

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

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Housekeeping

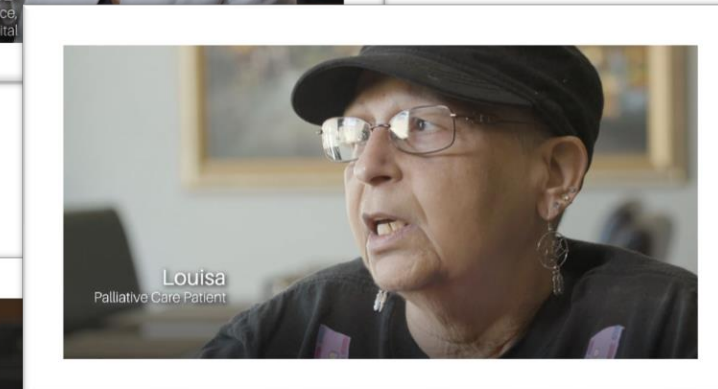
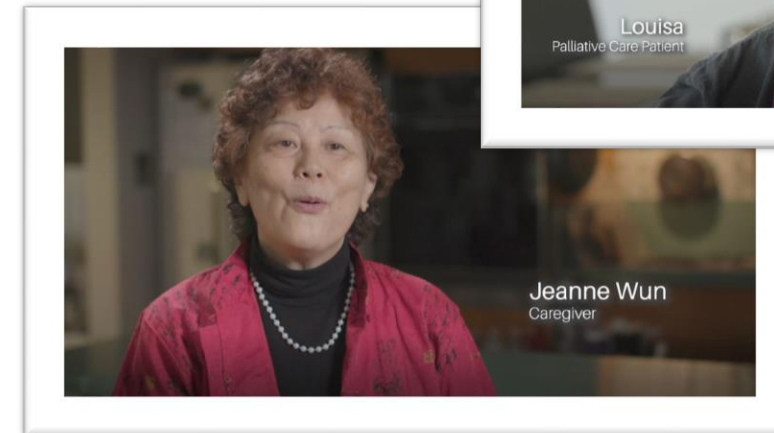
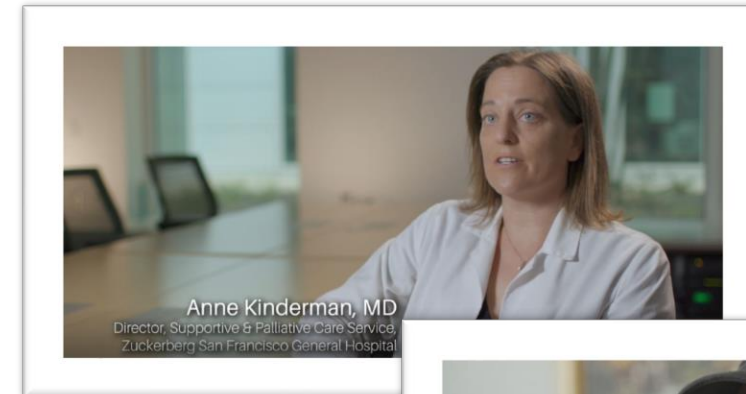
- All lines will be muted.
- Submit questions online at any time through the Q&A platform.
 - Please *only* use the Chat function if you're having technical difficulties.
- This webinar will be recorded.
- Recording and slides will be available within two weeks on the CHCF website.

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?

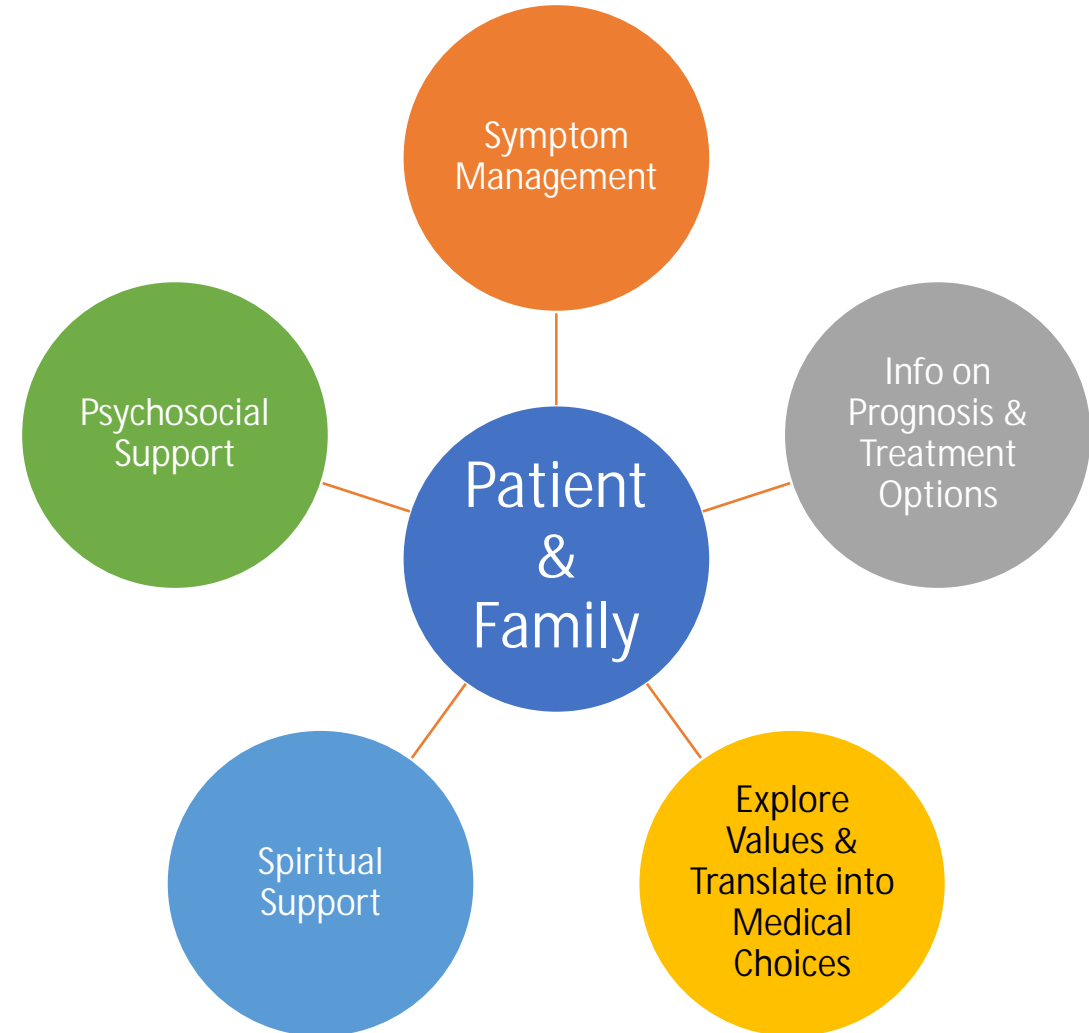
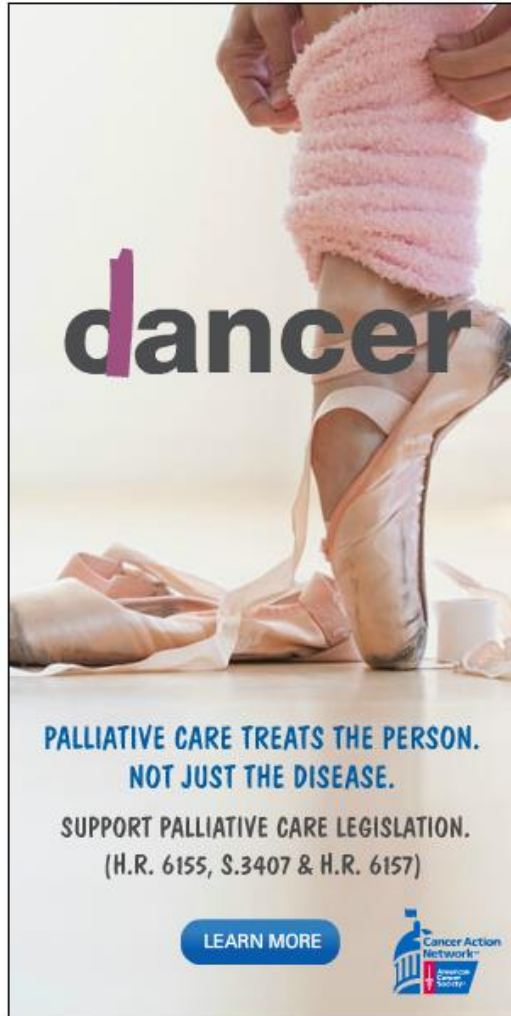


What is Palliative Care?

