Opportunities and challenges to improve care at the end of life

Sandra R. Hernández, MD
CEO, California Health Care Foundation
The California Health Care Foundation (CHCF) is dedicated to advancing meaningful, measurable improvements in the way the health care delivery system provides care to the people of California, particularly those with low incomes and those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.
The care many patients receive doesn't reflect what they want, what we know works, and what provides value. CHCF supports policies and care models that align with patient preferences, are proven effective, and are affordable.

Goals for Palliative Care:

• Increase access to community based palliative care
• Eliciting and honoring patient wishes: POLST and the POLST eRegistry
Goal of this Presentation

Explore palliative care in context of current health care trends

• Relationship to the triple aim
• National climate around “the conversation”
• Palliative care capacity
• POLST
Californians' Attitudes and Experiences with Death and Dying

• 8 in 10 say that if seriously ill, they would want to speak with their doctor about end-of-life care

• But fewer than 1 in 10 report having had a conversation, including just 13% of those age 65 or older.
What is important to people

*In their own words*

- Don’t want to burden family with finances: 67%
- Want to be without pain: 66%
- Being at peace spiritually: 61%
- Having loved ones around me: 60%
- Don’t want to burden family w/tough decisions: 60%
- Being able to pay for the care I need: 58%
- Making sure medical wishes are followed: 57%
- Providers understand my cultural beliefs: 44%
- Living as long as possible: 36%

Californians’ Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months. From “Final Chapter: Californians’ Attitudes and Experiences with Death and Dying” California Health Care Foundation. Available at: [http://www.chcf.org/publications/2012/02/final-chapter-death-dying](http://www.chcf.org/publications/2012/02/final-chapter-death-dying)
...but gaps persist

Assessments of EOL-care quality reported by 586 bereaved family members (2011-2013)

- Unaddressed religious/spiritual concerns: 58%
- Needed more help for anxiety/sadness: 50%
- Needed more help for pain: 25%
- Needed more help for dyspnea: 21%
- Family not always kept informed: 20%
- Not always treated with respect: 15%
- Decision made pt would not have wanted: 11%

1 in 5 individuals who died in an ICU got care they would not have wanted

And costs are high …

EOL population accounts for 11% of top 5%

National interest in the issue

Mandela’s Illness Exposes Little End-of-Life Planning in Modern World
New America Media, News Feature, Vi"la Sandman, Posted: Jul 17 2013
Nelson Mandela is about to turn 95 with his condition shrouded in mystery, exposing the global need for palliative care to comfort those at life’s end.

Palliative Care Key to Dignity at Life’s End for Elders
News For Change, News Analysis, Jeff Mc Debbin Juan, Posted: Sep 04, 2013
Efforts in the United States have slowly planted the seed of the end-of-life care movement in Chinese communities here in recent years.

The Last Chapter of Life
German New America Media, News Feature, Nadja Iman, Posted: Sep 13, 2013
The palliative care team Dr. Cary Lee heads at Santa Clara Valley Medical Center in San Jose, Calif., faces terminal illness 10 times per day.

Have You Spoken with Loved Ones About Your End-of-Life Care Wishes?
A priority for aging Californians is to not burden their loved ones. But less than half have spoken to family about care they’d want at the end of life.

Why Ethnic Elders Forego Hospice and Palliative Care
RedwoodsAge.com, News Feature, Pamela A. MacLean, Posted: Sep 16, 2013
Dealing with the reality of a terminal illness is something that prompts many African-Americans to look to the clergy and spiritual leaders, but not necessarily for comfort and support in hospice care.

Why Are Latinos Not Using Palliative and Hospice Care?
As the older U.S. Hispanic population grows, many will face the end of their lives unprepared spiritually or financially. Palliative care offers an important solution.

‘It’s About Life’ - Changing Korean American’s View of Palliative Care
Korea Times, News America Media, News Feature, Anna Lee, Posted: Nov 11, 2013
End of life care experts say the Korean American community can benefit from a “culturally sensitive” discussion on end of life care.

Palliative and Hospice Comfort Chinese Seniors at the End of Life
Chinese families mistakenly avoid palliative and hospice care for lack of information on its benefits for patients facing the end of life.

More Filipino Americans Will Need Palliative Care
Inquirer.net, News Feature, James Dalo, Posted: Sep 18, 2013
Palliative care will be increasingly important for the growing number of older Filipino Americans, but so far few take advantage of comfort care at the end of life.

Church’s Compassion Creates Community-Care Model for AIDS Patients
RedwoodAge.com, News Feature, Pamela A. MacLean, Posted: Sep 15, 2013
Giuseppe Riga volunteered in 1983 to help the dying—their found comfort at the same innovative church program when he was diagnosed with HIV.

Filipino Americans “In Denial” On Palliative Care Benefits
Filipino families should seriously consider palliative care enrollment for their terminally ill or very seriously ailing elders.

At Life’s End Filipino Care Decisions Relate on God, Family, Home
Inquirer.net, News Feature, James Dalo, Posted: Sep 25, 2013
For Filipino immigrants facing life’s end, their reliance on religion, family and home in making health decisions can challenge providers of palliative care.

For Indian Americans, Need Grows for Culturally-Sensitive Palliative Care
For South Asian Americans, the increasing need for eldercare will require more end-of-life decision-making. Palliative care holds answers for many.

Hispanics Overcoming Barriers to Elders’ End-of-Life Care
Latinos traditionally avoid formal eldercare, but new services can help them when elders need professional hospice or palliative care.
Physicians perspective on the conversation

Conversation Stopper: Physicians’ Views Toward End of Life and Advance Care Planning Insights From Polling among Physicians, April 2016
Virtually all say conversations about advance care planning are important – half say extremely important.

