Palliative Care across the Continuum: 
Transforming the Healthcare Landscape

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Helen Diller Family Comprehensive Cancer Center
Professor of Clinical Medicine
Division of General Internal Medicine
UCSF
“It is amazing what you can accomplish if you do not care who gets the credit.”

- Diane Meier, MD
- David E. Weissman, MD
- Lynn H. Spragens, MBA
- Amber B. Jones, M.Ed
- Kate O’Malley, RN, MS
- Many of the people in this room
The Challenge

- Outpatient palliative care as the **Wild West**
- Many models/experiments/pilots (few with scale sufficient to manage growing expectations)
- Business case is very dependent on local variables
- Unclear boundaries between palliative care and other domains/specialties
Most patients spend *most* of their time outside of hospitals

Outpatient PC

- Improves quality patient care
- Potentially decreases mortality
- Increases efficiency in health care systems & accountable care organizations

The **frontier is an opportunity** for those who know what they want
The Explosion

- Massive, unregulated growth within palliative care AND in the health care system at large
- Exciting times AND in the midst of this explosion, we need to build the system that we are going to use
Main Points

- Definition
- Need
- Benefit
- Availability
- Future
“It may be wrong, but it’s how I feel.”
Awareness of End-of-Life Terms, California, 2011

PERCENT SAYING THEY HAVE HEARD OF THESE TERMS

Hospice care 73%

Do-not-resuscitate (DNR) order 63%

Advance directive 38%

Palliative care 17%

POLST 13%

Note: POLST is a form that is signed by a patient and his/her doctor, clearly stating what kinds of medical treatment the patient wants toward the end of life. It must be honored by health care providers, even if the patient later loses the ability to indicate his/her wishes.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.
“Palliative Care...”
Once They Know About Palliative Care…

- Extremely positive about it and want access

- >92% say:
  - It is important
  - Patients with serious illness and their families should be educated
  - Likely to consider PC for a loved one
  - It is important that palliative care services be made available at all hospitals
The “Perfect” Marketing Opportunity

- Don’t know
- When we explain it to them, everyone likes it
- But.. Remember the Death Panels
Palliative care is *specialized* medical care for people with *serious* illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness *whatever the diagnosis*.

The goal is to improve *quality of life* for both the *patient and the family*. Palliative care is provided by a *team* of doctors, nurses, and other specialists who *work with* a patient's other doctors to provide an *extra layer of support*. Palliative care is appropriate at any age and at any stage in a serious illness, and can be *provided together with curative treatment*. 
“…Across the Continuum”

 Everywhere in our system: inpatient & non-inpatient
  “Outpatient”
  “Ambulatory”
  “Clinic and community”
  “Etc etc.”

 What people/patients think of as “life”
  Time & Space
Main Points

- Definition
- Need
- Benefit
- Availability
- Future
Patients and families suffer with serious illness and at the end of life (so we should provide palliative care)

People with sticks say we have to
“...combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.”
S2.4 “Palliative care services are available to patients either on-site or by referral.”
Main Points

- Definition
- Need
- Benefit
- Availability
- Future
Proven Benefits

- Improved patient and family satisfaction
- Reduction in symptom burden
- Prolonged life (hospice, outpatient)
- Reduced costs (to be discussed later)

Improved Clinical Care

- Improved outcomes pre/post for cancer pts
  - Pain, Fatigue, Nausea, Depression, Anxiety, Drowsiness, Appetite, Dyspnea, Insomnia, Constipation, and Satisfaction

- Improved outcomes in a controlled trial
  - The CCT Trial at UCSF: outpatient palliative care team working with primary care physicians
  - Dyspnea, Anxiety, Sleep, Spiritual Well-being improved compared to routine primary care

Yennurajalingam, JPSM, 2011
Follwell, J Clin Onc, 2008
Rabow, Arch Intern Med, 2004
Kim, JPM, 2012
Palliative Care at Home for the Chronically Ill
Improves Quality, Markedly Reduces Cost

RCT of Service Use Among Heart Failure, Chronic Obstructive Pulmonary Disease, or Cancer Patients While Enrolled in a Home Palliative Care Intervention or Receiving Usual Home Care, 1999–2000

KP Study Brumley, R.D. et al. JAGS 2007
RCT of Nurse-Led Telephonic Palliative Care

