Help Wanted: Californians’ Views and Experiences of Serious Illness and End-of-Life Care

November 5, 2019

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Housekeeping

• All lines will be muted.

• Submit questions online at any time through the Q&A platform.
  • Please *only* use the Chat function if you’re having technical difficulties.

• This webinar will be recorded.

• Recording and slides will be available within two weeks on the CHCF website.
Goals for Today

• Describe context – what did we seek to learn and why?
• Discuss survey methodology
• Present selected key findings
• Describe how providers, health plans, and others can apply this knowledge to meet the needs of people with serious illness
Survey Findings and Related Products
Available at www.chcf.org/helpwanted
Context

- Previous statewide surveys (2006 and 2011) on attitudes and experiences with end-of-life care
- CHCF portfolio moved upstream to serious illness care; sharpened focus to Californians with low incomes
- Desire to understand:
  - What has changed and what has stayed the same?
  - How do needs of Californians with low incomes differ?
  - Are people interested in / open to services and support typically provided by palliative care?
- Apply learnings to improve serious illness care in California
What is Palliative Care?

palliate means relieve
What is Palliative Care?

• “Palliative care is the medical subspecialty focused on preventing, treating and relieving the pain and other debilitating effects of serious and chronic illness.”

• “Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.”

Center to Advance Palliative Care
What is Palliative Care?

- Symptom Management
- Info on Prognosis & Treatment Options
- Explore Values & Translate into Medical Choices
- Psychosocial Support
- Spiritual Support

Patient & Family
Review of Methods
Phase 1: Qualitative

Focus groups

Pasadena (Dec 11, 2018)
Chinese group in Cantonese
Chinese group in Mandarin

Los Angeles (Dec 12, 2018)
Latinx group in English

Oakland (Dec 13, 2018)
Latinx group in Spanish
White group in English
Black group in English

In-depth interviews

Pasadena (Dec 11, 2018)
Chinese woman in Cantonese
Chinese woman in Mandarin

Los Angeles (Dec 12, 2018)
White woman in English
Latina woman in English

Oakland (Dec 13, 2018)
White woman in English
Black woman in English
Black woman in English
Latina woman in Spanish
Phase 2: Quantitative

Ipsos’ KnowledgePanel

- Address-based sampling (97% of households)
- English and Spanish
- Mail and phone recruitment
- Robust Latino sample
- Provide internet access
- Online method, better data quality

Survey of n = 2,588 adults 18+ in California

- N = 929 respondents under 150% FPL
- N = 871 respondents 150% to 399% FPL
- N = 788 respondents 400% FPL +
- N = 711 Latino respondents
- N = 722 Black respondents
- N = 180 Asian American respondents
- N = 913 white respondents
- N = 588 with a serious illness
- N = 1,276 experience with a loved one’s recent death

Note: FPL is federal poverty level. In 2019, the federal poverty level was $12,490 for a single person and $25,750 for a household of four.
Select Survey Findings
Awareness of Serious Illness and End-of-Life Terms
California, 2011 and 2019

PERCENTAGE RESPONDING YES
Have you ever heard of any of the following terms? Base: all respondents (n = 2,588)

<table>
<thead>
<tr>
<th>Term</th>
<th>2011</th>
<th>2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice Care</td>
<td>73%</td>
<td>80%</td>
</tr>
<tr>
<td>Do-Not-Resuscitate (DNR) Order</td>
<td>63%</td>
<td>72%</td>
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<tr>
<td>Advance Directive</td>
<td>38%</td>
<td>50%</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>17%</td>
<td>37%</td>
</tr>
<tr>
<td>POLST (Physician Orders for Life-Sustaining Treatment)</td>
<td>13%</td>
<td>22%</td>
</tr>
</tbody>
</table>

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, Prexylumet, 2019.

Awareness of terms is higher than in 2011.
Low-income respondents are least aware.
End-of-Life Wishes in Writing, by Demographic Groups
California, 2019

Do you have any of your wishes regarding the medical treatment you would want in a written document? Base: all respondents (n = 2,588)

- **No Response**: 1%
- **Yes**: 34%
- **No**: 66%

**Most Likely to Say Yes**
- 65+: 61%
- White: 42%
- Has Serious Illness: 40%
- 400%+ FPL: 40%

**Most Likely to Say No**
- Latino: 76%
- <150% FPL: 74%
- 150%-199% FPL: 69%
- Black: 68%

Note: In 2019, the federal poverty level (FPL) was $12,490 for a single person and $25,760 for a household of four. Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or alcohol liver disease, chronic or end-stage kidney disease, or another serious illness. Segments may not total 100% due to rounding.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, Pentecost, 2019.
But, no change in proportion that has talked with preferred decisionmaker about wishes.
Some of the most important factors at end of life include not burdening family.
Some factors were more important to some subgroups than others.
Consistent with 2011 findings, 7 in 10 say they would prefer to die at home.

Preferred Location of Death
California, 2019

If given a choice at the end of your life, where would you want to be when you die? Base: all respondents (n = 2,588)

- Home: 71%
- Hospital: 15%
- Somewhere Else: 6%
- Hospice Facility: 5%
- Nursing Home or Skilled Nursing Facility: 1%
- Assisted Living Facility: 1%
- No Response: 1%

Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.
Proportion dying at home is slowly increasing, but gap between preferences and reality persists.
When palliative care is described, 9 in 10 without a serious illness say they would want this type of help if they had a serious illness.
Among those with serious illness, nearly 8 in 10 say they would want this type of help; about 4 in 10 say they already get it.
Californians want more information rather than less.

