Bill Passed Assembly 56-[illegible] Coparied

Coming to Carl's committee.

WISCONSIN RIGHT TO LIFE

Life without limits

State Affiliate of the
National Right to Life Committee, Inc.,
Washington, DC 36004-1193

January, 2003

CONSCIENCE CLAUSE BILL

LEGISLATIVE ANALYSIS

- Does not Cover Contraceptives

The Sub- expressly excludes contraceptives.

Why this Bill is Necessary

Health care professionals who object to abortion, assisted suicide and euthanasia do not want to be forced to participate in these immoral activities. They want to exercise their right, as a matter of conscience, to refuse to participate in activities related to abortion, assisted suicide or euthanasia without losing their jobs or being subject to professional or civil liability.

How this Bill Would Work

Wisconsin already has conscience clause laws on the books for hospitals, hospital employees, schools and students (s. 253.09), physicians (s. 253.09 and s. 448.03 (5)) and nurses (s. 441.06 (6)) which recognize the right of these persons to refuse, based on religious or moral precepts, to be involved in the performance of an *abortion* or a *sterilization* procedure.

The conscience clause bill extends the current protections under Wisconsin's conscience clause laws by doing all of the following:

1. Creating a conscience clause law for pharmacists.

2. Extending the protection of Wisconsin's current conscience clause laws to other related issues such as the destruction of or experimentation on human embryos, use of fetal tissues, withholding or withdrawal of nutrition or hydration, assisted suicide, and euthanasia.

3. Clarifying that each of these conscience clause laws grants protection from employment discrimination, professional liability and civil liability.

Strengthens professional immunity

Very new

4. Granting persons whose conscience rights are being violated the right to sue for injunctive relief and damages.

This has been amended (sub amend)

Wisconsin Right to Life urges you to vote in favor of the Conscience Clause Bill.

Wisconsin Right to Life, Inc.
10625 W. North Ave., Suite LL
Milwaukee, WI 53226-2331

Ph: 414-778-5780
Toll Free: 877-855-5007
Fax: 414-778-5785
Email: legis@wrtl.org
Home Page: www.wrtl.org

AB67

May 29, 2003

AB 67 -- FLOOR ARGUMENTS

Table of Contents

GENERAL CONSCIENCE CLAUSE CONCEPTS

Most objections to this legislation can be answered by the following general concepts:

Not a ban

This legislation does not ban any of the covered activities. It merely protects the right of health care professionals to not be forced to participate in acts involving the deliberate destruction of human life.

Health care professionals can continue to provide any legally authorized medical procedure they are qualified to provide, if they so desire. For example, any physician who is willing to perform elective abortions can continue to perform them on women who want them. Any woman desiring an elective abortion can easily find the names of abortion clinics in the Yellow Pages and make her own arrangements to obtain an abortion. She does not need to force an unwilling health care provider to help her get an abortion.

Participation cannot be forced

This legislation protects the conscience rights of health care providers to not be forced to participate in acts involving the deliberate destruction of human life such as abortion, killing in vitro human embryos, use of tissues or organs from aborted babies, causing someone to die of starvation or dehydration, to assist in a suicide or to euthanize someone.

Acts involving the destruction of human life are not part of mainstream medicine and no one has the right to force health care professionals to participate in these deadly acts.

Referrals

Contrary to the assertion of the Medical Society of Wisconsin, there is no general law in Wisconsin requiring physicians unwilling or unable to perform a particular medical procedure to refer their patients to another physician who is willing or capable of performing the medical procedure. The Medical Society may have a policy that states this, but there is no legal requirement. The only exception to this is the provisions in the advance directive laws (see page 8).

The definition of "participate in" that is in the bill not only protects the right of health care professionals to not perform the objectionable activity, it also protects their right to not be complicit in the activity by being forced to refer or otherwise assist a patient to find another physician who will participate. Conscientious health care professionals object to all aspects of being forced to participate in acts involving the deliberate destruction of human life.

WHY DO MANY HEALTH CARE PROFESSIONALS HAVE MORAL OBJECTIONS TO LIVE HUMAN EMBRYO RESEARCH?

Where did you get the definition of "human embryo" used in AB 67?

The term "human embryo" in AB 67 "includes any organism that is derived by fertilization, parthenogenesis, cloning, or any other means from one or more human gametes or human diploid cells."

The definition was taken directly from the current law banning federal funding of human embryo research.

What is involved in live human embryo research and experimentation?

Live human embryo research and experimentation involves creating or using live human embryos, causing risk to the embryo not to benefit the individual embryo but to gain knowledge or obtain cells for medical experimentation. The live human embryo is generally destroyed in the experiment or discarded once the experiment or extraction of cells is accomplished. An example of this is the embryonic stem cell research being carried out at UW Madison by Dr. James Thomson where live human embryos, obtained from fertility clinics, are destroyed in order to extract their stem cells.

Many health care professionals have strong moral or religious objections to the use of live human embryos for use in medical experimentation. Many also oppose the creation of human embryos for the express purpose of destroying them for research purposes.

If, in the future, medical treatments are developed based on human embryonic stem cells, health care providers should not be forced to participate in providing these treatments to their patients.

Given the grave moral concerns surrounding live human embryo research and experimentation, no health care professional or health facility, who objects to it on moral or religious grounds, should be forced to engage or participate in it.

WILL THIS LEGISLATION ADVERSELY IMPACT IN VITRO FERTILIZATION (IVF)?

IVF is not regulated in Wisconsin

There are no statutes or regulations in Wisconsin on the in vitro fertilization procedure. Consequently, there are no laws to prevent the intentional destruction of spare human embryos or to prevent harmful research on human embryos.

There is no evidence that any IVF clinic in Wisconsin is actually destroying spare human embryos, even if the genetic parents have chosen this option. There are stories that some human embryos are being subjected to pre-implantation tests to determine if the embryo has a certain sex or certain genetic abnormalities. It is possible that the embryos who do not meet the testing criteria are destroyed.

IVF is not banned

Absolutely nothing in this legislation would ban the normal IVF procedure where human embryos are created and transferred into the mother's womb for gestation until the birth of the child.

Employment protection for lab technicians

This legislation would, however, protect lab technicians from being forced to destroy living human embryos or subject them to harmful research.

An employer would not be able to fire or refuse to hire a lab technician who refuses to participate in the destruction of living human embryos.

Given the grave moral concerns surrounding what happens to live human embryos, no health care professional or health facility, who objects to the destruction of human embryos on moral or religious grounds, should be forced to engage or participate in it.

WHY FETAL TISSUE TRANSPLANT IS OBJECTIONABLE TO MANY HEALTH CARE PROFESSIONALS

What is fetal tissue transplant?

It is the transplant of tissue from dead babies who have been aborted, or live unborn babies who are about to be aborted, into individuals who have incurable conditions or diseases.

Techniques for obtaining fetal tissue:

1. Sifting through the remains of aborted babies to locate specific tissues.
2. Using an abortion method that produces a relatively intact aborted baby in order to obtain tissue or organs.

Many health care professionals believe these babies should not have been aborted in the first place and should not be further exploited by the scavenging of their tissues and body parts.

Given the grave moral concerns surrounding fetal tissue transplant, no health care professional or health facility, who objects to it on moral or religious grounds, should be forced to participate in it.

WHY DO SOME HEALTH CARE PROFESSIONALS HAVE AN OBJECTION TO THE WITHHOLDING OR WITHDRAWAL OF NUTRITION AND HYDRATION FROM CERTAIN PATIENTS?

Some health care professionals view the withholding or withdrawal of nutrition and hydration from a patient ***who is not dying*** as tantamount to euthanasia, unless such withholding or withdrawal is medically contraindicated.

These health care professionals have moral objections to withholding or withdrawing nutrition and hydration because:

1. Withholding or withdrawing nutrition and hydration will kill the patient.
2. Death by starvation and dehydration is painful and slow.
3. The most common means of providing nutrition and hydration are not burdensome.
4. For patients who are not dying, the withholding or withdrawal of nutrition and hydration will kill the patient within three to ten days.

Health care professionals and health care facilities should not be forced to participate in the withholding or withdrawal of nutrition and hydration from patients who are not dying.

WHY DO PROTECTIONS IN THIS BILL EXTEND TO ASSISTED SUICIDE AND EUTHANASIA? THESE ACTS ARE NOT LEGAL IN OUR STATE.

Even though assisted suicide and euthanasia are not legal in Wisconsin, there are actions taken right now in our state that are tantamount to assisted suicide and euthanasia. While the extent of these actions is not known, they do take place. We know this because confidential calls have been received from health care personnel and family members relating instances where death has been hastened in patients who are not dying.

Health care professionals who object, on moral or religious grounds, to acts intended to cause an individual's death should not be forced to participate.

ADVANCE DIRECTIVES – DUTY TO TRANSFER ISSUE

Current law

Contrary to the assertion of the Medical Society of Wisconsin, there is no general law in Wisconsin requiring physicians unwilling or unable to perform a particular medical procedure to refer their patients to another physician who is willing or capable of performing the medical procedure. The Medical Society may have a policy that states this, but there is no legal requirement. The only exception to this is the provisions in the advance directive laws

Under the current law for advance directives, a physician is granted civil, criminal and professional immunity for failing to comply with a living will, a power of attorney for health care, or the decision of a health care agent only if the physician makes a "good faith attempt to transfer" the patient to "another physician who will comply" with the directive.

What does a "good faith attempt to transfer" mean?

This is a vague term with no definition. According to Debora Kennedy at LRB, the duty to transfer involves one physician calling another to see if he or she would take the case. It is the transfer of the medical responsibility for the patient. It does not speak to physically transporting the patient from one place to another.

Patient is free to find another physician

This conscience right will not prevent any patient from having end of life decisions honored. The legislation expressly provides that any physician, upon receiving a living will or a power of attorney for health care, is required to immediately "review" the document and, if the physician intends to invoke his or her conscience rights, to inform the patient orally and in writing as soon as possible. This gives the patient advance notice of the physician's concerns, if any, about the advance directive.

If the patient is not satisfied with the physician's refusal to participate in the protected activity, then the patient can take his or her business to another physician who will provide the desired service. If the issue arises when the patient is incapacitated, then the health care agent or a family member can find another physician. If necessary, a guardian can be appointed to arrange for the patient's health care preferences.

A narrowly drawn exception is made to cover a case where the patient (1) is so incapacitated that the patient cannot speak for him or herself, (2) has a living will and no agent to speak for the patient, and (3) is in a terminal condition. In this limited circumstance, the physician would be required to withhold or withdraw a feeding tube or find another physician willing to comply with this directive.

NOTIFICATION REQUIREMENTS

Current notification requirements

Under the current conscience clause provisions (ss. 253.09, 441.06 (6) and 448.03 (5)), written notification of a health care provider's intention to assert a conscience right is only required under certain circumstances.

Wisconsin's current conscience clause laws protect a health care provider's right to refuse to participate in a sterilization procedure or the removal of a human embryo or fetus. These laws also provide legal protection from the consequences of the refusal, such as disciplinary or recriminatory action, employment discrimination, civil damages, and loss of staff privileges or student status.