- “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?



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.

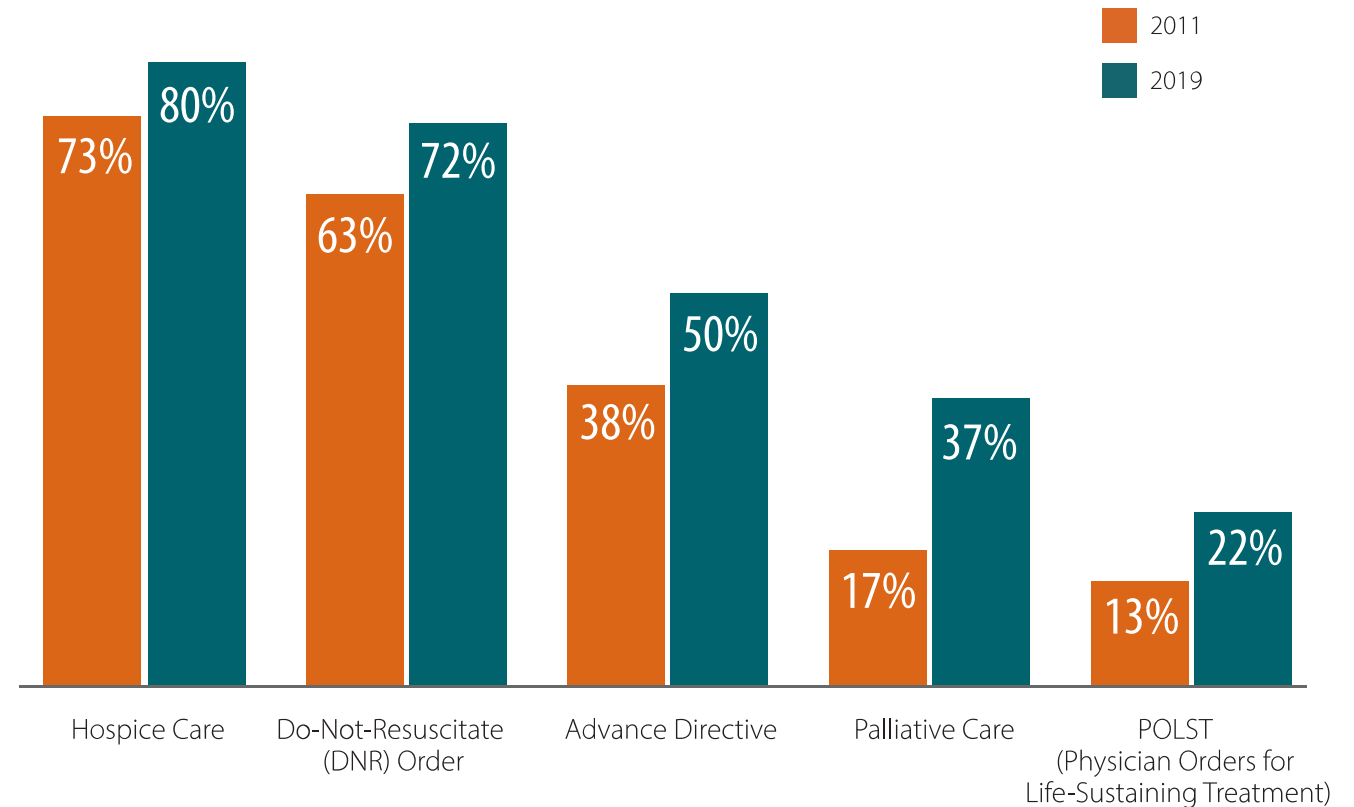
Select Survey Findings

**Awareness of
terms is higher
than in 2011.**

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)



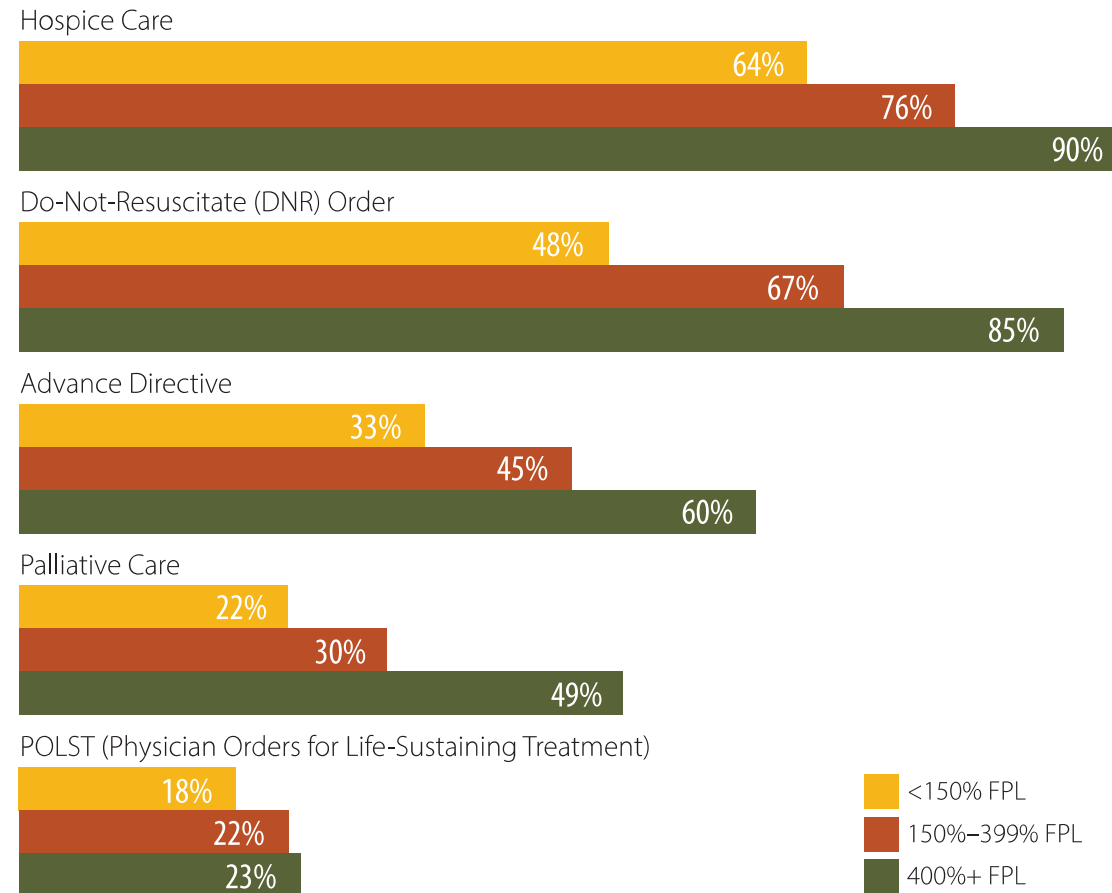
Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Low-income respondents are least aware.