Information Preferences Around Serious Illness, by Race/Ethnicity and Income Level, California, 2019

If you had a serious illness, how much information would you want from your health care provider? Base: respondents without a serious illness (n = 2,000)

Notes: Respondents without a serious illness are those who do not report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or liver failure, liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was $12,690 for a single person and $25,750 for a household of four.

Source: Californians’ Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,548 adult Californians. Perry/Undem, 2019.
Most with a serious illness do not feel “very prepared” to deal with their illness as it progresses.
Among respondents with serious illness, those with low incomes rate helpfulness of supportive services higher than higher income groups.
Implications and Opportunities
What do the Survey Results Tell Us?

Challenges & Opportunities:

- Communication with providers
- Access to type of support palliative care provides
- Different levels of help needed for different populations
Key Finding:
Gap Between Desired and Actual Communication

82% of respondents would probably/definitely want to talk about their end-of-life wishes with a doctor. Only 21% of those with a serious illness had been asked about this by a doctor.

92% of respondents would want “as much information as possible” about what to expect. Finding persists across ALL racial/ethnic groups.
What is being done to meet these needs?

Communication is desired, but not happening.
Solution: Empower patients using the right tools

- Online tool tested in English- and Spanish-speaking vulnerable adults
- Higher engagement in advance care planning behaviors
- Increased advance care planning documentation

Sudore R, 2018 JAMA Int Med
Key Finding: People still don’t know to ask for palliative care

Just over 1/3 of respondents said they’d heard of palliative care

9 in 10 people said they’d want the type of services palliative care provides, if they had a serious illness
Knowledge Gap Differs by Race, Education Level

Have You Ever Heard of Palliative Care?

- College grad, 39%
- Some college, 31%
- HS or less, 16%
- Black, 25%
- Latinx, 23%
- White, 38%

Trivedi N, 2019 J Palliative Med
What is being done to meet these needs?
Key Finding:
Income changes what, how much people need

*Lower income respondents with serious illness felt less prepared for disease progression (33% vs. 14% felt unprepared)*

- Low-income patients are more likely to present with advanced cancer\(^1,2\)
- Less financial cushion, work flexibility

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\(^1\) Abdelsattar ZM, 2017 Cancer
\(^2\) Walker GV, 2014 J Clinical Onc
Key Finding:
Income changes what, how much people need

Patient & Family
Symptom Management
Info on Prognosis & Treatment Options
Explore Values & Translate into Medical Choices

Psychosocial Support
Spiritual Support

150-399% FPL
Symptom Management
Info on Prognosis & Treatment Options
Explore Values & Translate into Medical Choices

Patient & Family
Psychosocial Support

<150% FPL
Symptom Management
Info on Prognosis & Treatment Options
Explore Values & Translate into Medical Choices

Patient & Family
Psychosocial Support

400%+ FPL
Symptom Management
Info on Prognosis & Treatment Options
Explore Values & Translate into Medical Choices

Patient & Family
Psychosocial Support

Spiritual Support

Explore Values & Translate into Medical Choices
**Key Finding:**
Income changes what, how much people need

*Assistance which at least half of respondents thought would be somewhat-very helpful*

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<th>400%+ FPL</th>
<th>150-399% FPL</th>
<th>&lt;150% FPL</th>
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</thead>
<tbody>
<tr>
<td>1. Pills or medication sent to your home</td>
<td></td>
<td></td>
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<tr>
<td>2. Help with pain or other side effects</td>
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<td></td>
</tr>
<tr>
<td>1. Help with pain or other side effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Financial help to pay bills</td>
<td></td>
<td></td>
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<tr>
<td>3. Pills or medication sent to your home</td>
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<td></td>
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<tr>
<td>4. Help paying for healthy food</td>
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<tr>
<td>5. Help with sadness/stress/other hard feelings</td>
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<tr>
<td>5. Better/more affordable housing &amp; Help with sadness/stress/other hard feelings</td>
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</tr>
</tbody>
</table>

(ALL 10 items >50%)
Casey

- Widely metastatic poorly differentiated adenocarcinoma → brain met causing symptoms
- Longstanding kidney disease
- Opioid use disorder
- Limited social/caregiving support
- Housing instability
- Beloved dog
Senate Bill (SB) 1004: Palliative Care Access for Medicaid Beneficiaries in California
SB 1004: Lessons Learned in Implementation

- Patients can be hard to engage
  - Disconnected phones, changed address
- Leveraging trusting relationships is key, once contact is made
- Palliative care teams trying to meet high psychosocial needs
  - Social work is most prevalent member of IDTs
  - Partnership with health plans, community organizations
  - “Address their immediate needs, whatever they may be. This leads back to palliative care support/services.”
Call to Action

• Improve quality and timing of communication
  • More investigation on bias by race/ethnicity as well as income

• Develop strategies to inform vulnerable communities about the benefits of palliative care – *including psychosocial assistance*

• Address access gaps – policy/logistics/both

• Palliative care programs which serve vulnerable communities need to invest in partnerships to meet needs that go beyond typical palliative care team scope
THANK YOU

Questions/Discussion