- N = 322 advanced cancer patients in rural NH+VT
- Improved quality of life and less depression (p=0.02)
- Trend towards reduced symptom intensity (p=0.06)
- No difference in utilization, (but v. low in both groups)
- Median survival: intervention group 14 months, control group 8.5 months, p = 0.14

Bakitas M et al. JAMA 2009;302(7):741-9
Prolonged Survival

- 151 patients with NSCLC at Mass General
- Immediate vs. delayed palliative care along with usual oncologic care
- Early pc patients with...
  - Improved QOL
  - Less depression
  - Less chemo in last 2 weeks
  - Fewer hospitalizations in last month
  - Nearly 3 months longer survival (11.6 mos. vs. 8.9 mos., p<0.02)

Temel, NEJM, 2010
Main Points

- Definition
- Need
- Benefit
- Availability
- Future
# of U.S. Hospital Palliative Care Programs 2000-2009

*(AHA Annual Survey)*
Where is Inpatient PC Available?

Increasing:
- 24.5% (658) in 2000 to 65.7% (1,635) in 2010
- 148.5% increase from 2000-2010 (CAPC 2012)

Large hospitals (300 or more beds) 87.9%
- Mid-size hospitals (50-299 beds) 56.5%
- Small hospitals (fewer than 50 beds) 22%

The Northeast 75.8%
- The South 52.7%
### Outpatient PC in Cancer Centers

- 142 cancer centers (Hui et al. JAMA. 2010)

<table>
<thead>
<tr>
<th>Service</th>
<th>NCI site</th>
<th>Non-NCI site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care program</td>
<td>98%</td>
<td>78%</td>
</tr>
<tr>
<td>Inpatient palliative care consult team</td>
<td>92%</td>
<td>56%</td>
</tr>
<tr>
<td>Outpatient palliative care</td>
<td>59%</td>
<td>22%</td>
</tr>
</tbody>
</table>
2012 Outpatient Services among California Inpatient PC Programs

- 18% with Adult outpatient PC services; 19% with Pediatric

- Funding from:
  - Institutional support (Adult=80.0%, Pediatric=62.0%),
  - Foundations (Adult=10.3%, pediatric=23.0%)
  - Billing (Adult=8.8%, Pediatric=0%)
  - Philanthropy (Adult=0.9%, Pediatric=15.0%)

Rabow, Riodan, Pantilat, AAHPM, 2013
Availability of Expertise: Certification in Palliative Care

- **Physicians**
  - ABMS approved PC as a sub-specialty (2006)
  - Grandfathering ended 2012
  - 10 participating boards
  - 5,000 physicians certified in HPM

- **Nurses**
  - National Board for Certification of Hospice & Palliative Care RNs
  - 17,000 nurses, advanced, pediatric, nursing asst.

- **Social Workers**
  - Certified Hospice & Palliative Social Worker and Advanced Certified Hospice & Palliative Social Worker

- **Chaplains**
  - Palliative Care Chaplaincy Specialty Certificate (HealthCare Chaplaincy & The CSU Institute for Palliative Care)
But...

- 1 cardiologist for every 71 heart attacks
- 1 oncologist for every 145 new patients with cancer
- 1 PC doc for every 300 deaths
- 1 PC doc for every 1300 patients with serious illness

= 6,000-18,000 projected gap in pc physicians

- Just for hospitals and hospices!

Lupu, J Pain Sx Mgmt, 2010
The Big Question…

How will palliative care grow/transform to meet the need?
Main Points

- Definition
- Need
- Benefit
- Availability
- Future
The Future
The Future

- Challenges
- Opportunities
1. **Workforce** constraints

2. Clinical and administrative **capacity**

3. **Clarity of purpose**, role, and criteria

4. **Financial** support and alignment
1. Workforce Constraints

- Staffing the service
  - Disciplines involved, scope of service, ability to bill
  - PC expertise and certification
  - Assume care vs. co-management vs. consultation

- Support for service staff
  - Administrative support
  - Preventing clinician burnout
### Staffing Ranges in Current Practice

