Legal & Ethical Considerations for Advance Care Planning and Palliative End of Life Care

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Patient Self-Determination Act of 1990[1]

- Mandates that patients must be queried about the existence of advance directives and that such advance directives be made available to them if they wish
  - To make Patient Self-Determination Act reality, health care providers must themselves understand the act and its purposes and should be able to answer patients' questions.

Advance Directives Are Challenging

- The most challenging aspect of preparing an advance directive is assisting patients in identifying their preferences for treatment.
- WI Nursing Coalition Summit was held in 2012 to discuss the nurse's role in advance care planning and develop an action plan for Wisconsin.
  - Create one form
  - Standardized nursing role in advanced planning
  - Disseminate advance directive information

Individuals Who Should Consider Advance Directives

- Patients who have no legally designated surrogate or who could be denied the right—e.g., same sex partners
- Patients with unusual or highly specific preferences
- Patients and families for whom the existence of a document will reduce anxiety

Self-Determination

- Patient self-determination involves the right of individuals to decide what will or will not happen to their bodies.
- Competent adults have the right to forego treatment even if the refusal is certain death.
- Advance directives can assist in clarifying a patient's wishes for end of life decisions.

Natural Death Acts

- Natural death acts are written, legally recognized advance directives but with statutory enforcement
- Vary state to state
  - Chapter 154 of the Wisconsin Statutes—Living Wills
  - Chapter 155 of the Wisconsin Statutes—Power of Attorney for Health Care

Living Wills

- Directives from competent individuals to medical personnel and family members regarding the treatment they wish to receive when they can no longer make the decision for themselves
  - withhold or withdraw life-sustaining treatment from patients if they are ever in a terminal state

Wisconsin Living Will[2]

- Living Will only applies when a patient is diagnosed with either:
  - Persistent vegetative state—complete & irreversible loss of cerebral cortex
  - Terminal condition—death imminent
- ***Does not allow for surrogate decision-maker***

Wisconsin Living Will[2]

- Allows patient refusal of life-sustaining procedures for PVS:
  - Assistance in respiration
  - Artificial maintenance of BP & heart rate
  - Blood transfusion
  - Kidney dialysis
- Does not include pain meds, nutrition & hydration
- Allows refusal of feeding tubes for PVS & terminal condition.

Power of Attorney for Health Care

- Power of attorney for health care (PAHC) allows patients to appoint a surrogate or proxy to make health care decisions in the event that the patient lacks “capacity” to do so.
- It is a common-law concept that allows one person to speak for another.

WI Power of Attorney for Health Care[3]

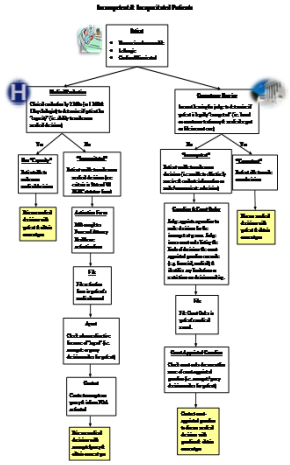
- Applies when patient incapable of managing health decisions (e.g. evaluate information; communicate decisions)
- Incapacitated; <u>not incompetent</u>
  - Document only takes effect when patient meets criteria for incapacity
- Old age, eccentricity or physical disability are insufficient
- Uses <u>best interest standard</u>
- ***Allows for surrogate decision-maker***

WI Power of Attorney for Health Care[3]

- Limitations--agent cannot admit for inpatient mental health treatment
- Options:
  - Admit to CBRF or nursing home
  - Withdraw or withhold feeding tube
  - Make decisions if patient pregnant
  - Special provisions or limitations
  - Anatomical gifts
- Optional Addendum

Decision Making for the Incapacitated or Incompetent Patient

- Who should decide?
  - Guardian, adult designated in an advanced directive, surrogate
- What standard should be used?
  - Best interest, substituted judgment



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Decision Making Capacity

- Elements to determine decision making capacity. The patient can:
  - Understand the information given
  - Evaluate the consequences and make a decision
  - Communicate a decision
- **Incapacity** = patient not capable of making a medical decision.

