

## The Case of Jennie M: To Tube Feed or Not

### Analysis by Saint Luke's Hospital Ethical Concerns Committee

*This committee, consisting of four RNs, two chaplains, two social workers, one dietitian and one librarian, discussed the case of Jennie M. after establishing the medical facts available.*

### Discussion

The easiest thing to do for Jennie would be to insert a feeding tube to maintain her nutritional status with a minimal investment of time and trouble from the nursing home. This would also alleviate Mary's fears that her mother will die of starvation. Only the advance directive prevents this course of action. The signed directive, then, forms the core of the dilemma. Shall the institution honor the previously stated wishes of a now mute patient even when there is some reason to believe that she may not have understood the full implications of her decision?



By law the signed advance directive requires the caregivers to forgo tube feeding. In reality, the advance directive, unless it has a human champion, is not a match for an insistent family member. In Jennie's case, her daughter, Mary, has admitted her mother to the nursing home to assure that she will get good care. Now the caregivers seem to be backing off on that agreement. She feels betrayed, especially since continuance of adequate nutrition seems so very basic. Mary did not foresee that the advance directive might mean her mother would starve to death. This, added to her grief over her mother's declining health, has created an enormous emotional burden for the daughter. She is not yet prepared for Jennie's death, especially by this means. Her problem is one of beneficence; she needs to prevent harm from coming to her mother.

The problem for the nursing home is one of distributive justice. It must allocate its limited resources so that all patients are treated fairly. This does not mean that all patients will receive the same amount of care, but rather that all patients will receive care commensurate to their needs. Jennie's needs have begun to require more care than the nursing facility can give without neglecting others. Therefore, the home is ethically obligated to scale back. However, Jennie's death is not imminent, and they do not want to precipitate it, nor do they want to prolong it, which a feeding tube might do. They also have divided loyalties. Their first duty is to the patient but, since Jennie now has little contact with reality, they have only the advance directive and Mary to tell them her wishes, and they are in opposition. They also have a duty to Mary to provide the care they have promised. It is very tempting to agree to Mary's wishes since she is vocal, and Jennie is not. If not for the advance directive, that is probably what they would do.

The third and most important player here is Jennie. We know very little about her except that she did not want to be maintained on machines and now seems to be in the process of withdrawing from the world. If Jennie could speak, there would be no dilemma. Since she cannot, we must discern her wishes from her advance directive and, perhaps, from her actions.

Her difficulty in eating might be a normal part of her process of dying, not a physiological problem. In that case, the feeding tube will only lengthen her dying. The question is raised: to what end are we putting in the feeding tube? To continue her life for her sake, or for the family's benefit? If it is only to make all involved feel that they have extended her life and not "killed" her, then we are not acting on her behalf. Jennie's autonomy is the strongest factor in the case; she signed the directive, and it is, after all, her life we are altering. If we were to ignore both the advance directive and her apparent disinterest in eating, then we would be gravely neglecting her personhood and autonomy. On that basis, the committee decided to forgo the feeding tube and focus on appropriate terminal care for Jennie. The aides will continue to help her eat if she so desires, but there will be a time limit put on her meals. This should assure that Jennie's needs are met and that others are not harmed.

## **Conclusion**

After much discussion, the committee concluded that the advance directive had been accepted as the patient's wishes at the time of her admission to the facility. While the daughter had been the appropriate surrogate decision maker for her mother's care for the past four years, apparently her decisions had not related to those items specified in her mother's advance directive. When the patient has left specific written instructions about a treatment, this directive should be followed. Granted she may not have fully understood all the implications of the choices she made, but that is true of many of our decisions. The only reason for ignoring or overriding a patient's directive is evidence of a clear, positive benefit from the treatment being considered. It would appear that this patient's condition is not going to improve much with treatment. Therefore, the ethics committee would not support placement of a feeding tube.

The daughter felt that the problem was one of money; that is, that the institution had an obligation to feed and provide whatever care her mother needed, and that the lack of adequate staff created the issue regarding the feeding tube. The committee somewhat un comfortably agreed that continuing to provide the level of care her mother required (six hours of feeding time per day) would not be a reasonable expectation of the nursing home (although the aide was willing to continue to do so), and that family members might want to take on this duty. The nursing home aide should feed the patient for up to a half hour per meal, the usual time allowed to feed a patient. The family would be encouraged to bring in her favorite foods. However, the committee agreed that the patient may be passively expressing her wishes by not eating, and that, even without the tube feeding, forcing her to eat would impose a burden on the patient rather than a benefit.

