Legal and Ethical Aspects of Palliative Care: Addressing Consent and Decision-Making Challenges

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Professional Code of Ethics

- Palliative care in all care settings
- Consistent with existing professional codes of ethics, conflicts of interest, scopes of practice, and standards of care for all relevant disciplines.
- Clinicians aim to prevent, identify, and resolve ethical dilemmas common to the provision of palliative care,
  - Forgoing or discontinuing treatments,
  - Instituting do not resuscitate (DNR) orders or other state-specific portable medical orders (eg, POLST)
  - Use of sedation of the imminently dying.

Autonomy:

The principle of respect for autonomy is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive.

Patients' autonomy

Beneficence

Beneficence
All choices for a patient are made with the intent to do good

The ethical principle of beneficence requires healthcare professionals to treat their patients in a way that provides maximum benefit to that patient.

Nonmaleficence

Obligation not to inflict harm intentionally.

Non-Beneficial Care/Treatment

A treatment determined based on current medical knowledge and experience and to hold no reasonable promise for contributing to the patient's well-being, or of achieving the goals of care as agreed upon.

Doctrine of Double Effect

"…draws a distinction between impermissible intended consequences and permissible (merely) foreseen consequences."

There are four conditions that are applied:

1) **"the action itself (as distinct from its consequences or effects) must not be inherently morally wrong,"**
2) **"the intention must be to produce the good effect,"**
3) **"the good effect must not be brought about via the bad effect,"**
4) **"…there is an appropriate balance (ie, proportionality) between the good and the bad effects, such that the good effect must outweigh the bad."**

Ethical Considerations

- Medically Non-Beneficial Care
- Patient's right to decline treatments of any kind
- Cessation of medically provided nutrition and hydration
- Foregoing or discontinuing technology *(ventilators, dialysis)*
- Use of high-dose medications
- Sedation of the imminently dying
- Requests for physician-assisted death

Legal Considerations

- Disclosure of medical records and health information
- Medical decision-making
- Advance care planning and advance directives
- The roles and responsibilities of surrogate decision-makers
- Guardianship
- Abuse and neglect – vulnerable adult
- Concurrent hospice care provision for pediatric patients
- Prescribing of controlled substances
- Death pronouncement and death certification processes
- Autopsy requests, organ and anatomical donation
- Emerging issues (eg, medical marijuana, physician aid in dying, opioid abuse)

Substituted Judgment

Substituted judgment refers to the ethical duty of guardians and surrogate decision-makers to try to understand the patient's beliefs and values prior to making decisions on the patient's behalf.

Legal Guidelines for Incapacitated Patients

The provision of palliative care occurs in accordance with federal, state, and local regulations and laws, as well as current accepted standards of care and professional practice.

North Dakota Century Code section 23-12-13 *authorizes which persons to give informed consent for an incapacitated patient*

Legal and Ethical Issues Combined

- Patient or family requests for care that is not medically indicated or may cause undue burden on the patient
- Withdrawal of technology (eg, ventilators, dialysis, cardiac devices)
- Cessation of medically provided oral nutrition and hydration
- Sedation of the imminently dying
- Requests for physician aid-in-dying
- Determination of capacity to make medical decisions
- Children in foster care or protective custody
- Safety and other considerations for patients without caregivers or support
- Patients who are in custody, on parole, or have other legal issues impacting their care

Medical Professional Obligations

Advance Care Planning Documents

"...allow individuals to share their treatment preferences in the event they can no longer speak for themselves."