Capacity Evaluation

- Medical evaluation of "capacity" to make medical decisions:
  - Two physicians or one physician and one psychologist
  - Document decision-making capacity (i.e. results of evaluation) in medical record
  - Complete activation form (i.e. triggers PAHC)
  - Contact agent listed in power of attorney document
  - Confirm agent's willingness to serve as surrogate decision-maker

Two Decision Making Standards

- The **best interest standard** allows a person to determine what one thinks would be in the best interest of an incompetent adult and then pursue that plan of care.
- **Substituted judgment** is the subjective determination of how, if a person were capable of making opinions and wishes known, he or she would have chosen the right to refuse.

Standards in Life-Threatening Situations

- If patient's preferences are known, then the standard one applies in life-threatening situations is that of substituted judgment.
- If preferences are not known, then standard becomes one of best interests on behalf of patient.

Practical Problems with Advance Directives

- Lost advance directives
- Unclear statement of wishes
- Surrogate unaware of selection
- Surrogate does not wish to follow directive
- Health care provider does not wish to follow directive
- Advance directives comparison Chart

Burden on Surrogates

- Shift in medicine from paternalism to abdication
  - Early bioethics cases = physician paternalistically overrode patient's wishes to forego treatment
  - Now = physicians frequently do not provide recommendations
- Making treatment decisions has emotional effect on many Surrogates
  - Stress
  - Guilt over decisions made
  - Doubt re: whether made right decision

Right to Forego Treatment

- **Competent adults** also have the right to forego treatment even if the refusal is certain death.
  - Right to refuse intervention
    - Examples: feeding tube, blood products
  - Right to withhold/withdraw life sustaining treatment (aka right to die)
    - Examples: ventilator, left ventricular assist device (LVAD), pacemaker

Right to Forego Treatment

- **Incompetent and incapacitated adults** also have the right to forego treatment even if the refusal is certain death.
  - Right to refuse intervention
    - Examples: feeding tube, blood products
  - **Right to withhold/withdraw life sustaining treatment** (aka right to die)
    - Examples: ventilator, left ventricular assist device (LVAD), pacemaker
  - Someone else has to make decision for them

In re Quinlan (1976)[4]

- First case to decide **all patients** have right to withdraw, even if incapacitated
- Karen Ann Quinlan was 21; became unconscious after party where consumed combination of drugs and alcohol
  - Stopped breathing twice for 15 minutes or more
  - EMTs called and taken to hospital
  - Progressed into permanent vegetative state and kept alive on a ventilator

Cruzan Case (1990)[5]

- Nancy Cruzan was involved in a motor vehicle accident in 1983
- Started on life support and eventually went into permanent vegetative state
- Parents requested discontinuation of fluids & hydration
- After multiple appeals, the court ultimately allowed the father to decide to withdraw fluids and hydration

Cruzan Case (1990)[5]

- Key points from case:
  - **All patients** have the right to withdraw life sustaining treatment, even if incapacitated.
  - **Artificial nutrition and hydration** is considered medical treatment that may be refused.
  - Withdrawing life sustaining treatment is **not homicide or suicide**.

Wisconsin Cases

- ***In re: L.W. (1992)[6]***
  - Facts: 79 year old chronic schizophrenic, in and out of group homes, had corporate guardian. She had a cardiac arrest, progressed into **permanent vegetative state (PVS)** and was ventilator dependent.
  - Decision: Guardian has authority to consent to withdrawal of life sustaining treatment (LST), without court approval, if withdrawal is in the individual's best interest.

Wisconsin Cases

- ***In re: L.W. (1992)[6]***
  - Factors to consider:
    - Degree of humiliation
    - Dependence
    - Loss of dignity resulting from condition & treatment
    - Life expectancy
    - Prognosis with or without treatment
    - Options

Wisconsin Cases

- ***In re: Edna M.F. (1997)[7]***
  - Facts: 71 year old in late stage Alzheimer's dementia. Patient was close to PVS, but exhibited some minimal responses. Her guardian was her sister & best friend. Sister wanted to discontinue tube feedings. Past statement re: treatment preferences = "I would rather die of cancer than lose my mind."
  - Decision: When an incompetent individual is not in a persistent vegetative state, it is not in the person's interest to withdraw life sustaining treatment, unless there is clear evidence that it would be in the person's best interest.