<table>
<thead>
<tr>
<th>Unique patients/year</th>
<th>50-100</th>
<th>101-200</th>
<th>201-300</th>
<th>&gt;300</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barebones Staffing Model</strong></td>
<td>0.25 MD</td>
<td>1.0 NP</td>
<td>0.50 MD x 4</td>
<td>0.50 MD x 3</td>
</tr>
<tr>
<td></td>
<td>0.25 SW</td>
<td>1.0 RN</td>
<td>0.25 SW</td>
<td></td>
</tr>
<tr>
<td><strong>Generous Staffing Model</strong></td>
<td>1.0 MD</td>
<td>.025 MD</td>
<td>0.25 MD</td>
<td>0.50 MD x 3</td>
</tr>
<tr>
<td></td>
<td>1.0 RN</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.0 SW</td>
</tr>
</tbody>
</table>
2. Clinical Capacity: More and Sicker Patients

✅ Space, time, staffing, acute needs, coverage
  - Capacity impacts quality
  - California Study: Wait time = 10.7 days

✅ If you build it... (Smith Landscape Study)
  - 11/20 with staffing shortages
  - Established practices overwhelmed with referrals

✅ Multi-morbidity and Complexity
3. Clarity of Purpose, Role, and Criteria

- **Who are our patients?**
  - Be prospective, not reactive

- Identify program objectives *before* design
  - Model and structure fitted to the goals
  - Alignment of benefits and costs
  - Funding criteria must precede implementation

- There are many gaps & needs – be cautious about taking them on
4. Finances: Support & Alignment

- Most primary care practices & geriatric practices owned by hospitals operate at a loss.
- Business case depends on aligning objectives (**mission alignment**) & identification of financial benefits.
The Big But of PC Finances

- If you provide outpatient clinic with long appointment times and IDT care, and cover support staff costs and overhead – you will lose money unless you have revenue in addition to CPT Billing

  Billing = <50% of expenses

**BUT** other benefits may be sufficient to justify funding

- Clinical (paying for quality)
- Financial (paying for value)
Mean cost savings of $2,282

Accounted for by…
- Reduced costs
  - Inpatient visits (mean of $3,110/patient)
  - Chemotherapy (mean of $640/patient)
- Longer lengths of hospice stays
- Higher hospice costs (mean of $1,125/patient)

Emerging Evidence on Utilization & Costs

- Enguidanos HMO
  - Decreased re-admissions after inpatient consultation

- PAMF Home-based

- OACIS Home-based
  - Decreased hospitalizations, re-admissions, cost

- Sutter AIM Home-based
  - Increased hospice; Decreased hospitalization, ICU, costs
Easy to slip back into stridency
- < 50% costs covered by revenue
- So who will pay me?

To sustain and grow, we have to continue to be strategic
- Mission alignment: how to be part of the solution
- Needs assessment
  - Patients
  - Payors
  - Community organizations
To meet the challenge... Visit IPAL-OP
Opportunities

- Improve the care experience for individuals
- Improve the health of populations
- Reduce cost

Value = Quality (#40) / Cost (17%, 50% for 5%)  
(The expensive ones are our patients)

Historic alignment:
Everyone now wants the same thing
Quality, Quantity, and Cost Savings
It’s not about who will pay for us
Or who will pay for the things we like to do

It’s about how we help achieve the triple aim
PC is a service, not a demand
About what we offer, not what we need
Aligned with the mission of our time

How do we align with reality?
Claiming our seat at the table (the adult’s table)
My Predictions for the Post-Temel Universe

1. Better care

2. Primary palliative care

3. Accessing the innovations and trends of our time

4. Patients at the center
   Reforming around that

5. Managing populations
1. Better Care

- Better drugs
  - Ketamine
  - Something for anorexia-cachexia
  - Methadone and senna in one pill!

- Better science

- Better communication
  - Better shared decision-making

(We’ll always have to do some magic)

Palliative Care Clinicians as Experts
2. Primary Palliative Care

The Workforce/Capacity Issue

- Be clear about what we do
  - Train and certify new and mid-career clinicians to do it
- Teach everyone else to do the basics
  - Primary care physicians, NPs
  - Super subspecialists
  - Assistants, Home health aides
- Requires regulation and education
- Make use of technology: ASCO/AAHPM Virtual Learning Collaborative

Integrated (not just consult, not just concurrent)

Quill & Abernethy, NEJM, 2013
3. Tapping into What’s Trending

- Molecular/personalized medicine
- Social media
- MOOC (massive online open courses)

Information Technology

- Continuity
- Quantified Selves (iPhone health)
- Prognosis (knowing when to intervene, when to spend resources)
- Big Data (a little Orwellian but will allow ACOs to succeed)
4. Patients at the Center
“Be There Now”

- We’ve always said what we did was **align care** with patient wishes.

