1987

Ethics Withholding Food; Series I; File 74

Juanita Hunter

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NEW YORK STATE TASK FORCE ON LIFE AND THE LAW

35 West 51st Street, Third Floor, New York, NY 10019-9071  (212)635-2296

David Agency, M.D.
Chairman

January 8, 1987

Juanita Hunter, President
New York State Nurses Association
2113 Western Avenue
Guilderland, N.Y. 12085

Dear Ms. Hunter:

Thank you for your letter of December 16, 1987. I was delighted to learn that the Nurses Association supports the health care proxy legislation and read your comments about the report with great interest. The Task Force debated the question of when the proxy should commence at considerable length. Underlying the issue is a judgment about ethical and practical concerns related to the informed consent process. The views of the State Nurses Association are therefore an important element of the public debate about the issue.

Over the summer, the Nurses Association expressed interest in the appointment of another nurse to the Task Force to replace Janice Nelson. Denise Hanlon, a pediatric nurse specialist from Buffalo, New York, has been appointed. The Governor’s Office concluded that a nurse with clinical pediatric experience would fill an important need in the Task Force’s deliberations.

Enclosed is a copy of the public hearing notice announcing the dates for hearings on the proxy legislation. I look forward to the Nurses Association testimony and to working with the Association to ensure passage of the bill which I believe would provide invaluable guidance to both patients and health care professionals.

Very truly yours,

Tracy E. Miller
Executive/Director

NYS ASSEMBLY COMMITTEE ON HEALTH
NYS SENATE COMMITTEE ON HEALTH
NOTICE OF JOINT PUBLIC HEARING

SUBJECT: Proposed Health Care Agent Legislation

PURPOSE: To receive comments on the Health Care Agent bill proposed by the Governor’s Task Force on Life and the Law.

The bill would enable an individual to designate a “health care agent” who would be legally empowered to make health care decisions on the individual’s behalf if the individual becomes incapable of making his or her own treatment decisions. A health care agent would be appointed by means of a “health care proxy,” a document which could also provide instructions or limitations on the scope of the agent’s authority to make treatment decisions. A copy of the bill accompanies this notice.

ALBANY
Wednesday, January 27, 1988
9:30 a.m.
Hearing Room C
Legislative Office Building

NEW YORK CITY
Thursday, February 4, 1988
10:00 a.m.
Winston Conference Room
St. Luke’s/Roosevelt Hospital Center
Roosevelt Division
428 West 59th Street (use 9th Avenue entrance)

People wishing to testify should complete and return the attached reply form as soon as possible. It is important that the reply form be completed and returned so that people may be notified in the event of emergency postponement or cancellation of the hearing.

Oral testimony will be limited to 10 minutes. In preparing the order of witnesses, the Committees will attempt to accommodate individual requests to speak at particular times in view of special circumstances. These requests should be made on the reply form as soon as possible.

Ten copies of written testimony should be submitted at the hearing registration desk.

In order to further publicize these hearings, please inform interested parties and organizations. For further information, contact Debra Cohn, Assembly Committee on Health, at (518) 435-8911.

RICHARD N. GOTTFRIED
Chairman, Assembly Committee on Health

TARKY LOMBARDI, JR.
Chairman, Senate Committee on Health

Return to: Debra Cohn, NYS Assembly Committee on Health, 822 Legislative Office Building, Albany, NY 12248

☐ I plan to testify at the hearing in:
☐ Albany, January 27, 1988
☐ New York City, February 4, 1988

☐ I plan to attend but not testify.

Name: ____________________________
Organization: ______________________
Address: __________________________
Telephone: _________________________
Ethics Withholding Food
Ethics Withholding Food

Section 1. The public health law is amended by adding a new article twenty-nine-C to read as follows:

ARTICLE 29-C

APPOINTMENT OF A HEALTH CARE AGENT

SECTION 29-C.1. Definitions.