State's Interest

- The state can override right to refuse, forego, or withdraw medical treatment in certain considerations:
  - Preserving life if no terminal illness
  - Protecting third parties, such as children
  - Protecting public health

Wisconsin Supreme Court Case

Homicide convictions upheld for Wisconsin parents who treated dying daughter with prayer[8]

Minors and the Right to Die

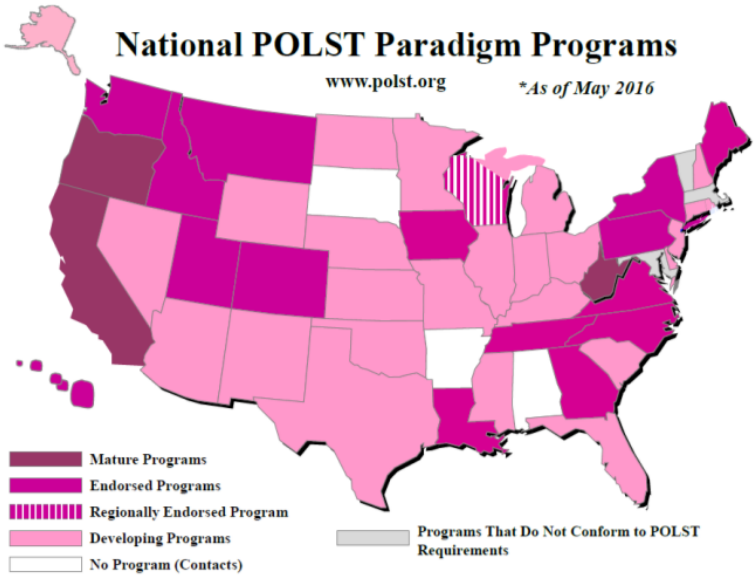
- Courts continue to debate the rights of minors in medical decision making.
- There are various standards adopted by state legislatures and state courts (e.g. mature minor consent).
- Whose voice should have the most weight with the courts—that of the mature minor or that of the parent?

Other Directives

- **Medical or physician directive** allows for a directive that lists a variety of treatments and lets patients decide what they would want.
- **The Uniform Rights of the Terminally Ill Act** provides alternative ways in which a terminally ill patient's desires regarding the use of life-sustaining procedures can be legally implemented.

Physician Orders for Life-Sustaining Treatment

- POLST contains information on person's end-of-life directives
- Developed for Emergency Medical Service (EMS) personnel to provide initial responders with written physician orders that give specific instructions concerning medical intervention
- Portable and easy to complete and recognize



Screenshot Source: http://www.ohsu.edu/polst/

WI POLST Form

Screenshot Source: http://www.ohsu.edu/polst/programs/sample-forms.htm

POLST and Advance Directive

- Advance directive and POLST share similarities, in that:
  - They are designed to assist persons with making their final wishes known
  - They encourage open and frank conversations
  - They encourage communication to take place when the patient is competent to understand the ramifications of alternative options
- POLST outlines preferences while an advance directive provides more details.

Pre-Hospital Do-Not-Resuscitate Directives

- Patients and surrogate decision makers need the ability to state their preferences for or against resuscitative measures.
- More limited than an advance directive or POLST.

Pre-Hospital DNR Bracelet[9]

- **Wis. Stat. §154.19**—attending physician may issue do-not-resuscitate order for EMTs, first responders and emergency health care facilities personnel not to attempt CPR in the event of a cardiac or respiratory arrest.
  - DNR bracelet must be affixed to wrist.

In-Patient DNR Orders

- **Do-not-resuscitate directives**: patients and surrogate decision makers need the ability to state their preferences for or against resuscitative measures.
  - Generally used in hospitals and nursing homes
  - Typically executed upon admission
  - Usually suspended during surgery

Hospice Care

- Some terminally ill patients prevent the need for natural death acts by entering hospice centers, where a patient is cared for until death occurs.
- Patients receive care without the fear that they will be resuscitated or placed on life-support systems when death occurs (i.e. sign DNR upon admission).

New Developments

- **Right to Know Laws** (CA & NY)
  - CA—must provide information & counseling related to end of life options, **if patient asks**
  - NY—must provide palliative care information & end of life options to patient or person authorized to make health care decisions for patient

New Developments

- **Surrogate Consent Law** (IL)
  - Hierarchy of surrogates—spouse, adult child, parent, adult sibling, adult grandchild, close friend, guardian
  - If decision involves life sustaining treatment, patient must be terminal, permanently unconscious or have irreversible coma

Poll Everywhere

- **Should the Wisconsin legislature adopt a "Death with Dignity" or "Aid in Dying" Act to legalize physician-assisted suicide?**
  - Yes
  - No