Under the current conscience clause provisions, written notification of a health care provider's intention to assert a conscience right is required as indicated in the following circumstances:

Right to refuse to participate	Written notification required?
Hospital – refusal to admit a patient or allow use of facilities	No
Hospital employee – refusal to participate	Yes
Staff physician – refusal to participate	Yes
Any other person who is a member of a hospital – refusal to participate	Yes
Any other person associated with hospital staff – refusal to participate	Yes

Availability of legal protection	Written notification required?
Immunity for civil damages – Hospital or hospital employee	No
Immunity for civil damages – Physician, physician assistant, etc.	No
Immunity for civil damages – Nurse	No
Protection from disciplinary or recriminatory action	Yes
Protection from employment discrimination	No
Protection from discrimination regarding staff status	No
Protection from discrimination regarding student status	No

Note: There appears to be a pattern to these notification requirements:

- Written notification is required where there is an established employment relationship, staff privileges, or a professional licensing relationship.
- Written notification is not required in situations where there is an unknown third party such as a patient who presents him or herself for treatment at a hospital or a physician's office.

Notification requirements under AB 67

AB 67 retains the current conscience clause provisions and expands these laws to cover more activities, to protect more individuals, and to provide more legal protections.

Under AB 67, the current structure for written notification of a health care provider's intention to assert a conscience right is virtually the same. The new provisions in AB 67 require written notification of a health care provider's intention to assert a conscience right in a manner consistent with the current conscience clause law. The *new* written notification requirements are as follows:

Right to refuse to participate	Written notification required?
Pharmacist – refusal to participate	Yes

Availability of legal protection	Written notification required?
Protection from employment discrimination based on creed	No
Civil action for equitable relief, including reinstatement, or damages	No
Professional immunity	Yes

Shouldn't medical professionals provide prior notification to patients?

Opponents of this legislation argue that medical professionals who are "unwilling to provide treatments, dispense medications or discuss medical options" should provide prior notification to patients. This would not be practicable.

All health care professionals limit their practices. The list of what they do not provide would be enormous. For example, surgeons do not provide routine vaccinations. Eye doctors do not set broken bones. Even family physicians do not provide every treatment a patient may request. For example, if the patient inappropriately requests an antibiotic for a viral infection, the physician would correctly refuse to provide this treatment because it would not be effective. These kinds of discussions happen every day in the medical profession. As they come up, the physicians will simply tell the patients that they do not provide the requested treatment and may suggest more appropriate options.

CONTRACEPTIVES NOT COVERED

AB 67 does not cover contraceptives. This is clear in two ways: the substitute amendment expressly excludes contraceptives and the definition of abortion precludes coverage of contraceptives.

Contraceptives are expressly excluded from AB 67

AB 67, as introduced, did not cover contraceptives and it was never intended to cover contraceptives.

The substitute amendment (ASA 1 to AB 67) resulting from the work of the Assembly Labor Committee makes this exclusion clear by expressly excluding contraceptives from the coverage of the bill. The cross-referenced definition of contraceptive is as follows:

> 450.155 (1) (a) "Contraceptive article" means any drug, medicine, mixture, reparation, instrument, article or device of any nature used or intended or represented to be used to prevent a pregnancy.

The definition of abortion in AB 67 does not cover contraceptives

AB 67 covers the conscience right to refuse to participate in "an abortion, as defined in s. 253.10 (2) (a)". The cross-referenced definition of abortion is as follows:

> 253.10 (2) (a) "Abortion" means the use of an instrument, medicine, drug or other substance or device with intent to terminate the pregnancy *of a woman known to be pregnant or for whom there is reason to believe that she may be pregnant* and with intent other than to increase the probability of a live birth, to preserve the life or health of the infant after live birth or to remove a dead fetus.

This definition does not cover contraceptives. In order for this definition of "abortion" to apply, the woman who takes a drug or to whom a drug is given must be "known to be pregnant" or there must be "reason to believe that she may be pregnant'. A woman taking a contraceptive pill, for example, does not fall within either category. Neither does the health care professional who prescribes the contraceptive pills or the pharmacist who dispenses them.

Specifically, AB 67 does not provide conscience protection for a health care professional or pharmacist who "believes" that a contraceptive may sometimes operate after fertilization and prior to implantation of a human embryo. By virtue of the definition of abortion, AB 67 only covers drugs, such as RU 486, that are intended to abort women known to be pregnant or when there is reason to believe they may be pregnant – which is not the case with the contraceptive pill, whether or not it may sometimes have a later anti-implanting effect.

WOMEN WILL NOT BE HARMED

Opponents of AB 67 falsely claim that women will be harmed

Planned Parenthood falsely claims that AB 67 "will allow health care workers to deny women access to basic health care and referrals for medical services including prenatal care and fertility treatments."

AB 67 merely protects individual health care professionals who refuse to participate in specified acts involving the destruction of human life.

There will continue to be health care providers who are willing to provide abortions and participate in the other activities covered by the bill. Any patient desiring these procedures will continue to be able to do business with these health care providers.

What if the mother's life is in danger?

If there is an emergency and a pregnant woman's life is in danger, the woman or someone else should call 911 and she should go to an emergency room. Everything will be done to save her life and to save the life of her unborn child.

Do pro-life doctors ever perform a pregnancy termination?

A local OB/GYN stated: (1) It is very rare for a pregnant woman to have an illness that is so life-threatening that an early delivery is necessary. He only had one case in his 12 years of practice. He related an incident involving a mother with a terrible case of lupus and kidney disease and developed preeclampsia at 22 weeks. She began to go into renal failure and premature delivery was needed.

(2) Probably the most common example of inducing a pre-viable live baby is the case of pre-term (in this case before 23-24 weeks) rupture of membranes. Not all of these babies need to be delivered, but the risk of infection is present. If intrauterine infection begins, delivery must be carried out or risk of possible overwhelming sepsis may develop. This is a circumstance well recognized by pro-life obstetricians as well as the Catholic Church.

A local family physician stated: (1) In cases involving an ectopic pregnancy or uterine or cervical cancer, treatment of the disease would be performed even though it means the death of the baby since the intent is to treat the disease, not kill the baby.

What if the mother's life is in danger?

A local family physician stated: (1) In the case of a cancer of other organs such as the breast or leukemia, treatment may threaten the life of the baby, but if it is necessary, it is not withheld. Sometimes lower doses of the medications might be used, if the mother

so chooses. The baby is delivered, usually prematurely, and then treatment begins in earnest.

(2) The examples of physicians refusing to treat a woman's high blood pressure or diabetes is nonsense. In those examples, the health of the mother is paramount to preserve the life of the baby. If she is on a medicine that could cause problems, another can be substituted. In fact, some women are on antiseizure medications, which physicians know can cause birth defects, but are continued on them to protect the life and health of both mother and child.

(3) What the family physician has heard, instead, are cases where women are pressured to abort before treatment is begun or because there is no guarantee that a treatment won't hurt the child.

In summary, in life-threatening situations pro-life physicians do all they can to save both the mother and the child. However, it is not always possible to save the child in the course of treating the mother's disease. Pro-life physicians sadly accept this fact.

UNDUE HARDSHIP EXCEPTION WOULD GUT THE BILL

Opponents will try to amend the bill to add an undue hardship exception

The current Wisconsin Fair Employment Act (WFEA) discrimination provision based on creed is as follows:

111.337 (1) Employment discrimination because of creed includes, but is not limited to, refusing to reasonably accommodate an employee's or prospective employee's religious observance or practice *unless the employer can demonstrate that the accommodation would pose an undue hardship on the employer's program, enterprise or business.* (emphasis added)

The bill creates a new discrimination provision based on creed to cover eight specified conscience activities dealing with acts involving the destruction of human life. There is no "undue hardship" exception for any of these activities.

Adding an undue hardship exception would gut the bill

The current "undue hardship" exception deals with reasonably accommodating an employee's "religious observance or practice". This could be going to a religious service or ceremony at a church or synagogue, or going to a religious education class. It could also entail not working on a Sabbath day.

These activities are NOT comparable. It is one thing to allow an employer to deny an employee the opportunity to take time off from work for a religious activity or to require an employee to work on a Sabbath. It is quite another to allow an employer to FORCE an employee to participate in an act involving the destruction of human life.

Adding an "undue hardship" exception would allow an employer to either force an employee to engage in a protected activity or to fire the employee for refusing to participate in the activity. This is no protection at all and guts the bill.

Employees who object, on moral or religious grounds, to acts involving the destruction of human life should not be forced to participate.

Planned Parenthood®
Advocates of Wisconsin, Inc.

AB 67

Anti-Health Care Bill

(A.K.A "Conscience Clause" bill)

Hotline: 1(800) 261-2464 | *Madison* (608) 256-7549 | *Milwaukee* (414) 271-8045 | *Appleton* (920) 731-6064 | *Eau Claire* (715) 833-2390

Planned Parenthood®
Advocates of Wisconsin, Inc.

OPPOSE Assembly Bill 67
Health Care Denial Bill

Updated 9/3/03

- **The public overwhelming opposes bills like AB 67**
  - In a recent poll of 600 voters, 85.4% stated that they would be less likely to vote for a candidate who supported a law that would allow pharmacists and physicians, because of their moral or religious beliefs, to deny women access to birth control and health care.
- **AB 67 Threatens Women's Health**
  - Doctors, nurses and health care workers can refuse to administer needed health care to pregnant women:
    - Pregnant women with epilepsy could be denied anti-seizure medication;
    - Pregnant cancer patients could be denied chemotherapy;
  - Prenatal care and tests, such as amniocentesis, can be denied to pregnant women.
  - Permits a hospital and its employees to deny women any referral or information about pregnancy termination, even when the woman's life and health are in danger.
  - Elevates a fetus or embryo above the health care needs of a woman.
- **AB 67 Harms Patients**
  - Allows health care professionals to deny patients vital health care services, even if the denial of care harms the patient.
  - Eliminates an injured patient's right to sue a hospital, physician, or worker even if the patient suffers a permanent, life-threatening injury, if the employee or hospital claims that he or she had a moral or religious objection to providing patient care.
  - Prohibits all disciplinary actions against all health care professionals and workers who permanently and perhaps fatally injure patients because of a supposed moral or religious belief.

- **AB 67 Eliminates Patient Choices**

  - **Allows hospitals and all employees to** ignore patients' living wills and advanced directives regarding end of life issues.

- **AB 67 Harms Hospitals and Employers**

  - Prohibits hospitals from firing an employee who refuses to administer health care to patients because of an unreasonable moral or religious belief--even when a patient is harmed.

  - Gives employees a new legal claim against employers.

  - In certain situations, AB 67 conflicts with the Emergency Medical Treatment and Active Labor Act (EMTALA), a federal law which requires hospitals to administer certain emergency treatment to patients. Complying with AB 67 could expose a hospital to sanctions and liability under EMTALA.

- **AB 67 Could Cost Taxpayers Money**

  - According to the Department of Health and Family Services' (DHFS) fiscal estimate, AB 67 could expose DHFS to federal penalties and an increase in Medicaid costs.

