


# Attitudes Toward End-of-Life Care in California



Lake Research Partners  
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# Introduction

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An overwhelming majority of Californians would not want to be kept alive if they were in a coma with no hope of significant recovery, but 25% believe that doctors and nurses should do everything possible to save a patient's life. As California's population ages, these and other questions surround the difficult and sensitive topic of medical care at the end of life (EOL).

This chart book compiles the results of a statewide survey of a diverse group of Californians, along with focus groups held with individuals from various ethnic groups – White, Latino, African-American and Chinese – who have recently lost a loved one. Topics explored include views toward life support, EOL care planning, hospice care, and pain management. These results also highlight cultural differences that affect EOL care and the special concerns minorities may have, including overcoming language and communication barriers between medical staff and family members of those who are dying and finding staff who are sensitive to cultural differences.



## Introduction (continued)

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Among the findings:

- More than 80% of Californians say their loved ones “know exactly” or have a “good idea” of what their wishes would be if they were in a persistent coma, but only 50% say they’ve talked to them about their preferences.
- Eight out of ten people say it is “very” or “somewhat” important to write down EOL wishes, but only 36% actually have written instructions.
- Nearly 40% of families struggled with whether to remove life support from their loved ones, but only 6% of those said there were serious disagreements.
- Views on a patient’s right to die varied significantly by ethnicity, with Whites far more willing to allow a loved one to die than any other ethnic group in the state.



# Methodology

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- Survey of 1,778 Californians age 18+
  - Oversamples of:
    - Californians who have lost a loved one in the past year
    - African-American Californians
    - Mandarin and Cantonese-speaking Chinese Californians\*
- Focus groups with Chinese, Latino, African-American, and White Californians who have lost a loved one in the past year


Data slides: “Chinese” refers to the Mandarin and Cantonese-speaking subset of the Asian population surveyed.



## Summary of Findings I: Most support withholding life-sustaining treatment

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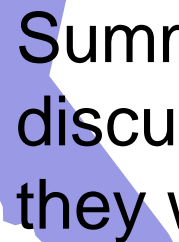
- Most Californians (70%) believe there are circumstances in which patients should be allowed to die. A quarter (27%) believe doctors and nurses should do everything possible to save a patient.
  - California's minority communities are more divided on these issues. Over four in ten Latino (44%) and African-American (44%) Californians, and three in ten Asian Californians (28%), believe everything possible should be done in all circumstances to save a life. Only 14% of White Californians hold this opinion.
- The overwhelming majority of Californians (80%) would *not* want to be kept alive on life support if they were in a coma with no hope of significant recovery.
  - African-American (70%) and Latino (72%) Californians are less likely than Whites (87%) to say they would want life support removed.



## Summary of Findings II: Most report that they have thought about their EOL wishes and that these wishes are known

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- About three-quarters of Californians (73%) say they have given at least some thought to their own wishes for EOL medical treatment.
- The overwhelming majority of Californians (84%) believe that the person they would like to make EOL decisions on their behalf knows their EOL wishes. Over half (55%) feel this person knows their *exact* wishes.
  - Among those who say they, themselves, have given little or no thought to their EOL wishes for medical treatment, the majority (72%) believe their loved one knows their wishes, including 39% who believe this person knows exactly what they want.



## Summary of Findings III: Half say they have discussed their EOL wishes with the person whom they would want to make decisions on their behalf

