FR21- Advancing Resident-Centered Care in LTC Facilities: The Value of Ethics Committees and Resources

Friday, March 23
3:30 PM - 5:00 PM

Session Description
This session, presented by an attorney, bioethicist, and a long time medical director, will detail and reinforce the use of the interprofessional bioethics committee format in skilled nursing facilities, with a specific eye toward promoting resident-centered care and autonomy, and taking into account risk management principles. The session will also review determination of decisional capacity, and includes content on working with incapacitated, unrepresented patients. In addition to didactic content, case presentations and small group discussion will be utilized.

Learning Objectives
Implement an interprofessional ethics evaluation framework to support resident-centered care decisions in PA/LTC, including the medical director as a vital participant.
Assess decision-making capacity for nursing home residents with respect to a variety of situations.
Apply the principles of bioethics to direct resident-centered care in light of risk management concerns.
Formulate strategies to improve medical decision-making for incapacitated unbefriended (unrepresented) nursing home residents.

Presenter(s): Christine Wilson, JD, RN; Karl Steinberg, MD, HMDC, CMD

Presenter(s) Disclosures: Karl Steinberg, MD, HMDC, CMD: Has a financial disclosure; Sunovion: Scientific Advisory Board, honoraria; All other speakers have reported they have no relevant financial relationships to disclose.
Advancing Resident-Centered Care in Long-Term Care Facilities: The Value of Ethics Committees and Resources

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Dr. Steinberg has no relevant financial relationships to disclose.

Ms. Wilson has no relevant financial relationships to disclose.

Learning Objectives

By the end of the session, participants will be able to:

- Implement an interprofessional ethics evaluation framework to support resident-centered care decisions in PA/LTC, including the medical director as a vital participant
- Assess decision-making capacity for nursing home residents with respect to a variety of situations
- Apply the principles of bioethics to direct resident-centered care in light of risk management concerns
- Formulate strategies to improve medical decision-making for incapacitated unbefriended (unrepresented) nursing home residents

Meet John

John is a long-term custodial nursing home resident who has intact decisional capacity.

Nursing staff are required by policy to check on him every two hours during the night but, because he is a light sleeper, this wakes him up.

John offers to sign a waiver of liability if the facility will agree to leave him alone for 8 hours of uninterrupted sleep.

Meet Mary

Like John, Mary is also a long-term nursing home resident with decisional capacity. She has dysphagia and is prescribed a pureed diet.

Mary finds the pureed diet to be unappetizing and requests a soft diet instead. She is fully aware of the risk that she may aspirate or choke, and the potential consequences including pneumonia and death.

Due to her physical condition, Mary is unable to reside in the community, and must rely on the food she is served by the long term care facility for all of her nutritional needs.
Meet the Lawyers

Mary may have decisional capacity, but if shechokestodeathher
decision to choosesomeatthathincreasedherchokingriskmaybe
viewed as poor judgment indicative of incapacity.

Mary may understand and accept therisk, but if sheshould die (or
sustainsevereanoxicbrain damage) it is hereamilymembers, not
Mary, who willbringthesuit.

It is probably in the best interests of the facility to finda
superficially credible reason to deny the request.

Meet Arturo

Arturo hasadvanced Alzheimer’s Disease. He hasprogressed to the point
where he is unable to take food and fluids orally. The only medical
alternative to providenutrition would be artificial feeding by G-tube, although
the medical benefit of this procedure in end stage Alzheimer’s is known to
be marginal, and there are also significant risks. He has no advance health
care directive.

Arturo has twochildren. Onechild says that “my father would never have
wanted to have an artificial feeding tube under these circumstances.” The
other says “my father was devoutly religious and would believe that forgoing
artificial nutrition and hydration is tantamount to the sin of suicide.”

Meet the Lawyers

Both children are involved in their father’scare and there doesn’t seem
to be any evidence as to what Arturo actually wanted, or whichchild he
would want to speak for him were he to become incapacitated.

One child says he would not have wanted artificial nutrition and
hydration, but the other makes a serious and credible argument
allegedly based upon their father’s religious beliefs.

This is very difficult situation but, when in doubt, we ought to “err on the
side of life”, the child who is opposed to tube feeding can go to court
and we will, of course, advise the facility to comply with any court order.