Planned Parenthood®
of Wisconsin, Inc.

For Immediate Release
June 3, 2003

Media Contact: Lisa Boyce or Chris Taylor
608 256-7549

HEALTH CARE LEADERS DENOUNCE AB 67

Health care providers and organizations deem the bill an unconscionable attack on patient rights

Madison, WI – Representatives from prominent health care organizations joined Representatives Terese Berceau, Jon Richards, and Mark Miller today to urge Assembly members to oppose AB 67 scheduled for a final vote before the Assembly tomorrow. Dr. Doug Laube from the UW Medical School and past vice-chair of the American College of Obstetricians and Gynecologists (ACOG), Georgina Dennik-Champion, executive director for the Wisconsin Nurses Association, and Melanie Ramey, executive director with the Hospice Organization and Palliative Experts of Wisconsin, gathered at a press conference to highlight the devastating impact AB 67 would have on patients.

"Elected officials are playing politics with people's lives by ignoring the repeated pleas of qualified health care organizations and providers, who know what is best for patients, to oppose AB 67," stated Lisa Boyce, vice president for public affairs at Planned Parenthood of Wisconsin. "Clearly the officials who support AB 67 are more interested in advancing their personal ideologies and grandstanding for special interest groups than advocating for polices that are in the best interest of patient's health and well-being."

Dr. Laube commented, "AB 67 is an unconscionable attack on maternal health that would restrict valuable prenatal diagnosis and care that is integral to the health and well-being of women and their babies." Under AB 67, health care providers could deny pregnant women, medicine and prenatal care-even if doing so would harm a patient.

Ms. Dennick-Champion discussed the Wisconsin Nurses Association's opposition to AB 67 describing it as an attack on a patient's right to health care and the medical code of ethics. "A health care provider's primary commitment is to adhere to the code of ethics and their patient's needs." Demick-Champion commented. "AB 67 violates the Nurses code of ethics and a medical provider's commitment to the patient by granting them the right to walk away from a patient in their most vulnerable state."

Melanie Ramey addressed AB 67's impact on end-of-life issues, summarizing the bill as "an abomination." Ramey commented, "AB 67 encourages unethical behavior by allowing health care providers to disregard a dying patient's wishes specified in their living wills."

State Representatives present at the event summarized AB 67 as the most egregious attack on patient health care ever considered by the state Legislature and called on members to oppose the bill on the Assembly floor tomorrow.

OUR OPINION

Fanatic 'conscience' bill violates patients' rights

Should a nurse be able to withhold pain medication from a dying patient — medication prescribed by the patient's doctor — because the medication might hasten the patient's death, and the nurse finds that morally objectionable?

Most reasonable people would say "No. That's not her call to make."

Should a pharmacist be able to refuse AIDS medication to a gay man — medication prescribed by the man's own doctor — because the pharmacist has moral objections to homosexuality?

Most reasonable people would say "No. That's not the pharmacist's call."

Alas: Most of the people in the state Assembly are not reasonable people in this case. They are zealots bent on inserting their own personal beliefs between patients and their doctors — and posing for holier-than-thou card pictures with the religious right.

This bill, AB 67, known as the "conscience" bill, is promoted as a way to allow health care workers to follow their consciences by protecting them from liability and employment discrimination if they refuse to participate in listed procedures involving embryos, assisted suicide and euthanasia. But make no mistake: The bill is not about abortion. It is not about assisted suicide. It is not about euthanasia. State law already protects doctors, nurses and other health care providers who object to abortion. Assisted suicide and euthanasia are already illegal.

So whom would this bill protect? Even its backers have yet to produce evidence that any health-care workers are being forced to perform tasks they find morally objectionable or are being fired for refusing to do so.

Meanwhile, the list of groups that oppose the bill is growing. It includes

The bill authorizing health care workers to disregard doctors' decisions and patients' wishes is contrary to medical ethics.

AARP, the State Medical Society, the Wisconsin Nurses Association, the Hospice Organization, Planned Parenthood — even the Lutheran Church. A doctor from the UW Medical School called the bill "an unconscionable attack on maternal health." The head of the Nurses Association said it violated the Nurses Code of Ethics. The executive director of the Hospice Organization called it "an abomination" that would allow health care workers "to disregard a dying patient's wishes specified in their living wills."

The bill passed the Assembly 59 to 38 on an almost strict party-line vote, minus three Republican legislators brave enough to buck their party: state Reps. DuWayne Johnsrud, R-Eastman, Mike Powers, R-Albany, and John Ainsworth, R-Shawano. We wish them luck reminding their fellow Republicans that the GOP once stood for individual rights — not the right of legislators to insert their personal beliefs into the relationship between a doctor and a patient.

All South Central Wisconsin Democrats in the Assembly opposed the bill — except for state Rep. Wayne Wood, D-Janesville.

The bill now goes to the Senate, where it is expected to pass. Gov. Jim Doyle has promised to veto it, but whether there are enough votes to sustain the veto is a matter of concern.

Once more with feeling: This bill is not about abortion; it's not about assisted suicide; it's not about euthanasia. It is a wholly unnecessary attack on patients' rights. Those who support it should be ashamed.

Wisconsin State Journal

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Wisconsin Medical Society

Your Doctor. Your Health.

TO: Members, Wisconsin Assembly

FROM: Alice O'Connor, VP Advocacy & Policy
Elizabeth Schumacher, Legislative Counsel

DATE: May 28, 2003

RE: AB 67: Oppose Unless Amended

On behalf of nearly 10,000 members, the Wisconsin Medical Society urges members of the Wisconsin Assembly to vote against AB 67 in order to protect a patient's right to referral in order to receive desired medical care. After careful review by our physicians with medical ethics expertise, we urge you to support current law mandating that a physician refer a patient if he/she cannot provide such care. **This is an ethical standard that all physicians must follow.**

The Society has urged the author of this bill to remove section 26 in AB 67, which would protect a physician from discipline if the physician chose not to transfer a patient despite the fact that the patient had an instrument for power of attorney for health care, or health care decision of a health care agent decision requesting such care. This language creates bad policy and exposes ill patients who are most vulnerable to an inability to receive the care that the patient desires.

The Society acknowledges that current Wisconsin law protects a physician's choice not to provide certain types of treatments or procedures if he/she has moral or religious objections. The Society is not taking a position on this specific issue. The Society urges you to remove all language that would remove a physician's duty to refer. The fundamental elements of any medical decision must honor the covenants of the patient and physician relationship and informed consent. The physician is both intellectually and morally obliged to act as the advocate for his/her sick patient whenever the patient's health is threatened. Physicians hold the highest ethical obligation to provide lifesaving care to the patient. This includes respecting the patient's wishes for medical care and ensuring that the patient's wishes are followed.

This legislation, if it passes in its current form, will harm the most vulnerable people.

330 East Lakeside Street • PO Box 1109 • Madison, WI 53701-1109 • wisconsinmedicalsociety.org • Phone: 608-442-3800 • Toll Free: 866-442-3800 • Fax 608-442-3812

AARP Wisconsin

April 23, 2003 / FOR IMMEDIATE RELEASE

For additional information, please contact:

Jeremy Janes (AARP Wisconsin) at 608/286-6308

"HEALTHCARE PROVIDERS MUST RESPECT LEGAL END-OF-LIFE DIRECTIVES"

AARP WISCONSIN ANNOUNCES OPPOSITION TO SPECIFIC PROVISIONS IN AB 67

AARP Wisconsin has informed members of the Assembly's Labor Committee that it strongly opposes parts of Assembly Bill 67 (AB 67).

In a letter delivered to Committee members yesterday, AARP Wisconsin State Director D'Anna Bowman wrote, "In seeking to protect healthcare providers from any liability that might result from refusal to perform specific tasks, AB 67 empowers doctors and nurses to determine, without penalty, whether the wishes articulated in a valid living will should be honored or denied."

"In other words," Bowman added, "healthcare providers would be free to disregard living wills whose authors had legally recorded their wish not to be kept alive by artificial means following a diagnosis that promised only a vegetative or moribund existence.

"The notion that any healthcare providers' moral or religious scruples should be given legal precedence over the express wishes of any patient should be abhorrent to all Wisconsin residents. For many people, rejection of artificial means of resuscitation at the conclusion of life asserts both a fundamental dignity and a choice that should be sacred."

AARP Wisconsin, Bowman explained, will not address or discuss any other provisions of AB 67.

In conclusion, Bowman urged Labor Committee members to revise AB 67 in order to protect end-of-life rights and choices for Wisconsin residents.

more . . .

AARP WISCONSIN ANNOUNCES OPPOSITION TO SPECIFIC PROVISIONS IN AB 67

continued . . .

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Tube Feeding in Patients With Advanced Dementia

A Review of the Evidence

Thomas E. Finucane, MD
Colleen Christmas, MD
Kathy Travis, MD

Patients with advanced dementia frequently develop eating difficulties and weight loss. Enteral feeding tubes are often used in this situation, yet benefits and risks of this therapy are unclear. We searched MEDLINE, 1966 through March 1999, to identify data about whether tube feeding in patients with advanced dementia can prevent aspiration pneumonia, prolong survival, reduce the risk of pressure sores or infections, improve function, or provide palliation. We found no published randomized trials that compare tube feeding with oral feeding. We found no data to suggest that tube feeding improves any of these clinically important outcomes and some data to suggest that it does not. Further, risks are substantial. The widespread practice of tube feeding should be carefully reconsidered, and we believe that for severely demented patients the practice should be discouraged on clinical grounds.

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PATIENTS WITH ADVANCED DEmentia commonly develop difficulty eating, often when they become bedridden and dependent in all activities of daily living. They may resist or be indifferent to food, fail to manage the food bolus properly once it is in the mouth (oral phase dysphagia), or aspirate when swallowing (pharyngeal phase dysphagia). Enteral tube feeding is intended to prevent aspiration pneumonia, forestall malnutrition and its sequelae, including death by starvation, and provide comfort. We reviewed data about whether any type of tube feeding can accomplish these goals in this group of patients. Studies limited to patients with cancer, burns, trauma, dysphagic stroke, mechanical obstruction, critical illness, pediatric patients, or patients receiving ventilatory assistance were not considered. We did not include discussion of ethical issues, since our focus was on clinical evidence.

We searched MEDLINE from 1966 through March 1999 and found no relevant randomized clinical trials comparing tube feeding with oral feeding in the severely demented. Thus, a meta-analysis was not possible; rather, we have presented a summary of the data available. In each section, we describe how articles were identified and summarize the findings. Our goal is to present the relevant data in a way that is useful to clinicians, patients, families, and perhaps policy makers.

For editorial comment see 1380.

DOES TUBE FEEDING PREVENT ASPIRATION PNEUMONIA?