Assisted Suicide

- Most states prohibit assisted suicide.
- The American Medical Association and the American Nurses Association object
- Most cited reasons for obtaining physician-assisted suicide:
  - Loss of autonomy, decreasing ability to participate in activities that made life enjoyable, loss of dignity, and fear of inadequate pain control

Caselaw[10]

Table 8–1 Rights of the Terminally Ill: Case Law and Major Legislative Decisions

Year	Case/Legislation	Description
1976	*In re Quinlan*	Right to remove person in prolonged vegetative state from ventilator
1990	*Cruzan v. Director, Missouri Department of Health*	Right given to states to decide whether families can remove artificial feeding tubes from persons in prolonged vegetative states
1991	Patient Self-Determination Act	Requires health care facilities receiving Medicare funds to provide information to patients at the time of admission about advance directives
1994	Oregon Death with Dignity Act	Allows competent terminally ill adult patients to obtain prescriptions for lethal drugs
1995	*Compassion in Dying v. Washington*	Court decision stating that the Washington State ban on the right of terminally ill adult patients to request assistance in committing suicide from a qualified professional was unconstitutional
1997	*Vacco v. Quill* and *Compassion in Dying v. Glucksberg*	Supreme Court rulings that states can ban physician-assisted suicide; states may also legalize and regulate physician-assisted suicide

Source: Legal and ethical issues in nursing (3rd ed.), by G. W. Guido, 2001. Upper Saddle River, NJ: Prentice-Hall, Inc.

Criteria for Physician-Assisted Suicide

- In order to prescribe a lethal drug prescription for competent, terminally ill adults, the following provisions must be met:
  - Certify that the patient is terminal, and understands prognosis and alternatives
- In order to prescribe a lethal drug prescription for competent, terminally ill adults, the following provisions must be met:
  - An oral or written request for the prescription, signed, dated, and witnessed by two individuals who attest to patient's competency and that no coercion has taken place

Criteria for Physician-Assisted Suicide

- This must be followed by a second request at the end of 15 days.
- Determine whether patient is making an informed and voluntary request.
- Evaluate patient for any psychiatric or psychological disorder or depression that could cause impaired judgment.
- No medication to end life shall be prescribed until patient is determined to be sound.

Model State Act to Authorize Physician-Assisted Suicide

- Not adopted by any state
- Developed to prevent potential managed care abuses with physician-assisted suicide
- The patient must be competent.
- The choice must be enduring, stated to physician on at least two occasions that are two weeks apart.

Poll Everywhere

- **If adopted by a state, physician-assisted suicide (PAS) should be available to which of the following types of patients? Choose all that apply**
  - Terminally ill patients with less than 6 months to live
  - Competent patients suffering from debilitating pain
  - Incapacitated patients, who previously documented a desire for PAS, and have a willing surrogate decision-maker acting under a Power of Attorney for Health Care.
  - Anyone over 65 years old, with no family and no caregiver, who would be a "burden" on society
  - Anyone who requests it because the right to die with dignity is a basic human right

Nursing and End-of-Life Objectives

- The End-of-Life Competency Statements were developed as terminal objectives for undergraduate nursing students; they apply to all nurse professionals.[11]

End of Life Position Statements

- American Nurses Association— *Euthanasia, Assisted Suicide and Aid in Dying*[12]
  - Prohibits participation in Euthanasia and Assisted Suicide because it directly violates the Code of Ethics for Nurses, the ethical traditions of the profession, and nursing's covenant with society
  - Nurses are obligated to provide humane, compassionate care the respects patient rights, but upholds the standards of the profession at the end of life

End of Life Position Statements

- Wisconsin Nurses Association— *Palliative Care and End-of-Life Care in Wisconsin*[13]
  - WNA supports educating nurses to participate in meaningful conversations regarding end of life care and palliative care
  - Participation in assisted suicide is a violation of the ANA Code of Ethics for Nurses
  - WNA supports continued efforts to meet end of life and palliative care needs of patients and families and health plans that cover such services

ANA Code of Ethics[14]

- ANA Code of Ethics Provisions that apply to informed consent and end of life care include:
  - **1.3 The nature of health**
    - Nursing care is at the end of life should prevent and alleviate the cascade of symptoms and suffering that are common with dying
    - The nurse should have conversations about advance care plans throughout multiple clinical encounters

ANA Code of Ethics[14]