Awareness of Serious Illness and End-of-Life Terms, by Income Level, California, 2019

PERCENTAGE RESPONDING YES

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



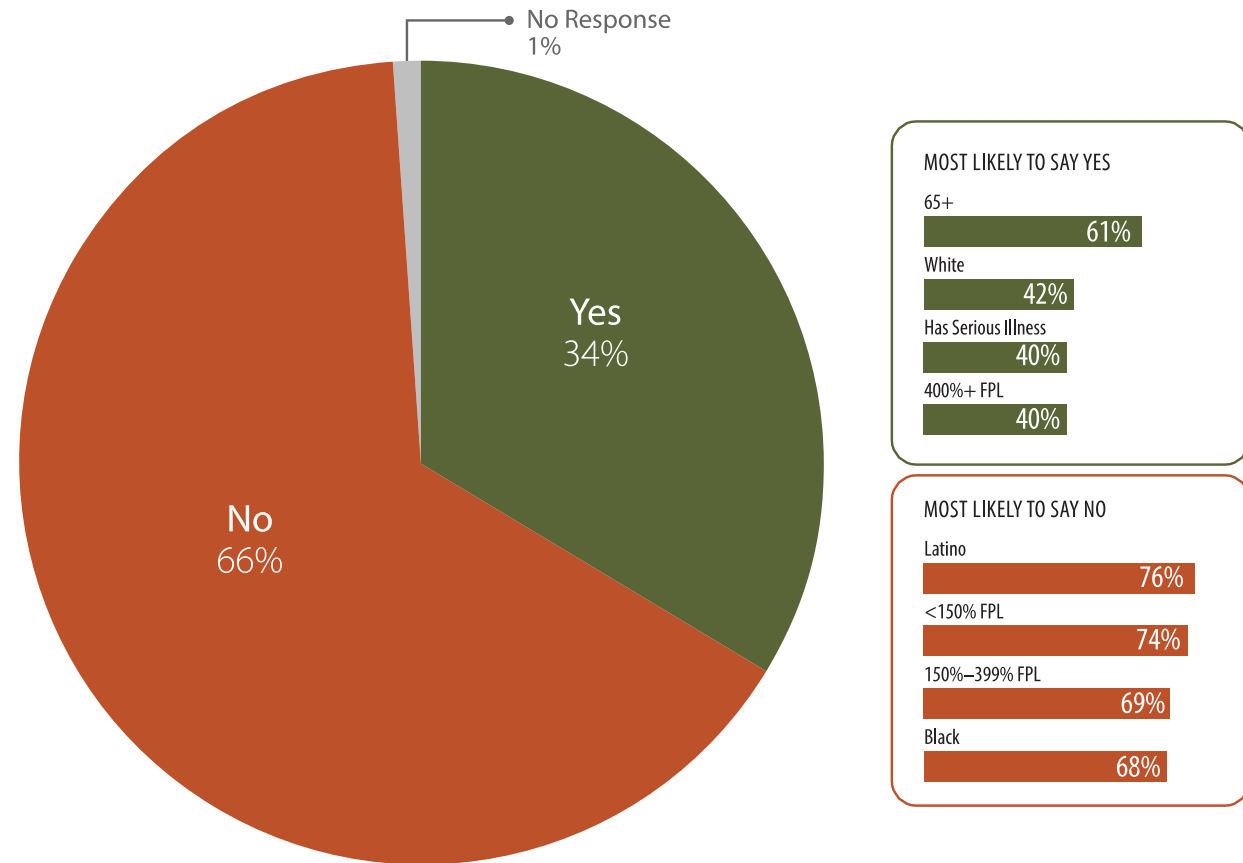
Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

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

Proportion that has documented wishes in writing (34%) is higher than in 2011 (23%).

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)



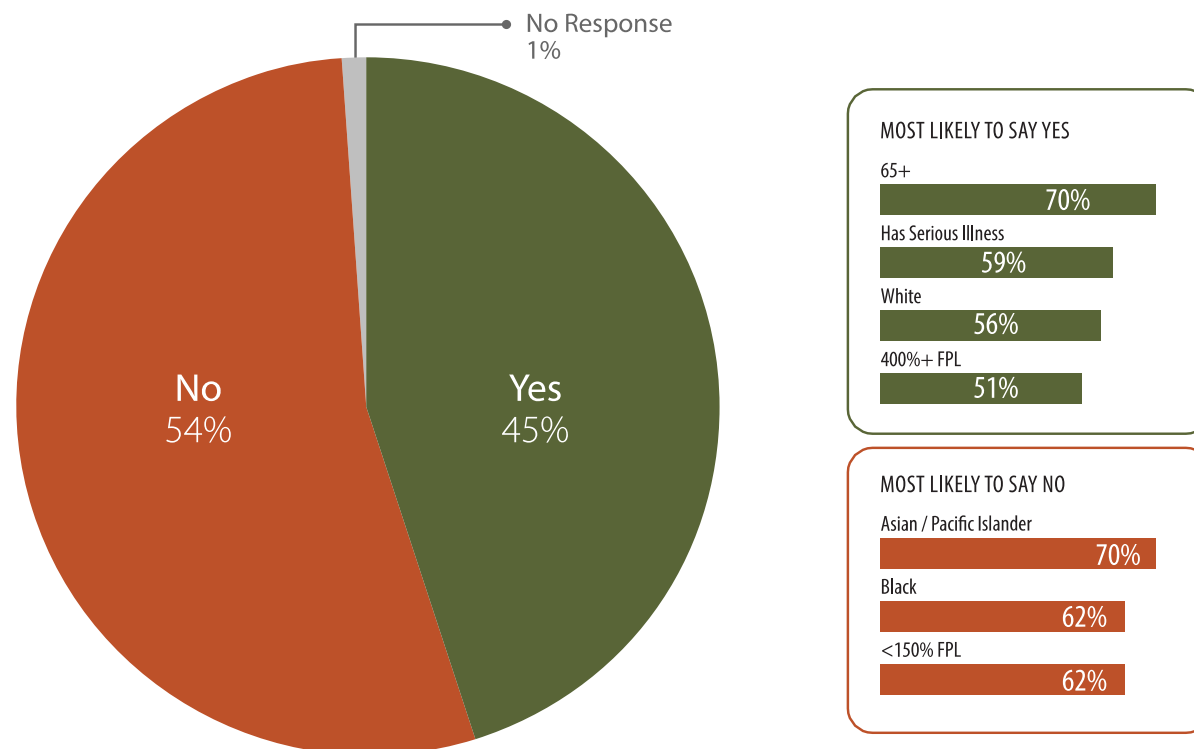
Note: In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver 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, PerryUndem, 2019.

But, no change
in proportion
that has talked
with preferred
decisionmaker
about wishes.

Discussed End-of-Life Wishes, by Demographic Groups California, 2019

Have you talked with this person (preferred decisionmaker) about the kind of medical care you would want near the end of your life? Base: all respondents (n = 2,588)



Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four.