29-C.1. Appointment of health care agent...health care proxy.
29-C.2. Rights and duties of agent.
29-C.3. Intervention of a health care agent...health care decisions, for the purposes of providing health care.
29-C.5. Resolutions.
29-C.6. Rights to be published.
29-C.7. Health care proxy form.

1. Article 29-C. Definitions, as used in this article:

29-C.1. Appointment of a health care agent means an agreement entered into by a patient, who has primary responsibility for the health care and safety of the patient, to designate another person to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.
29-C.2. Rights and duties of an agent means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.
29-C.3. Intervention of a health care agent means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.
29-C.4. Principles of health care decisions means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.
29-C.5. Resolutions means a person who has executed a health care proxy.
29-C.6. Health care proxy means a person who has executed a health care proxy.
29-C.7. Health care proxy form means a form approved by the department of health care and the office of health care to be used in the appointment of a health care agent.

Section 29-C.2. Appointment of a health care agent means an agreement entered into by an individual, who has primary responsibility for the health care and safety of the patient, to designate another person to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

2. Rights and duties of an agent means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

3. Intervention of a health care agent means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

4. Principles of health care decisions means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

5. Resolutions means a person who has executed a health care proxy.

6. Health care proxy means a person who has executed a health care proxy.

7. Health care proxy form means a form approved by the department of health care and the office of health care to be used in the appointment of a health care agent.

8. Definitions, as used in this article:

9. Appointment of a health care agent means an agreement entered into by an individual, who has primary responsibility for the health care and safety of the patient, to designate another person to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

10. Rights and duties of an agent means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

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29. Intervention of a health care agent means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

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42. Principles of health care decisions means the legal authority to make health care decisions, in accordance with the requirements of this article, for the patient in the event of incapacitation.

43. Resolutions means a person who has executed a health care proxy.

44. Health care proxy means a person who has executed a health care proxy.

45. Health care proxy form means a form approved by the department of health care and the office of health care to be used in the appointment of a health care agent.
Ethics: Withholding Food

1. A patient who, over the objections of health care decision makers, refuses to have surgery, treatment, or to consent to any health care decision, may be considered a patient who, under the law, has a right to refuse medical treatment. However, the physician who, at the time of the decision, is treating the patient, has a duty to provide information about the benefits and risks of the proposed treatment and to ensure that the patient understands the consequences of refusing the treatment. The physician should, if possible, consult with the patient's family or legal representative to determine the patient's wishes. If the patient is unable to make a decision, the physician should consider the best interests of the patient, taking into account the patient's past medical history, current medical condition, the availability of alternative treatments, and the likelihood of success. The physician should then document the decision and the reasons for it in the patient's medical record.

2. A patient who, in a medical emergency, is unable to make a decision, may be considered a patient who has a right to refuse medical treatment. However, the physician who, at the time of the decision, is treating the patient, has a duty to provide information about the benefits and risks of the proposed treatment and to ensure that the patient understands the consequences of refusing the treatment. The physician should, if possible, consult with the patient's family or legal representative to determine the patient's wishes. If the patient is unable to make a decision, the physician should consider the best interests of the patient, taking into account the patient's past medical history, current medical condition, the availability of alternative treatments, and the likelihood of success. The physician should then document the decision and the reasons for it in the patient's medical record.
Ethics Withholding Food
Is it morally permissible to withhold or withdraw food or fluid from sick patients—and should nurses ever be involved in doing so? The answer to these two related questions is No, under most circumstances, and Yes, in a few instances. The focus of these guidelines, therefore, is upon the circumstances under which it is morally permissible to withhold food and fluid.

The starting point for our understanding of what nurses ought to do is based on the general moral consensus of civilized societies, religions, and generations regarding the usual obligation to provide food and fluid to the needy, sick, and dependent who can be helped by it. Such an obligation is central to the common understanding of nurses' professional and moral duties.