Aspiration pneumonia is often an imprecise diagnosis both conceptually and clinically. Mendelson[1] described a group of parturient women who underwent ether anesthesia and vomited and aspirated gastric contents. All developed tachypnea, wheezing, rales, and cyanosis and all recovered uneventfully in a few days. Some authors use "aspiration pneumonia" to refer to this syndrome, a pneumonitis that follows aspiration and resolves spontaneously without antibiotics.[2] The term is also used to describe pulmonary infection due to misdirection of contaminated pharyngeal contents, especially oral secretions, into the airway. This syndrome is usually insidious in onset, associated with fever, and when a microbiologic diagnosis can be made, polymicrobial. Infection probably results when normally nonpathogenic organisms arrive in high enough inoculum to overcome host defenses.

Tube feeding cannot be expected to prevent aspiration of oral secretions, and no data show that it can reduce the risk from regurgitated gastric contents. In fact, in children[3] and in animal models,[4] gastrostomy tube placement may reduce lower esophageal sphinc-

Author Affiliations: Division of Geriatric Medicine and Gerontology, Johns Hopkins Bayview Medical Center, Baltimore, Md.
Corresponding Author and Reprints: Thomas E. Finucane, MD, Johns Hopkins Geriatrics Center, 5505 Hopkins Bayview Cir, Baltimore, MD 21224 (e-mail: tfinuc@jhmi.edu).

ter pressure and increase the risk of gastroesophageal reflux, with "a change in the gastroesophageal angle (as) the suspected mechanism."[4] No comparable studies have been reported in the elderly.

A 1996 review of tube feeding to prevent aspiration pneumonia conducted by 1 of the authors (T.E.F) and Bynum[5] found that "No randomized trials of the intervention have been done, and some data suggest ineffectiveness." A MEDLINE search from 1966 through March 1999 using the same search terms as that article, *enteral nutrition*, *deglutition disorders*, and *aspiration pneumonia*, confirmed these observations. Three additional case-control studies identified tube feeding as a risk factor for aspiration pneumonia and demonstrated high rates of pneumonia and death in tube-fed patients.[6-8] In a nonrandomized, prospective study,[9] orally fed patients with oropharyngeal dysphagia had significantly fewer major aspiration events than those fed by tube. The authors conclude, "Artificial feeding does not seem to be a satisfactory solution for preventing pneumonia in elderly prandial aspirators." Jejunostomy is not associated with lower rates of pneumonia than gastrostomy.[10,11] We found no published studies suggesting that tube feeding can reduce the risk of aspiration pneumonia.

DOES TUBE FEEDING PREVENT THE CONSEQUENCES OF MALNUTRITION?

Demented patients with problems eating frequently lose weight and develop other abnormal markers of nutritional status such as lowered serum albumin levels or total lymphocyte count, diminished triceps skin fold or body mass index, or impaired skin-test reactivity. Tube feeding may then be initiated to try to prevent or correct consequences of malnutrition including pressure ulcers, infection, debility, and death.

However, in several clinical situations, provision of increased nutrients to patients with abnormal markers of nutritional state had no effect on meaningful clinical outcomes. For 40 patients receiving tube feeding in long-term care (the majority due to neurologic impairment), "adequate calories and protein were provided . . . still, subjects showed weight loss and severe depletion of lean and fat body mass. . . . Despite administration of apparently adequate formula, micronutrient deficiencies and marasmic malnutrition exist in chronically ill patients."[12] In 2 additional clinical situations, patients with abnormal markers of nutritional status did not benefit from increased administration of nutrients. Of 17 trials studying patients with advanced cancer, most of whom were emaciated, no trial showed a survival benefit from parenteral nutrition.[13] Megestrol acetate in patients with acquired immunodeficiency syndrome (AIDS)–cachexia improved intake and nutritional markers; however, death rates in each of 4 treatment groups were more than double that of placebo controls.[14,15] For wasting disorders associated with AIDS and cancer, a 1997 conference sponsored by the National Institutes of Health, the American Society for Parenteral and Enteral Nutrition, and the American Society for Clinical Nutrition concluded that "there are no published observations providing direct evidence that wasting is a cause of death or that reversal of wasting improves outcome."[16]

For patients with advanced dementia and eating difficulties, the relationships among nutritional intake, markers of nutritional status, and clinically meaningful outcomes remain uncertain. For some patients with catabolic illness, delivery of additional nutrients may not provide benefit. For others, additional nutrients might provide benefits, but these may be outweighed by adverse effects of tube feeding. The relevant clinical question is whether tube feeding improves outcomes putatively ascribed to malnutrition.

IS SURVIVAL IMPROVED BY TUBE FEEDING?

We conducted a MEDLINE search of the terms *survival* and *enteral nutrition* from 1966 through March 1999 as well as the bibliographies of many articles related to these topics. Four lines of evidence undermine the apparently commonsense practice of tube feeding emaciated, demented patients to prevent death due to starvation.

First, survival of very low-weight, hand-fed demented patients can be substantial. Survival of demented and nondemented patients was not different in a long-term care facility with a program of careful feeding by hand.[17] A 2-year prospective observation of 71 demented patients in long-term care found similar mortality rates among 4 groups: those who fed themselves, those who required assistance but otherwise had no eating difficulties, those who refused food, and those who coughed and choked on food. Only 1 patient was tube fed.[18]

Second, feeding tube placement itself can cause death. Mortality during percutaneous endoscopic gastrostomy (PEG) tube placement ranges from 0% to 2%[19,20] and perioperative mortality ranges from 6% to 24%.[21-25] In a study of 882 fluoroscopic nasogastric tube placements, 3 patients died of arrhythmia during the procedure.[26]

Third, mortality among tube-fed patients is substantial. Several retrospective studies describe survival after feeding tube placement in patients with eating difficulties, although none are restricted to those with dementia. A review of studies of PEG tubes, each comprising more than 50 patients, found mortality rates of 2% to 27% at 30 days and 50% or more at 1 year.[27] Mortality data from articles not included in that review show 1-month mortality rates ranging from 8% to 67%, and median survival appears to be well under 1 year (TABLE 1). The 2 largest studies included 7369 and 81 105 patients, respectively. The former reported that median survival after PEG tube placement was 7.5 months.[25] The latter found that 63% of patients had died by 1 year after PEG or surgical gastrostomy tube placement and 81.3% were dead by 3 years.[23]

Finally, nonrandomized, retrospective observations of nursing home residents have found no survival advantage with tube feeding. No difference in sur-

vival was found between groups treated with and without tube feeding among 1386 patients with recent progression to severe cognitive impairment. This finding persisted after adjustment for age, prior history of pulmonary aspiration or stroke, presence of swallowing disorder, decubitus ulcer, functional state, resuscitation wishes, and cognitive status.[37] A separate article based on the same data set described 5266 residents with chewing and swallowing problems and reported a significant increase in 1-year mortality among tube-fed patients (risk ratio, 1.44).[38]

We found no published studies suggesting that tube feeding can prolong survival in demented patients with dysphagia.

ARE PRESSURE ULCERS PREVENTED OR IMPROVED BY TUBE FEEDING?

Data linking poor nutrient intake or abnormal markers of nutritional status to pressure ulcers are extremely limited. In a 1995 review[39] that excluded orthopedic and spinal cord injury patients, 13 studies found very weak associations between nutritional status and pressure sores. Data relating nutrient intake to pressure sores were similarly inconclusive. No prospective trials of tube feeding were found, and retrospective studies found only an increased risk or no benefit associated with tube feeding.[39] A MEDLINE search of *enteral nutrition* and *decubitus ulcer* from 1966 through March 1999 found no controlled clinical trials of tube feeding in those with or at risk for pressure ulcers. Two studies that used an administrative database of more than 800 patients during 6 months of follow-up reported that tube feeding was not associated with healing of preexisting pressure sores,[40] nor with protection from new pressure sores.[41]

Bedfast, incontinent patients with dementia who are tube fed are more likely to be restrained[42] and will probably make more urine and stool. Pressure sore outcomes could be worsened. We found no published studies suggesting that tube feeding can improve pressure sore outcomes.

IS THE RISK OF OTHER INFECTIONS REDUCED BY TUBE FEEDING?

Aspiration pneumonia and pressure ulcers, conditions that are sometimes infectious, have already been considered. We searched MEDLINE from 1966 through March 1999 using the terms *enteral nutrition* and *infection* and limited our search to studies involving humans. We found no studies of tube feeding to reduce the risk of other infections—eg, urinary tract, viral, gastrointestinal, or eye infections. In contrast, feeding tubes can cause infection. Nasogastric tubes predispose to infections of the sinuses and middle ear. Gastrostomy tubes have been associated with diarrhea (infectious and noninfectious), cellulitis and abscess (at a rate of 3% to 8%), and rarely with necrotizing fasciitis and myositis.[43] Enteral feeding solutions can be contaminated with bacteria, perhaps leading to gastrointestinal symptoms.[44] Case reports have described streptococcal bacteremia following insertion of a PEG tube[45] and contaminated enteral solution causing nosocomial bacteremia.[44,46,47] We found no published studies suggesting that tube feeding can reduce the risk of infection in dysphagic patients with dementia.

CAN TUBE FEEDING IMPROVE FUNCTIONAL STATUS?

Providing an emaciated patient with artificial feeding is sometimes intended to improve strength, function, or self-care. We reviewed a MEDLINE search of the terms *function*, *functional status*, *recovery of function*, *strength*, or *activi-*

Table 1. Mortality After Feeding Tube Placement: Observational Studies*

Study, y	Intervention	Type of Patient, No.	Outcome
Heimbach,[28] 1970	Surgical feeding tube	Neurogenic, 100	63% Mortality by 1 mo
Matino,[29] 1981	Jejunostomy tube	Neurogenic, 54	33% Mortality by 1 mo, 50% mortality among survivors by 6 mo
Golden et al,[30] 1997	PEG tube	Mixed population, 102	24% Mortality by 6 mo, 55% mortality by 2 y
Kaw and Sekas,[31] 1994	PEG tube	Mixed population, 46	20% Mortality by 1 mo, 59% mortality by 18 mo
Hull et al,[19] 1993	PEG tube	Mixed population, 49	8% Mortality by 1 mo, mean survival <6 mo
Kohli and Block,[20] 1995	PEG tube (review of 4 studies)	Mixed population, 612	16%-30% Mortality by 1 mo
Nevins,[21] 1989	PEG tube or gastrostomy tube	Neurogenic, 22	41% Mortality by 3 wks
Fay et al,[32] 1991	PEG vs nasoenteric tube	Mixed population, 109	50% Mortality by 4 mo for both populations
Hassett et al,[22] 1988	Gastrostomy tube	Neurogenic, 87	20% Mortality by 1 mo, 40% mortality by 1 y
Grant et al,[23] 1998	PEG tube or gastrostomy tube	Mixed population, 81 105	24% Mortality by 1 mo, 63% mortality by 1 y, 81.3% mortality by 3 y
Finocchiaro et al,[24] 1997	PEG tube	Mixed population, 136	9.5% Mortality by 1 mo, 58% mortality by 1 y, 65% mortality by 2 y
Loser et al,[33] 1998	PEG tube	Mixed population, 210	66% Mortality by 1 y
Fisman et al,[34] 1999	PEG tube	Mixed population, 175	18% Mortality by 30 d, 61% mortality by 1 y
Light et al,[35] 1995	PEG tube	Mixed population, 416	9% Mortality by 1 mo
Bergstrom et al,[36] 1995	Gastrostomy tube	Mixed population, 77	21% Mortality by 1 mo, 64% mortality by 1 y

*Neurogenic indicates dementia, cerebrovascular accident, trauma, anoxic brain injury, Parkinson disease, Guillain-Barré syndrome, or motor neuron disease; PEG, percutaneous endoscopic gastrostomy; and mixed population, patients with neurogenic mechanical disorders and cancer.

ties of daily living, and *enteral nutrition* from 1966 through March 1999. In stroke patients, emaciation may be associated with slower functional improvement,[48,49] but we found no study in which a nutritional intervention facilitated recovery of function. Among 100 frail nursing home residents, oral protein supplements produced no improvement in measures of strength or function unless combined with resistance strength training.[50] A retrospective review found that no nursing home patients had improvement in functional status as measured by the Functional Independence Measurement scale during 18 months after PEG tube placement.[31] We found no published studies suggesting that tube feeding can improve function or mitigate its decline in dysphagic demented patients.