Advance Care Planning Documents

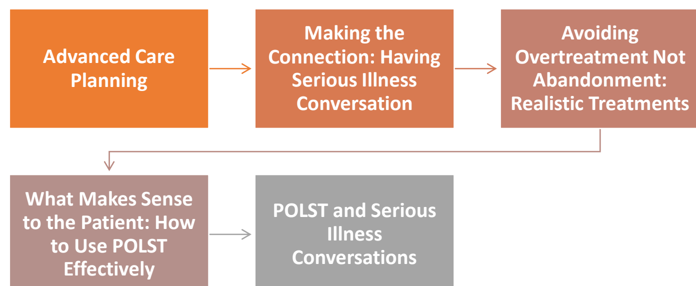
LEGAL DOCUMENTS:

Legal and financial power of attorney, living will, health care directive, HIPAA Release

MEDICAL ORDERS:

DNR: do not resuscitate order, POLST: physician orders for life-sustaining treatment

See Previous Project ECHOs:



https://www.legis.nd.gov/cencode/t23c06-5.pdf

North Dakota Century Code Chapter 23-06.5:

ND Health Care Directives

Honoring Choices® North Dakota (HCND)

Vision of HCND:

The health care choices a person makes become the health care the person receives

Goal of HCND:

To assist communities to develop a successful advance care planning process

- Established in 2013 as a statewide initiative to improve advance care planning in the state
- Non-profit organization
- The board is comprised of individuals from various professions and organizations

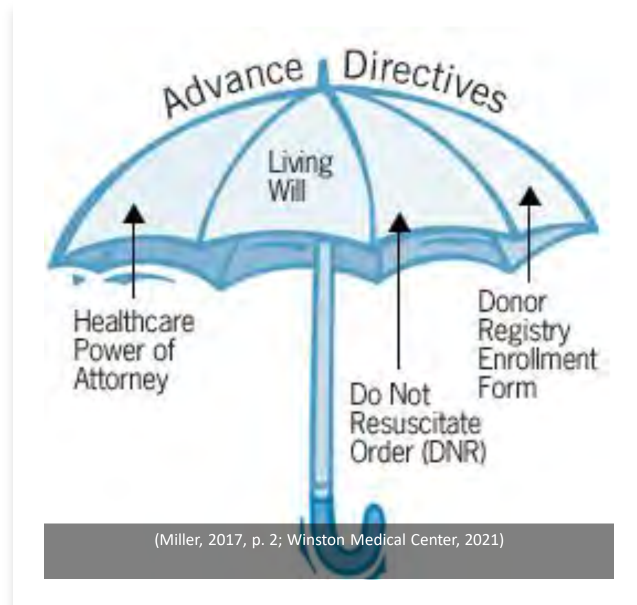
See Previous Project ECHO:

Honoring Choices North Dakota: Relationships with Rural Palliative Care

(HCND, 2021)

What is an Advance Directive?

- **“Advance directives are legal documents that allow patients to put their healthcare wishes in writing, or to appoint someone they trust to make decisions for them, if they become incapacitated.”**



(Miller, 2017, p. 2; Winston Medical Center, 2021)

Living Will or Financial Will?

Health Care Directive (HCD)/ Advance Directive (AD)	Living Will	The” Will”/ Living Trust
A written document that is used to express preferences guiding future medical decision-making **and/or** appointment a healthcare agent May or may not include the healthcare agent	A written statement about the kinds of medical care wanted to receive under specific conditions	Financial documents that to distribute financial assets and properties after death Estate planning “Personal Will and Testament”

***Advance Directives** and **Living Wills** are often used interchangeably**

(Institute of Medicine, 2015; Splendore & Grant, 2017) with attribution to Karli Olson, RN, DNPS

Different Names for Advance Directives

- Health Care Directive (North Dakota Century Code)
- Living Will
- Personal Directive
- Medical Directive
- Advance Decision
- Mental Health Advance Directive

Different Names for the Health Care Agent

- Health Care Proxy/Agent
- Medical Power of Attorney (POA)
- Healthcare Power of Attorney (POA)
- Health Care Attorney-in-Fact
- Health Care Representative
- Health Care Surrogate
- Surrogate Decision Maker
- Guardian and Conservator

North Dakota Health Care Directive Examples

Statutory Form HEALTH CARE DIRECTIVE
http://www.legis.nd.gov/cencode/t23c065.pdf

Health Care Directives from Honoring Choices® North Dakota

- Health Care Directive – Short Form

  Applicable for healthy adults ages 18-40
- Health Care Directive – Long Form

  Comprehensive HCD
- Catholic ND Healthcare Directive
- Tribal Advance Directive (coming soon)

North Dakota 23-06.5-16.
Use of Statutory Form.

