We Can’t Fix the End of Life by Merely Fixing Health Care

Ira R. Byock, MD
Director of Palliative Medicine
Dartmouth-Hitchcock Medical Center

Dennis 83 yo man

• Stable: CHF & ESRD on dialysis (3x/wk)
• Admitted: Fall with facial laceration
• Hypotension, severe dyspnea on exertion
• New Dx: critical aortic stenosis
• Lives alone
• Church when has transportation, senior center, barber
• Has Life Alert pendant
• Needs med mgmt, Meals on Wheels, housekeeping

The 17th Princeton Conference
Examining End of Life Care: Creating Sensible Public Policies for Patients, Providers, Providers, and Payers
Session VII - Next Steps in Creating End of Life Policies May 20, 2010
If all we do is improve medical treatment for dying people...

...the best we will achieve is a better medical experience of dying.
Patient-centered or Person-centered?

Etymology of Patient (from Latin)
One who suffers
When does a person become a patient?

Improving the End of Life

Dying is personal
Improving the End of Life

It Takes a Family

An individual receives a diagnosis…
Improving the End of Life

…a family gets the illness.

Definition of Family

“For whom it matters…”

Bastienne Schmidt & Philippe Cheng
53.4 million caregivers in the United States – more than one in five adults – provide unpaid care to people with disabilities and chronic illness.

National Alliance for Caregiving and AARP 2004
www.caregiving.org

29% loss of most – or all – of their major source of income
31% reported loss of most – or all – family savings
20% a family member made a major life change

Caregiver Health

Family caregivers who report mental or emotional strain associated with the chronic stress of caregiving had mortality risk 63% higher than non-caregiving controls.

Schulz and Beach
The Caregiver Health Effects Study
JAMA. 1999; 282:2215-2219

What Families Value

- Ensuring the “best care possible”

Bastienne Schmidt & Philippe Cheng
What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed

Mal Warshaw collection
What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed
- Knowing the person was treated in a dignified manner
- A chance to say and do the things “that matter most”
- Honoring and celebrating the person in his/her passing
What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed
- Knowing the person was treated in a dignified manner
- A chance to say and do the things “that matter most”
- Honoring and celebrating the person in his/her passing
- A chance to grieve together

Improving the End of Life

It Takes Community
The Shrinking Pool of Caregivers

- **1990**: 11 to 1
- **2010**: 10 to 1
- **2030**: 6 to 1
- **2050**: 4 to 1

Population age 65 and over living alone, by age group and sex, selected years 1970-2004

Reference population. These data refer to the civilian noninstitutionalized population.

www.AgingStats.Gov
The Current & Coming Crises in Nursing

Source: Projections by Division of Nursing BHP, HRSA, USDHHS, 1996

Why Community?

- Volunteerism
- Engaged local leaders
- Innovative approaches
- Local solutions
- Community-based surveillance
- Quality improvement initiatives
Community

• Congregations / Faith communities
• Neighborhoods or apartment buildings
• Workplaces
• Schools
• Non-profit agencies (food banks, shelters)
• Service groups (Lions, Kiwanis, Elks, Junior League)
• Youth groups (Scouts, 4H, FFA)
• Social clubs
• Fire and Police

Caring for One Another

Parish Nursing
A specialty practice in nursing, functioning within health ministry to integrate faith and health across the age span of the congregation.

We’d love to hear from you. Please call us at 407-303-7153
Improving the End of Life

Policy Matters
Thinking Beyond Health Care
Improving the End of Life

It Will Take

Advocacy and Activism
Attorneys General in each state are charged with protecting constituents in matters affecting the public interest, including consumer protection of those who are dying.

Advocacy and Activism

National Association of Attorneys General

Will my pain be managed?
Will my wishes be known and honored?
Will I receive competent care?
Will my family be supported?

www.ReclaimTheEnd.org
What We Want Policymakers to know

8 Citizens Forums throughout New Hampshire

www.ReclaimTheEnd.org

What We Want Policymakers to know

www.ReclaimTheEnd.org
Key Findings

> 80% said it was very or extremely important to have:

- Dignity respected
- Preferences honored
- Pain controlled
- Not leave family with debt.

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009

Key Findings

> 80% strongly endorsed
- Palliative care requirements for clinical licensure & reimbursement
- Expansion of family caregiver leave
- Respite care
- Bereavement support

< 50% strongly endorsed
- Being kept alive as long as possible
- Being prayed with
- Being prayed for

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009
Key Findings

Conclusion

By avoiding actions which elicit strong divergence of opinion and focusing on actions on which consensus exists, public officials and candidates can respond to problems and improve care and experience for frail elders, dying Americans, and their families.

Byock IR, Corbeil YJ, Goodrich ME. Beyond Polarization: Public Preferences Suggest Policy Opportunities to Address Aging, Dying, and Family Caregiving. Am J Hospice & Palliative Care 2009

Policy Levers

• Eliminate statutory-regulatory distinction between curative and palliative care
• Require insurers to include hospice & palliative care as benefit similar to Medicare
• Publish clinical standards for professionals and institutions
• Publish “reasonable expectations” for consumers and citizens
• Make data public in “report card” fashion
• Expand funding Senior Centers & Aging Services
Policy Levers

- Require adequate (evidence-based) staffing of aides in SNF, LTC, ALF
- Require living wages for aides in SNF, LTC, ALF
- Est. standards for training of physicians, nurses & allied clinicians – as a condition for certification and public financial support
- Fund health service research into delivery of continuum of care
- Resolve political barriers to effective pain management
- Public “report cards” and bulletin boards of all health services (a public “Angie’s List”)
Policy Levers

Grants to civic and faith-based organizations for home care to frail elders and ill people

Expanded family leave and caregiving support

Health insurance coverage for family caregiving

Tax deductions for family caregiving expenses

Expanded NIH / AHRQ supported research in
• Family caregiving
• Secondary prevention
• Community-based services