The committee agreed that the director of nursing would not have allowed six hours of aide time per day to feed this patient for more than a day or two. They also agreed that the director of nursing was premature in offering the feeding tube without considering other alternatives and/or allowing the family to reach some understanding about the patient's terminal decline.

Jennie M., a seventy-nine-year-old female, was admitted to St. Francis Nursing Home four years ago. At that time Jennie had little contact with reality although legally she had not been declared incompetent. Jennie had a medical history of hypertension, diabetes and several small strokes. Over the past four years she has deteriorated to the point of being unable to feed herself. More and more time has been required to feed Jennie and she has been consuming less. The nursing home staff became concerned about Jennie's nutritional status and the exorbitant amount of staff time required to feed her.

Neurologically, Jennie has dementia. Four years ago, she had difficulty comprehending and had little contact with reality. Presently, the deterioration has progressed, and Jennie is unable to feed herself. Jennie's condition is terminal. Regardless of the treatment modality, Jennie's body cannot respond. As her dementia progresses, Jennie will be unable to swallow. The tube feeding merely prolongs the inevitable.

## **Assumptions**

Since Jennie had not appointed a Durable Power of Attorney of Health Care, the nursing home assumed that Mary is the appropriate surrogate for making health care decisions. Mary has fulfilled her obligations to her mother and cares about her mother's wellbeing. When it was "impossible for Mary to do all for her mother that she hoped to do" she placed her mother in a nursing home.

Jennie no longer has decisional capacity, since she apparently cannot process information and give reasonable replies. Hopefully alternative reasons for her dementia have been fully investigated and a speech therapy evaluation has been performed, giving her every chance to communicate, not just at this crucial time, but also early in her stay at the nursing home.

Mary assumes her mother did not understand the implications of initialing the "no tube feeding" directive. The question must be asked whether or not her mother was the type of individual who would sign papers without scrutinizing the content.

We cannot assume that no one else is interested in the care of Jennie. There may be other children, grandchildren or other relatives with whom Jennie discussed her wishes. The committee has the responsibility to contact the neighbor who was with Jennie the day she signed her advance directive. With the neighbor's assistance, Jennie's wishes may be further defined.

## **Values**

Jennie valued autonomy as evidenced by her advance directive. She has indicated in the directive that she did not want surgery, heart-lung resuscitation, antibiotics, dialysis, mechanical ventilation or tube feedings. She also told her daughter that she did not want to be kept alive by machines.

Mary, Jennie's sixty-year-old daughter, values Mary's life. Although Mary was Jennie's primary care giver, Jennie developed her advance directive in the company of a neighbor, not Mary. We ask if Jennie had capacity at the time of making her advance directive. Mary now believes that Jennie did not understand about tube feedings, and she (Mary) does not think a tube feeding is a machine. Antibiotics are also not "a machine"; Jennie, however, initialed those as well.

The nursing home staff, including the medical director, director of nursing, administrator and nurses have a responsibility to honor and respect the rights of all residents. At times, the balance can be difficult. The primary rights in this case include autonomy for Jennie and justice for Jennie and the other residents. Nursing homes function with limited staff, and time spent feeding Jennie takes time from other residents. In this case, six hours of feeding Jennie could

be reduced dramatically by inserting a feeding tube. Although there would be no reimbursement for staff time, there is reimbursement for feeding tubes and supplies.

Beneficence toward Jennie seems evident from all parties involved. The aide has spent six hours a day feeding her. Mary has cared for Jennie's needs, "visiting frequently" and cooperating with the nursing center. The director of nursing, concerned about Jennie's physical needs and about other residents' needs, wants to use the feeding tube. The administrator, concerned about prolonging and deforming Jennie's dying, "feels uneasy" about putting the tube in. This conflict is a good example of persons supporting different courses of action while focusing on the needs of the patient.