An aspect of nursing care, as carried out regularly and routinely by all bedside nurses, is the provision of some form of food and fluid. Patients need food and fluid in order to feel better, physically, and emotionally. The benefits of life and health from receiving food and fluid are so clear that, especially for those in the health professions (and perhaps most especially for nurses), there is a generally unambiguous moral duty to provide them. Thus, under most circumstances, it is not morally permissible to withhold or withdraw food or fluid from persons in their care, and nurses should not do so.

The most frequent instance when it is morally permissible, indeed obligatory, for nurses to withhold feedings are those occasions when patients would clearly be more harmed by receiving than by withholding feeding. Clinical examples include patients preparing for or just recovering from surgery, infants with such conditions as tracheo-esophageal fistula or anal atresia, and certain overeating disorders. These circumstances are temporary and usually involve substitute provision of specified nutrients. The goal is to provide proper nutrition later, when it is safe and beneficial. Harm, as used in this moral reasoning, is not simply synonymous with hurt, pain, or discomfort, though it may involve each. It refers rather to serious damage, often irreversible, and involving the loss of valued capacities or pleasures. There are occasions when the provision of food and fluid is both painful and beneficial and the justification for the temporary imposition of some short-term discomfort from hunger and thirst.

Thus far, we have identified the two most ethically clearcut and common instances. First, nurses should almost always provide food and fluid because it is almost always an essential, life-preserving, health-giving benefit. Second, nurses should temporarily withhold food and fluid when their very provision clearly causes harm.

Ethical difficulties arise when it is unclear whether food and fluid are more beneficial or harmful. Since they are essential for life, this uncertainty ultimately leads to questions about whether life, under certain conditions, might be a greater harm than death. Determination of benefit and harm are further complicated by questions about whose evaluation of benefit and harm should be decisive. Should the evaluation by the patient, the family, the professional caregiver, a religious advisor, or that of society, through the court, predominate? There are also questions about whether possible harms and benefits to others, in addition to the patient, should be considered.

Since competent, reflective adults are generally in the best position to evaluate various harms and benefits to themselves in the context of their own values, life projects, and tolerance of pain, their acceptance or refusal of food and fluid should usually be respected. This ethical judgment is now well established legally through various cases affirming the right of competent patients to refuse treatment, including food and fluid. It is morally, as well as legally, permissible for nurses to honor the refusal of food and fluid by competent patients in their care. The Code for Nurses', the historical evolution of nurses' professional responsibilities as patient advocates, and the general moral principle of respect for persons, sometimes referred to as the principle of autonomy, supports this view.

It is important, however, to guard against the possibility that respect for a competent patient's right to refuse food and fluid could lead to indifference or a misplaced respect for patient autonomy. The danger, in this instance, results in nurses' failure to interest themselves in a patient's reason for exercising their presumed right. It is the patient's reason which established the right and which, therefore, are pivotal in determining what the nurse should do. Moreover, because such serious harms to the patient are associated with the refusal...
of food and fluid (usual discomfort from hunger and thirst, illness, physical wasting, and ultimately, death), it is not enough simply to fulfill the obligation to respect the wishes of competent persons. Obligations to prevent harm and bring benefit also require that nurses seek to understand the patient's reasons for refusal.

First, it is important to establish clearly the patient's ability to understand her or his situation, the alternatives, and the attendant harms and benefits. The refusal of food and fluid, however, is not itself evidence of incompetence. Patients who refuse based on their evaluation of life with severe physical constraints, or with intractable pain, or as a choice about way and time to die in the face of an eventually fatal illness, or as a last resort to draw attention to important social causes will usually have weighed carefully the various harms and benefits associated with their refusal, in the light of their own values and capacities. Such reasoned reflection should be respected by nurses. Thus, in the case of competent patients with good reasons, "the patient" is the answer to questions about whose evaluation of benefit and harm should be decisive.

This answer should not, however, be taken automatically to apply to all circumstances of competent refusal. Competent patients can refuse for incongruous reasons. They may not have an accurate picture of the facts or they despise for reasons that are reversible, though they may not presently think this is true. These patients should receive special, sympathetic attention from nurses. Nurses should make every effort to correct inaccurate views, to modify superficially held beliefs and overly dramatic gestures, and to restore hope where there is reason to hope.