DOES TUBE FEEDING IMPROVE PATIENT COMFORT?

We searched MEDLINE from 1966 through March 1999 using the terms *palliative care* and *enteral nutrition*. For many demented patients, data about symptoms and symptom control can be based only on inference. In a prospective observation of palliative care for terminally ill patients with anorexia, primarily with cancer or stroke, few experienced hunger or thirst. Of those who did, relief was achieved with small amounts of food and fluids or by ice chips and lip lubrication.[51]

Patients with amyotrophic lateral sclerosis and dysphagia who had feeding tubes placed continued to cough, have difficulty managing oral secretions, and develop aspiration pneumonia. Hunger and nausea often began or increased after tube placement, and human contact was diminished.[52] Tube-fed patients may be denied the pleasure of eating or made uncomfortable by the tube or frequent repositioning; some require restraints. We found no published studies suggesting that tube feeding makes dysphagic demented patients more comfortable.

ADVERSE EFFECTS

We searched MEDLINE from 1966 through March 1999 using the terms *complication* and *enteral nutrition* and limited our search to studies of humans age 65 years or older. The many adverse effects of tube feeding have been divided into 4 major categories: local or mechanical, pleuropulmonary, abdominal, and other (TABLE 2). The most common adverse effect associated with all types of tube feeding is aspiration pneumonia (0%-66.6%[5]). For PEG tubes, common adverse effects are tube occlusion (2%-34.7%[19,31,37]), leaking (13%-20%[31,32]), and local infection (4.3%-16%[19,31,32,60]). Approximately two thirds of nasogastric tubes require replacement.[32,68]

CONSERVATIVE ALTERNATIVES

Discontinuing nonessential medications may reduce eating difficulties. Among psychiatric patients, swallowing dysfunction and choking have been associated with certain medications, especially those with anticholinergic effects.[71,72] Several drugs cause inattention (eg, sedatives), movement disorders (eg, major tranquilizers), xerostomia (eg, anticholinergics), esophagitis (eg, alen-

Table 2. Burdens and Complications Associated With Tube Feeding

Adverse Effect Category	Type of Tube		
	Nasogastric	Gastrostomy and/or Jejunostomy	Both
Local/mechanical	Erosion/necrosis, bleeding of nose, pharynx, and/or esophagus[52,53,55]; postcricoid perichondritis[54]; tube misplacement into lung or brain[43,56]; high extubation rate; otitis media; sinusitis	Wound dehiscence; bleeding at insertion site; closure or stenosis of stoma; skin excoriation; hematoma; erosion of bumper into abdominal wall	Knotting of tube; tube malfunction[64]; tube migration; discomfort from tube; tube placement failure
Pleuropulmonary	Tracheoesophageal or bronchopleural fistula[55]; hemothorax, hydrothorax, pneumothorax[53,55,57]; tracheobronchial perforation; pneumonitis, lung abscess; pneumomediastinitis; airway obstruction; infusion into lung	Erosion of tube into pleural cavity	Aspiration of feeding
Abdominal	Perforation of esophagus or duodenum; esophageal stricture; esophageal bezoar[58]; reflux esophagitis	Gastric perforation[60]; gastric prolapse; gastrocolic fistula[59]; pneumoperitoneum; pneumatosis intestinalis[61]; prolonged ileus; evisceration[62]; acute gastric dilatation[65]; intussusception[66]; gastric wall defects[66]; laceration of esophagus[54]; peritonitis[54,60,64,67,68]; cellulitis[59,62]; necrotizing fasciitis; abdominal or subphrenic abscess[67]	Diarrhea; gastrointestinal bleeding[62,67]; bowel obstruction[64]; nausea[62]; vomiting; promotion of gastroesophageal reflux[70]
Other	Agitation[53,68]; requirement for frequent repositioning; increased secretions or frequent suctioning	Arrhythmia[26,62]; laryngospasm; shock; mediastinitis[62]	Fluid overload; increased skin moisture; death; use of restraints[63,68,69]; weight loss[53]; metabolic disturbance[53]; loss of gustatory pleasure; anorexia; loss of dignity; loss of social aspects of feeding; altered cosmesis[43,59]

dronate), or anorexia (eg, nonsteroidal anti-inflammatory drugs). Careful attempts to limit use of such medications may yield small but critical increments in eating ability.

Several conservative feeding strategies have been tried. In nursing home patients who were previously less than 80% of ideal body weight, an 8-week trial including staff education, ad lib diets, medication adjustment, assistive devices, changes in the environment, dental care, swallowing evaluations, and augmented energy intake during illness demonstrated that 50% of patients gained an average of 4.5 kg without feeding tubes.[73]

While body position during feeding is poorly studied in patients with dementia, supine (vs semirecumbent) position and length of time supine are risk factors for aspiration of gastric contents in patients receiving ventilatory assistance who are fed by nasogastric tube.[74] Potentially useful techniques include the use of finger foods and preferred foods,[75] strong flavors, hot or cold rather than tepid food, gravy or juices, and enrichers such as cream.[54,76,77] Other helpful techniques are reminders to swallow and swallow multiple times per bolus,[75,77] gentle coughs after each swallow,[77] bolus size of less than 1 teaspoon,[77] liquid supplements,[75] and facilitation techniques such as vibration, gentle brushing, and icing of the cheeks and neck.[52] Additional methods include increasing personal assistance with meals[75]; altering size and frequency of meals; evaluating for other illnesses, especially depression[75]; placing food and fluid well into the mouth[52]; and modifying environmental aspects such as noise level and the company of disruptive patients. These techniques require increased staff time and have not been rigorously studied. They do offer less invasive alternatives to tube feeding.

CONCLUSIONS

We identified no direct data to support tube feeding of demented patients with eating difficulties for any of the commonly cited indications. Tube feeding is a risk factor for aspiration pneumonia; to our knowledge, it has never been shown to be an effective treatment, and neither regurgitated gastric contents nor contaminated oral secretions can be kept out of the airways with a feeding tube. Survival has not been shown to be prolonged by tube feeding. Periprocedure mortality is substantial and prolonged survival of very underweight, dysphagic, demented patients without tube feeding is common. Feeding tubes have not been shown to improve pressure sore outcomes, and in fact, the relationship between nutrient intake and pressure sores is tenuous at best. Improved delivery of nutrients via tube has not been shown to reduce infection, but, on the contrary, feeding tubes have been shown to cause serious local and systemic infection. Functional status has not been improved and demented patients are not made more comfortable with tube feeding while dozens of serious adverse effects have been reported. Conservative measures are available although these are not well studied. Randomized clinical trials of this intervention in this population would be tremendously complex both ethically and clinically.

Several factors likely contribute to the widespread use of tube feeding in elderly patients with dementia. Artificial sustenance retains special status in some discussions about life-sustaining treatment. The apparent validity of tube feeding is very persuasive; if patients have trouble eating, it seems sensible to feed them by any means. Several other factors probably also contribute—administrative convenience, ease of use by nursing staff, and misunderstanding by health care professionals and family members.

A demented patient with eating difficulty can present formidable clinical challenges. We believe that a comprehensive, motivated, conscientious program of hand feeding is the proper treatment. If the patient continues to decline in some clinically meaningful way, tube feeding might be considered as empirical treatment; however, all who help make the decision should be clearly informed that the best evidence suggests it will not help.

REFERENCES

1. Mendelson CL. The aspiration of stomach contents into the lungs during obstetric anesthesia. *Am J Obstet Gynecol*. 1946;52:191-204.
2. DePaso WJ. Aspiration pneumonia. *Clin Chest Med*. 1991;12:269-284.
3. Grunow JE, Al-Hafidh AS, Tunell WP. Gastroesophageal reflux following percutaneous endoscopic gastronomy in children. *J Pediatr Surg*. 1989; 24:42-45.
4. Canel D, Vane B, Gotto S. Reduction of lower esophageal sphincter pressure with Stamm gastrostomy. *J Pediatr Surg*. 1987;22:54-58.
5. Finucane TE, Bynum JP. Use of tube feeding to prevent aspiration pneumonia. *Lancet*. 1996;348:1421-1424.
6. Pick N, McDonald A, Bennett N, et al. Pulmonary aspiration in a long-term care setting: clinical and laboratory observations and an analysis of risk factors. *J Am Geriatr Soc*. 1996;44:763-768.
7. Bourdel-Marchasson I, Dumas F, Pinganaud G, Emeriau JP, Decamps A. Audit of percutaneous endoscopic gastrostomy in long-term enteral feeding in a nursing home. *Int J Qual Health Care*. 1997;9:297-302.
8. Langmore SE, Terpenning MS, Schork A, et al. Predictors of aspiration pneumonia: how important is dysphagia? *Dysphagia*. 1998;13:69-81.
9. Feinberg MJ, Knebl J, Tully J. Prandial aspiration and pneumonia in an elderly population followed over 3 years. *Dysphagia*. 1996;11:104-109.
10. Lazarus BA, Murphy JB, Culpeper L. Aspiration associated with long-term gastric versus jejunal feeding: a critical analysis of the literature. *Arch Phys Med Rehabil*. 1990;71:46-53.
11. Fox KA, Mularski RA, Sarfati MR, et al. Aspiration pneumonia following surgically placed feeding tubes. *Am J Surg*. 1995;170:564-566.
12. Henderson CT, Trumbore LS, Mobarhan S, Benya R, Miles TP. Prolonged tube feeding in long-term care: nutritional status and clinical outcomes. *J Am Coll Nutr*. 1992;11:309-325.
13. Koretz RL. Nutritional support: how much for how much [review]? *Gut*. 1986;27(suppl):85-95.
14. Oster MH, Enders SR, Samuels SJ, et al. Megestrol acetate in patients with AIDS and cachexia. *Ann Intern Med*. 1994;121:400-408.
15. Von Roenn JH, Armstrong D, Kotler DP, et al. Megestrol acetate in patients with AIDS-related cachexia. *Ann Intern Med*. 1994;121:393-399.
16. Klein S, Kinney J, Jeejeebhoy K, et al. Nutrition support in clinical practice: review of published data and recommendations for future research directions. *Am J Clin Nutr*. 1997;66:683-706.
17. Franzoni S, Frisoni GB, Boffelli S, Rozzini R, Trabucchi M. Good nutritional oral intake is associated with equal survival in demented and nondemented very old patients. *J Am Geriatr Soc*. 1996;44:1366-1370.
18. Volicer L, Seltzer B, Rheaume Y, et al. Eating difficulties in patients with probable dementia of the Alzheimer type. *J Geriatr Psychiatry Neurol*. 1989;2:189-195.
19. Hull MA, Rawlings J, Murray FE, et al. Audit of outcome of long-term enteral nutrition by percutaneous endoscopic gastrostomy. *Lancet*. 1993;341: 869-872.
20. Kohli H, Block R. Percutaneous endoscopic gastrostomy: a community hospital experience. *Am Surg*. 1995;61:191-194.
21. Nevins MA. Gastrostomy tube-feeding. *N J Med*. 1989;10:779-780.
22. Hassett JM, Sunby C, Flint L. No elimination of aspiration pneumonia in neurologically disabled patients with feeding gastrostomy. *Surg Gynecol Obstet*. 1988;167:383-388.
23. Grant MD, Rudberg MA, Brody JA. Gastrostomy placement and mortality among hospitalized Medicare beneficiaries. *JAMA*. 1998;279:1973-1976.