- To impact care, we need to have patients at the center:
  - Be there (when it’s happening, at their house)
  - From the beginning
  - Without gaps (“timely access”)

  - **Any hole** in the system makes it easy to slip back to bad habits (just send ‘em to the ER, code them, etc)
1/3 of patients with chronic illness and hospitalization had no post-discharge follow-up arrangements

"Coordinating Care – A Perilous Journey through the Health Care System"

T. Bodenheimer, MD  NEJM  358  March 2008)

1 in 5 Medicare patients re-hospitalized within 30 days of discharge

Half of these occurred before seeing outpatient physician

Estimated cost 17.4 billion

Jencks, Williams, and Coleman  NEJM  2009, Vol 360, 1418-1428
Conceptual Model of Outpatient Palliative Care

SYSTEM-BASED PRACTICE
* HOSPITAL/HEALTH SYSTEM
* HOSPICE

Clinic Practice
- Stand-Alone
- Co-located
- Embedded

Community Practice
- Facility Visits (SNF, AL)
- Home Visits

INDEPENDENT PRACTICE
The Patient-Centered Model

- Inpatient PC and Hospitalization
- Hospice
- Telemedicine
- Lab and Radiology Services
- Home Visiting Program, including PC
- CAM
- Rehab
- Nutrition
- Outpatient Specialty Clinics, including PC and non-PC
- PCP Clinics
- Intervention Clinics
- EMS
- Social Services
- Pharmacies
- SNF & Consult Service
Keep the patient at the center of Design

What do patients want?

- Pain and symptom control
- Avoid inappropriate prolongation of the dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones


Do we know how and where they want help with this?

*Doubt it is only when in the hospital… ?at Home*
Strategic Partnerships/Alignment

Supportive Care Coalition
Advancing Excellence in Palliative Care

American Cancer Society

C-Change
Collaborating to Conquer Cancer

American Hospital Association

The Joint Commission

Institute for Healthcare Improvement

Commission on Cancer
A multidisciplinary program of the American College of Surgeons

National Quality Forum

Family Caregiver Alliance

LIVESTRONG

AAMC
Tomorrow’s Doctors, Tomorrow’s Cures®
From health system’s perspective
The providers and sites of care involved in delivery of medical services (usually constrained by payment and benefit rules)
- May be limited to segments owned by system
- Or segments linked to the overall finances
  (i.e. Definition is changing with payment reform)

From patient’s perspective...
All the places & providers that assist with their journey and the gaps in-between them, all time and everywhere, life

These two perspectives are aligning
✓ EVERYONE has skin in the game
5. Managing Populations

- Regulation
- Reimbursement
- Reform

(Get comfortable with our role in improving systems)
The Sticks of the Future: The 3 Rs

- Regulation, Reimbursement, Reform
- Joint Commission (not just ASCO and CoC)
  - What is now a gold star (Advanced Certification), will become a requirement for accreditation
- Health Systems (vertically-integrated)
- Payors:
  - Medicare/Medicaid
  - Commercial Insurers
  - Employers
Payers Have Skin in this Game

Highmark Introduces Advanced Illness Services Program

Beginning Jan. 1, 2011, Highmark will offer the Advanced Illness Services (AIS) program as part of its Medicare Advantage plans. The program will provide 100 percent coverage for as many as 10 outpatient care visits by AIS network hospice and/or palliative care providers to promote quality of care for members with progressive, life-limiting illness.

Stratis Health

Leading collaboration and innovation in health care quality and safety

Quality Update

RURAL PALLIATIVE CARE EMERGING AS A HEALTH CARE PRIORITY

@HOMe Support™
“On the Map” with IHI

http://www.ihi.org/IHI/Programs/ImprovementMap

Palliative Care

**Overview**
Establish reliable processes for delivering palliative care to people facing serious illness.

**Elements**
- Provide an interdisciplinary team of skilled palliative care professionals
- Ensure timely access to services for families and patients
- Establish and use criteria to identify patients needing palliative care support
- Deliver effective treatment for relief from symptoms such as pain, shortness of breath, weight loss, weakness, nausea, serious bowel problems, delirium, and depression
  - Regular assessment
  - Use evidence-based guidelines when available
- Provide help with psychological, social, and spiritual needs to patients with serious illness, and their families
Health Care Reform: Game Changing Options

