Introduction

An eighty-nine-year-old nursing home resident refusing to eat and taking only minimal fluids and sporadic medications is referred for psychiatric consultation and intervention. Already, she has been sent to the hospital emergency department three times for intravenous fluids. Some staff are distressed that she has not been enrolled in hospice and are appalled about her being “put through” a psychiatric evaluation.

She is frail, moderately demented, melancholic, and nihilistic. She says that she wants to be left alone to die. Is it appropriate to honor her request and recommend invoking hospice services? Should you advise that she is not competent to refuse care, and recommend treatment against her will? What if she has severe aortic stenosis with flash pulmonary edema and has recently endured three difficult ICU admissions? What if she has an over-enmeshed daughter who insists on futile care and favors a feeding gastrostomy so she can be administered antidepressants?

With such questions, not uncommonly faced by nursing home psychiatrists, I would like to introduce Volume 2 of the American Association for Geriatric Psychiatry’s long-term care forum, “The Clinical View—Geriatric Psychiatry in Long-Term Care.” This first issue highlights the critical contributions nursing home psychiatrists make to patients at the end of life. Ronald Bailyn and Joseph Rubin emphasize the importance of the regular presence of psychiatrists in nursing homes in order to be effective in end-of-life care. David Greenspan reviews ethical issues that psychiatrists may encounter in this context. Finally, Jules Rosen presents a case to illustrate the palliative benefit to dying patients of a psychotherapy relationship with a consulting psychiatrist. Subsequent issues dealing with psychosocial interventions and unique behavioral challenges will further emphasize the importance of eclecticism in nursing home psychiatry. Volume 2 will be rounded out with an issue covering practice management considerations in long-term care psychiatry.

I hope you find “The Clinical View” interesting and helpful. If you have ideas for topics you would like to see covered in Volume 3, please feel free to contact me at ClinicalView@aagponline.org. I would like to thank the members of the Editorial Advisory Board for their assistance in topic selection and content and the authors for their well-written articles. Finally I would like to thank AstraZeneca for the unrestricted education grant that made this project possible.

By Gary S. Moak, M.D., Editor-in-Chief
Author Disclosures
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Ronald E. Bailyn, M.D.—Reported being on the speakers’ bureau of Pfizer and Lilly.

David Greenspan, M.D.—Reported no actual or potential conflict of interest in relation to this educational activity.

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Joseph E. V. Rubin, M.D.—Reported no actual or potential conflict of interest in relation to this educational activity.

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Intended Audience
This activity is intended for psychiatrists.

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Learning Objectives
Upon completion of this activity, participants should be able to:

• Illustrate the difficulty in distinguishing among and between experiences of psychiatric illness, the symptoms of general medical conditions, and the normal reactions to extreme life circumstances.
• Explain the relationship between treatment success and a well-established working team.
• Define the four common principles that encompass a medical ethics analysis.
• Discuss familiar issues that raise ethical questions during psychiatric nursing home care.
• Describe the variety of effective tools that geriatric psychiatrists can use in end-of-life care.
Psychiatric Treatment Challenges at the End of Life

By Ronald E. Bailyn, M.D., and Joseph E. V. Rubin, M.D.

An 83-year-old man with severe heart failure and macular degeneration becomes anxious and depressed. He repeatedly changes his advanced planning decisions choosing emergency transport from home and aggressive treatment for illness exacerbations. Within days of moving to a nursing home he dramatically shares his plans for suicide by asphyxiation.

A 70-year-old woman with a long-standing schizoaffective illness with paranoia develops metastatic lung cancer. She leaves the perceived safety of her home and moves between assisted living, hospital, and nursing homes. She is fearful of dying alone and frequently believes her caregivers wish to poison or otherwise harm her. Both are patients in long-term care settings where psychiatric care is allowed for quality of life at the end of life.

