Death Panels, Politics and Patient Centered Care:

Examination of a National Advanced Care Planning Policy

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People, Places and Vision

- Special thanks to my mentors:
  - Sarah Davis JD, MPA
  - Kathy O’Connell PhD, ATC
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- Center for Patient Partnerships
  - Multi-disciplinary patient advocacy practice.
  - Promote education, research and advocacy for healthcare improvement.

- Support
  - University of Wisconsin School of Medicine and Public Health 2011 Shapiro Summer Research Program
  - The Center for Patient Partnerships
Study Methods

- **Qualitative Study Design**
- Review the history and literature on Advanced Care Planning
- Review the current Legislation
- Interview Key Informants on the subject
- Identify themes
- Discuss next steps
Background
Background

- 1970s – Introduction of Advanced Health Care Directives
  - Living Will, Health Care Proxy

- 1991 – Patient Self Determination Act
  - Healthcare centers to inquire and inform all patients about advanced directives


- Inadequacies remain with End-of-Life care
  - Unnecessary care, pain, emotional burdens, expense, disability
  - As of 2007 ~40% of Americans had a Living Will
  - Nationally ~30-40% have formally identified a Healthcare Proxy
Solution – create a Better Policy

- 2009 – Patient Protection and Affordable Care Act
  - Medicare/Medicaid to provide reimbursement for providing End-of-Life counseling service
  - Then...two little words...
The Unwitting Birthplace of the 'Death Panel' Myth

LA CROSSE, Wis. -- This city often shows up on "best places to live" lists, but residents say it is also a good place to die -- which is how it has been for most of the summer.

The town's biggest hospital, Gundersen Lutheran, has long been a pioneer in ensuring that the care provided to patients in their final months could be covered by Medicare and that physicians were compensated for advising patients on end-of-life planning.

When it comes to healthcare, the U.S., Britain and Canada...

When Sarah Palin said that the emerging healthcare reform legislation would lead to "death panels" and government rationing of care, her language was explosive, but her premise about rationing was not.

The most critical test of any reform proposal is whether it will empower individuals or impose on them. It is a fact that the leading bills in Congress would increase the power of government and decrease the ability of families to make their own healthcare decisions.
How to get to a better Policy

Bundle It – 2009 – PPACA
Bury It – 2010 – Bury in Medicare payment schedules as part of routine care “Advanced Care Planning”
Start Over – 2011 – Free Standing Bill

H.R. 1589: Personalize Your Care Act of 2011

112th Congress: 2011-2012
To amend the Social Security Act to provide for coverage of voluntary advance care planning consultation under Medicare and Medicaid, and for other purposes.
H.R. Bill 1589, 112th congress
Personalize Your Care Act of 2011

1. Voluntary advance care planning consultation reimbursement under Medicare and Medicaid
   - **Voluntary advance care planning consultation**: an optional consultation between the individual and a physician, nurse practitioner or physician’s assistant regarding advance care planning

2. Provide federal grants to establish or expand programs for ACP documentation
   - Physician Orders for Life-Sustaining Treatment (POLST).


VALUE with ACP

- **Patient Centered Care**
  - Assures patient autonomy
  - Moral thing to do for patient
  - Decreases ambiguity of patients wishes, values and goals

- “There are a number of issues that come up every year with patients and there is a dispute between the ethics committee and/or the care team and/or the family with respect to what should be done. **And if there were a clear advanced directive hopefully those things would go away.** – Jim Dechene JD
VALUE with ACP

- **Cost and resource savings**
  - Avoid costs of unnecessary or unwanted care
  - 50% of medical expenses in the last 6 months of life
  - Increase efficiency of healthcare delivery with proper time and resource utilization
  - “Engaging in ACP ... gives a huge opportunity for us to be better stewards of healthcare resources. “ – Tammy Baldwin
  - “.. if a drug had the same outcomes as this intervention, it would be talked everywhere on the TV as the next miracle” - Bud Hammes PhD
Drawbacks -- Specific to this bill

- Are physicians the right person to do ACP?
- Money for implementation
- No guarantee that the passing the bill would improve ACP practices
  - Oversight?
- Documentation – does it matter?
Drawbacks – Politics

- This bill will NOT pass through the House with the current political environment
  - “There are reasons to object to it, but they are relatively mild and they are certainly not in the league of OH MY GOD we have to get rid of this! ... there is a grander game (going on)” – Tom Oliver PhD
  - “... anything that Obama did was pretty much opposed, healthcare reform in particular. So it seems to me that most of opposition was that kind of politics, harsh.” - Norm Fost MD, MPH

- Current national opinion
  - Emotional, visceral topic
  - Demagoguery and political rhetoric influences, misguides and misinforms public opinion
  - Other Priorities – Economy, Jobs, National Debt
Why we need a *National* Policy?

- "*Medicaid* and *Medicare* between the two of them have ... close to 80 million enrollees? When you do pass a law at national level you are **engaging these huge healthcare systems.**" — Tammy Baldwin

- "It seems to me that doctors talking to patients about EOL care is a manifestly good idea. And **having reimbursement for that will make it more likely to happen.**" — Norm Fost MD, MPH

- "The value of the role of this legislation is that it would at least **establish a precedent that this service should be paid for.**" — Bud Hammes PhD
Next Steps
Moving Forward

- National-based policy difficult at this time
  - “I don’t think this issue is going away forever, I just think in this political moment we won’t see this bill advance.” – Tammy Baldwin

- Creating bipartisan support
  - Rebranding ACP
  - Circumvent the politics
    - Fold ACP outcomes into Accountable Care Organization metrics
    - JCAHO vs. Federal standards?
Moving Forward

- Someone needs to take ownership to improve ACP

Leaders, Decision-Makers

Patients, Community Based

- Local, regional and state levels
Moving Forward

- Collaboration needs to occur across healthcare systems, insurers and community leadership.
  - "We all do CPR the same, this model that says we should all be doing ACP about the same too." – Bud Hammes PhD

- Model Systems
  - Gundersen Lutheran
    - LaCrosse, WI
  - Honoring Choices Minnesota
    - Twin Cities, MN
Moving Forward

“Create a **positive information campaign** and go out and put it in a way that people would probably say ‘that’s a good idea’.” – Tom Oliver PhD

- **Educate...**
  - Healthcare workforce
  - Patients and communities
  - Health system administration
  - Insurance providers

- **Time is of the essence...**
  - Healthcare costs rising
  - “Baby Boomer” population getting older
Conclusions
Conclusions

• Comprehensive ACP system provides VALUE to healthcare
• National level passage of an ACP policy is VERY difficult in the current political environment
• Local, regional and state entities need to take the lead
• Matter of prioritization
• It is about creating a culture of change
  ○ “The organization at some level would have to say EOL planning is really important ... because it’s the right the to do, our patients ... and you don’t want to be doing low value care.” – Sally Kraft MD
Recommended Resources

- National healthcare Decisions Day – April 16th 2012
  - http://www.nhdd.org/

- Consider the Conversation
  - http://www.considertheconversation.org/
"Just like we know if a patient has an allergy to a medication, it would be a huge mistake if we didn't know a patient was allergic to penicillin and we gave it to them. We should have the same type of value and attention to the patient's values and goals.

- Bud Hammes PhD

ACP transcends the boundaries of traditional departments or management structures. I mean this truly is as patient centered as you get.

- Sally Kraft MD

Autonomy is at the top of the flagpole in American values. Since most adults are incompetent at the time that decisions have to be made, because they are sick or unconscious or medicated... We should have the same type of value and attention to the patients' values and goals.

- Norm Fost MD, MPH