- Hospice Concurrent Care Pilots
- Medicare Independence at Home Demonstrations
- Patient-Centered Medical Homes
- Bundled Payments Pilots
- Accountable Care Organizations

- All increase odds of more aligned payment & fewer barriers to collaboration across entities
- From “On the Map” to “At the Table”
Exciting Times for California

- Challenges
- Opportunities
Patients Admitted to ICU/CCU During the Hospitalization in Which Death Occurred, California vs. United States, 1996 to 2007


©2012 California Healthcare Foundation
Patients Spending 7+ Days in ICU/CCU During the Last Six Months of Life, California vs. United States, 1996 to 2007


©2012 California HealthCare Foundation
Location of Deaths,

Hospital
- 1989: 47%
- 2001: 42%
- 2009: 58%

Home
- 1989: 13%
- 2001: 27%
- 2009: 32%

Nursing Home
- 1989: 22%
- 2001: 21%
- 2009: 18%

Inpatient Hospice
- N/A

Other
- 1989: 5%
- 2001: 8%
- 2009: 6%

Preferred Location of Death, California, 2011

- Home: 70%
- Hospital: 16%
- Hospice facility: 4%
- Refused: 2%
- Don’t know/Not sure: 2%
- Other: 7%

Note: Segments may not add to 100% due to rounding.
Source: Californians’ Attitudes Toward End-of-Life Issues, Luka Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

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Hospitals with Palliative Care Services,
California, 2007 and 2011

PERCENTAGE OF HOSPITALS WITH PALLIATIVE CARE PROGRAMS

- 43%
  141 hospitals
  2007

- 53%
  192 hospitals
  2011

Note: Hospitals provide palliative care in a variety of settings beyond the acute care hospital, including clinics and the patient’s home. Hospital-based palliative care is provided through both consultation and primary services. Consultation services offer recommendations for treatment, and primary services provide treatment for the patient.

Source: Survey of Palliative Care in California Hospitals, National Health Foundation and University of California, San Francisco, 2011.

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# Palliative Care Programs in Selected Hospital Systems, California, 2011

## Percentage of System Hospitals with Palliative Care Programs

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Percentage</th>
<th>Count of Programs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kaiser Foundation</td>
<td>100%</td>
<td>33 of 33</td>
</tr>
<tr>
<td>Scripps Health</td>
<td>100%</td>
<td>4 of 4</td>
</tr>
<tr>
<td>University of California</td>
<td>100%</td>
<td>8 of 8</td>
</tr>
<tr>
<td>Catholic Healthcare West</td>
<td>96%</td>
<td>27 of 28</td>
</tr>
<tr>
<td>Sutter Health</td>
<td>84%</td>
<td>21 of 25</td>
</tr>
<tr>
<td>County of Los Angeles</td>
<td>67%</td>
<td>2 of 3</td>
</tr>
<tr>
<td>Memorial Health Services</td>
<td>67%</td>
<td>4 of 6</td>
</tr>
<tr>
<td>St. Joseph Health System</td>
<td>56%</td>
<td>5 of 9</td>
</tr>
<tr>
<td>Adventist Health Systems</td>
<td>43%</td>
<td>6 of 14</td>
</tr>
<tr>
<td>Daughters of Charity</td>
<td>40%</td>
<td>2 of 5</td>
</tr>
<tr>
<td>Sharp Healthcare</td>
<td>40%</td>
<td>2 of 5</td>
</tr>
<tr>
<td>Tenet</td>
<td>9%</td>
<td>1 of 11</td>
</tr>
</tbody>
</table>

Note: This is not a comprehensive list of California hospital systems.

Source: Survey of Palliative Care in California Hospitals, National Health Foundation and University of California, San Francisco, 2011.

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California Innovation

- Center for Medicaid & Medicare Innovation sites
- Pioneer ACOs
- Palliative Care Action Community
  - Our own start at Big Data
  - Innovative statewide collaboration and learning community
California State University = California’s largest educator of health system professionals

CSU Palliative Care Institute providing education, workforce training and public outreach has been established at Cal State San Marcos

Funders include CHCF and Archstone and a private donor
Where do we stand?
- PC is not transforming the health care landscape
- PC is part of the transformation of health care

We are a part of something greater, part of the whole
- To find happiness and peace, we must find our place in the Universe
- Not standing apart, being a part

Back to the future
- Not something distinct and precious... something routine
- Reconnect with the lineage of compassion and healing