Overview of Issues Represented by These Cases

Steven Levenson, MD

Two cases are presented this month. The first case concerns Ms. O., a 75-year-old nursing home resident with marked functional dependencies due to Parkinson's Disease. The resident was seen engaging in sexual activity. The staff was concerned about the resident's competence and about whether to inform the family. Matters were complicated by the resident's husband being the primary decision maker.

The staff requested a psychiatrist to evaluate the resident's decision-making capacity; especially, her capacity to consent to a sexual relationship. She was determined to have the decision-making capacity to consent to this relationship.

In this case, the resident's husband was the designated substitute decision maker. However, the staff decided that they were not obliged to inform her husband about her sexual activity. They contended that the resident's autonomy took precedence over the husband's right to know about anything other than health care decisions.

Case 2 is that of Mrs. P., an 85-year-old woman with vascular dementia and treated depression, who was having sexual activity with another resident with mild dementia. The activity occurred in public areas. Although the staff believed that she was capable of consenting, a son insisted that the staff intervene and prevent such activity. However, the resident's daughter—her health care proxy—apparently did not object.

A psychiatrist determined that the resident could consent to the relationship, despite her cognitive limitations. Discussion with the family apparently helped to reduce the son's objections. The staff took measures to provide the resident with privacy.

MEDICAL DIRECTOR ROLES

These cases illustrate several issues relevant to medical directors. As with end-of-life issues, decision making about “everyday” ethical issues also involves similar steps (Table). Medical directors can be involved successfully in several ways: (1) ensure that the process is followed effectively, in order to optimize decision-making capacity in individual cases, (2) intervene effectively in case of disagreements or need for clarification, (3) evaluate the quality of the facility’s decision making by evaluating the performance of those steps.

ESTABLISHING CONDITION AND PROGNOSIS

As with end-of-life decision making, it is important to identify any underlying conditions that could affect the individual's decision-making capacity. Both of these residents had some cognitive impairment, although from different disorders. Mrs. P. also had a history of depression. As the authors note, it is possible to retain some decision-making capacity despite having cognitive impairment. Decision-making capacity can vary, and may depend on the decisions to be made at a given time. The presence of active depression may also affect the ability to make decisions in one's own interest.

An important role for the medical director is to ensure that staff and physicians distinguish symptoms and causes, and ensure that they define the issues correctly. Not uncommonly, nursing home staff react to undesired or socially inappropriate behaviors, and may attribute them to existing diseases or conditions. It would have been easy to try to attribute the sexual activity of both of these individuals to pathological conditions such as dementia or depression, thereby making behavior into pathology, leading to seeking medications or other treatments to try to suppress the behaviors.

In each case, however, it appears that the staff appropriately tried to make these distinctions. They requested additional evaluation to determine whether these were pathological behaviors or simply behavior requiring social decisions and environmental adjustments. Similar clarification should occur in all nursing homes for any behaviors. The medical director should guide the staff and physician to perform proper problem definition, and intervene appropriately when these processes are inadequate.

IDENTIFYING PATIENT WISHES

In both of these cases, it was important to clarify the resident’s wishes. In cognitively impaired individuals, expressions of wishes may be implicit rather than explicit; that is, they may show what they want by doing something, but may not be able to explain their desires or reasons in detail. The medical director should help the facility ensure that patient wishes are determined effectively, and that their participation in such activity with another person reflects their wishes.

In both these cases, it was comparatively clear that the sexual activity was desired and not coerced. Often, however, the evidence is more ambiguous. As a consultant or as a member of the ethics committee, the medical director should ensure that the staff and physician have accurately identified the individual's wishes or used available evidence to determine those wishes as best as possible.

ESTABLISHING DECISION-MAKING CAPACITY

Each of these cases presented challenges to determining decision-making capacity. The medical director should ensure that decision-making capacity is determined appropriately. Partial decision-making capacity should be recognized, and
the individual’s participation should be targeted to the extent of their capacity. In each case, decision-making capacity was considered adequate for consenting to participation in sexual activity, although criteria for such capacity are not well established. As in other situations with partial decision-making capacity, participation may need to be identified for each situation that arises.