24. Finocchiaro C, Galletti R, Rovera G, et al. Percutaneous endoscopic gastrostomy: a long-term follow-up. *Nutrition*. 1997;13:520-523.
25. Rabeneck L, Wray NP, Petersen NJ. Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. *J Gen Intern Med*. 1996; 11:287-293.
26. Gutierrez ED, Balfe DM. Fluoroscopically guided nasoenteric feeding tube placement: results of a 1-year study. *Radiology*. 1991;178:759-762.
27. Cowen ME, Simpson SL, Vettese TE. Survival estimates for patients with abnormal swallowing studies. *J Gen Intern Med*. 1997;12:88-94.
28. Heimbach DM. Surgical feeding procedures in patients with neurological disorders. *Ann Surg*. 1970; 172:311-314.
29. Matino JJ. Feeding jejunostomy in patients with neurologic disorders. *Arch Surg*. 1981;116:169-171.
30. Golden A, Beber C, Weber R, Kumar V, Musson N, Silverman M. Long-term survival of elderly nursing home residents after percutaneous endoscopic gastrostomy for nutritional support. *Nurs Home Med*. 1997;5:382-389.
31. Kaw M, Sekas G. Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Dig Dis Sci*. 1994;39:738-743.
32. Fay DE, Poplansky M, Gruber M, Lance P. Long-term enteral feeding: a retrospective comparison of delivery via percutaneous endoscopic gastrostomy and nasoenteric tube. *Am J Gastroenterol*. 1991;86:1604-1609.
33. Loser C, Wolters S, Folsch UR. Enteral long-term nutrition via percutaneous endoscopic gastrostomy (PEG) in 210 patients: a four-year prospective study. *Dig Dis Sci*. 1998;43:2549-2557.
34. Fisman DN, Levy AR, Gifford DR, Tamblyn R. Survival after percutaneous endoscopic gastrostomy among older residents of Quebec. *J Am Geriatr Soc*. 1999;47:349-353.
35. Light VL, Slezak FA, Porter JA, Gerson LW, McCord G. Predictive factors for early mortality after percutaneous endoscopic gastrostomy. *Gastointest Endosc*. 1995;42:330-335.
36. Bergstrom LR, Larson DE, Zinsmeister AR, Sarr MG, Silverstein MD. Utilization and outcomes of surgical gastrostomies and jejunostomies in an era of percutaneous endoscopic gastrostomy: a population-based study. *Mayo Clin Proc*. 1995;70:829-836.
37. Mitchell SL, Kiely DK, Lipsitz LA. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch Intern Med*. 1997;157:327-332.
38. Mitchell SL, Kiely DK, Lipsitz LA. Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems? *J Gerontol*. 1998;53A:M1-M7.
39. Finucane TE. Malnutrition, tube feeding and pressure sores: data are incomplete. *J Am Geriatr Soc*. 1995; 43:447-451.
40. Berlowitz DR, Brandeis GH, Anderson J, Brand HK. Predictors of pressure ulcer healing among long-term care residents. *J Am Geriatr Soc*. 1997;45:30-34.
41. Berlowitz DR, Ash AS, Brandeis GH, Brand HK, Halpern JL, Moskowitz MA. Rating long-term care facilities on pressure ulcer development: importance of case-mix adjustment. *Ann Intern Med*. 1996;124: 557-563.
42. Quill TE. Utilization of nasogastric feeding tubes in a group of chronically ill, elderly patients in a community hospital. *Arch Intern Med*. 1989;149:1937-1941.
43. Keymling M. Technical aspects of enteral nutrition. *Gut*. 1994;S1:S77-S80.
44. Fernandez-Crehuet NM, Jurado D, Guillen JF, Galvez R. Bacterial contamination of enteral feeds as a possible risk of nosocomial infection. *J Hosp Infect*. 1992;21:111-120.
45. Tsai CC, Bradley SF. Group A streptococcal bacteremia associated with gastrostomy feeding tube infections in a long-term care facility. *J Am Geriatr Soc*. 1992;40:821-823.
46. Thurn J, Crossley K, Gerdts A, Maki M, Johnson J. Enteral hyperalimentation as a source of nosocomial infection. *J Hosp Infect*. 1990;15:203-217.
47. Levy J, van Laetham J, Verhaegen G, Perpete C, Butzler JP, Wenzel RP. Contaminated enteral nutrition solution as a cause of nosocomial bloodstream infection: a study using plasmid fingerprinting. *JPEN J Parenter Enteral Nutr*. 1989;13:228-234.
48. Davalos A, Ricart W, Gonzalez-Huix F, et al. Effect of malnutrition after acute stroke on clinical outcome. *Stroke*. 1996;27:1028-1032.
49. Finestone HM, Greene-Finestone LS, Wilson ES, Teasell RW. Prolonged length of stay and reduced functional improvement rate in malnourished stroke rehabilitation patients. *Arch Phys Med Rehabil*. 1996; 77:340-345.
50. Fiatarone MA, O'Neill EF, Ryan ND, et al. Exercise training and nutritional supplementation for physical frailty in very elderly people. *N Engl J Med*. 1994; 330:1769-1775.
51. McCann RM, Hall WJ, Groth-Juncker A. Comfort care for terminally ill patients: the appropriate use of nutrition and hydration. *JAMA*. 1994;272:1263-1266.
52. Scott AG, Austin HE. Nasogastric feeding in the management of severe dysphagia in motor neurone disease. *Palliat Med*. 1994;8:45-49.
53. Sullivan RJ. Accepting death without artificial nutrition or hydration. *J Gen Intern Med*. 1993;8:220-224.
54. Vreugde S. Nutritional aspects of dysphagia. *Acta Otorhinolaryngol Belg*. 1994;48:229-234.
55. Miller KS, Tomlinson JR, Sahn SA. Pleuropulmonary complications of enteral tube feedings. *Chest*. 1985;88:230-233.
56. Stolke D, Winkelmuller W. Perforating craniocerebral trauma as a complication of a nasogastric feeding tube [in German]. *Anasth Intensivther Notf Med*. 1982;17:104-105.
57. Roubenoff R, Ravich WJ. Pneumothorax due to nasogastric feeding tubes. *Arch Intern Med*. 1989; 149:184-188.
58. Blasco Navalpotro MA, Zaragoza Crespo R, Malaga Lopez A, Alfonso Moreno V. Esophageal bezoar: an exceptional complication of enteral nutrition [in Spanish]. *Rev Clin Esp*. 1998;198:487-488.
59. Park RH, Allison MC, Lang J, et al. Randomized comparison of percutaneous endoscopic gastrostomy and nasogastric tube feeding in patients with persisting neurological dysphagia. *BMJ*. 1992;304:1406-1409.
60. Larson DE, Burton DD, Schroeder KW, DiMagno EP. Percutaneous endoscopic gastrostomy: indications, success, complications, and mortality in 314 consecutive patients. *Gastroenterology*. 1987;93:48-52.
61. Zern RT, Clarke-Pearson DL. Pneumatosis intestinalis associated with enteral feeding by catheter jejunostomy. *Obstet Gynecol*. 1985;65(3 suppl):81S-83S.
62. Wasiljew BK, Ujiki GT, Beal JM. Feeding gastrostomy: complications and mortality. *Am J Surg*. 1982; 143:194-195.
63. Peck A, Cohen CE, Mulvihill MN. Long-term enteral feeding of aged, demented nursing home patients. *J Am Geriatr Soc*. 1990;38:1195-1198.
64. Adams MB, Seabrook GR, Quebbeman EA, Condon RE. Jejunostomy: a rarely indicated procedure. *Arch Surg*. 1986;121:236-238.
65. Ghosh S, Eastwood MA, Palmer KR. Acute gastric dilatation—a delayed complication of percutaneous endoscopic gastrostomy. *Gut*. 1993;34:859-860.
66. Levine CD, Handler B, Baker SR, et al. Imaging of percutaneous tube gastrostomies: spectrum of normal and abnormal findings. *AJR Am J Roentgenol*. 1995;164:347-351.
67. Cogen R, Weinryb J, Pomerantz C, Fenstemacher P. Complications of jejunostomy tube feeding in nursing facility patients. *Am J Gastroenterol*. 1991; 86:1610-1613.
68. Ciocon JO, Silverstone FA, Graver LM, Foley CJ. Tube feedings in elderly patients: indications, benefits, and complications. *Arch Intern Med*. 1988;148: 429-433.
69. Baeten C, Hoefnagels J. Feeding via nasogastric tube of percutaneous endoscopic gastrostomy: a comparison. *Scand J Gastroenterol*. 1992;27:95-98.
70. Russell GN, Yam PC, Tran J, et al. Gastroesophageal reflux and tracheobrachial contamination after cardiac surgery: should a nasogastric tube be routine? *Anesth Analg*. 1996;83:228-232.
71. Craig TJ. Medication use and deaths attributed to asphyxia among psychiatric patients. *Am J Psychiatr*. 1980;137:1366-1373.
72. Craig TJ, Richardson MA. "Cafe coronaries" in psychiatric patients [letter]. *JAMA*. 1982;248:2114.
73. Abbasi AA, Rudman D. Undernutrition in the nursing home: prevalence, consequences, causes, and prevention. *Nutr Rev*. 1994;52:113-122.
74. Torres A, Serra-Batlles J, Ros E, et al. Pulmonary aspiration of gastric contents in patients receiving mechanical ventilation: the effect of body position. *Ann Intern Med*. 1992;116:540-543.
75. Morley JE. Dementia is not necessarily a cause of undernutrition. *J Am Geriatr Soc*. 1996;44:1403-1404.
76. Boylston E, Ryan C, Brown C, Westfall B. Preventing precipitous weight loss in demented patients by altering food texture. *J Nutr Elder*. 1996;15:43-48.
77. Horner J, Massey EW, Riski JE, Lathrop DL, Chase KN. Aspiration following stroke: clinical correlates and outcome. *Neurology*. 1988;38:1359-1362.