Nearly 2.5 million Americans die each year. By 2020, it is predicted that 40 percent of all deaths in the United States will occur in nursing homes. While death is not a psychiatric disorder, nearly 59 percent of terminally ill cancer patients seriously desiring death may have depressive syndromes. As with terminally ill cancer patients, psychiatry has an important role at the end of life, whether the issue is a new psychiatric disorder or the challenge of approaching death for an individual with persistent mental illness. We must advance from the current position where psychiatry’s “presence is only beginning to be felt” in the care of the terminally ill.

Where can psychiatry contribute? One of the challenges to recognizing the need for psychiatric treatment at the end of life has been the difficulty in distinguishing among and between experiences of psychiatric illness, the symptoms of general medical conditions, and the normal reactions to extreme life circumstances. Psychiatry is well positioned to collaboratively assess the etiology and appropriate response to patients presenting with issues of loss, grief, anxiety, depression, hopelessness, personality change, and confusion. Psychiatrists also can provide the sophisticated assessments needed in “gray area” capacity evaluations when a patient's cognitive or emotional abilities for medical and other decision making are in question. Our psychotherapy and mediation skills can assist patients, families, and providers when the stress of approaching death triggers unusual conflict. Psychiatrists also are making strides in recognizing and responding to the spiritual and cultural needs of the patients in our care.

As a medical director of a nursing home and a psychiatrist providing consultation and treatment services, we believe that the best means of providing high-quality end-of-life
As a medical director of a nursing home and a psychiatrist providing consultation and treatment services, we believe that the best means of providing high-quality end-of-life psychiatric care in the long-term care setting is to establish programs that offer collaborative on-site psychiatric care for the severely medically ill.

psychiatric care in the long-term care setting is to establish programs that offer collaborative on-site psychiatric care for the severely medically ill. We hold this opinion for two reasons.

First, while the origin of the palliative care movement brought a much needed focus on the care of the patient with terminal cancer, the psychiatric care appropriate to the end of life will increasingly involve patients with end-stage chronic illnesses such as diabetes, lung disease, heart disease, and progressive dementia. In these cases, the terminal phase of illness is more difficult to predict.

Second, as important as an individual psychiatric clinician can be in the care of a particular patient, establishing programs of psychiatric care provides the best chance for the identification and treatment of psychiatric disorders in the nursing home and assisted living settings. A greater engagement in the emotional needs of residents occurs when a facility’s staff understands that psychiatric expertise is readily available and that plans of care will be constructed by clinicians who know the staff and the reality of the work.

The patient with heart failure was a gruff and emotionally isolated man whose life experience had been significantly shaped by harsh experiences in World War II in Europe. His sense of self had much to do with his substantial business success, previous active leisure pursuits, and the practical support of his disabled wife. His adult daughter was extremely upset by his profound distress and desire for death. Seeing the apparent impotence of initial treatment efforts, she drew on her knowledge of palliative treatments to advocate for narcotic treatment for his anxiety even, in her words, “if it shortens his life.”

Through individual and family psychotherapy, his experience of isolation, concern with leaving his wife behind, ongoing importance to his children and grandchildren, and fears of an uncomfortable death were addressed. Acknowledging the limits of research on psychopharmacologic treatment at the end of life, informed treatment was undertaken, aided by nursing staff observations. Later treatment included the use of stimulant medication for fatigue and depression. The patient showed a significant reduction in his anxiety and depression. While never a popular resident, he gradually developed positive relationships with several staff members and began to re-engage in his life. He died at the nursing home holding to a decision to forgo aggressive care.

Successful psychiatric care for this patient was greatly facilitated by a care staff, primary care physician, and psychiatrist who knew each other and were comfortable working as a team. Staff members had received both formal in-service training on mental health topics (supported by a small contract for non-clinical services) and informal psychiatric education in the process of clinical care. General criteria suggesting the need for an attending physician to evaluate the appropriateness of direct treatment or psychiatric referral had been reviewed. A facility policy on nursing assessment and environmental management of patients with thoughts of suicide had been established with input from the psychiatric clinicians.