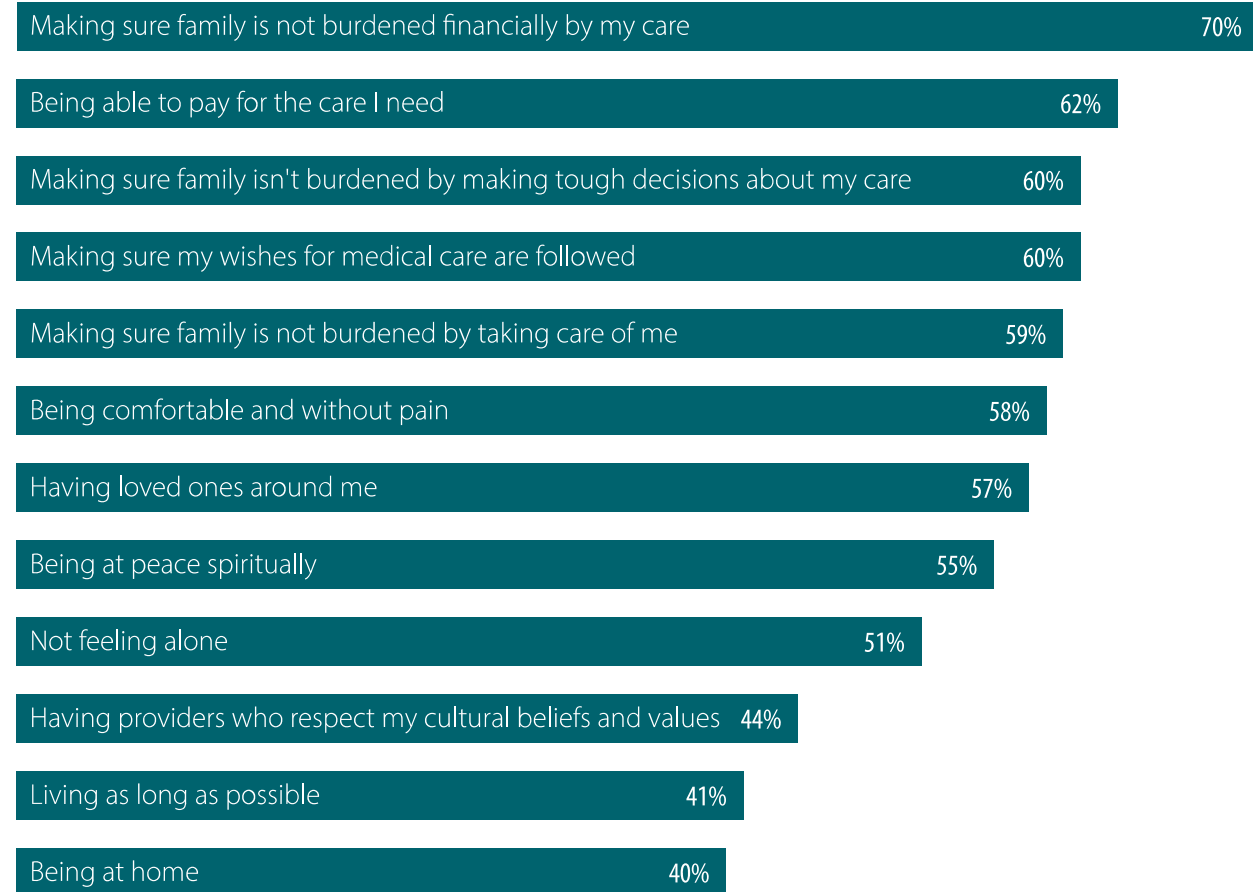
Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Some of the most important factors at end of life include not burdening family.

Most Important Factors at End of Life California, 2019

PERCENTAGE RESPONDING "EXTREMELY IMPORTANT"

How important is each of the following to you at the end of your life? Base: all respondents (n = 2,588)



Notes: Question is based on a 1-to-7 scale, from 1 being "not at all important" to 7 being "extremely important." Data reflect the percentage of respondents who rated each response a 7. Additional responses included: "A close relationship with my doctor" (32%), "Seeing friends or family I have not seen in a long time" (25%), and "Going back to my hometown or country where I'm from" (15%).

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

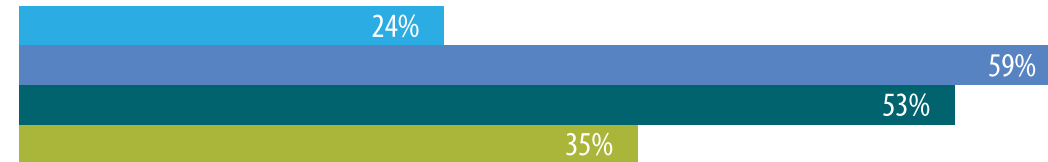
Some factors
were more
important to
some subgroups
than others.

Variation in End-of-Life Preferences, by Race/Ethnicity California, 2019

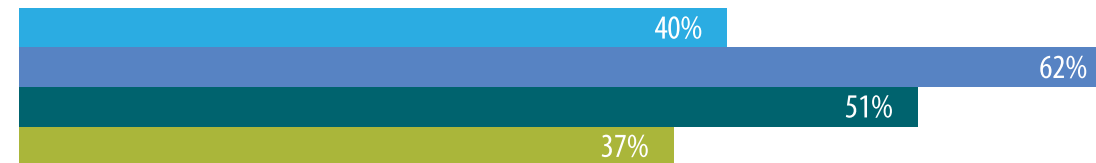
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How important is each of the following to you at the end of your life? Base: all respondents (n = 2,588)

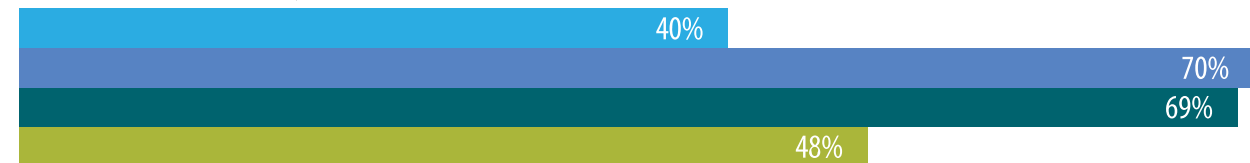
Living as long as possible



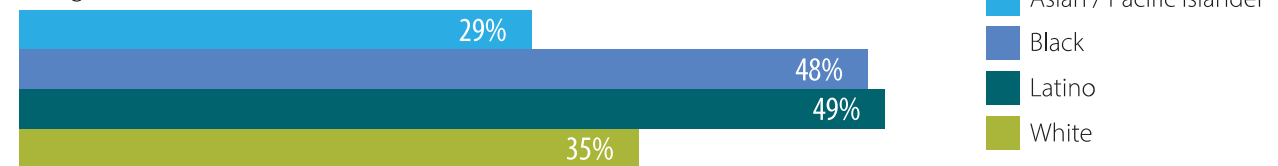
Having doctors and nurses who will respect my cultural beliefs and values