Until more definitive data are available regarding the role of HDC-PBSCT, patients with breast cancer should look to their physicians to provide them with information regarding all their treatment options. At present, clinical research in breast cancer is focusing on a variety of promising therapeutic strategies, such as new chemotherapy agents, endocrine agents, antibody therapy, vaccines, and antiangiogenesis agents. Ultimately, these larger, randomized trials should contribute to an evidence-based approach for selection of the most appropriate and efficacious therapy for patients who have breast cancer.

REFERENCES

1. Antman KH, Rowlings PA, Vaughan WP, et al. High-dose chemotherapy with autologous hematopoietic stem-cell support for breast cancer in North America. *J Clin Oncol*. 1997;15:1870-1879.
2. Zujewski J, Nelson A, Abrams J. Much ado about not . . . enough data: high-dose chemotherapy with autologous stem cell rescue for breast cancer. *J Natl Cancer Inst*. 1998;90:200-209.
3. Rowlings PA, Williams SF, Antman KH, et al. Factors correlated with progression-free survival after high-dose chemotherapy and hematopoietic stem cell transplantation for metastatic breast cancer. *JAMA*. 1999;282:1335-1343.
4. Falkson G, Tormey DC, Carey P, Witte R, Falkson HC. Long-term survival of patients treated with combination chemotherapy for metastatic breast cancer. *Eur J Cancer*. 1991;27:973-977.
5. Falkson G, Gelman RS, Leone L, Falkson CI. Survival of premenopausal women with metastatic breast cancer: long-term follow-up of Eastern Cooperative Group and Cancer and Leukemia Group B studies. *Cancer*. 1990;66:1621-1629.
6. Rahman ZU, Frye DK, Smith TL, et al. Results and long term follow-up for 1581 patients with metastatic breast carcinoma treated with standard dose doxorubicin-containing chemotherapy: a reference. *Cancer*. 1999;85:104-111.
7. Bezwoda WR, Seymour L, Dansey RD. High-dose chemotherapy with hematopoietic rescue as primary treatment for metastatic breast cancer: a randomized trial. *J Clin Oncol*. 1995;13:2483-2489.
8. Kennedy MJ. High-dose chemotherapy of breast cancer: is the question answered [comment]? *J Clin Oncol*. 1995;13:2477-2479.
9. Stadtmauer E, O'Neill A, Goldstein L, et al. Phase III randomized trial of high-dose chemotherapy and stem cell support shows no difference in overall survival or severe toxicity compared to maintenance chemotherapy with cyclophosphamide, methotrexate and 5-fluorouracil for women with metastatic breast cancer who are responding to conventional induction chemotherapy: the Philadelphia Intergroup Study (PBT-1) [abstract]. *Proc Am Soc Clin Oncol*. 1999;18:1a.
10. Early Breast Cancer Trialists' Collaborative Group. Polychemotherapy for early breast cancer: an overview of the randomised trials. *Lancet*. 1998;352:930-942.
11. Fisher B, Anderson S, Wickerham DL, et al. Increased intensification and total dose of cyclophosphamide in a doxorubicin-cyclophosphamide regimen for the treatment of primary breast cancer: findings from National Surgical Adjuvant Breast and Bowel Project B-22. *J Clin Oncol*. 1997;15:1858-1869.
12. Wood WC, Budman DR, Korzun AH, et al. Dose and dose intensity of adjuvant chemotherapy for stage II, node-positive breast carcinoma [published correction appears in *N Engl J Med*. 1994;331:1391]. *N Engl J Med*. 1994;330:1253-1259.
13. The Scandinavian Breast Cancer Study Group 9401. Results from a randomized adjuvant breast cancer study with high-dose chemotherapy with CTCb supported by autologous bone marrow stem cells versus dose escalated and tailored FEC therapy [abstract]. *Proc Am Soc Clin Oncol*. 1999;18:2a.
14. Bezwoda W. Randomized, controlled trial of high-dose chemotherapy versus standard dose chemotherapy for high risk, surgically treated primary breast cancer [abstract]. *Proc Am Soc Clin Oncol*. 1999;18:2a.
15. Peters W, Rosner G, Vredenburgh J, et al. A prospective, randomized comparison of two doses of combination alkylating agents as consolidation after CAF in high-risk primary breast cancer involving ten or more axillary lymph nodes: preliminary results of CALGB 9082/SWOG 9114/NCIC MA-13 [abstract]. *Proc Am Soc Clin Oncol*. 1999;18:1a.
16. Rodenhuis S, Richel D, van der Wall E, et al. A randomized trial of high-dose chemotherapy and hematopoietic progenitor cell support in operable breast cancer with extensive axillary lymph node involvement [abstract]. *Proc Am Soc Clin Oncol*. 1998;17:123a.
17. Hortobagyi G, Buzdar A, Champlin R, et al. Lack of efficacy of adjuvant high-dose tandem combination chemotherapy for high-risk primary breast cancer: a randomized trial [abstract]. *Proc Am Soc Clin Oncol*. 1998;17:123a.

Lack of Evidence About Tube Feeding—Food for Thought

Robert McCann, MD

FOOD PLAYS IMPORTANT BIOLOGICAL, SOCIAL, RELIgious, and symbolic roles in our society. From a mother breastfeeding her infant to a grandmother serving a meal, the provision of nutrition is a common way to demonstrate love and affection. Given these important roles of food, great concern arises when a person loses the ability to eat, a characteristic that often accompanies the dying process. During this time of great distress, families turn to familiar ways of providing comfort and expressing love, and the inability to provide food can be very unsettling.

It is easy to lose sight of the fact that not eating may be one of the many facets of the dying process and not the cause. Abnormal swallowing is often a marker for severe, multisystem illness and carries a high mortality regardless of intervention with artificial feeding.[1] Although our society has come to expect that cancer is often a terminal disease, degenerative neurologic diseases like dementia are often not thought of as "end stage" illnesses. This makes the decision about the use of artificial nutrition in dementia a difficult one for many physicians and families.

In this issue of THE JOURNAL, Finucane and colleagues[2] present a thoughtful review that addresses the lack of evidence supporting the use of tube feeding in patients with advanced dementia. The article challenges reasons often used for starting tube feeding, such as preventing aspiration pneumonia, providing comfort, preventing the consequences of malnutrition, improving survival, and improving functional status. Because few randomized, controlled studies have been performed in this area, the evidence cited is of-

See also p 1365.

Author Affiliation: Department of Medicine, Highland Hospital/University of Rochester, Rochester, NY.
Corresponding Author and Reprints: Robert McCann, MD, Department of Medicine, Highland Hospital/University of Rochester, 1000 South Ave, Rochester, NY 14620 (Robert_McCann@URMC.Rochester.edu).

ten retrospective or observational, or is based on patient populations other than those with dementia. Despite these limitations, the article still presents convincing arguments that clinicians should consider before initiating tube feeding and, if tube feedings have been initiated, highlights the importance of periodically reviewing the goals of treatment.

The adverse effects of tube feedings noted in the article include aspiration, obstruction of the feeding tube, and agitation. The high percentage of aspiration that occurs in patients being tube fed is striking given that "prevention of aspiration" is often an indication used to initiate placement of a feeding tube. Aspiration occurs in up to 50% of patients with feeding tubes regardless of whether nasogastric or gastric tubes are used.[3,4] Finucane et al[2] correctly point out that tube feeding could not be expected to prevent aspiration of mouth secretions and may actually increase aspiration. The authors also cite many articles demonstrating the high mortality experienced by patients who require tube feedings. The use of chemical and physical restraints is an often forgotten "complication" of tube feeding in patients who become agitated and attempt to remove the tube.[4]

Given the lack of evidence that tube feeding makes patients live longer or improves quality of life and the known adverse effects documented in this article, clinicians and families should think carefully about the goals of therapy before initiating tube feeding. The goals should be in concert with patients' previously expressed values and wishes. Statements like "We can't just let him starve to death" or "If we don't put this tube in she will get pneumonia" need to be put into perspective and replaced with more meaningful, thoughtful, and individualized approaches to care based on the available evidence of efficacy.

Families should be presented with reasonable alternatives to tube feeding and educated in ways that they can provide comfort and support to their loved ones. Alternative approaches to tube feeding should include altering flavors, amounts, consistency, and availability of food. Increased personal assistance with eating is often required. Although feeding appropriately positioned patients by hand can be very time consuming and a greater financial burden to institutions, tube feeding should not be implemented simply out of convenience. As the population ages, long-term care institutions must change to meet the needs of patients with advanced dementia. This will include changes in staffing, altering the environment, and increasing personal assistance with activities of daily living such as feeding. Some institutions have developed interdisciplinary teams that focus on altering the diet, environment, and personal assistance for patients to better ensure adequate nutrition.[5]

Efforts in caring for patients with advanced dementia should be aimed at keeping them safe and comfortable in the least restrictive environment possible. Every effort should be made to remove dietary restrictions and let a patient's preferences guide the type and amount of food provided. If tube feeding is instituted, such an intervention should be made with very specific goals in mind, and the benefits and burdens of therapy must be reassessed regularly. When those goals are not met, or when adverse effects occur, a decision to stop tube feeding should be considered. It is not unreasonable to forgo unproven and potentially harmful tube feeding therapy when the patient has advanced dementia and lack of nutrition would not be the primary cause of death. The medicalization of death has been termed a modern "coping mechanism" that helps caregivers deal with death, and there is a tendency to look to medicine for answers even when death is inevitable.[6] Placing food in its proper perspective will enhance the care of patients and prevent unnecessary harm.

REFERENCES

1. Cowen ME, Simpson S, Vettere T. Survival estimates for patients with abnormal swallowing studies. *J Gen Intern Med*. 1997;12:88-94.
2. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA*. 1999;282:1365-1370.
3. Ciocon J, Silverstone F, Graver LM, Foley C. Tube feedings in elderly patients. *Arch Intern Med*. 1988;148:429-433.
4. Quill T. Utilization of nasogastric feeding tubes in a group of chronically ill, elderly patients in a community hospital. *Arch Intern Med*. 1989;149:1937-1941.
5. Musson N, Kincaid J, Ryan P, et al. Nature, nurture, nutrition: interdisciplinary programs to address the prevalence of malnutrition and dehydration. *Dysphagia*. 1990;5:96-101.
6. McCue J. The naturalness of dying. *JAMA*. 1995;273:1039-1042.

Jermstad, Sara

From: Asbjornson, Karen
Sent: Thursday, May 29, 2003 12:17 PM
To: Jermstad, Sara
Subject: FW: concerns about AB 67 - scheduled for May 29

CR email

Karen Asbjornson
Office of Senator Carol Roessler
(608) 266-5300/1-888-736-8720
Karen.Asbjornson@legis.state.wi.us

-----Original Message-----
From: Sumi, Gail [mailto:GSumi@aarp.org]
Sent: Wednesday, May 28, 2003 4:59 PM
Subject: concerns about AB 67 - scheduled for May 29

AB 67 - AARP Wisconsin's concerns about physician referral of end-of-life directives is expressed in the attached memo. We support Rep. Sinicki's amendment to delete this section of the bill.