The Attorney-Client Relationship

A lawyer’s primary responsibility is to protect the facility’s interests.
This is appropriate as the facility is the client and “a lawyer must also
act with commitment and dedication to the interests of the client and
with zeal in advocacy upon the client’s behalf.” (ABA Model Rules,
1983).

So... if the facility had ethics resources available, could this
provide a mechanism to similarly act with commitment and
dedication to residents’ interests and their own autonomy? Could
these resources ultimately benefit the facility as well by providing
ethical support for the health care decision in question?

Ethics Resources in Long Term Care

Long-Term Care providers are understandably focused upon
regulatory compliance.

The term “compliance and ethics program,” when used in the
current regulations, refers to a committee focused upon regulatory
compliance issues such as billing fraud and abuse.

There is no current federal regulation that calls for a committee or
other specified mechanism to address the kinds of ethical issues
typically addressed by ethics committees and consultants.

Ethics Resources in Long Term Care

Since 1992, hospitals accredited by The Joint Commission
are required to have “a mechanism to educate stakeholders
and aid in the resolution of ethical dilemmas.”

The Society for Post-Acute and Long Term Care Medicine
began to recommend that nursing facilities have bioethics
committees in order to provide a forum for discussion of
end-of-life issues in 1997. By 2008, this issue resulted in
White Paper C08 which became policy in March 2008.
Resident-Centered Care

A philosophy that places great emphasis upon the ethical principle of autonomy and involves centering care around the resident’s personal desires and choices. It is also referred to as nursing home “culture change.”

Advocates of resident-centered care include Pioneer Network (www.pioneernetwork.net) and The Mayer-Rothschild Foundation (www.themayer-rothschildfoundation.org)

Culture change has been shown to positively impact quality improvement


Gratuitous (Therapy) Dog Photos

Chris Wilson, RN, JD, CLBNCJY*

*Cat Lady But Not Crazy Just Yet

Introducing . . .

Francis Albert Paul Newman Tabbytail aka “Newman the Energetic One”

Indigo aka “Indy the Obedient One”

What about CMS and the Regulations?

Thomas Hamilton, Director of the CMS Survey and Certification Group in 2006 noted the positive aspects of “culture change” in nursing homes and said that surveyors would help providers to incorporate culture change into regulatory compliance.


Recent CMS regulations (2016) require a long-term care facility to “develop and implement a comprehensive person-centered care plan for each resident, consistent with the resident rights . . . that includes measurable objectives and timeframes to meet a resident’s medical, nursing, and mental and psychosocial needs.” 42 CFR § 483.21 (b)(1)

So, what’s the problem?

“Sometimes the greatest barrier to nursing home culture change is not the actual wording of the regulations or [CMS] interpretive guidelines, but instead the often inconsistent and incoherent manner in which those words are interpreted and enforced at the ground level by state employees who regularly survey facilities and issue them citations for perceived noncompliance”


Got Litigation?

“The average amount paid in settlement to nursing home plaintiffs is “three times the rate of payment typically observed among medical malpractice claims.”


Long-term care loss rates (the term used by insurers to describe the amount spent annually on claims) have been steadily increasing at the rate of 6% per year. AON Risk Solutions (2016). 2017 Long term care general liability and professional liability actuarial analysis.

In one West Virginia case against a nursing home, a jury awarded $91.5MM (later reduced to $36.5MM) Manor Care, Inc. v. Douglas, 234 W.Va 57, 763 S.E. 2d 73 (2014).
Can Ethics Resources Help?

An ethics committee (often called a bioethics committee) consists of healthcare providers and others who review and make recommendations about ethical issues.

Ethics committee members and consultants can help and support physicians, nurses, residents and families who face difficult health care decisions.

The role of the ethics committee members and consultants is education, evaluation and recommendation. Their primary purpose is not to serve as decision-makers, although their advice can provide significant support to those who make health care decisions.

Advance Health Care Directives

A recent study found that 73.7% of Americans over the age of 18 do not have an AHCD and almost half of people age 65 and older (48.8%) do not have one.

In another study, only 50% of 1,877 nursing home patient records reviewed contained an AHCD.

Even if there is an advance directive, not all situations can be anticipated. There may also be different interpretations of the printed words: e.g. “Irreversible,” “Incurable,” “Terminal,” “Dementia” and “Alzheimer’s.”

Is there a willing and able agent who has talked with the resident before he or she became incapacitated, who can speak to his or her known wishes?