- ANA Code of Ethics Provisions that apply to informed consent and end of life care include:
  - **1.4 The right to self determination**
    - Nursing interventions to relieve pain & other symptoms in the dying patient should be consistent with palliative care standards
    - Nurses may not act with the sole intent to end life
    - A surrogate should be consulted if the patient lacks capacity to make decisions
    - Best interest standard should be used in the absence of a surrogate

ANA Code of Ethics[14]

- ANA Code of Ethics Provisions that apply to informed consent and end of life care include:
  - **2.1 Primacy of the patient's interests**
    - The nurse's primary commitment is to the patient receiving nursing services. If a conflict arises, the nurse's commitment remains to the patient

Ethical Issues

- Physician-assisted suicide vs. other final stage of life options
  - Right to intensive pain and symptom management
  - Right to forgo life-sustaining therapy
  - Voluntarily stopping eating and drinking
  - Sedation to unconsciousness

Endnotes

1 The Patient Self Determination Act, Pub. L. No. 101-508, §§ 4206 & 4751, 104 Stat. 1388 (codified at 42 USC §§ 1395cc(f), 1396a(w) (1994)).

2 Wis. Stat. §154.03 (2016).

3 Wis. Stat. §155.30 (2016).

4 In re Quinlan, 355 A.2d 647, (N.J.), cert. denied, 429 U.S. 922 (1976).

5 Cruzan v. Director, Mo. Dep't of Health, 110 S. Ct. 2841, 2841 (1990).

6 In re: L.W., 167 Wis.2d 53, 482 NW.2d 60 (1992).

7 In re: Edna M.F., 210 Wis.2d 558, 563 N.W.2d 485 (1997).

8 State of Wis. v. Neumann & Neumann, 816 N.W.2d 324 (2012). Retrieved from http://usnews.nbcnews.com/_news/2013/07/03/19275007-homicide-convictions-upheld-for-wisconsin-parents-who-treated-dying-daughter-with-prayer?lite

Endnotes

9 Wis. Stat. 154.19 (2016).

10 Guido, G. W. (2014*). Legal and ethical issues in nursing* (6th ed.). Upper Saddle River, J: Pearson.

11 American Association of Colleges of Nursing. Competencies and recommendations for education undergraduate students: Preparing nurses to care for the seriously ill and their families. Retrieved from http://www.aacn.nche.edu/elnec/New-Palliative-Care-Competencies.pdf

12 American Nurses Association. (2013). Euthanasia, Assisted suicide and aid in dying. Retrieved from http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements/Euthanasia-Assisted-Suicide-and-Aid-in-Dying.pdf

13 Wisconsin Nurses Association. (2016) Palliative care and end of life care in Wisconsin.

14 American Nurses Association. (2015). *Code of Ethics for Nurses with Interpretative Statements*. Silver Spring, MD: Author.

Incompetent & Incapacitated Patients

Patient

- Unconscious/unarousable
- Lethargic
- Confused/disoriented

Medical Evaluation

Clinical evaluation by 2 MDs (or 1 MD & 1 Psychologist) to determine if patient has "capacity" (i.e. ability to make own medical decisions)

Yes

Has "Capacity"

Patient able to make own medical decisions

Discuss medical decisions with patient & obtain consent prn

No

"Incapacitated"

Patient unable to make own medical decisions (see criteria in State of WI PAHC statutory form)

Activation Form

MD completes Power of Attorney Healthcare activation form

File

File activation form in patient's medical record

Agent

Check advance directive for name of "agent" (i.e. surrogate or proxy decision-maker for patient)

Contact

Contact surrogate or proxy & inform POA activated

Discuss medical decisions with surrogate/proxy & obtain consent prn

Competency Hearing

In court hearing for judge to determine if patient is legally "competent" (i.e. based on courtroom testimony & medical report on file in court case)

No

"Incompetent"

Patient unable to make own decisions (i.e. unable to effectively receive & evaluate information or make/communicate a decision)

Guardian & Court Order

Judge appoints a guardian to make decisions for the incompetent person. Judge issues court order listing the kinds of decisions the court-appointed guardian can make (e.g. financial, medical) & identifies any limitations or restrictions on decision-making.

File

File Court Order in patient's medical record.

Court-Appointed Guardian

Check court order document for name of court-appointed guardian (i.e. surrogate/proxy decision-maker for patient)

Contact court-appointed guardian to discuss medical decisions with guardian & obtain consent prn

Yes

"Competent"

Patient able to make own decisions

Discuss medical decisions with patient & obtain consent prn