In certain instances, when a patient is no longer competent but it is possible to establish with certainty the patient's projected refusal, the same respect for a patient's values is indicated. Documents such as a living will, or other written or well-established verbal Advance Directives, or the legal assignment of a Durable Power of Attorney for healthcare, can be taken as aids in discerning the patient's view. The application of a previously stated refusal will, of necessity, require the judgment—both clinical and moral—of nurses and other caregivers as to whether the current situation is one to which the patient intended her or his refusal to apply. In general, Advance Directives, even those involving the withholding or withdrawing of food and fluid should carry great weight in caregivers' discussions with the patient's family or surrogate. It is imperative, in this process, that nurses not substitute their own views about which lives are worth saving and living for the views of their competent or formerly competent patients.

In circumstances where the patient never has been competent (including infants, children, many mentally retarded persons, and the never competent mentally ill), nurses along with others have the moral and professional responsibility to decide whether provision of food and fluid is in the patient's best interest. The same moral and professional responsibility falls to caregivers in the situation of a patient who is not now competent, and where the patient's views, while competent, cannot be discovered. Patients who are incompetent make an exceedingly vulnerable population dependent upon caregivers for careful thought and compassionate action, including the provision of nutrition.

The withholding of food and fluid might be indicated only when feeding is futile because of underlying, incurable, irreversible absorption problems; when it is itself severely burdensome to the patient or sustains life only long enough to die of other more painful causes. Only under very special circumstances is it morally permissible to withhold feeding or give less than adequate feeding to those who cannot speak for themselves. In such circumstances, the nurse's responsibility for care continues and special attention should be given to mouth and skin care, and other forms of compassionate touch.

If withholding food and fluid appears more harmful than expected, or if the patient's condition changes and hydration or nutrition appears potentially beneficial, the giving of food and fluid should be reinstated. The views and moral sensibilities of caregiving family members should be influential in decisions for such patients unless there is clear indication that the family does not wish to be involved in decision-making or is not competent, or substitutes their own interests for those of the patient.

In almost all cases the provision of food and fluid is in the patient's best interest. For some, it is one of life's central pleasures. Rarely is feeding more burdensome than beneficial. In addition, the nurse's obligation to fulfill the duties of her office or profession and remain faithful to her patients includes the general role promise that the nurse will engage in activities that are narrative, even when such care is not clearly beneficial so long as it is not harmful.

Central to the benefit of life itself is the benefit of nourishment which sustains physical being and provides psychological or emotional comfort. Thus, even in circumstances where food and fluid does not provide adequate nourishment, it should be continued if it provides comfort. For example, infants with irreversible absorption problems still enjoy sucking and mouthing food, or older adults who have refused further renal dialysis may still derive pleasure from sips of fluid or bits of food despite their impending death. Feeding should not be continued or forced, however, when it is futile and when it inflicts suffering or harm that is not outweighed by an important long-term benefit.

The nursing profession believes that the social and economic responsibilities which result from this position should be shared by all citizens, not solely those with a family member in need of nursing. We further believe that the good conscience, security, and sense of well-being among citizens rests in part on the knowledge that the vulnerable will be nourished and that carefully considered refusals of food and fluid will be respected.

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4. Suicide attempts as a prima facie refusal of life itself should not be taken as unquestionably entailing a refusal of food and fluid. Intervention to halt or reverse suicide rightly includes the emergency provision of food and fluid until the patient's reasons for the suicide attempt can be ascertained.
5. A durable power of attorney is an individual's written designation of another person to act on his or her behalf, when the designation is authorized by a state's durable power of attorney statute. Under state law, a power of attorney terminates when the designating individual loses decision-making capacity, whereas a durable power of attorney does not.

Issued by 1985-1987 American Nurses' Association Committee on Ethics.

Mila A. Aroskar, Ed.D., R.N., F.A.A.N., chairperson
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