Good psychiatric care for the woman with cancer was a significantly greater systemic challenge. Treatment again succeeded in large part because of established relationships. The patient had strong connections with her psychologist and clinical nurse specialist. They were able to help bridge connections to new providers and offer a degree of stability across changing environments and treatments. The patient’s primary care physician respected the role of psychiatry in the patient’s care and sought informal input when the patient was hospitalized or domiciled at facilities where the psychiatrist lacked privileges. Periods when office contact was possible allowed for the early detection of delirium against the backdrop of a frequently disorganized psychotic illness. Mood stabilizer and antipsychotic treatments were appropriately adjusted. The psychologist worked with the patient’s family, care manager, and residential staff to promote understanding of her psychiatric illness and end-of-life needs.
A significant part of the psychiatric care provided was not billable under current insurance parameters. The patient was at times able to movingly express her feelings of a life “half-lived” due to her struggle with psychiatric illness as well as her fears of physical pain and of being abandoned by her children. She died in relative physical and emotional comfort with her family present. Her obituary included specific appreciation for the efforts of her primary care physician and psychologist.

The palliative care and hospice movements have done much to expand and improve end-of-life care. Widely endorsed core principles for end-of-life care recognize the importance of psychological health and the need to provide access to treatments that may “realistically be expected to improve the patient’s quality of life.” To deliver on these principles, psychiatrists need to expand the current body of end-of-life care research and promote mental health service delivery and training in the long-term care settings. We also will need to actively address the barriers of stigma, the normalization of severe end-of-life depression, and the inadequate insurance benefits and carveouts for our care.

### Resources

**Websites**

Education for Physicians on End of Life Care (End of Life/Palliative Education Resource Center):
www.eperc.mcw.edu

Growth House:
www.growthhouse.org

American Academy of Hospice and Palliative Medicine:
www.aaahpm.org

Harvard Medical School Center for Palliative Care:
www.hms.harvard.edu/cdi/pallcare

Project on Death In America:
www.soros.org/death

Academy of Psychosomatic Medicine:
www.apm.org

See position paper on end-of-life care.

American Association for Geriatric Psychiatry:
www.aagponline.org

**Journals**

Journal of Palliative Medicine:
www.liebertpub.com

Journal of Palliative Care:

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**References**


Ethics in Geropsychiatry
Long-Term Care

By David Greenspan, M.D.

You hear a growl as you walk into the small crowded nursing home room. Three others watch as you pull away the curtain to see a young man glaring at what must be your patient Ms. Mary T. He has the oatmeal all over them both, fencing with a spoonful. But Mary’s stare, her lightning quick hand, and clenched teeth defend her mouth like a hockey goalie. You quickly appreciate the meaning of the consultation request, “Evaluate patient, non-compliant. Is she competent to refuse a feeding tube?”

Every clinical situation such as this one has embedded three distinct questions: what can I do, which is the clinical question; what must I do, which is the legal question; and what should I do, the ethical question. The code for geropsychiatrists, the American Medical Association code of ethics with annotations to psychiatry, constrains us, and devalues certain clinical solutions as it elevates our contributions to the health and welfare of our patients and society.

The code utilizes four principles that must be then balanced in a medical ethics analysis. The first principle asks us to protect a patient’s individual rights and privacy, or autonomy. The second principle warns us to do no harm, or non-malfeasance. The third principle requires us to act with beneficence, or to do good. The last principle demands that we act with justice or fairness. Any attempt to guide recommendations for Ms. Mary would need to weigh these four principles.

