volunteers, and health care providers caring for the patient. This section will focus on the support of the health care provider who is on the staff of a long-term care unit or facility and is involved in the care of patients on the unit. The staff who are most often faced with clinical ethical issues and decisions in long-term care are physicians, nurses, social workers, rehabilitation therapists, chaplains, and nurse assistants.

#### Unique Attributes of Long-Term Care Settings

The need for caregiver support in long-term care settings reflects the special attributes of the patients and the clinical setting. These patients include individuals who may be frail, elderly, and/or chronically disabled from medical or psychiatric disorders or both. (This discussion excludes from consideration those patients who are in a nursing home or spinal cord injury unit for rehabilitation with plans for discharge to home.) Many individuals in our society, including health care providers, have difficulty confronting and accepting advanced age and frailty for themselves and for others. Arriving at any consensus about what constitutes quality of life for this chronically disabled, institutionalized patient population is difficult. While much attention has been given by VHA to the training of staff and students in the care of elderly and chronically ill patients, continued support for the health care provider in long-term care is important. Ongoing education and training activities and use of support groups are examples of initiatives that may assist staff in dealing with difficult situations arising in longterm care.40

Long-term care settings differ greatly from acute care settings in ways that affect caregiver attitudes about their patients. Use of medical technology is more limited, and patients' medical problems are often more disabling and less reversible. Patient lengths of stay are longer and



often indefinite. The relationships between patients and staff often become close and personal, developing over time and often lasting several months or even years. Staff frequently become surrogate family for those patients who have no family involved in their daily lives. Collopy summarizes some of the ethical issues arising out of these relationships in this way: "Daily personal care shapes the ethical environment of a long-term care unit for staff providing the hands-on care. For the patients themselves, this care is liable to carry intensely personal relational meaning. On both sides of these relationships, problems can develop around issues of choice and control, dignity and competency, modes of authority and accommodation."41 Caregivers in long-term care need a structured forum in which to discuss the differences between responsibilities in familial relationships versus those in patient-caregiver relationships. A formal support group or ethics committee meeting devoted to the unique issues in long-term care settings may be an appropriate forum for these discussions.

#### Social and Institutional Perceptions of Long-Term Care

Society's perceptions of long-term care, as well as the health care institution's corporate perception of institutional long-term care, have significant impact on caregiver morale. The cultural view of nursing homes as grim keepers of the elderly seems still to prevail, even though much of it is based on past history rather than current reality, and on worst-case examples rather than more typical ones. <sup>42</sup> Caregivers may feel their work is undervalued by society. VHA's long-term care units and caregivers may be less affected by these negative perceptions than other long-term care facilities. VHA units are a well-recognized component of a large, comprehensive health care system required to meet the high standards prescribed by a single accreditation organization. The staff are well-trained in interdisciplinary primary care for long-term care patients. While well-respected in VHA, caregivers may still feel they receive less recognition and respect for their work from the community at large.

Literature about the health care institution's corporate perceptions of long-term care units is meager, but the value and expense of such care has been widely debated. At a time when fiscal resources are

limited and the demands of the expanding aged population on the health care system (both VHA and community) are projected to become even greater, debates on the high cost of institutional long-term care versus less costly community-based care are frequently heard. Decisions on resource allocation are being made at the corporate level of every health care institution. <sup>43</sup> The ethical issues related to these decisions should be discussed along with the fiscal issues. Caregivers in long-term care settings who have generally been strong advocates of elderly and disabled patients may find it beneficial to broaden their knowledge of ethical issues in resource allocation decision-making and become active participants in allocation decisions at social and institutional levels.

#### Ethical Issues Confronted by Caregivers

There currently is a limited but growing literature specifically relating to ethical issues in long-term care settings. 44 Collopy notes that in the world of bioethics, long-term care has lived something of a marginal existence, cutting its ethics from the cloth of acute care, largely from issues that cluster around autonomy, e.g., patient self-determination, medical decision-making, informed consent, and advance directives. 45 Two areas that are identified in the literature and important for consideration by caregivers are discussed below. 46

