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

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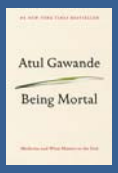
End-of-life is the new black . . .



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

"Every system is perfectly designed to achieve the results it achieves."

Paul Bataldan

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

What results are we trying to achieve?

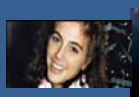
- Shape care in a way that honors a person's values, preferences, and life story
- Avoid premature dying
- Avoid preventable suffering
  - Physical pain and other symptoms
  - Emotional and spiritual distress
- Support positive developmental goals
  - Enhance personhood as death approaches
- Aid caregivers'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

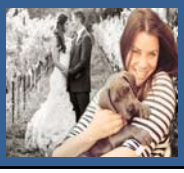
The transformation of dying in the US

	1900	2000
Age at death	46 years	78 years
Top Causes	Infection Accident Childbirth	Cancer Organ system failure Stroke/Dementia
Disability	Not much	2-4 yrs before death
Financing	Private, modest	Insurance, FFS 27% of Medicare $$
Context	Primarily at home Few tx available	Primarily institutional Interventions used
freely	ICUs absent	ICU care common

Who has driven EOL care in the US?







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

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

Original Contributions

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)

The SUPPORT Principal Investigators

The SUPPORT Investigators. *JAMA* 1995;274:1591-1598

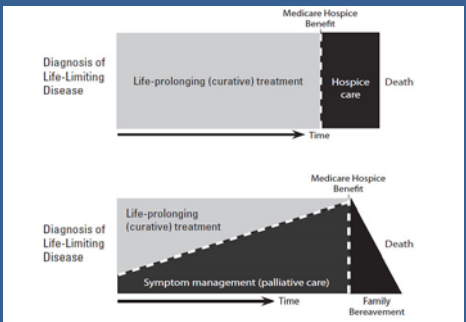
SUPPORT -- Results

- 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

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

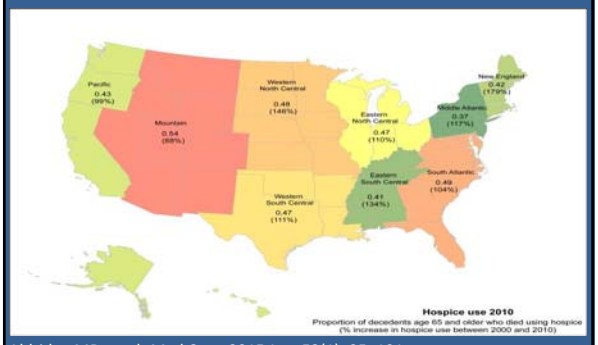
The system response to SUPPORT: the palliative care model



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 (Teno)
  - "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



Aldridge MD, et al. *Med Care*. 2015 Jan; 53(1): 95–101.

Medicare EOL outcomes 2000-2009

	2000	2005	2009
No. of decedents	270 202	291 819	286 282
Deaths in acute care hospitals, % (95% CI)	32.6 (32.4–32.8)	26.9 (26.7–27.1)	24.6 (24.5–24.8)
ICU use in last month of life, % (95% CI)	24.3 (24.1–24.5)	26.3 (26.1–26.5)	29.2 (29.0–29.3)
Hospice use at time of death, % (95% CI)	21.6 (21.4–21.7)	32.3 (32.1–32.5)	42.2 (42.0–42.4)
Health care transitions in last 90 d of life per decedent, mean (median) (IQR)	2.1 (1.0) (0–3.0)	2.8 (2.0) (1.0–4.0)	3.1 (2.0) (1.0–5.0)
Health care transitions in last 3 days of life, % (95% CI)	10.3 (10.1–10.4)	12.4 (12.3–12.5)	14.2 (14.0–14.3)

Teno JM, et al. *JAMA*. 2013 February 6; 309(5): 470–477

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Next steps in palliative care design: population health

DIMENSION	CURRENT MODEL	POPULATION HEALTH MODEL
How cases are identified	Referral-based	Proactive case-finding
Focus of performance measurement	"Numerator" of who is referred	Both "numerator" and "denominator" (population in need)
Paradigm of care	Biomedical; physiology-driven	Biopsychosocial; physiology and person/family-driven
Primary location of care	Hospital-centered	Community-centered
Pattern of care delivery	Episodic, fragmented	Registry-based, coordinated
Financing	Revenue-driven	Revenue and cost avoidance-driven
Workforce development	Staffing to referral demand and reimbursement	Staffing guided by population-at-risk and need intensity