Ethical Issues Common to the Long-Term Care Setting

The typical nursing home is a “hot bed” of ethical challenges. The residents of the typical home have already lost much of their independence, may have few resources, are commonly confused, disabled, and may not have an effective advocate. They are always dependent on others and endure greatly reduced privacy. In short, the nursing home resident represents the most vulnerable in our society. In addition, the staff of these facilities may have limited training, substantial work demands, and limited resources. These factors can combine to create the following issues, which should raise the ethical “red flag”:

Informed Consent—In our case, Ms. Mary is refusing food. Autonomy supports Mary’s choice even if it conflicts with staff preference. We often need to advocate for

Confidentiality: Whom to Tell and What to Tell—Privacy is a concept embedded in autonomy and has been in each code from Hippocrates to the present American Psychiatric Association. Should Ms. Mary’s son be consulted about her condition? If Ms. Mary refuses his participation, should we honor that refusal? Assuming the impaired elderly need family or staff involvement demeans their right to privacy. But if Mary’s decision-making capacity is suspect, consulting someone close to her, such as her son, may be invaluable to protecting her rights.

Behavior Problems—Ms. Mary’s “agitation,” in this case, throwing food, may be her best effort at protecting herself and her autonomy. Her anger is evidence that confronting her can cause psychological harm. Forcing her to participate in an evaluation, or to use restraint and a feeding tube, can cause further psychological harm and potential physical harm. However, beneficence warrants an intervention to reduce Ms. Mary’s immediate distress. We cannot ignore her presumed suffering, which is likely contributing to her refusal of food and resulting in pain from starvation. Justice demands attention to everyone’s needs and the precedents set by past decisions. When is it “fair” to let Mary starve, or provide one-on-one care, or put staff at risk when feeding her? Ethics requires a balanced approach utilizing least restrictive means to assist Ms. Mary as well as attention to her autonomy and the distribution of nursing home resources.

Diagnostic Truth-Telling—There is no consensus around truth telling and dementia. Even in the early stages, there are those who see little to be gained by informing patients that they have a progressive disease without cure. Non-malfeasance would want to protect them from this news, or as a member of Ms. Mary’s family might say, “Don’t tell Mom.” Others argue that the patient must have the opportunity to know and therefore plan. For them, the preservation of autonomy outweighs the “harm” that the truth might bring.
Prevention/Primary Treatment—Prescribing pharmacological agents such as acetylcholinesterase inhibitors can have side effects or have the inadvertent effect of causing patients to reexperience cognitive or functional “losses twice,” which means taking the principle of non-malfeasance and justice into account. Yet, often they can improve quality of life, which upholds the principle of beneficence, and increase autonomy. Ethical conduct demands attention to these questions. Understanding how Ms. Mary might feel about these issues can be a useful guide.

Death and Dying—Advanced Directive “Over-ridden”—Death and dying, humanely with minimal pain and with a maximum opportunity to have one’s wishes expressed, have led to some of the best known cases in the ethical and legal literature. When, if ever, does a frail, elderly patient near the end of life have a right to die of depression?

Research—This area has come under considerable scrutiny in the past five years. If patients are unable to consent for themselves, what protections are needed to balance against the possible good that comes from the research findings? How trustworthy are those whose livelihoods depend on subjects in a research protocol? With the abuses of the Tuskegee experiments and those revealed during the Nazi Nuremberg trials still accessible for comparison, neither the resulting knowledge nor a reliance on the ideal that scientists are “above doubt” will be satisfactory.

Facility Quality of Care—In order to deliver care, we need referrals. Moreover, justice demands that we distribute our time and expertise fairly. This obligation can create a dilemma when we serve in facilities where the quality of care is less than optimal. The legal and ethical obligation to report abuse is clear. But without compensation for staff teaching, program evaluation, and improvement, we may be forced to choose between risking our referral relationship, accepting the status quo, or volunteering time to address a facility’s limitations. Patients in all facilities need care. In many cases, balancing the “have’s” with the “have-not’s” can be a viable solution. Advocating for staff training and compensation for program development also can satisfy this ethical demand.

