Dying by design: reimagining the end of life in health systems and communities

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Objectives of today’s conversation:

• Describe the evolution of health care near the end of life, from a system perspective
• Propose a re-design of advanced illness care using population health principles
• Introduce how community-driven innovation may help transform the end of life experience

Health care near the end of life: the design-oriented reality

“Every system is perfectly designed to achieve the results it achieves.”
Paul Bataldan

What results are we trying to achieve?

– Shape care in a way that honors a person’s values, preferences, and life story
– Avoid premature dying
– Avoid preventable suffering
  • Physical pain and other symptoms
  • Emotional and spiritual distress
– Support positive developmental goals
  • Enhance personhood as death approaches
– Aid caregivers’ well-being and adjustment during the process, and afterwards
– Enhance supports and connections within communities
The transformation of dying in the US

<table>
<thead>
<tr>
<th>Age at death</th>
<th>1900</th>
<th>2000</th>
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<tbody>
<tr>
<td></td>
<td>46 years</td>
<td>78 years</td>
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<table>
<thead>
<tr>
<th>Top Causes</th>
<th>1900</th>
<th>2000</th>
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<tbody>
<tr>
<td></td>
<td>Infection</td>
<td>Cancer</td>
</tr>
<tr>
<td></td>
<td>Accident</td>
<td>Organ system failure</td>
</tr>
<tr>
<td></td>
<td>Childbirth</td>
<td>Stroke/Dementia</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Disability</th>
<th>1900</th>
<th>2000</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Not much</td>
<td>2-4 yrs before death</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Financing</th>
<th>1900</th>
<th>2000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Private, modest</td>
<td>Insurance, FFs, 27% of Medicare $5</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Context freely</th>
<th>1900</th>
<th>2000</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Primarily at home</td>
<td>Primarily institutional Interventions used</td>
</tr>
<tr>
<td></td>
<td>Few tx available</td>
<td>ICU care common</td>
</tr>
<tr>
<td></td>
<td>ICU absen</td>
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Who has driven EOL care in the US?

- **1973** – hospice introduced in the US
- **1980s-1990s** – growing interest in advance directive design
- **1990** – Patient Self-Determination Act (PSDA)
- **1994** – first physician-assisted suicide law approved
- **1995** – first POLST form introduced in OR
- **1995** – SUPPORT study published

Response to the changing experience of EOL

- **1973** – hospice introduced in the US
- **Autonomy-oriented model of EOL embraced**
  - 1980s-1990s – growing interest in advance directive design
  - 1990 – Patient Self-Determination Act (PSDA)
  - 1994 – first physician-assisted suicide law approved
  - 1995 – first POLST form introduced in OR
  - 1995 – SUPPORT study published

SUPPORT -- Results

- **47%** of MDs knew their pts. did not want CPR
- **38%** of patients who died spent ≥10 days in ICU
- **50%** of patients who died had moderate or severe pain for most of their last 3 days of life
- Intervention designed to improve care had no impact on any primary outcome measure

A history of EOL design: SUPPORT

- **RCT** of an intervention to improve EOL care
- **1989-1994**, 5 large U.S. hospitals
- **9105** pts, 9 life-threatening diagnoses
- **6 mo. mortality = 47%**
- Nurse-led intervention

The SUPPORT legacy: making sense of the advanced illness experience

- Patients misunderstand their condition, prognosis, and the effectiveness and burdens of treatments
- MDs are poor judges of pt prognosis
- MDs do not know pt values/preferences
- Physicians/hospital culture drive decision making
- Pt/family decision making driven by factors other than tx benefits/burdens/tradeoffs, and is not driven by a simple autonomy model
- Society and health systems are pathologically death-avoidant
The system response to SUPPORT: the palliative care model

The growth of palliative care and hospice

- Palliative care programs
  - Increase from 25% to 63% of US hospitals 2000-2009
  - Palliative care consultation teams -> PC units
  - Shown to improve quality/satisfaction, reduce costs
  - Referral-based, generally late in the illness course
  - Mostly hospital-based: inpatient, episodic, discontinuous

- Hospice
  - Home > nursing facility-based
  - Better pain mgmt, emotional support, overall quality
  - “Terrible choice” of comfort vs disease-directed care
  - Occurs very late in illness course -- >1/3 in last week

Change in hospice use 2000-2010

Medicare EOL outcomes 2000-2009

Next steps in palliative care design: population health

- DIMENSION
  - CURRENT MODEL
  - POPULATION HEALTH MODEL

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Current Model</th>
<th>Population Health Model</th>
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<tbody>
<tr>
<td>How cases are identified</td>
<td>Referral-based</td>
<td>Proactive case-finding</td>
</tr>
<tr>
<td>Focus of performance measurement</td>
<td>&quot;Numerator&quot; of who is referred</td>
<td>Both &quot;numerator&quot; and &quot;denominator&quot; (population in need)</td>
</tr>
<tr>
<td>Paradigm of care</td>
<td>Biomedical; physiology-driven</td>
<td>Biopsychosocial; physiology and person/family-driven</td>
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<tr>
<td>Primary location of care</td>
<td>Hospital-centered</td>
<td>Community-centered</td>
</tr>
<tr>
<td>Pattern of care delivery</td>
<td>Episodic, fragmented</td>
<td>Registry-based, coordinated</td>
</tr>
<tr>
<td>Financing</td>
<td>Revenue-driven</td>
<td>Revenue and cost avoidance-driven</td>
</tr>
<tr>
<td>Workforce development</td>
<td>Staffing to referral demand and reimbursement</td>
<td>Staffing guided by population-at-risk and need intensity</td>
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Population health-based advanced illness care: core elements

- Patient population – all patients with debilitating chronic or life-limiting illness
- Timing – ideally from time of diagnosis thru death and bereavement
- Systems and processes that support:
  - Comprehensive person/family-centered care – individualized, goal-based
  - Concurrent with disease-directed care
  - Coordination and continuity across venues/providers
- PC and hospice intertwined and fluid

Natl Consensus Project, Clinical Practice Guidelines for Quality PC

Population health and palliative care: intervention trials

Number of Patients

<table>
<thead>
<tr>
<th>Intervention component</th>
<th>Number of Patients</th>
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<tr>
<td>TURBO</td>
<td>120</td>
</tr>
<tr>
<td>Phone calls to patient</td>
<td>78</td>
</tr>
<tr>
<td>Telephone support</td>
<td>67</td>
</tr>
<tr>
<td>Care conferences</td>
<td>44</td>
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Transforming community consciousness

NEJM lead articles

Proactive, collaborative PC:
- Improved HRQOL
- Reduced depression sx
- Improved satisfaction
- Earlier hospice transition
- Reduced costs of care
- Survival was 2.7 months LONGER

Greer JA et al, J Clin Oncol 2012 Feb 1;30(4):394-400

Improving EOL from the outside: community-driven transformation

- Why communities should drive change
  - Most of the EOL experience occurs outside of hospitals
  - Health care system is not incentivized to drive better EOL
  - Health care will shift when patients/families/communities demand person-centeredness
- Components
  - Transforming community consciousness
  - Community-based innovation
  - Community activation and engagement

Transforming community consciousness

Community-based innovation

Death has no “do over.”
Let’s get it right.

Re-designing EOL: the OpenIDEO End of Life Challenge

OpenIDEO End of Life Challenge

OpenIDEO End of Life Challenge: Top Ideas

Community activation and engagement

Re:Imagine / End of Life

Conclusion: can we re-design dying?

• Clear societal demand for a better EOL experience
• Health care has an integral role to that experience
  -- But, “it’s complicated”
• Communities have the potential to drive transformation
Questions?