- **The statutory health care directive form described in section 23-06.5-17 may be used and is an optional form, but not a required form, by which a person may execute a health care directive pursuant to this chapter.**
- **Another form may be used if it complies with this chapter.**
- **https://www.nd.gov/dhs/info/docs/hcdirective.pdf**

HEALTH CARE DIRECTIVE

http://www.legis.nd.gov/cencode/t23c065.pdf

I________________________________ , understand this document allows me to do ONE OR ALL of the following:

PART I: Name another person (called the health care agent) to make health care decisions for me if I am unable to make and communicate health care decisions for myself. My health care agent must make health care decisions for me based on the instructions I provide in this document (Part II), if any, the wishes I have made known to him or her, or my agent must act in my best interest if I have not made my health care wishes known. AND/OR

PART II: Give health care instructions to guide others making health care decisions for me. If I have named a health care agent, these instructions are to be used by the agent. These instructions may also be used by my health care providers, others assisting with my health care and my family, in the event I cannot make and communicate decisions for myself. AND/OR

PART III: Allows me to make an organ and tissue donation upon my death by signing a document of anatomical gift.

What is POLST?

A process.
Part of advance care planning recognized through a National Paradigm, state program, and medical order completion

A conversation.
Risks, benefits, burdens, expected outcomes, patient preferences

A medical order.
A form that travels across various care settings

State Specific name and form

Previous Project ECHO-What Makes Sense to the Patient: How to Use POLST Effectively and POLST and Serious Illness Conversations

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

North Dakota POLST: Physician Orders for Life Sustaining Treatment

Physician Orders for Life-Sustaining Treatment (POLST)

A CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.

B MEDICAL INTERVENTIONS: Patient has pulse and/or is breathing.

C Artificially Administered Fluids and Nutrition

D DOCUMENTATION OF DISCUSSION (Required)

E PATIENT or Health Care Agent/Legal Representative (Required)

F ATTESTATION OF MD/DO/APRN/PA (Required)

2018 North Dakota POLST SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED 1

Essential Palliative Care Skills Needed by All Clinicians

Ensure the provision of high-quality care in alignment with patient goals.

- Medical ethics education
- Understanding the ethical principles
- Focus on serious illness/ end of life
- Learn about advance care planning
- Know common scenarios that cause ethical and legal conflicts.
- Know how to access legal experts, ethicists, or ethics committees
- Know how to reach specialist-level palliative care teams

Practice Example Long Term Care

- A long-term care setting
- Provide day center, residential care, and long-term care programs.
- A physician assistant and social worker
- Improve advance care planning and completion of formal directives.
- Varying levels of decision-making capacity
- Need help determining capacity.
- Hospital-based palliative care team and ethics consult service
- Education on determination of capacity and help with challenging scenarios.

Practice Example
Rural Palliative Care Program

- Care in patients' homes across a large geographic area.
- Staff often alone on these visits
- Stress with some of the ethical issues
- Impaired decision-making,
- Requests for medical aid-in-dying (MAD),
- Family conflicts
- Ethics forum for education, discussion of challenging cases, and identification of practical measures for support
- Host online education
- Provide educational podcasts for team members.
- Dual visits of the practitioners and social workers

Ethical Case Study

Ethel is an 86 y.o. lady living in a skilled nursing facility with severe dementia. She no longer recognizes family and is dependent on others for all her Activities of Daily Living (ADLs). She is being offered spoon feedings but often turns her head away or tightly closes her mouth. The staff have only 15 minutes over mealtime to assist her.

Family is insistent that Ethel be fed but are out of state and unable to assist. They are asking for forced syringe feedings or a tube feeding to be inserted.

What steps or actions should be taken?