Being at peace spiritually



Being at home



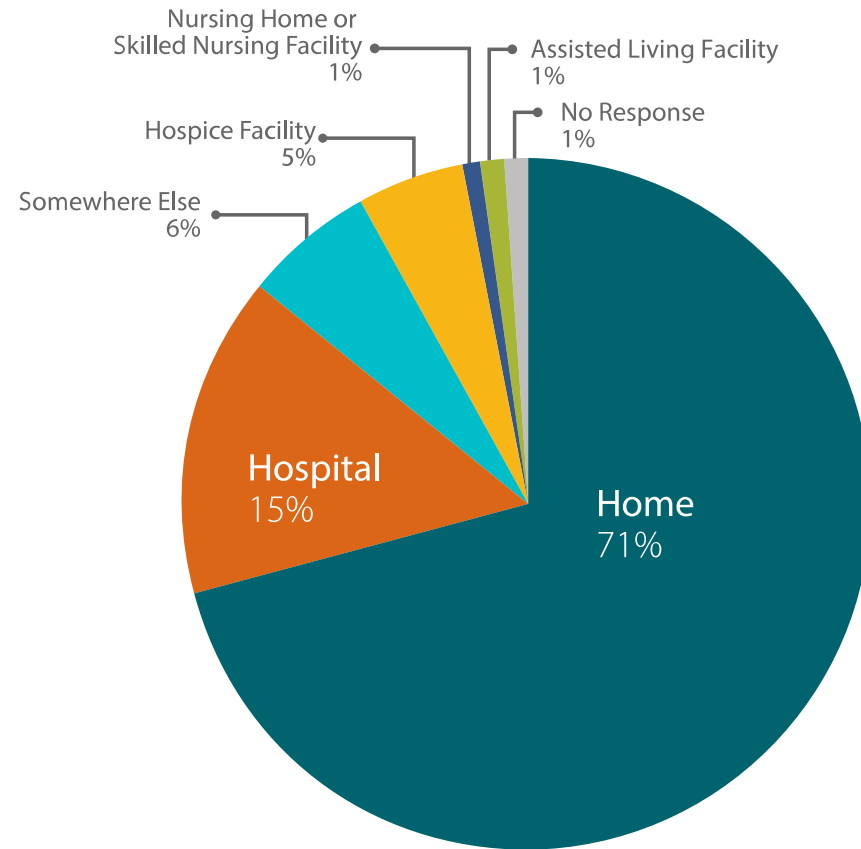
Notes: Question is based on a 1-to-7 scale, from 1 being "not at all important" to 7 being "extremely important." Data reflect the percentage of respondents who rated each a 7.

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

**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)

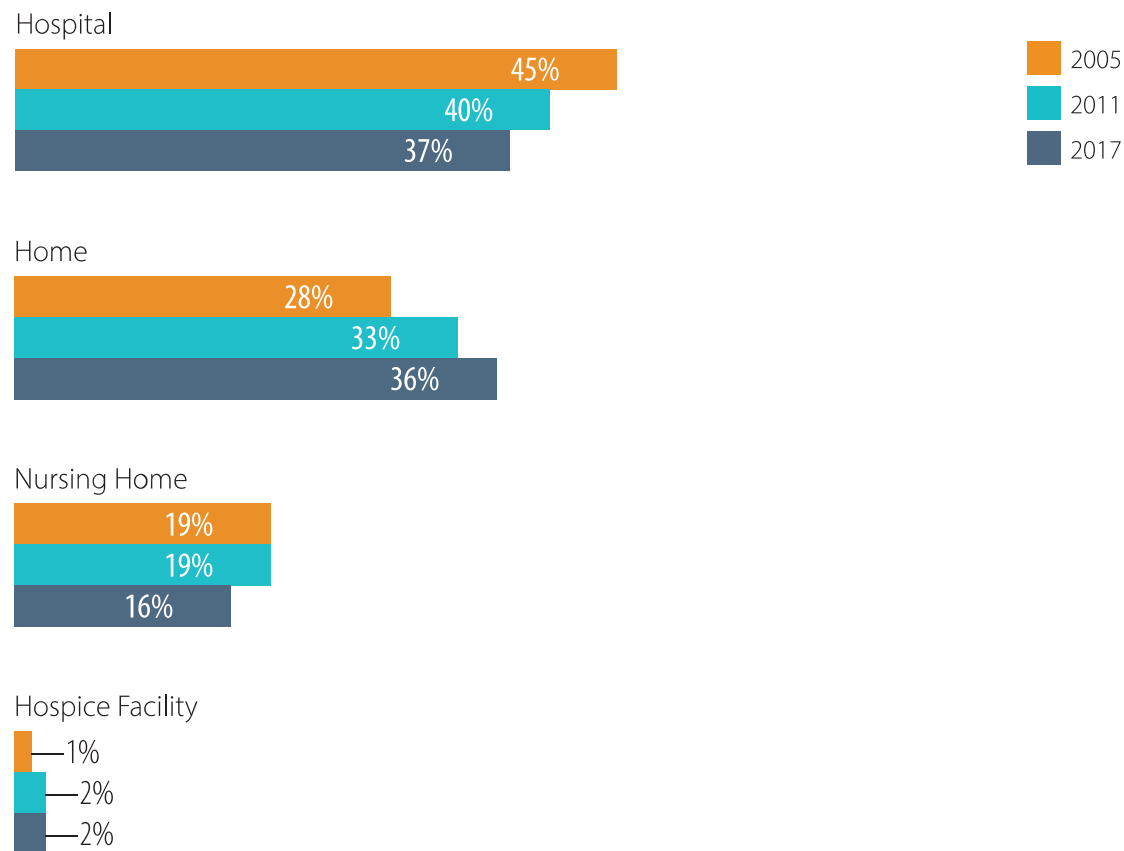


Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Proportion dying at home is slowly increasing, but gap between preferences and reality persists.

Location of Death

California, 2005, 2011, and 2017



Notes: *Hospital* includes inpatient, outpatient, emergency room, or dead on arrival at hospital. *Other* and *place of death unknown* are not shown.

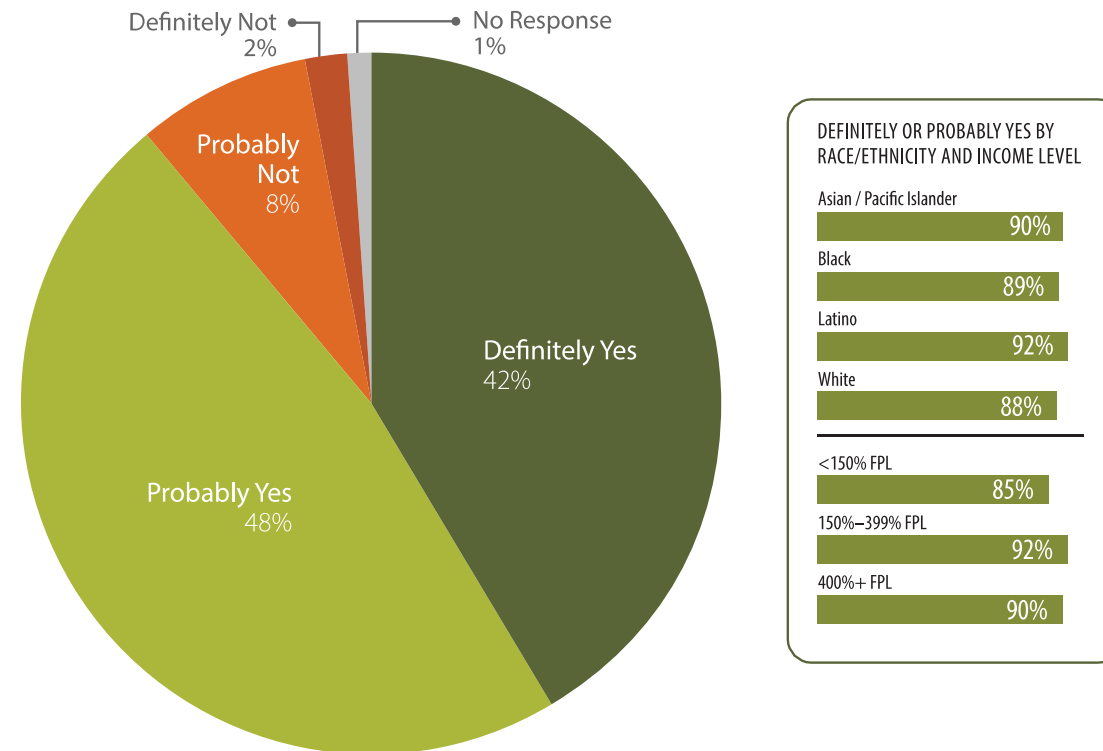
Source: Multiple Cause of Death files (1999–2017), CDC WONDER Online Database, Centers for Disease Control and Prevention, accessed September 4, 2019, <http://wonder.cdc.gov>.