#### Conflict Arising When a Patient Refuses Nutrition

It is recognized that in the long-term care setting, a personal as well as a professional relationship develops between the patient and the caregiver based on their long-term association. As a result caregivers may be particularly troubled when a patient in their care requests withholding or withdrawal of treatment that will result in the patient's death. One of the most difficult situations for staff to deal with arises when a long-term care patient who has decision-making capacity decides that the time has come for him/her to die and refuses to eat or be fed.<sup>47</sup> Several issues arise in such situations, including respect for the patient's autonomy versus beneficence (professional responsibility to protect the patient's welfare), the question of whether the patient's



refusal of nutrition clearly communicates an informed decision about his/her care, and conflicting personal, professional, and institutional values.<sup>48</sup>

Caregivers' discomfort with these requests may be ameliorated by consideration of four issues. First, respect for patient autonomy requires caregivers to accept the competent patient's decisions regarding treatment. Second, careful discussion with the patient may reveal the basis for his/her decisions, e.g., a patient's religious views or family financial concerns. Third, judicial rulings support the right of patients to accept or reject treatment. Finally, many medical experts involved in palliative care believe that the withholding or withdrawal of artificial hydration and nutrition reduces suffering. This occurs by decreasing pulmonary secretions, reducing incontinence, and increasing a patient's pain threshold.

Although careful discussions with the patient, family, and ethics consultants and reflection from legal, religious, and philosophical perspectives may be extremely useful, caregivers who have provided high-quality and personal care over several months or years to a patient in a long-term care unit may still find it difficult to watch the patient slowly deteriorate and slip into death. Therefore, continuing support for the staff caring for these patients, as well as the family and significant others of the patient, is also critical.

#### Diversity of Cultures and Values

In the community long-term care setting, there is increasing recognition of ethical issues arising from the diversity of cultural perspectives, i.e., multiculturalism for nursing home administrators, ethicists, and ethics committees. <sup>51</sup> Although the VHA long-term care patient population differs in some respects from that in the private sector, notably in gender, the distribution of ethnic backgrounds, race, and religions is usually similar to the patient population in community long-term care facilities. In addition, staffing in VHA's long-term care units is as diverse as that in private sector facilities. Conflicts may arise when the cultural background of patients is different from caregivers

because situations are viewed from different culturally-based ethical perspectives.  $^{\rm 52}$ 

For example, one patient's cultural tradition values decisionmaking by family consensus versus the individual alone for all important life situations, including those related to health care. In a long-term care unit where patient autonomy in decision-making is highly valued and encouraged by the staff, a conflict between the patient, his/her family, and the staff over the meaning of autonomy may arise. A second example involves the impact of differences in religious beliefs. These differences may be more pronounced in the long-term care setting because of the amount of time that patients and staff are together in the long-term care setting. Strong disagreements over privacy, autonomy, and fairness may emerge when one patient, because of his/her strong moral beliefs, is offended by programs watched by his/her roommate on television. Sensitivity to and respect for the cultural beliefs and values of patients and staff is a first step in dealing with differences that create conflict among staff and patient. In some situations, no conclusive resolution will be possible. As Boyle noted: "Whether the clash of values is created by religion, ethnicity, race or gender, the incommensurability of the values will lead to an impasse at times. Nevertheless, the process of moral struggle is not merely to arrive at a clinical solution. Those who struggle to split the difference honor others and in doing so become more human."53

#### Ethical Principles as Guidance for Caregivers

The long-term care setting provides an opportunity, as well as a challenge, for caregivers to foster a relationship with each patient that considers the patient as an individual and in the context of family and community. Community for these patients includes the present environment of other patients and staff in the long-term care unit and the past social environment in which the patients resided. Caregivers in the long-term care setting frequently consider a broad range of issues with patients and their families, including patient-caregiver relationships, the quality of everyday living in a long-term care setting, decisions related to medical care, and the quality of dying. Three ethical



principles that may be used to guide these important discussions are autonomy, beneficence, and justice.<sup>54</sup>

Autonomy and beneficence were discussed earlier in this report as they relate to health care decision-making. In that context, autonomy is patient focused and beneficence is caregiver focused. Examples were given where tensions may arise between respect for patient autonomy and the caregiver acting beneficently. In these situations the importance that the caregiver maintain an appropriate balance between these two ethical principles was emphasized. The ethical principle of justice frames most discussions about equitable distribution of resources. In these situations, the patient's decisions regarding daily living and health care and respect for autonomy may need to be tempered with justice for the entire community of patients in the long-term care unit. Concerns about justice and the effects of a patient's decisions also may be relevant in consideration of burdens imposed on the patient's family.<sup>55</sup>