Who should be involved?

Legal Case Study

- Nearly 30 years have passed since the portable orders for life-sustaining treatment (POLST) initiative began.
- The growth in the use of POLST speaks to the overwhelming yearning of individuals to have their preferences regarding end-of-life care known and respected.
- However, the phenomenal increase in those availing themselves of POLST also presents new challenges, particularly in the present climate of managed care.
- Attorneys frequently express concern that POLST form orders have replaced the advance directive. Although an advance directive is often not sufficient, POLST form orders were always meant to support, not supplant, the advance directive. Part of the reason for the misunderstanding concerning how POLST form orders complement the advance directive is that attorneys often lack familiarity with what actually happens in the clinical setting throughout the trajectory of a client's illness.

Legal Case Study

This case study presents scenarios in which medical doctors work with patients and their families throughout the course of an illness to ensure quality care for patients and implementation of their end-of-life treatment preferences.

The case study also illustrates how both the medical and legal professions can ensure that patient's and client's wishes for care near the end of life are elicited sensitively, recorded accurately, and honored when needed.

In addition, to highlight several important new developments in POLST programs, elder law attorneys, in collaboration with health care professionals, can play a vital role in preserving the public trust by ensuring the integrity of advance directive and POLST discussion and implementation.

Legal Case Study

To illustrate the practical approach to the challenging medical and legal issues in health care decision-making, we trace the journey of an aging couple working with their children, their attorney, and the health care system as the couple's health declines.

Ralph and Judy

Scenarios

- Meeting with Attorney after Ralph's Diagnosis
- Ralph's Health Slowly Declines and Loss of Ralph's Driver's License
- Four Years After Diagnosis, the Couple's Health Worsens
- Judy's Declining Health
- Challenging Surrogate Decisions Arise During Ralph's Acute Illness
- Ralph Is Admitted to a Skilled Nursing Facility
- Ralph's Life Comes to an End

Issues

- **Lack of communication between elder law attorney and medical provider**
- **Knowing when a POLST is necessary**
- **Patient should never feel pressured into completing a POLST form**
- **Unexpected complexities and circumstances might occur in the course of an illness**
- **The emergency room is not the ideal location for an immediate family member to learn that he or she was not chosen as surrogate**
- **Spouse's illness trajectory, which differs from patient, presents its own inherent challenges**
- **Listening to the patient even if an advance directive exists and understanding the value of supported decision-making for elderly patients**

LESSONS LEARNED

- Share copy of advance directive(s) with health care professional(s)
- Send a copy to all appointed agent(s)/surrogate(s)
- Provide a list of resources and information to agent(s)/surrogate(s)
- With permission, share a copy with immediate family members not nominated as agent(s)/surrogate(s)
- Client should seek medical advice regarding whether completion of a POLST is necessary

LESSONS LEARNED (cont.)

- Understand difference between DNR and limited treatment
- Education from medical provider regarding the effectiveness of treatments such as tube feeding a patient with dementia
- POLST form orders work
- Good advance care planning is a process, a product of teamwork that takes place over a lifetime

Conclusion

POLST form orders, when used appropriately, function much like a trust protector does for a trust.

It ensures that the client's intent, the client's wishes as expressed in an advance directive, are consistently honored despite changing circumstances.

Rather than usurping the advance directive, the POLST form order functions as the co-pilot, translating the patient's wishes into actionable medical orders near the end of life to preserve the patient's autonomy.

Attorneys collaborating with health care professionals toward a common goal of honoring client's and patients' wishes is a worthy aspiration.

For More Information

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Coming together is a beginning, keeping together is progress, working together is success.

--Henry Ford

References

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- https://theconversationproject.org/
- https://polst.org/
- https://www.honoringchoicesnd.org/polst/
- Living Wills, Health Care Proxies, & Advance Health Care Directives (American Bar Association)
- Advance Care Planning: Strategic for All Adults, Even the Healthy (Temple, 2018)
- Advance Care Planning for Rural Families (SD)