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.

Interest in Palliative Care Services California, 2019

DO YOU THINK YOU WOULD WANT THIS TYPE OF HELP IF YOU HAD A SERIOUS ILLNESS, LIKE CANCER?

Some people with a serious illness get extra help. This type of help is on top of regular medical care. It could be help with things like dealing with side effects or pain, dealing with stress and other hard feelings, figuring out how to live better with your illness, or finding out what services you might qualify for. Do you think you would want this type of help if you had a serious illness, like cancer? 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 late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Segments may not total 100% due to rounding.

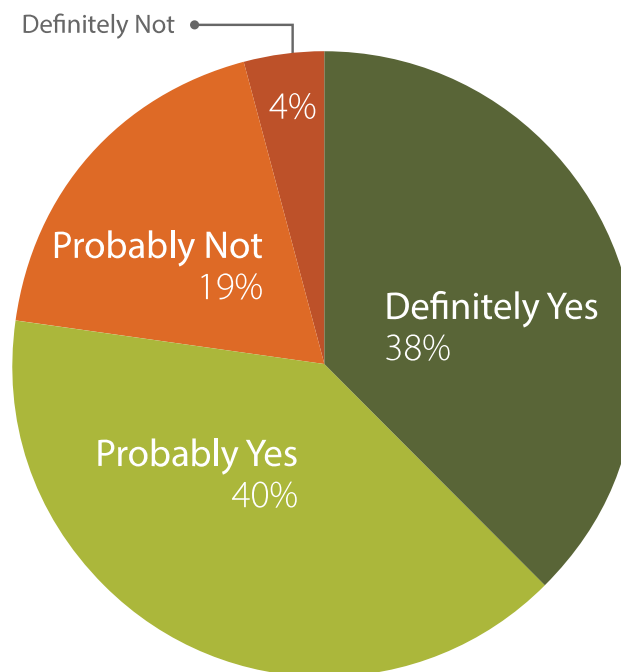
Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

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.

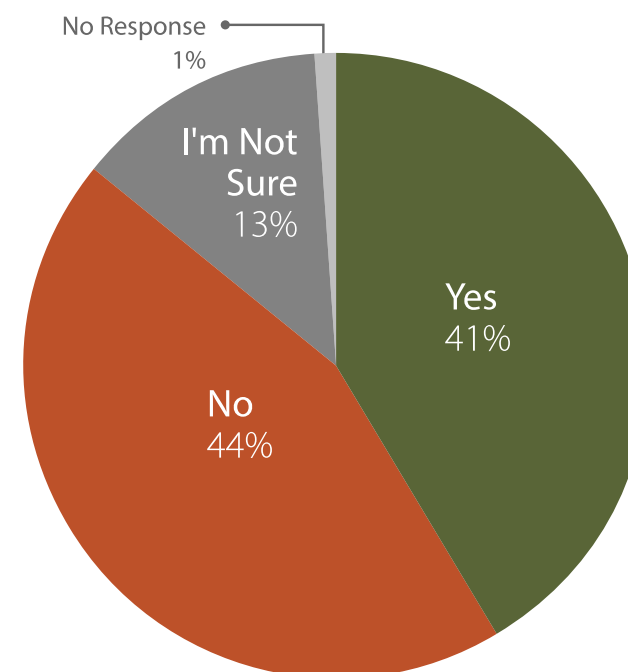
Interest in and Receipt of Palliative Care Services California, 2019

Some people with a serious illness get extra help. This type of help is on top of regular medical care. It could be help with things like dealing with side effects or pain, dealing with stress and other hard feelings, figuring out how to live better with your illness, or finding out what services you might qualify for. Base: respondents with a serious illness (n = 588)

Would you want this type of help to deal with your illness(es)?



Do you already get this type of help?



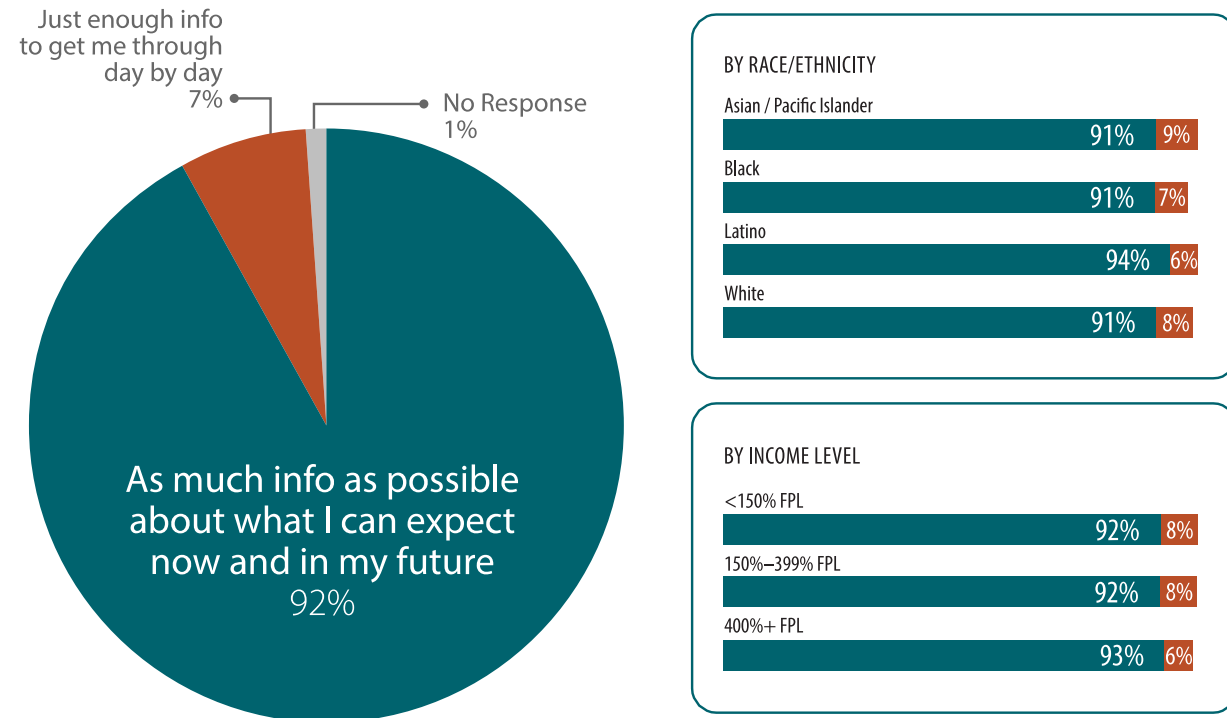
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Source: Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

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)