In the case of Mrs. P., the current status of her depression was also relevant. An actively depressed individual may or may not be capable of making appropriate decisions and acting in his or her best interest. But, the mere existence of a diagnosis does not necessarily imply that actions are prudent or irrational. As in many other situations, the medical director may need to help the staff distinguish between a diagnosis and a problem; that is, an individual can have a diagnosis but not have a problem (for example, have a diagnosis of depression but not be depressed) or a current symptom or action may be related to something other than an existing diagnosis (for example, confusion in an individual with chronic obstructive pulmonary disease may be due to fluid and electrolyte imbalance rather than hypoxia).

**IDENTIFYING THE PRIMARY DECISION MAKER**

The medical director should help ensure that the appropriate primary decision maker is consulted, which may be either the patient or an appropriate substitute decision maker. The case of Mrs. O. is of interest because her husband was the primary decision maker, yet the staff decided that he shouldn’t be consulted in either capacity (as husband or as primary decision maker) regarding her sexual activity. Mrs. P. also had a health care proxy, but here again the staff considered her to be able to make decisions about sexual activity without involving a substitute decision maker.

Many nursing homes might not agree with these conclusions. As the individual with primary oversight of care practices, the medical director should help ensure that such decisions have a rational rather than an emotional or excessively legal basis. The medical director may also need to promote alternative ways to address liability and regulatory concerns without imposing unwarranted restrictions or treatments. When applicable, the medical director should help the facility influence a substitute decision maker to focus on the resident’s “best interests” in making treatment requests.

**PRESENTING AND OBTAINING DECISIONS ABOUT MANAGEMENT OPTIONS**

As with treatment options for end-of-life care, review of management options in cases of everyday ethics should emanate from the appropriate application of the preceding steps. The medical director should help ensure that the attending physician and staff identify and offer relevant options.

In both these cases, the facility staff and practitioners appeared to strongly support the notion of autonomy; that is, an individual with sufficient decision-making capacity has the right to make decisions and the staff should support those decisions. The conclusion in both of these cases was to manage rather than treat the situation. Again, this stems from determining that these were not pathological behaviors needing medical interventions, but were nonetheless sensitive enough to require some management. The management also depended on determinations of decision-making capacity and consideration of the rights and sensitivities of other residents and staff.

However, many nursing homes would have handled these cases very differently. Nursing home staff appear to react to many behaviors as pathological, in need of suppression. Often, what is tolerated depends on the personal beliefs or cultural preferences of individual nurses or management. Not infrequently, concerns about liability and regulatory consequences lead facility management to advise their staffs not to tolerate such behavior. However, as the authors also note, sexuality is challenging because it invariably affects others; for example, the husband of Mrs. O. and the staff and residents who may have seen Mrs. P’s activity.

The medical director should review a facility’s clinical policies and practices to ensure that they recognize notions of autonomy even in the case of cognitive impairment, and that they balance respect for autonomy with notions of obligation to prevent or stop certain behaviors. It is also vital that medical directors ensure that facility policies and procedures are evidence-based and consistently applied, and don’t just reflect the arbitrarily applied personal habits and preferences of staff and management.

**SUMMARIZING THE ISSUES**

Again, as in previous cases in this series, this month’s cases reflect important management as well as clinical and ethical principles. The medical director should help reconcile these elements and focus on optimizing decision-making processes and practices. Whether or not formal ethics committees or bioethicists are available, the medical director can help staff and physicians consider and discuss openly the basis for their conclusions, and help them identify and accommodate the patient’s and family’s perspectives rather than simply imposing their own viewpoints. While relevant, legal and regulatory concerns should be considered in the context of the patient’s condition, prognosis, values, and wishes.

**REFERENCES**