## **Dilemma**

The dilemma in this case involves Jennie's right to autonomy (no tube feeding) versus the rights of justice (equitable time) for the other residents. Specifically, being able to tube feed Jennie would enable the staff to spend more time with other residents.

## **Course of Action**

The following questions need to be addressed to determine an appropriate course of action:

- What information can the neighbor provide to the committee about the day Jennie completed her advance directive? Did she understand and consider each treatment carefully?
- Is Jennie in a terminal state? Neurologically, Jennie is experiencing dementia and regardless of treatment has no hopes of recovery; she will progressively decline.
- Is Jennie incapacitated? Yes. Jennie was unable to comprehend her move to the nursing home four years ago. Her further deterioration regarding inability to feed herself indicates progression of a deteriorating mental state.
- Did Jennie have advance directives and what were her wishes? Jennie initialed "no tube feeding." What did Jennie say about tube feeding to her friends and family?
- Although Jennie did not sign a durable power of attorney, are there other significant people in Jennie's life to clarify her wishes?

Assuming that she had capacity at the time she made her advance directive, Jennie does not want a feeding tube. Though her daughter does not believe a feeding tube is a machine, Jennie specified other parameters that did not involve machines, i.e., antibiotics.

## **Recommendations**

We believe the nursing home can respect the rights of all of the residents: no tube feeding for Jennie and equitable time for the other residents. Asking family members and volunteers to assist in feeding Jennie would accomplish this. When Jennie progresses to the point of being

unable to swallow, the nursing home must continue to support her without inserting the tube, thereby allowing her the autonomy she desired.

The Baptist Medical Center Ethics Committee met in review of the case of Jennie M. Following is a summary of the committee's discussion, including questions raised, ethical issues encountered, and mechanisms proposed for resolving the conflicts. A number of principles were discussed and used in the analysis of the case. Each of these areas will be addressed specifically.

### **Process**

After a reading of the case to the committee, volunteers from the group role-played each of the main characters in the scenario. Discussion of general and specific issues in the case followed. Ethical principles were utilized to address and clarify the issues.

### **Medical Facts**

The discussion began with a view of the written medical facts of this case. The committee acknowledged the progressive mental deterioration of this seventy-nine year old lady and her chronic medical conditions. Participants agree that there are missing medical facts concerning the case. More information or clarification is needed in the following areas:

- dementia related to strokes or other etiologies
- an assumption that the increased mental deterioration led to the decreased appetite and decreased eating
- unclear prognosis. Committee assumed it to be six to eighteen months and directly related to the patient's ability to take in nutrition
- need for further evaluation of the patient's swallowing abilities
- report on the patient's history and evaluation for depression
- discussion on the use of medications which may decrease appetite
- additional information about weight loss

Several hypotheses related to possible patient outcomes were proposed for each of the above situations. Even with additional information, the ethical issues in the case change only slightly and the impact on outcome for the patient is probably inconsequential.

## **Ethical Principles**

*This case review entailed spending more time than usual addressing the allocation of nursing resources.*

### *Autonomy*

It is noted that the patient had executed an advance directive in which she specified the scope and limitations of her treatment in the event she could no longer make such decisions. Although it is not clear whether or not the patient's daughter has been appointed proxy, she is being put in that position by being asked to make the decisions related to enteral feeding. The daughter believes that her mother did not understand the tube feeding procedure. The daughter further asserts that if her mother had understood that component, she would not have refused that treatment.

A lengthy discussion ensued on the benefits and burdens of enteral feeding for this patient. Several committee members questioned the validity of the advance directive, but consensus was nevertheless achieved. Consensus indicated that without evidence to the contrary the advance directive was accepted as the patient's wishes.

The ethical dilemma in this case surrounds patient autonomy, choice, and the role of the "surrogate" and caregivers. The committee assumed that the patient had capacity when she prepared her advance directive and, therefore, that the directives should be honored.

### *Quality of Life*

The committee reached consensus that insertion of the feeding tube would be burdensome to the patient. All were in agreement that, based upon the patient's expressed wishes documented in the advance directive or the "reasonable person theory," that this patient would not wish to have a feeding tube inserted. It was noted that inserting the feeding tube might be a beneficent act if, without it, the patient would suffer to a greater degree. It was noted that if the patient resisted the therapy - enteral feeding - the nursing care required to maintain the treatment, including restraint, could outweigh the benefits of the treatment. This hypothesis was related to patient comfort and freedom from unnecessary restraint.