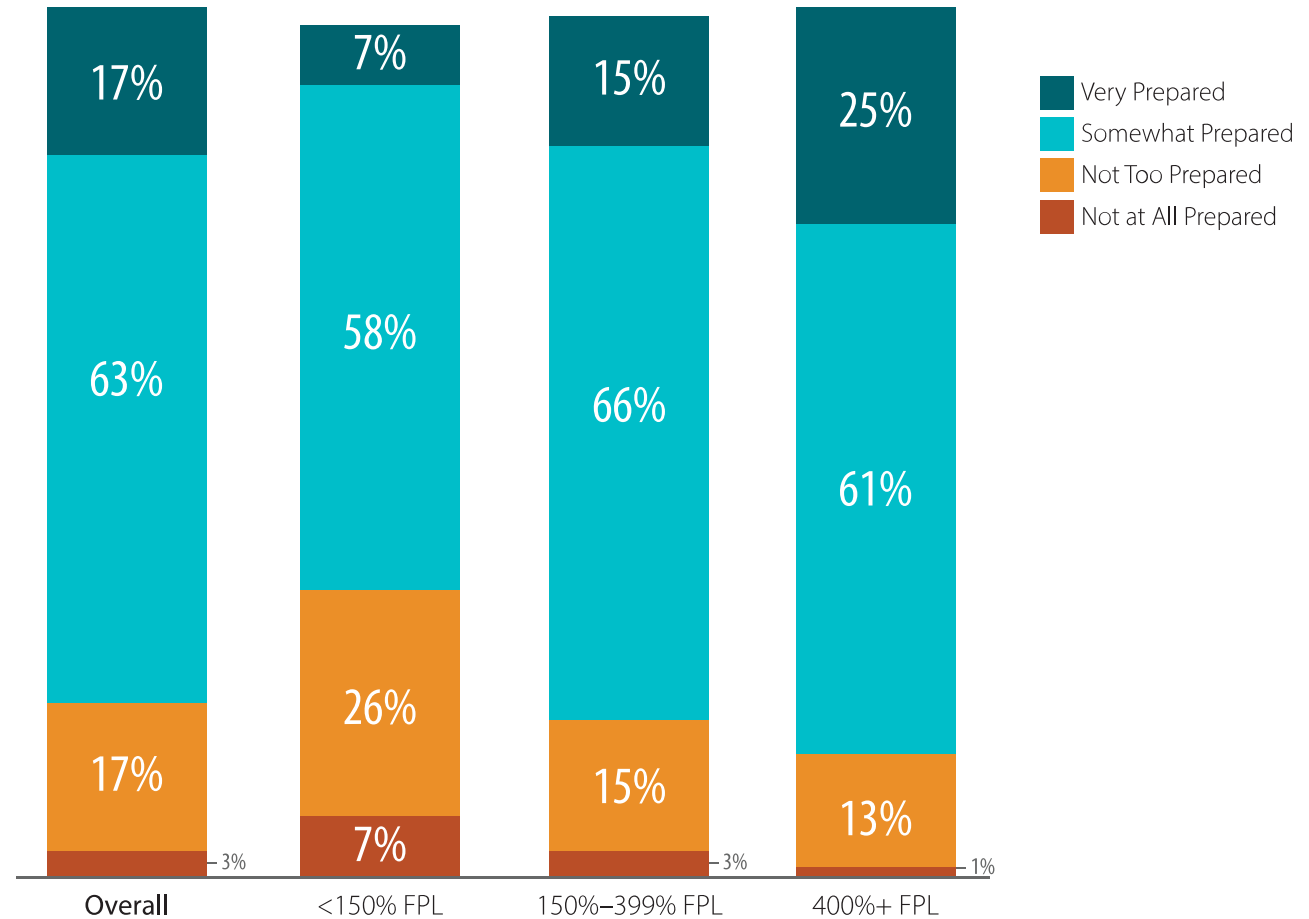
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Source: *Californians' Attitudes Toward and Experiences with Serious Illness and End-of-Life Care*, statewide survey of 2,588 adult Californians, PerryUndem, 2019.

Most with a serious illness do not feel “very prepared” to deal with their illness as it progresses.

Feeling Prepared If Illness Gets Worse, by Income Level California, 2019

How prepared do you feel to deal with your illness(es) if it gets worse in the future? By prepared, we mean you know what is going on, you can plan for what is coming, and you feel ready. Base: respondents with a serious illness (n = 588)



Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 for a single person and \$25,750 for a household of four. Nonresponders not shown. Segments may not total 100% due to nonresponse or rounding.

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

Among respondents with serious illness, those with low incomes rate helpfulness of supportive services higher than higher income groups.

Helpfulness of Supportive Services, by Income Level

California, 2019

PERCENTAGE RESPONDING "VERY HELPFUL" OR "SOMEWHAT HELPFUL"

How helpful would this be for you as you deal with your illness(es)? Base: respondents with a serious illness (n = 588)

Financial help to pay bills and make ends meet



Help with pain or other side effects



Pills or medication sent to your home



Help paying for healthy food



Help with sadness, stress, or other hard feelings



Having better or more affordable housing



Help with transportation



<150% FPL
150%–399% FPL
400%+ FPL

Notes: Respondents with a serious illness include those who report emphysema or chronic obstructive pulmonary disease, heart failure, cancer, a stroke, HIV/AIDS, cirrhosis or late-stage liver disease, chronic or end-stage kidney disease, or another serious illness. In 2019, the federal poverty level (FPL) was \$12,490 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 2,588 adult Californians, PerryUndem, 2019.

Implications and Opportunities

What do the Survey Results Tell Us?



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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:

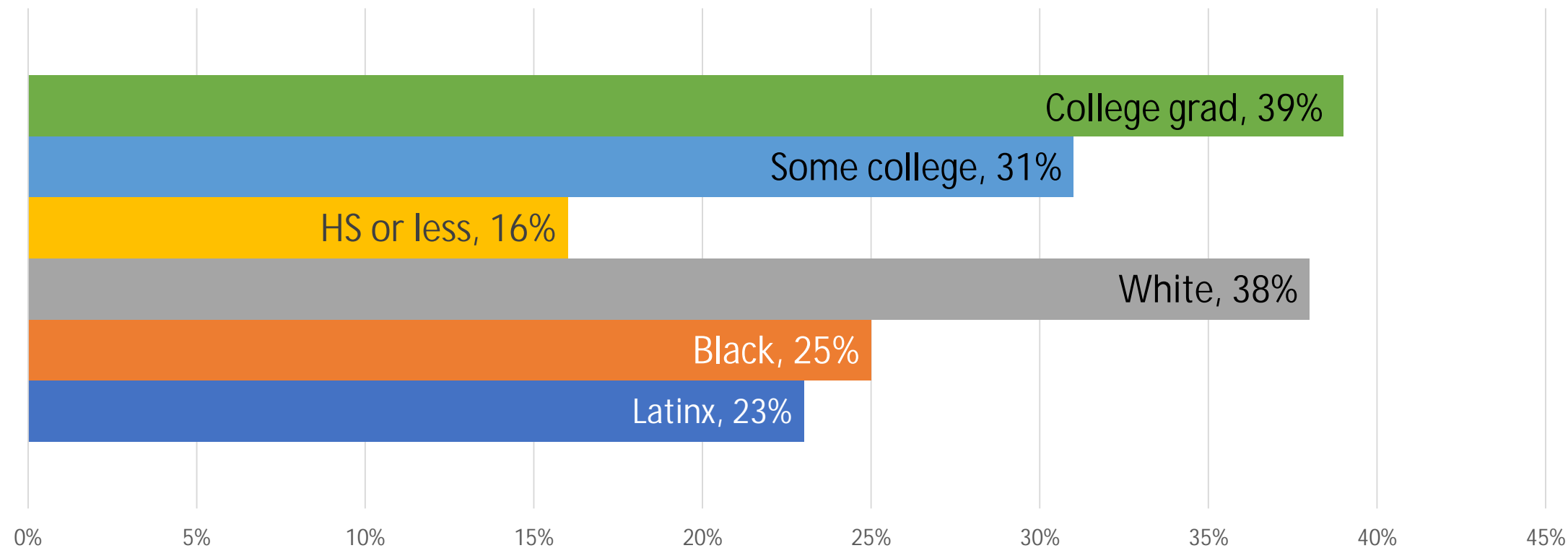
People still don't know to ask for palliative care

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?