In Summary
Ms. Mary T was not demented. Instead, her refusal to eat was based on a delusion that food and medicines were poison. She believed her situation and made logical and free choices. But the psychosis altered the “knowledge” that she utilized. She was happy to have her son support her refusal of a feeding tube. But he also allowed for involuntary antipsychotic medication that she took after a court order. As her delusion resolved she began to eat, appreciating how ill she had become. But Ms. Mary never wanted to see “that doctor who forced me to take medication. He should treat his elders with more respect!”

Ethics augments expertise by guiding professionals toward an ideal standard of behavior. Utilizing the four principles of autonomy, non-malfeasance, beneficence, and justice can usually provide the tools to achieve the best outcome for our patients, their families, and the community at large.

References


Websites
American Association for Geriatric Psychiatry: www.aagponline.org/prof/position_end.asp
American Psychiatric Association: www.psych.org
Bioethics.net: www.med.upenn.edu/bioethics/
Canadian Medical Association Journal’s clinical bioethics series: www.cmaj.ca/
Wishing for Death

By Jules C. Rosen, M.D.

IS THE ROLE OF A GERIATRIC PSYCHIATRIST TO CURE DEPRESSION IN AN ELDERLY PATIENT WHO IS TERMINALLY ILL? NO, OUR ROLE IS MUCH GREATER THAN THAT.

I was asked to see a 93-year-old woman who was admitted to the nursing home three weeks earlier. She had been eating poorly, had lost more than 12 pounds, and had openly expressed her willingness to die.

Approximately three months prior, she was on a cruise with one of her gentleman friends when she suffered a stroke resulting in paralysis on the left side of her body. She told me that she did not feel depressed, but rather, she was convinced it was her time to die. She had no living relatives in Pittsburgh, where she lived, and would not consider moving to another city for fear of “burdening” others.

After reviewing her symptoms, I informed her of my diagnosis of depression. I explained that depression often is associated with strokes and clarified to her that feelings of sadness are not necessarily dominant. I offered to treat her. She smiled and asked what the treatment would entail. I offered a trial of antidepressant medication. She told me I was naive and although she refused medication treatment, she willingly agreed for me to see her in one week.

Then for each of us the moment comes when the great nurse, Death, takes us by the hand and quietly says, “It is time to go home. Night is coming. It is your bedtime, child of earth. Come; you’re tired. Lie down at last in the quiet nursery of nature and sleep. Sleep well. The day is gone. Stars shine in the canopy of eternity. —Joshua Loth Liebman
I met with her for twenty minutes weekly for the next three weeks. She told me of her husband who died in 1939, and her only son who was killed in World War II. After years of feeling “lost,” she discovered that she could express herself as a writer. She had published poems, short stories, and magazine articles. She told me about her travels, her friends, and her lovers. She regretted that she would die before she could complete her novel. That was the only regret she expressed to me.

She appeared to enjoy our visits and told me that she looked forward to seeing me again. However, her appetite remained poor, her weight loss continued, and her death wish persisted. At my fourth visit, we once again discussed her wish to die. By that time, I appreciated the richness of her life and her feelings of accomplishment. I clearly understood her willingness for death.

As my understanding of her grew, she also gained new insights. She understood that her days of travel were over, but not necessarily her days of writing. She seemed to appreciate how I was able to learn from her. Perhaps, this made her feel useful once more. She finally accepted a trial of antidepressant medications.

She died three days later.

At first, I felt cheated. If only she had accepted the medication during our first visit, perhaps things would have gone differently. Perhaps she would have regained her appetite and her strength.

Some months later, I was thinking about my experience with this dying patient. Could I have been more aggressive in pushing for treatment of her depression? I realized that although the patient died, I felt secure in my actions. I respected her individuality and her need to maintain control over her life. The time I spent talking with her, reminiscing about the pains and the pleasures of her life, brought her a sense of comfort. This, by itself, was a relief from her only other expressed hope, which was for a peaceful and swift death.

