The Importance of Bioethics for Post-Acute Care:
Compliance and Risk Management Benefits
AHLA Long-Term Care and the Law 2018
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Christine J. Wilson RN, JD, MSHCE
Tyler & Wilson, LLP
5455 Wilshire Blvd., Suite 1925
Los Angeles, CA 90036
Email: CJW@tyler-law.com

Thaddeus Mason Pope JD, PhD
Director of the Health Law Institute
Professor of Law
Mitchell Hamline School of Law
875 Summit Avenue (Room 320)
Saint Paul, Minnesota 55035 USA
Email: Thaddeus.Pope@mitchellhamline.edu

AHLA has and will post these too

Importance of Bioethics for Post-Acute Care

Prevalence

Bioethics is rare in PAC

Edited to now start with primer, synopsis
Some statutory mandates

Some statutory roles

But usually not required

Consequently

Bioethics still rare in PAC
17 facilities responded to survey

“CECs are still an uncommonly used tool of nursing homes”

Some exceptions

Ethics support in institutional elderly care: a review of the literature

Sandra van der Dam,1 Bert Molewijk,1,2,3 Guy A M Widdershoven,3 Tineke A Abma3

Does your client have a bioethics committee?

Functions
- Education
- Policies
- Consults

Case consults
- "main" function

Usually prospective
also retrospective
What does a PAC bioethics committee do?

Resolve conflicts

Navigate uncertainty

About what?

End of Life
Surrogates
Other healthcare
Everyday

4 areas
End of Life

Advance directives
Completing
Interpreting

DNR / POLST
DNH
Stop dialysis
PEG / CANH

Other refusals
Antibiotics
Etc.

More controversial
VSED
MAID
2 Surrogate Decisions

Capacity
Identify surrogate
Support surrogate

Conflict among surrogates
“Bad” surrogates
No available surrogate
Healthcare

Covert medication
Coercion/restraints
Lack of time

Everyday ethics
Sex
Noncompliance
Racist requests

**Value**

**Little** direct research, measurement

Extrapolate research from **hospital** setting – where there is more research

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**Outcomes of Ethics Consultations in Adult ICUs: A Systematic Review and Meta-Analysis**

Au, Selena S. MD, FRCP, MSc; Couillard, Philippe MD, FRCP(1,2); Roze des Ordonn, Amanda MD, FRCP, MMed(1,3); Fiest, Kirsten M. PhD(1,4,5,6); Lorenzetti, Dianne L. PhD(4); Jette, Nathalie MD, FRCP, MSc

Critical Care Medicine. February 1, 2018 - Volume Online First - Issue - p
doi: 10.1057/CCM.000000000002999

**Meta-review** looked at 16 studies 1988 to 2015

Assessed **outcomes** after clinical ethics consultations in the ICU
5 main benefits

Consensus more often achieved

Higher surrogate & patient satisfaction

Less litigation

But even if so, courts defer to HEC

Lower resource utilization

Lower staff moral distress
That’s ICU where most bioethics consults go.

There are some PAC-specific studies that show same benefits.

“lead to consent on acceptable decisions . . . agreement acceptable for all involved parties”

Value for PAC recognized exactly 20 years ago.
Health Care Decision Making in Long-Term Care

What Comes to Mind?
- End of Life Care
- Advance Directives
- POLST
- Withdrawal of Nutrition/Hydration

Questions Raised
- “Irreversible”
- “Incurable”
- “Terminal”
- “Dementia” or “Alzheimer’s”

Advance Directives
- Some studies show that 50% of LTC residents may have
- Even then, what has been discussed directly with the agent?
- Family members may differ regarding resident's wishes
- Can the agent be found?
- Is the agent willing?

Ethics Iceberg

Everyday ethics issues:
• dignity and lack of resources
• treatment/care of people with cognitive impairment
• family conflicts
• use of restraints
• autonomy
• capacity to make decisions
• staff moral distress

“No right is held more sacred or is more carefully guarded by the common law than the right of every individual to the possession and control of his own person, free from all restraint or interference of others unless by clear and unquestionable authority of law.”

Union Pacific Railway Co. v Botsford, 141 U.S. 250, 251 (1891).

Meet Jane

Jane has difficulty swallowing
• Jane is considered a “choking risk.”
• Dietician recommends a pureed diet.

But Jane finds pureed food to be unappetizing.
• Jane requests a regular diet.
• Jane has decision-making capacity.
• She understands the risks of choking, including death.

Traditional risk management approach

➢ Find a superficially credible reason to decline Jane’s request.
➢ Risk management concerns:
  ➢ If Jane chokes and dies, will the facility get stuck with a multi-million dollar verdict?

*Manor Care v Douglas, 234 W. Va. 57, 763 S.E. 2d (2014).*

Jury awarded $11.5M in compensatory and $80M in punitive damages; These were later reduced to $6.5M compensatory and $32M punitive.

[Note: Entirely different set of facts]

The average settlement amount paid to nursing home plaintiffs is **three times** the amount typically paid to medical malpractice plaintiffs.


**LTC Loss Rates per Occupied Bed Limited to $1M Occurrence**

<table>
<thead>
<tr>
<th>Occurrence Year</th>
<th>Loss Rate</th>
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<tr>
<td>2007</td>
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<tr>
<td>2008</td>
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<td>2015</td>
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<td>2016</td>
<td>$2,170</td>
</tr>
<tr>
<td>2017</td>
<td>$2,300</td>
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2016 CMS Regs. “Person-Centered” Care

➢ 42 CFR 483.5
Focus on the resident as the locus of control and support the resident in making his or her own decisions and having control over his or her daily life.