Respondents are more likely to say it is extremely important for health care providers to have these conversation with their patients if they have had training.
Biggest physician barriers to the conversation: lack of time, disagreement between patient and family, and not knowing when the time is right.

Think about your patients 65 and older with a serious illness. Have any of the following ever gotten in the way of talking to them about their end-of-life wishes? IF YES: how often does this get in the way for you….

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Not too often</th>
<th>Never gets in way</th>
</tr>
</thead>
<tbody>
<tr>
<td>You don't have time with everything else on your plate</td>
<td>30%</td>
<td>36%</td>
<td>19%</td>
<td>15%</td>
</tr>
<tr>
<td>There's disagreement between family members and the patient</td>
<td>16%</td>
<td>49%</td>
<td>30%</td>
<td>5%</td>
</tr>
<tr>
<td>You're not sure the time is right</td>
<td>13%</td>
<td>47%</td>
<td>28%</td>
<td>11%</td>
</tr>
<tr>
<td>It might be an uncomfortable conversation</td>
<td>14%</td>
<td>37%</td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td>You don't want a patient to feel that you are giving up on them</td>
<td>12%</td>
<td>36%</td>
<td>32%</td>
<td>19%</td>
</tr>
<tr>
<td>You don't want a patient to give up hope</td>
<td>10%</td>
<td>36%</td>
<td>36%</td>
<td>19%</td>
</tr>
<tr>
<td>You may be unsure what is culturally appropriate for the patient</td>
<td>5%</td>
<td>39%</td>
<td>37%</td>
<td>19%</td>
</tr>
<tr>
<td>Someone else should be having the conversation with them instead of you</td>
<td>7%</td>
<td>27%</td>
<td>34%</td>
<td>32%</td>
</tr>
</tbody>
</table>
Have you had any training specifically on talking with patients and families about end-of-life care, or not?

Less than a third has had training on the issue.

Respondents most likely to have had training include younger physicians and those with a racially and ethnically diverse patient population. Two-thirds of physicians seeing patients nearly everyday who are near end of life do not have specific training on these conversations.
Almost half say they frequently or sometimes feel unsure of what to say during conversations about end-of-life care.
Similarly, less than a third says their practice has a formal system for assessing patients’ end-of-life wishes and goals for care.

In your practice or health care system, is there a formal system for assessing patients’ end-of-life wishes and goals of care, or not?

Physicians working in hospital settings are more likely to report a system in place than those in a mostly office or clinic based setting. Those who are having frequent conversations with patients around advance care planning are also more likely to report having a formal assessment system in place.

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>29%</td>
<td>67%</td>
</tr>
<tr>
<td>Mostly office/clinic based setting</td>
<td>26%</td>
<td>70%</td>
</tr>
<tr>
<td>Mostly hospital setting/both equally</td>
<td>39%</td>
<td>59%</td>
</tr>
<tr>
<td>Talks to patients about advance care planning (ACP) issues once/wk+</td>
<td>33%</td>
<td>64%</td>
</tr>
<tr>
<td>Talks to patients about ACP issues less often</td>
<td>20%</td>
<td>75%</td>
</tr>
</tbody>
</table>
Three in four say the new Medicare benefit makes them more likely to talk to patients about advance care planning.

Respondents most likely to say they are much more likely to have conversations given the new benefit include racially/ethnically diverse physicians, those under age 50, and physicians who are already talking to patients about these issues nearly everyday.
However, most say they have not had a conversation about advance care planning and billed Medicare for it this year.

Have you had this conversation and billed Medicare for it this year?
(Respondents who bill Medicare fee-for-service n = 626)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Total</td>
<td>14%</td>
<td>85%</td>
</tr>
<tr>
<td>Sees patients 65+ almost everyday+</td>
<td>15%</td>
<td>84%</td>
</tr>
<tr>
<td>Sees patients 65+ several times/wk or less</td>
<td>6%</td>
<td>92%</td>
</tr>
<tr>
<td>Had end-of-life (EOL) training</td>
<td>19%</td>
<td>80%</td>
</tr>
<tr>
<td>No EOL training</td>
<td>12%</td>
<td>87%</td>
</tr>
<tr>
<td>System in place for assessing EOL wishes</td>
<td>25%</td>
<td>75%</td>
</tr>
<tr>
<td>No system in place</td>
<td>9%</td>
<td>90%</td>
</tr>
</tbody>
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Strategies for Increasing Access

1. Payers contract with specialty providers
2. Health systems build specialty services in house
3. Health systems train current staff in primary palliative care
Northern California:
- Collabria
- ResolutionCare
- Interim Health Care
- Yolo Hospice

San Francisco:
- BlueShield
- Hospice by the Bay
- UCSF

Orange County, Long Beach, and LA:
- Health Net
- CareCHOICES

Los Angeles:
- WellPoint
- UCLA Health System

San Diego:
- LightBridge Hospice & Palliative Care
- Rady Children's

Payer-Provider Initiative
CA Examples of Building Capacity

• Sharp Health Care, San Diego

• The UC Medical Centers – Irvine, San Francisco, San Diego, Los Angeles

• CA public hospital systems
Train in primary palliative care

- CSU Institute for Palliative Care – interdisciplinary in-person & distance learning
- Stanford Health Care – interdisciplinary distance learning
- Project ECHO – ResolutionCare – using telemedicine
Eliciting and honoring patient wishes

- SB 19 (Wolk) authorized a pilot test for an electronic POLST registry (eRegistry).
- CHCF working with the Coalition and the Emergency Medical Services Authority to develop the pilot
  - Create cloud-based registry for completed POLST forms in 2016
  - Select pilot location to test ways to submit and retrieve POLST forms in 2017-2018
  - Evaluate project process and outcomes in 2018
  - Statewide spread strategy by 2020