This experience helped me better understand my responsibility as a psychiatrist caring for patients who are facing death. As psychiatrists, we often face the question of how aggressively to treat depression in a dying patient. Patients who are terminally ill may benefit from antidepressant medications, but there is no evidence to support that belief. Therefore, it is important that we expand our concept of treatment beyond the “pill.” Treatment may involve supportive therapy, hospice care, spiritual counselors, family support, as well as medications. Despite my patient’s persistent symptoms, and finally her death, I feel that this was a successful treatment. We had developed a strong therapeutic alliance, and she agreed to medication, in this context. Until the end, she maintained control over important aspects of her life, even as that life was slipping away.

Working with end-of-life depression requires the entire toolbox that geriatric psychiatrists bring into every patient’s life. It may be discomforting and make us feel powerless, but we must keep in mind that while our capacity to cure is imperfect, our capacity to comfort is unlimited. Understanding our role as the comforter will help us attain the cure for some patients and comfort for others. Death need not be dreaded.
On the answer form located on the next page, please circle the letter that corresponds to the single most appropriate answer for each of the following questions.

The deadline to receive credit is one calendar year from the date of publication. A CME Certificate will be sent to should you earn a passing grade of at least 70 percent.

1. By 2020, the percentage of deaths in the United States predicted to occur in nursing homes is:
   A. 70%
   B. 60%
   C. 50%
   D. 40%

2. The best means of providing end-of-life psychiatric care in long-term care settings is to:
   A. Encourage the practices of individual psychiatric clinicians
   B. Establish collaborative on-site psychiatric care
   C. Rely on staff to request consultations when needed
   D. Rely on family requests for consultation

3. To improve the patient’s quality of life at the end of life in nursing homes and other long-term care settings, psychiatrists must:
   A. Expand current end-of-life research
   B. Promote mental health service delivery
   C. Promote training
   D. All of the above

4. In deciding how to treat depression in a dying patient, psychiatrists must:
   A. Start medication as soon as possible
   B. Do nothing, depression shouldn’t be treated at the end of life
   C. Use a toolbox of devices that includes counseling and family support
   D. Rely on the input of nursing home staff for the best course of action

5. Freedom from being coerced, receiving adequate information needed to make a choice, and the capacity to process the information are all components of:
   A. Intuition
   B. Non-malfeasance
   C. Beneficence
   D. Autonomy

6. An important element of autonomy is:
   A. Privacy
   B. Justice
   C. Non-malfeasance
   D. Affordability

7. Name a factor that hampers the care provided by nursing home staff.
   A. High demands
   B. Language barriers
   C. Rundown facilities
   D. Poor training

8. The nursing home resident makes an autonomous decision when the patient:
   A. Readily agrees to a psychiatrist’s treatment plan
   B. Has the capacity to process information and is free from being coerced
   C. Decides it is time to die
   D. Refuses to eat

9. A dilemma of prescribing "acetylcholinesterase inhibitors" to a patient is:
   A. Improvement of condition versus prolonged debilitated state
   B. Helping one patient versus distribution of resources
   C. Best treatment versus rate of reimbursement
   D. Patient’s wishes versus family wishes

10. A substituted judgment is when:
    A. A family member makes a treatment decision for the patient
    B. The court decides on treatment for the patient
    C. The patient’s court-appointed guardian recommends a course of action
    D. A psychiatrist decides what treatment a patient is to receive
Personal Information

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Activity Evaluation

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Discuss familiar issues that raise ethical questions during psychiatric nursing home care. Yes No

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Did you find this activity to be fair, balanced, and free of commercial bias? Yes No

Comments:

Practical End-of-Life Psychiatry:
CME Self-Assessment Test Answer Form

Please circle the letter that corresponds to the single most appropriate answer and fax this page to the American Association for Geriatric Psychiatry at 301-654-4137 or mail your response to:

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Amount of knowledge gained:

Great 5 4 3 2 None

Level of material presented:

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1.0 1.25 1.5

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