The care ethic is an emerging ethical perspective that may have broad applicability in the long-term care setting where relationships between patients, patients and caregivers, and among patients, families and caregivers are critical to decision-making and resolution of conflicts. 56 The care ethic is grounded in the assumption that self and others are interdependent. An individual's response to situations is viewed as arising from a knowledge of and respect for another individual or individuals. The care perspective has been contrasted with the ethical principle of justice, where caring encompasses feelings and practical reasoning in moral decisions and justice is focused on thinking and theoretical reasoning. In situations that arise in the long-term care setting where moral decisions need to be made, the care perspective does not necessarily negate the principle of justice, but focuses attention on different dimensions of the situation. Since the issues in long-term care are complex and involve many caregivers of various backgrounds helping patients and their families make profound health care decisions, consideration of all ethical perspectives could enhance the process.

#### Recommendations

- 1. Ongoing education and training in clinical ethical theory and moral decision-making should be provided for caregivers in long-term care settings.
- 2. Formal support groups for caregivers on long-term care units should be established to provide an opportunity for discussion of ethical issues that frequently arise in this setting. These support groups may provide an opportunity to work through frequently emotion-laden issues for caregivers with peers who share the same concerns.
- A forum for discussion of ethical decisions should be provided for families of patients and caregivers in long-term care settings.
   Appropriate forums may be family conferences or ethics advisory committee meetings.
- 4. A service for resolution of ethical issues unique to the long-term care setting should be established at each VA facility. The facility ethics advisory committee could assume this as one of their specific responsibilities. Inclusion of long-term care staff on the ethics advisory committee might facilitate the establishment of this type of service.

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Joint Commission on the Accreditation of Health Organizations (JCAHO) and others, reflecting an awareness of the home-like status of the facility for the individual. Individuals residing in other long-term care facilities who are spinal cord injured, terminally ill, or undergoing rehabilitation are more appropriately referred to as patients. For the purposes of this report, we will use only the term patient to refer to all of these groups of individuals.

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- VHA policy as set out in Chapter 30, "DNR Protocols," does permit surrogates to agree to a Do-Not-Resuscitate order since "the entry of a DNR order is essentially a question regarding treatment." For a discussion of the ethical issues arising in advance directives written by surrogates see the VHA Bioethics Committee Report on "Surrogate-Written Advance Directives" in this volume.
- For a more complete discussion of these terms see Brock and Buchanan, *Deciding for Others*.
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- <sup>42</sup> Collopy B. "Home versus Nursing Home," p.57.
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- This report is accompanied by a bibliography that provides an overview of the ethical issues in long-term care.
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#### **Bibliographic Resources**

**The Scope Note Series** provides an overview of specific topics in bioethics. All of the sources cited in the *Scope Notes* are available from the National Reference Center for Bioethics Literature and may be obtained through its document delivery service. For information call 1-800-MED-ETHX. *Scope Notes* are also published in the *Kennedy Institute of Ethics Journal*.

Scope Note 13. McCarrick PM. "The Aged and the Allocation of Health Care Resources." Washington, DC: Kennedy Institute of Ethics National Reference Center for Bioethics Literature, 1993.

Scope Note 25. Bishop LJ and Coutts MC. Religious Perspectives on Bioethics, Part 1. KIEJ 1994;4(2).

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obtained from the National Reference Center for Bioethics Literature at 1-800-MED-ETHX.

**Bioethics Literature Review** is published monthly by the University Publishing Group and includes recent bioethics literature organized by subject headings. Many of the citations include abstracts. For more information call 1-800-654-8188.

**"Bibliography of Bioethics"** is an ongoing project of the Kennedy Institute of Ethics that provides a comprehensive cross-disciplinary bibliography of current English-language bioethics materials. Citations are presented in both a Subject Index and an Author Index. In the Subject Index, related keywords are provided with each citation and some also include brief abstracts. Twenty volumes have been published to date and new volumes are published annually.

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*GRECC Forum on Aging Newsletter* is sponsored by the Office of Geriatrics and Extended Care, VHA Headquarters. It is published quarterly by the Geriatric Research Education Clinical Center at the Seattle & American Lake VAMCs. Address: Seattle & American Lake GRECC (182B), VA Medical Center, 1660 South Columbian Way, Seattle, WA 98108.

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