Please contact me if you have questions or concerns. Thank you for your consideration.

Gail

Gail Sumi

AARP

Government Affairs Representative

Wisconsin State Office

3 South Pinckney St., Suite 801

Madison, WI 53703

(voice) 608-286-6307

(fax) 608-251-7612

gsumi@aarp.org

-----Original Message-----
From: Janes, Jeremy
Sent: Wednesday, May 28, 2003 2:07 PM
To: Sumi, Gail
Subject: AB 67

<<AB 67 Conscience 28May03.pdf>>

THE GUTTMACHER REPORT

ON PUBLIC POLICY

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Editorial Office:
1301 Connecticut Avenue N.W.
Suite 700
Washington, DC 20036
(202) 296-4012
fax (202) 223-5756
policyinfo@guttmacher.org

Circulation:
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New Refusal Clauses Shatter Balance Between Provider 'Conscience,' Patient Needs

By Adam Sonfield

A series of attention-grabbing lawsuits and a crop of new legislation have spotlighted a long-gathering movement to vastly expand the scope of policies allowing health care providers, institutions and payers to refuse to participate in sexual and reproductive health services by claiming a moral or religious objection. In some cases, these radical new policies are intentionally designed to undermine, if not actually eliminate, the ability of governments at all levels, and even private businesses, to balance providers' "conscience" rights with the ability of patients to exercise their own conscience and gain access to health care services that they want and need.

Ever-Expanding Objections

U.S. policymakers first enacted "refusal clauses" in response to the nationwide legalization of abortion in the 1973 *Roe v. Wade* decision. These early policies—adopted by the federal government and all but a handful of states—were designed to allow doctors and other direct providers of health care to refuse to perform or assist in an abortion, and hospitals to refuse to allow abortions on their premises ("Refusing to Participate in Health Care: A Continuing Debate," *TGR*, February 2000, page 8). The federal policy also applies to sterilization, and a minority of states' policies apply to sterilization or contraception more broadly.

Since the 1970s, and especially over the past decade, the refusal clause debate has spread to a larger range of health care activities and participants. Much of the new momentum comes from the advent of technologies and medical practices that some Americans find objectionable. Examples include in vitro fertilization and other assisted reproductive technologies; medical research involving human embryos or fetuses, or embryonic stem cells; and end-of-life practices such as assisted suicide or even adherence to living wills. Refusal clause advocates have used public misgivings about these technologies and practices to push for provisions applying to these activities specifically—or to any activity, without limitation—and for an increasingly wide group of individuals and institutions that they claim are unwilling "participants" in these activities.

The debate is expanding to implicate new 'participants' and increasingly indirect forms of 'involvement.'

An important example of this tactic capitalizes on public ignorance about emergency contraception, which many antiabortion and other conservative activist groups have tarred as causing abortion, despite broad consensus in the medical community that it prevents an unintended pregnancy. The growing use of emergency contraception has helped bolster a movement to give pharmacists the right to refuse to fill prescriptions, for this drug and for others ("Objections, Confusion Among Pharmacists Threaten Access to Emergency Contraception," *TGR*, June 1999, page 1).

Even for older technologies, however, the refusal clause debate is expanding to implicate new participants and increasingly indirect forms of involvement. Three news stories from one month this year alone illustrate the pattern: In May, an ambulance worker in suburban Chicago sued a company that had purportedly fired her for refusing to transport a patient suffering severe abdominal pain to a clinic for an abortion. Later that month, an Illinois county settled a lawsuit brought by an employee denied a promotion purportedly because she refused to translate into Spanish information for family planning clients on abortion options. Also that month, a Wisconsin pharmacist faced a disciplinary hearing for refusing to even transfer a woman's prescription for oral contraceptives to another pharmacy.

These are not isolated incidents. News reports and court cases from prior years also have highlighted examples of hospital workers refusing to clean surgical instruments or handle paperwork tied to abortion, as well as police officers refusing to protect reproductive health clinics. Furthermore, social conservatives have called over the past decade for the creation of refusal clauses for health care payers, seeking to exempt insurance companies and employers purchasing insurance from laws requiring private-sector coverage of contraception, and to exempt managed care plans from covering reproductive health services under Medicaid.

Avenues for Expansion

Conservative advocates have been working at both the state and the federal levels in their campaign to enact laws to expand the scope of refusal policies. At the state level, the prime example is a law signed in May by Mississippi Gov. Haley Barbour (R)—legislation he campaigned on and extolled as "the single most

expansive conscience exception law in the nation." Individuals and institutional providers and payers of health care may now refuse to be involved in any type of service to which they object on moral, ethical or religious grounds, free from any type of liability, regardless of the effects on patients and employers. The law is as sweeping as it is detailed, covering activities such as counseling, diagnosis and research, as well as dispensing or administering any type of drug, device, surgery, care or treatment. Individuals granted this right of refusal include any employee of a hospital, clinic, nursing home, pharmacy or medical school, along with students, counselors or "any other person who furnishes, or assists in the furnishing of, a health care procedure."

Proposed legislation would effectively negate the federal requirement that clinics supported by Title X family planning funds provide abortion referrals upon specific request, as part of counseling clients about their pregnancy options.

Expansive refusal legislation was vetoed in April by Wisconsin Gov. Jim Doyle (D). The legislation would have extended the refusal clause currently in state law beyond its focus on performing or assisting in abortion and sterilization. It would have applied to a broader range of activities (including counseling and prescribing drugs) related to reproductive health, embryo research and end-of-life care.

Legislation has also passed the Michigan House and is pending in the state's Senate that would vastly expand refusal provisions for individual and institutional providers and add new provisions for insurers. It would exempt individuals from participating in almost any way in any type of health care service, except for provision of a contraceptive medication "taken or used in advance of sexual intercourse." That language is designed to allow refusal for emergency contraception and such devices as IUDs. Similar exemptions for institutions and insurers do not even include this limited caveat for contraceptive medication.

At the federal level, most of the debate in recent years has centered on the Abortion Non-Discrimination Act (ANDA), which passed the House of Representatives in 2002. A provision with similar effects was inserted by the House Appropriations Committee into the bill that provides FY 2005 funding for the Department of Health and Human Services. If enacted, the provision essentially would forbid any federal, state or local government from requiring any individual or institutional provider or payer to perform, provide, refer for or pay for an abortion. Such a policy would effectively negate the federal requirement that all clinics supported by Title X family planning funds provide abortion referrals upon specific request, in the form of a simple list of providers, as part of counseling clients about their full range of pregnancy options. It also would limit states' ability to enforce the federal Medicaid requirement that indigent women have access to Medicaid-funded abortions in situations of life endangerment, rape and incest, since states no longer could require managed care plans with which they contract to provide abortions to their enrollees in these circumstances. And it might even be used in an attempt to override state laws requiring hospitals to provide emergency contraception to rape victims, under the pretext that the drugs are abortifacients.

Another effort has occurred under a broader canopy of religious rights. Title VII of the federal Civil Rights Act protects workers from discrimination on the basis of religion, but many religious rights advocates assert that courts have interpreted this protection too narrowly. Bipartisan legislation under consideration in Congress—the Workplace Religious Freedom Act—would amend Title VII to redefine when and how employers must accommodate an employee's religious practices. Most supporters of the measure, including a wide array of religious groups, say the legislation is needed to accommodate such things as religious apparel and scheduling for religious observances. The Family Research Council, however, cites cases of pharmacists' refusal to provide contraception as a reason to enact this legislation.

Loss of Balance

This campaign to expand refusal rights threatens the ability of governments, communities and private organizations to protect patients' access to information and care. Health care provider groups, for example, generally support a balance between respecting providers' moral and religious beliefs and protecting the ability of patients to give informed consent and gain access to the health care they need. The American Nurses Association, for instance, asserts that although nurses have a right to refuse to participate in particular cases, a provider has an obligation "to share with the client all relevant information about health choices that are legal." The American Pharmacists Association adopted a policy in 1998 attempting to counterbalance pharmacists' right of refusal with "the establishment of systems to ensure patient access to legally prescribed therapy."

Much of the most recent wave of legislation appears to have been tailored specifically to eliminate this balance, in effect asserting that patients have no real rights to care or even information—or that repro-

ductive health care is not really health care at all. In his veto message, Wisconsin's governor noted that under the legislation, "there are no requirements that the health care professionals advise patients of their treatment options, provide a referral to the patient, transfer certain patients, or render care if the patients' health or life is threatened." He also stressed its potential harm to patients with a limited choice of providers, such as those in rural areas. He could have added that the legislation allowed individuals to ignore essential functions of their job, meaning, for example, that an abortion clinic could not fire a worker who refused to participate in abortion.

The Mississippi legislation includes all of these flaws and more. For instance, its definition of what is considered illegal "discrimination" against a provider, institution or payer asserting a religious or moral objection would prohibit many actions that a government or private entity could take to protect individuals' access to health care. This includes reassigning a worker to a different shift, a standard way of accommodating such an objection. This same language, as well as ANDA and the appropriations language currently pending before Congress, would also block efforts by policymakers, communities and advocates to preserve aecess to reproductive health services in the face of plans by religious institutions to affiliate or merge with secular ones or to assert control over what doctors do in their private practices.

Another concern is that these increasingly broad refusal clauses will allow individuals and institutional providers and payers to deny services for any reason—even prejudice. Most existing laws have few if any restrictions as to why an entity may object to a service and few requirements for anyone to actually provide care, except perhaps in emergencies. Indeed, only in the latest crop of legislation—the Mississippi law and the bills pending in Michigan—have lawmakers prohibited providers from refusing to participate in a service based on specific patient characteristics, such as race, ethnicity or religion. In both cases, however, the breadth of these lists of protected characteristics can been questioned. In Michigan, opponents of the legislation have noted that the list (a part of the state's civil rights law) does not include sexual orientation and have argued that the legislation would give providers license to refuse care to homosexuals. The Mississippi law's list of protected characteristics includes sexual orientation but does not include marital status, implying that providers or payers could discriminate against single people, for example by refusing to provide contraceptives to unmarried women.

The campaign to expand refusal rights threatens the ability of governments, communities and private organizations to protect patients' access to information and care.

All hope for balancing the rights of providers and patients is not lost, however. State legislators crafting requirements that insurance coverage of contraceptives be on par with other prescription drugs, for example, have intensely debated the breadth and effects of exemptions from these requirements ("Contraceptive Coverage: A 10-Year Retrospective," *TGR*, June 2004, page 6). In March 2004, California's top court upheld a religious exemption in the state's contraceptive coverage law, noting that it was narrowly tailored to serve the state's compelling interest in eliminating gender discrimination in health care. In addition, a handful of states have enacted mechanisms designed to ensure patients' access to care despite the objections of religious employers or insurers; Hawaii, Missouri and New York, for example, enable employees to purchase contraceptive coverage directly from an insurer if their employer refuses to provide coverage. One can hope that all of these actions may light the way for future attempts at balance, in contraceptive coverage laws and beyond.

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