➢ 42 CFR 483.10(c)(2)
Resident or representative right to participate in development and implementation of person-centered plan of care.

➢ 42 CFR 483.10(b)(3)
Unless adjudged incompetent, the resident has the right to appoint a representative.

More regulations that bioethics resources support

General Residents’ Rights
42 CFR 483.10, F-550
Right to Be Fully Informed
42 CFR 483.10(c), F-552
Right to Refuse: Formulate Advance Directives  
42 CFR 483.10(c)(6), F-578

Personal Privacy  
42 CFR 483.10(h), F-583

Dignity  
42 CFR 483.10(a)(1), F-550, 557

Self-Determination—Right to Make Personal Choices  
42 CFR 483.10(f), F-561

Fundamental Principles of Health Care Ethics
➢ Respect for Autonomy  
➢ Beneficence  
➢ Non-Maleficence  
➢ Justice

"Culture Change"
An intentional transformation of LTC settings
➢ To become less institutional  
➢ To provide care centered on and directed by residents  
➢ To be more empowering of care workers

For example:
➢ Honor a resident’s wake and sleep times, dietary choices, and right to decline recommended medical treatments.
➢ Culture change has been shown to positively impact quality improvement

Thomas Hamilton
Director,  
CMS Survey & Certification  
2003-2016

doi:10.1111/jgs.12867
“Culture Change”
Noted the positive aspects of “culture change” in nursing homes and said that surveyors would help providers to incorporate culture change into regulatory compliance.


Regulatory Interpretation
The Devil is in the Details
“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.”


Back to Jane
A Person-Centered Care Plan
➢ Will this be enough if Jane comes to harm?
➢ Realistically, will this case likely even go to trial?
➢ What else might support her autonomy and her care plan?

What About An Ethics Committee?
➢ Healthcare providers and others who:
  ➢ Consider and discuss medical ethical issues
  ➢ Educate facility staff
  ➢ Mediate disputes related to patient care among family members
➢ Purpose: To support the decision-making process using ethical principles

What About An Ethics Committee?
➢ Frequently available in hospitals
➢ Not commonplace in post-acute care
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 Members

- Physicians (at least one not involved in care)
- Administrator
- Nurses (including DON)
- Social workers
- Ethicist
- “Outside” perspectives: former patient, family members, others interested in bioethics
- Clergy member
- Attorney for facility

Characteristics of Effective Ethics Committees

- Multi-Disciplinary
  - Not just MDs
  - Other professionals such as nurses, social workers and others
- Ethicist
  - Individual with some formal background
  - Conversant with ethics literature
  - Educational resource

Table 2. Member of Ethics Committees in Long-Term Care Facilities (LCTFs) Surveyed (n = 5)

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<th>Members</th>
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<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<tr>
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<td>x</td>
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<td>x</td>
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</tbody>
</table>

Ethics Committee Responsibilities (1)

- **Seek information** from patients, their friends or family members, and the facility
- **Ask** relevant questions
Ethics Committee Responsibilities (2)

➢ Educate facility staff, patients, and their families about bioethics and the role of the committee

Ethics Committee Responsibilities (3)

➢ Review cases
➢ Make policy recommendations
➢ Be accessible and available to physicians, staff, residents and families

Meet Dorothy

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
➢ “Terminal” diagnosis – wanted “no heroics” at the end but not there yet!

Dorothy & daughter in Ireland
Dorothy & NPO Order
➢ Came out of surgery “NPO”
➢ Order continued based upon speech pathology assessment of some swallowing risk

Dorothy & NPO Order
➢ Transferred to SNF with order still in place
➢ SNF MD refused to change order even after swallowing test at SNF and again at hospital both supported trial of fluids and soft foods

No Meeting of the Minds
➢ MD
➢ Dorothy
➢ Dorothy’s family

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.

No Meeting of the Minds
➢ 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.

No Meeting of the Minds
➢ 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.
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 and potentially risky psychological benefit may be substantial
- **Justice**: resident rights and recognition of her interests

Support for her decision beyond the care plan
- Possibly recommend transfer to a new physician
- Mediate issues between physician and patient on an equal playing field

Ethics Committees & Resources in Long-Term Care

**It’s Time!**

Questions

Two more cases

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 John 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 the Lawyers

Although John is competent, if there is an adverse outcome, then we will be on the defensive to prove this in hindsight.

Meet the Lawyers

What about the regulatory authorities?

Will failing to check on him translate to neglect?

Meet the Lawyers

If he is in the facility because he requires 24-hour care, how can we justify ignoring him for one-third of the time?
Arturo has advanced Alzheimer’s Disease.

He has progressed to the point where he is unable to take food and fluids orally.

The only medical alternative to provide nutrition would be artificial feeding by G-tube.

But the medical benefit of this procedure in end stage Alzheimer’s is known to be marginal, and there are also significant risks.

Arturo has no advance health care directive.

Arturo has two children.

One child 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’s care.

There doesn’t seem to be any evidence as to what Arturo actually wanted, or which child he would want to speak for him were he to become incapacitated.

Meet the Lawyers

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.

Meet the Lawyers

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.
Thaddeus Mason Pope, JD, PhD
Director, Health Law Institute
Mitchell Hamline School of Law
875 Summit Avenue
Saint Paul, Minnesota 55105
T 651-695-7661
C 310-270-3618
E Thaddeus.Pope@mitchellhamline.edu
W www.thaddeuspope.com
B medicalfutility.blogspot.com

Christine J. Wilson, JD, RN
Tyler & Wilson, LLP
5455 Wilshire Blvd
Los Angeles, CA 90036-4201
T (323) 655-7180
F (323) 655-7122
E CJW@tyler-law.com
W http://www.tyler-law.com