### *Justice*

The committee addressed the issue of allocation of nursing resources. The time required to feed the patient could not be justified because it reduces the time available to meet the needs of other patients. The justice model assures equal access to services and consistent quality of care for each patient. The committee suggested allocating a reasonable amount of time for the patient's nutrition-perhaps twenty minutes per meal with snacks between meals-and that the daughter be encouraged to participate in feeding when possible.

The committee noted the absence of a nursing care plan in the scenario. The consensus was that no tube feeding should be initiated, and an alternative care plan be developed that would meet the comfort and care needs of the patient without impacting the care of other patients. Resources such as the daughter can be used to assist in the nursing care, including feeding.



Possible outcomes of this could be twofold: to provide more care resources to the patient, and to allow the daughter and staff to address their feelings regarding the decisions made.

## **Recommendations**

After discussing a case, this committee usually provides written recommendations. Generally, these recommendations are ethically appropriate alternatives ranked in preference order. Recommendations for this case are the committee developed a sensitivity for the principle of justice as related to the difficult decisions a nursing administrator faces when he or she is responsible for providing care to a large number of patients with competing needs and simultaneously faces dwindling manpower resources, as follows (note that each is not exclusive of the other):

1. Do not insert a feeding tube at this time but continue oral nutrition to the extent possible as outlined in this document.
2. Alter the nursing care plan to include socialization and comfort measures (e.g., oral care, turning, skin care, etc.).
3. Provide support to the daughter to help her implement her mother's wishes and alleviate the guilt associated with this process.
4. Do not start additional treatments (e.g., antibiotics) as the patient's condition deteriorates, consistent with her advance directive.
5. Affirm and communicate the DNR status to all care providers so that this does not become an issue.

## **Summary**

This case presents many of the usual situations a committee encounters when it addresses the issue of "To Feed or Not to Tube Feed." The committee spent time clarifying medical facts and providing hypothesis on etiology and outcome because the facts were unknown or incomplete. A discussion of the legal issues involved related to the documents presented. Verification was made of the patient's capacity at the time the documents were signed and the relationship to the patient's care at the time the document was executed. The role of the surrogate in the decision-making process was addressed and clarified. This case review entailed spending more time addressing the nursing care requirements and the allocation of nursing resources in the institution than is sometimes allotted.

The case of Jennie M. represents many bioethical issues: autonomy, justice, enforceability of advance directives and rationality as a verifiable basis for decisional capacity. All parties in the case are motivated by beneficence; no harm is intended to anyone. With this established, the committee explored the factors relevant to formulating an ethical decision regarding Jennie's care and treatment. Agreeing that the case study lacked some information, the committee proceeded to examine those facts available in light of the issues mentioned above.

The first significant fact was that Jennie M. signed an advance directive waiving tube feeding. Was this an autonomous decision on her part? There is no indication of her level of understanding of the treatments she elected to forgo. Mary, in wanting what is best for her mother, believes Jennie did not make an informed decision; therefore, her life must be protected through the artificial means of tube feeding. Jennie's present condition renders her non-responsive. The dilemma, since no one has the power of attorney for health care decisions in this case, is a question of autonomy: whose is foremost, the mother's or the daughter's?

Justice is another issue in this case. Do the hours required to feed Jennie deprive the other residents of the nursing home of necessary care? Allocations of staff time must be considered in context when weighing the good of the individual versus the good of the community.

The director of nursing apparently espouses the value that food and hydration are basic human needs and not medical interventions. As such they must be met as a standard of good nursing practices. It is also possible that equitable allocation of staff time, doing the best for the most, may influence her judgment.

The hospital administrator may have concerns on several levels. She has a signed document that is valid unless proven otherwise. What are the legal implications for her and for the institution should the advance directive be superseded by Mary's request? Should she agree to tube feeding? Will a precedent be set for future, similar situations? Is it practical to refer all advance directive potential outcomes to an ethics committee? Should that occur, there would be no reason to secure such a document at the time of admission.

