Primary responsibility for managing ethics issues in nursing home patients falls to the attending physician in conjunction with the patients, families, and staff. The medical director is responsible for (1) helping establish and implement appropriate care systems and (2) for helping ensure that physicians and nursing facility staff apply appropriate care processes and practices to the care of individual residents and patients. Therefore, these comments on the cases in this series will consider (1) how the medical director can help nursing facilities develop and implement relevant systems and processes to manage ethics issues in their residents and patients, (2) the attending physician’s role in helping a facility manage individual cases, and (3) potential medical director interventions in individual cases to help the attending physician and facility fulfill their responsibilities more effectively.

OVERVIEW OF ISSUES REPRESENTED BY THIS CASE

An 80-year-old woman was admitted after hospitalization for an acute medical illness. She also had several significant chronic conditions including diabetes mellitus, peripheral vascular disease, and urinary and fecal incontinence.

After admission to the Hebrew Rehabilitation Center for Aged (HRCA), she had symptoms of psychosis as well as her underlying dementia, which were affecting her medical care and performance of basic activities of daily living (ADL)-related tasks. However, her daughter refused some recommended medications. The treatment team believed that the daughter was not acting appropriately as a substitute decision-maker. Eventually, a state-appointed guardian replaced the daughter as a substitute decision-maker.

After several years of relative stability, the patient’s medical and psychiatric condition deteriorated further. Her food and fluid intake became inadequate, but the patient’s advance directives had limited the use of artificial nutrition and hydration. And, apparently, the court order related to guardianship had limited the maximum antipsychotic dosage that could be used. Eventually, the patient became less resistant to hydration. And, apparently, the court order related to guardian-ship had limited the maximum antipsychotic dosage that could be used. Eventually, the patient became less resistant to hydration.

This case presents issues related to establishing a patient’s condition and prognosis, the role of a primary decision-maker, and identifying and presenting treatment options and obtaining treatment decisions.¹

ESTABLISHING CONDITION AND PROGNOSIS

As this case illustrates, substitute decision-makers may make decisions that are inconsistent with an incapacitated person’s needs as related to a medical condition. Sometimes, these inconsistencies stem from a misunderstanding of the condition or the proposed treatment, while at other times they result from different interpretations of whether a treatment is in a person’s best interests. This case discussion does not clarify whether the daughter misunderstood her mother’s medical condition and the nature of the proposed treatments, or if she disputed the proposed approaches despite understanding these things.

Historical concerns about the excessive use of psychotropic medications to treat uncomplicated dementia or random behavioral symptoms have been warranted. But often laymen, nursing home staff, and state and federal surveyors misunderstand the nature of psychosis and the substantial benefits of psychoactive medications for some of those people with psychotic symptoms that are not due to underlying treatable conditions such as fluid and electrolyte imbalance.²

The medical director can help clarify these issues by, for example, explaining the difference between dementia and psychosis, explaining how psychosis may contribute to functional decline, or showing examples of evidence about the effectiveness of antipsychotic medications in certain situations.

IDENTIFYING A PRIMARY DECISION-MAKER

In this case, the patient’s impaired decision-making capacity was not disputed. However, there were concerns about the daughter’s performance as a substitute decision-maker. In addition, other family members appeared to disagree with some of the daughter’s decisions.

Many patients do not appoint a substitute decision-maker. Often, substitute decision-makers, whether appointed or not, are either unavailable or inadequately prepared for their responsibilities. They may be incapable of performing the function because of illness, impaired cognition, or inability to understand the issues presented. Or they may not be able to distinguish their own wishes and interests from those of the person they are supposed to represent. State laws regarding substitute decision-making often identify both unavailability and incapacity of a substitute decision-maker as legitimate reasons for seeking another one. But there is less clarity about the situation where others disagree about the wisdom or judgement of the primary decision-maker.

When concerns arise about a substitute decision-maker, the medical director may help the facility staff decide which, if any, of these issues apply. For instance, the medical director

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might discuss the situation with the attending physician regarding his/her conversations with that person or may speak directly with the substitute decision-maker. As always, it is important to ask the individual about the basis for his/her requests or refusal, not just to discuss the reasons why the request or refusal may not be appropriate. The medical director’s evaluation of a substitute decision-maker’s responses may help the facility and courts identify situations in which someone else should assume these responsibilities.

IDENTIFYING AND PRESENTING TREATMENT OPTIONS AND OBTAINING DECISIONS

This case also illustrates some interesting issues related to presenting and obtaining treatment decisions. Concepts that are second nature to physicians, for example, psychosis and its appropriate treatments, may confuse others. A medical director may help a facility’s staff understand complex technical information so that they can present it effectively to others, for example, a substitute decision-maker or judge. Sometimes it may be necessary to write the information down for, or present it directly to, the patient or family.

It would be interesting to know what role a physician might have played in this case in presenting or helping to prepare the information for the court. It is difficult to imagine how any court could feel justified in dictating limitations in medication dosages, as apparently happened here. Psychosis often requires treatment with antipsychotic medications. Untreated individuals with psychosis often decline functionally or can die because of unmet needs. In this case, the patient’s psychosis adversely affected her quality of life. She needed antipsychotic medication but could not receive the dosage or medications she needed because of lay interference, both by the daughter and the judge. It is not clear whether either understood what they were doing. Although the case report closes by indicating that she appeared to improve, her symptoms are likely to return subsequently, requiring the same issues to be addressed once again.

The medical director can also help others identify how the proposed treatment relates to the goals for the patient. Of course, a treatment may be medically effective yet ethically undesirable, that is, while it may address the underlying medical condition, treating or resolving that condition is not likely to help achieve the overall goals for that individual. In this case, all parties appeared to desire Mrs. M’s stabilization or improvement, although her general condition was declining with time. Therefore, inhibiting potentially effective treatment does not appear to be consistent with the goals for this patient, at least at present.

In this case, physicians were undoubtedly trying to talk with the daughter, but it is not clear what information they presented or how they formulated it. It is also not clear whether a physician was involved in preparing or presenting the information for the court, or whether that was done via the ethics committee or the facility administration. Even if an ethics committee formulates a response or recommendation, a knowledgeable health care practitioner may need to present or interpret the information for others.

In addition, it may be worth noting that many years of regulations (plus the inappropriate interpretation of them by nursing homes and physicians) may have reinforced, not clarified, the sometimes hysterical misunderstanding of the nature and usage of psychotropic medications. It is not unusual for families or others (administrators, ombudsmen, etc) to demand that only certain psychoactive medications be used or to insist that only certain dosages can be used. Despite some progress related to the use of older antipsychotics (pentothiazines and butyrophenones), psychoactive medications still are apparently used ineffectively. That is, there may be inadequate treatment in situations where aggressive antipsychotic therapy is warranted, and there are many adverse drug reactions (ADRs) caused by using multiple categories or excessive dosages of supposedly “safer” medications. In their role as educators, medical directors may be able to help their facility staff and families better understand these technical issues. And, in their role of overseeing the facility’s quality of care and the physicians’ clinical practices, they can try to ensure that the patients receive appropriate care. Appropriate evidence-based care can help improve ethical decision-making by ensuring that treatments do the most good and the least harm possible.

REFERENCES


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