THE ETHICS ICEBERG

This Nurse Says it Best

“Ethics is an everyday issue, when you are doing the right thing, and for whom is it the best thing to do? Ethics is more than dilemmas about life and death.”

**Ethics Consultation**

"[A] set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care."


**Typical Ethics Committee Participants**

- Medical Director
- Another Physician (at least one MD should not be involved in the care of resident under discussion)
- Administrator
- Nurses (including DON)
- Social services designee/Social worker
- Ethicist
- "Outside" perspectives: former patient, family members, others interested in bioethics
- Clergy member
- Attorney for facility
- Ombudsman

**Characteristics of Effective Ethics Committees**

- Interprofessional/multidisciplinary
  - Not just MDs
  - Other professionals such as nurses, social workers and others
- Ethicist
  - Individual with some formal background
  - Conversant with ethics literature
  - Educational resource
- Confidentiality
- Meaningful deliberation from all members
- Focuses upon relevant ethical principles and application to the case presented

**The Role of the Medical Director**

- Advocate for ethics resources within his or her facilities
- Educate attending physicians and other practitioners, and serve as a liaison when ethical issues arise
- Confer with Director of Nursing and other facility staff, as appropriate, to assist in identification of relevant ethics issues
- Encourage and facilitate participation of non-physician members of the ethics committee to ensure that their voices are heard

**Ethics Committee Responsibilities**

- Seek information from patients, their friends or family members, and the facility
- Ask relevant questions
- Educate facility staff, patients, and their families about bioethics and the role of the committee
- Review cases
- Make policy recommendations
- Be accessible and available to practitioners, staff, residents and families

**Case study: Meet Dorothy**

Dorothy and her daughter in Ireland.

"Getting a jump on the new year" photo.
Who was Dorothy?

- Loved Irish music and often seen at the pub singing along with a drink in her hand
- Loved by her family and had many friends with a wide variety of ages
- If she has a "terminal" diagnosis wants “no heroics” at the end but is not there yet!

Dorothy and the NPO Order

- Came out of surgery “NPO”
- Order continued based upon speech pathology bedside assessment of some swallowing risk
- Transferred to SNF with order still in place
- SNF MD refused to change order even after MBS at SNF and again at hospital both supported supervised trial of thickened liquids and pureed foods

No Meeting of the Minds

- MD: As long as there is some risk, she might aspirate or choke. This could lead to pneumonia or death. Not on my watch.
- Dorothy: Hey, I’m realistic about my new diagnosis and I’ve had a good life. But I’m not ready to go yet! I want to give treatment a try first.
- Dorothy’s Family: We can’t help but sneak mom some protein shakes and she is doing well so long as we feed her slowly. We can’t get the doctor to change his mind and we don’t want to get caught and have him raise a ruckus. Communication has already broken down.

Assessment of Decisional Capacity

- It’s the responsibility of the attending physician to determine this
- Mental health consultation when complicated or unclear
- Generally requires these elements:
  - Understanding the nature of the choices being considered
  - Appreciating the potential consequences of the choices
  - Reasoning to demonstrate why a particular choice is preferred
  - Expressing the choice clearly (and ideally consistently/repeatedly on multiple occasions)

How Could An Ethics Committee or Ethics Consultant Have Helped Dorothy?

- Basic principles: Autonomy, beneficence, non-maleficence and justice
- Autonomy: Facilitate by giving her the opportunity to discuss risks and benefits and make her own choice
- Beneficence/Non-Maleficence: Even if not safe and potentially risky for physical/medical complications, psychological benefit may be substantial
- Justice: resident rights and recognition of her interests
How Could An Ethics Committee or Ethics Consultant Have Helped Dorothy?

- Support for her decision beyond the care plan
- Possibly recommend transfer to a new physician
- Mediate issues between physician and patient/family on an equal playing field
- Simple Medical Director involvement can sometimes solve problems like this one without full IDT/Ethics Committee

SUMMARY

- Person-centered care is both a best practice and a new SNF regulatory requirement.
- Ethics resources support person-centered care but are often lacking outside the acute hospital.
- The Medical Director and other clinicians have an important role in establishing the importance of bioethics in post-acute care.
- If available in the post-acute care setting, bioethics resources can benefit patients, families, clinicians, staff, and providers.

Ethics Committees and Resources in Long-Term Care

**It’s Time!**