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

NEJM lead articles

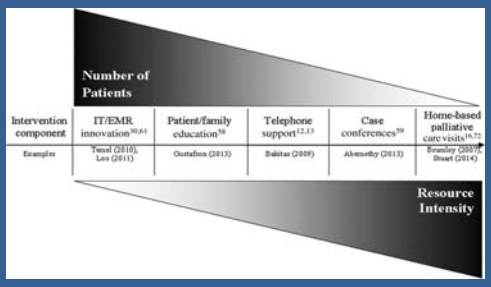

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Proactive, collaborative PC:

- Improved HRQOL
- Reduced depression sx
- Improved satisfaction
- Earlier hospice transition
- Reduced costs of care
- Survival was 2.7 months LONGER

Temel JS et al, *N Engl J Med* 2010;363:733-42
Greer JA et al, *J Clin Oncol* 2012 Feb 1;30(4):394-400
Greer JA et al, *J Palliat Med* 2016 Aug;19(8):842-8

Population health and palliative care: intervention trials

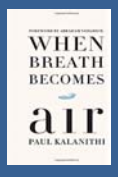


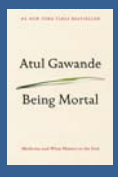
Smith G. *J Palliat Med.* 2015 Jun;18(6):486-94

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

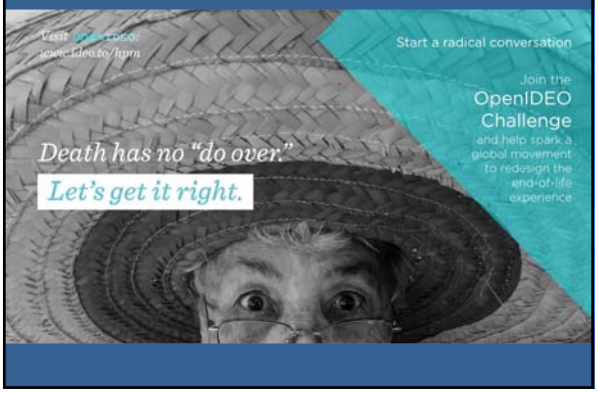




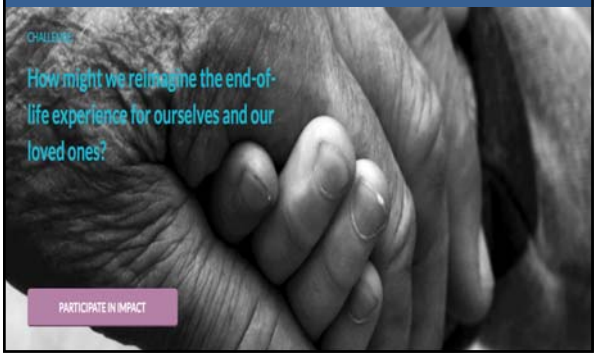
Transforming community consciousness


A better way to care for the dying

Community-based innovation



Re-designing EOL: the OpenIDEO End of Life Challenge



OpenIDEO End of Life Challenge

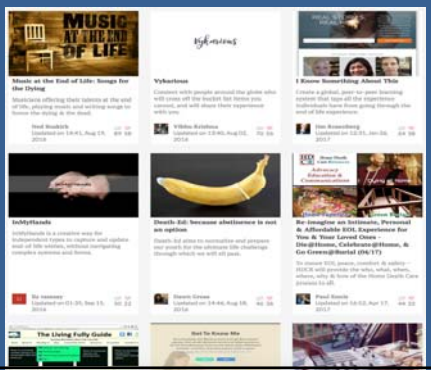
THE CHALLENGE PROCESS

We tackle each social issue via a challenge, a three to five month collaborative process that focuses our attention on the topic and creates a space for community members to contribute and build off each other. This approach is modeled on IDEO's design thinking methodology.

RESEARCH · IDEAS · REFINEMENT · FEEDBACK · TOP IDEAS · IMPACT

- **RESEARCH:** It all starts with an invitation for you and others around the world to share inspirations, stories, tools and successful examples on the challenge topic.
- **IDEAS:** Based on learnings from the Research phase, the OpenIDEO community shares new, wild or existing ideas and collaboratively refines them.
- **REFINEMENT:** We then focus on testing ideas with end users.
- **FEEDBACK:** This is when the OpenIDEO community shares comments and suggestions for next steps.
- **TOP IDEAS:** Working closely with the challenge sponsor, the OpenIDEO team chooses a set of top ideas based on their potential for impact, level of engagement and relevance to the challenge topic and evaluation criteria.
- **IMPACT:** This is where you can share learnings, find collaborators and share updates on how ideas are evolving.

OpenIDEO End of Life Challenge: Top Ideas



Community activation and engagement

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?