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



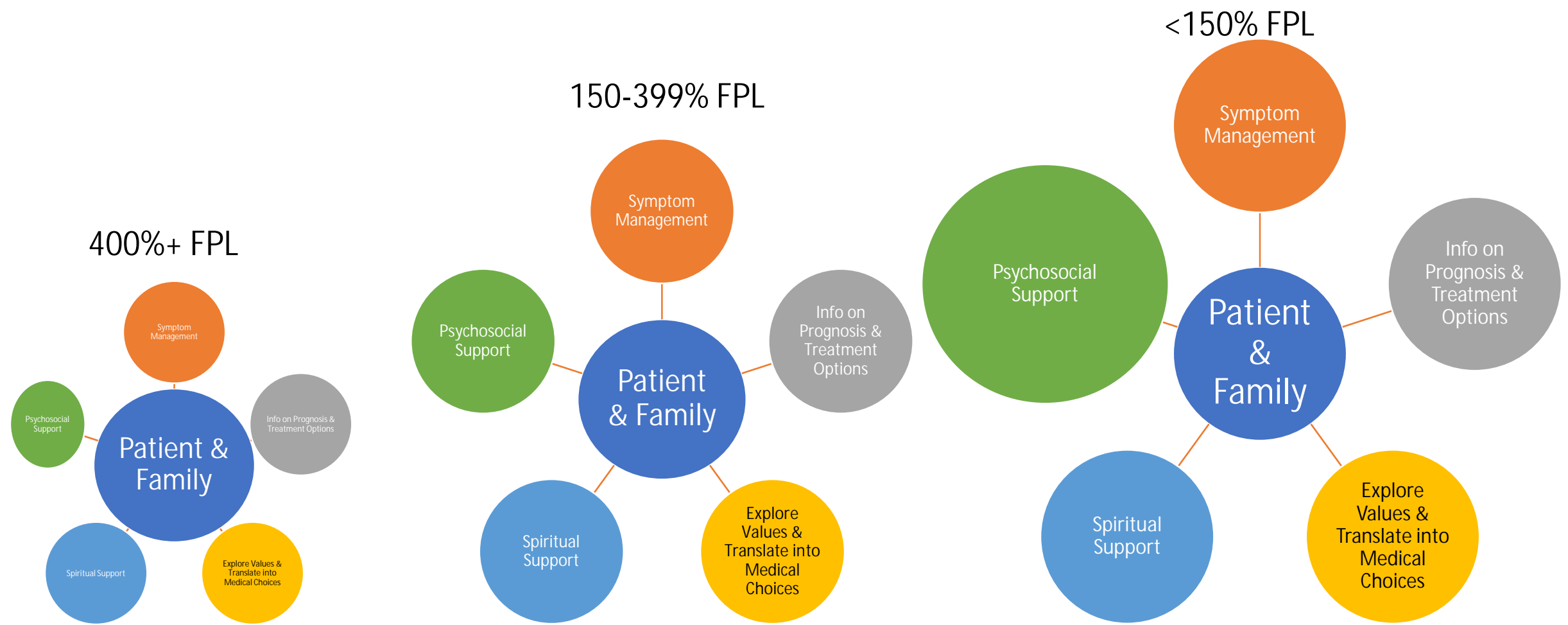
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¹Abdelsattar ZM, 2017 Cancer

²Walker GV, 2014 J Clinical Onc

Key Finding:

Income changes what, how much people need



Key Finding:

Income changes what, how much people need

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

400%+ FPL

1. Pills or medication sent to your home
2. Help with pain or other side effects

150-399% FPL

1. Help with pain or other side effects
2. Financial help to pay bills
3. Pills or medication sent to your home
4. Help paying for healthy food
5. Help with sadness/stress/other hard feelings

<150% FPL

1. Financial help to pay bills
 2. Help with pain or other side effects
 3. Pills or medication sent to your home
 4. Help paying for healthy food
 5. Better/more affordable housing & Help with sadness/stress/other hard feelings
- (ALL 10 items >50%)

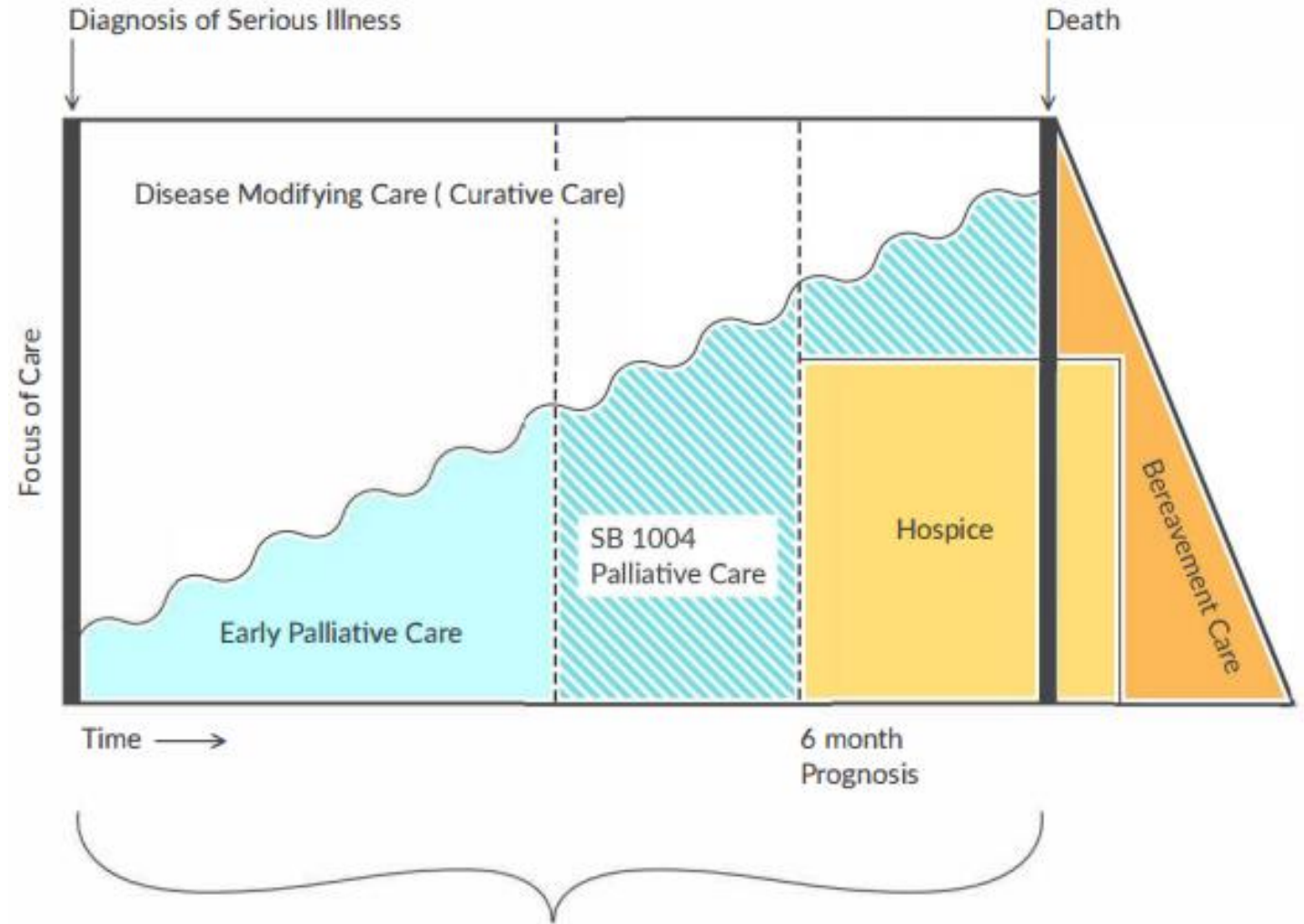
Casey

- 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

Care Model for SB 1004 Medi-Cal Palliative Care



Advance Care Planning can occur at any time, including the POLST* form for those with serious illness.

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