Should decisional capacity at the time of Jennie's signing the advance directive be authenticated, Mary's request for tube feeding should be denied. In general, the committee needs more information in order to make a decision. The following questions present themselves:

- Why and when did Jennie stop eating?
- Would tube feeding improve her quality of life?
- Would the friend or other family member(s) have insight as to Jennie's understanding of choices documented in her advance directive?
- Are there alternative nutrition supplements besides tube feeding?
- How would Jennie define quality of life?
- What was the staff's reaction to spending six hours a day feeding a single patient?
- Were Jennie's decisions based on particular religious or spiritual beliefs?
- Is denying hand feeding or tube feeding the same as starving a patient to death?
- What is the physician's knowledge of Jennie and her preferences?



## Recommendations

On the basis of the available facts, the committee offers the following recommendations:

- Since we have no evidence that Jennie M. was without decisional capacity at the time she signed the advance directive, it should be honored, and nature allowed to take its course.
- Work with Mary to enhance her understanding of the situation and to enable her to honor her mother's directive without bearing any burden of guilt.

## Conclusion

This case scenario is played out continuously in long term care settings. Ideally the patient, with full decisional capacity, would have signed an advance directive honored and understood by her family. In addition to the patient, the family would have been educated as to the terms of the directive before the health care crisis occurred, and all necessary medical data, consideration of beliefs and values of the patient and a mental status assessment made before the signing. Also, the physician should be knowledgeable about the patient's wishes and review the advance directive with an elderly patient annually. Finally, individuals should assign a power of attorney for health care decisions as a part of their advance directives.

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## SUMMARY: To Tube Feed or Not to Tube Feed

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*Nationwide studies indicate that ethics committees engage in educational projects and policy development and review far more than they participate in actual case consultations. Nevertheless, no project engages people in ethical dialogue more effectively than the discussion of cases. The fictitious case study below was submitted to several ethics committees in the Kansas City area for a mock case consultation. The committees' case reviews that follow illustrate the different strategies ethics committees use in a case consultation. Recommendations from case consultations, such as those arrived at in discussion of this mock review, are intended to help patients, their families and health care providers make ethically-sound treatment decisions.*

## Case Study

Jennie M., age seventy-nine, came into St. Francis Nursing Center four years ago. At that time, she appeared to have little contact with reality although she had not been declared incompetent by the court. Her sixty-year-old daughter, Mary, had taken care of her mother until Jennie's hypertension, diabetes, and several small strokes made it impossible for Mary to do all for her mother that she hoped to do. Upon arrival at the nursing center, Mary handed her mother's advance directive to the admitting clerk. The directive showed that Jennie had initialed "no surgery, heart-lung resuscitation, antibiotics, dialysis, mechanical ventilator, or tube feeding." Together they read through it while Jennie sat beside them, apparently uncomprehending everything about the move. Mary signed all papers. From that time on she visited her mother

frequently and has always been cooperative when the nursing center has requested information or guidance.

The years passed; Jennie has been eating less and taking more and more time to consume what little she does eat. She no longer feeds herself and often in the assisted-eating dining room, aides spend over two hours to ensure that minimal nutrition standards are met for Jennie's intake. The director of nursing has mentioned to Mary that consideration ought to be given to the insertion of a feeding tube. Jennie is not acutely ill; clearly, she is an elderly woman with multiple disabilities, but she is not in danger of imminent death. All she needs is sufficient nutrition, yet the director of nursing feels she cannot justify an aide's time being devoted to one patient for so long a period three times a day.

Mary knows that her mother's advance directive was made one day when a neighbor was visiting, and all that Jennie told her about it was that she didn't want to be "kept alive on a machine." When Mary and the director of nursing are talking, Mary says she does not consider tube feeding a "machine" and her mother most likely did not understand the implications of her initialed statement, "No Tube Feeding." The daughter concurs with the nursing director that it would be better for Jennie if a tube is inserted. But when the administrator was told of the decision, she felt uneasy because she saw that tube feeding would prolong and deform Jennie's dying, and she called together the ethics committee. Present at the meeting were the following: social worker-chair, administrator, the medical director, director of nursing, a dietitian and a minister who was asked to belong to the committee since he has a number of parishioners who are residents. Mary was invited as was one of the aides who has often fed Jennie.