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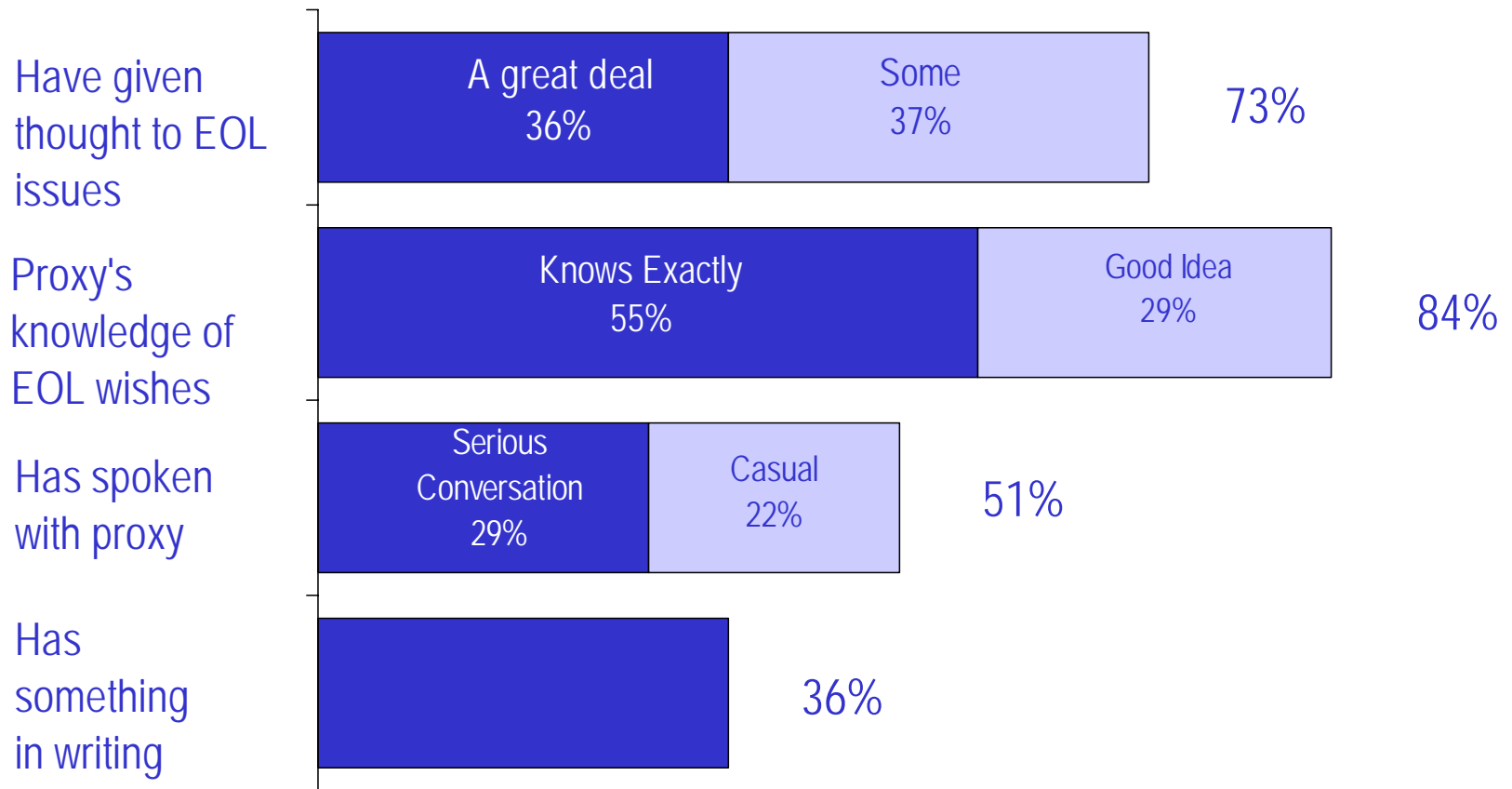
- Fifty-one percent of Californians say that they have talked about EOL issues with the person whom they would want to make decisions on their behalf. In many cases these conversations are casual (19%) – or are even just remarks made in passing (3%) – and incomplete.
- Just over a third of Californians (36%) report that they have their EOL wishes in writing.

*I have not  
spoken about it,  
but I've thought  
about it.*


-Latino Caregiver  
(focus group)



# Summary of Findings IV: A graphic view of Californians' EOL Preparation








## Summary of Findings V: Group differences on advance care planning

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- In general, California's minority communities have done less advanced care planning than Whites.
  - Latino and Asian Californians tend to be less comfortable talking about death and dying, and have given less thought to their wishes for EOL medical treatment.
  - Latino, Asian, and African-American Californians are less likely to say their loved one knows their wishes, to have talked with their loved ones about EOL wishes, and to have something in writing.
- Recent loss of a loved one does make people more likely to engage in advance care planning. However, even among those who lost a loved one in the past year, roughly four in ten have not talked with their loved one about their own EOL wishes and only 42% have their own EOL wishes in writing.



## Summary of Findings VI: Advance care planning experience among those with recent EOL experience

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- Among those who have lost a loved one in the past 12 months, two-thirds (67%) say they knew their loved one's EOL wishes to some extent, 39% knew them exactly.
  - Among those who played a major caregiving and decision making role, 86% knew their loved one's wishes, 61% knew them exactly.
- Only a third (32%) of those who lost a loved one say they had specifically discussed their loved one's EOL wishes.
  - Among those who played a major role, only four in ten (41%) say they specifically discussed EOL wishes.
- Four in ten (38%) report that their loved one had EOL wishes in writing.



## Summary of Findings VII: Honoring EOL wishes

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- Most believe (78%) their loved one's EOL wishes were followed; half (52%) feel they were completely followed and honored.
- Over a third (37%) report that issues about withholding or withdrawing life-sustaining treatment arose. In a small minority of these cases (6%), serious disagreement arose among family members.
- A quarter of Californians (27%) believe the state's health care system does a fair or poor job of making sure dying people's wishes about their medical care are followed.



## Summary of Findings VIII: Pain and pain control

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- Two-thirds of Californians (68%) say that when they think about death and dying they are concerned about pain and discomfort, including four in ten (39%) who are *very* concerned.
  - African-American (79% concerned, 56% *very* concerned) and Asian (79%, 47%) Californians are particularly concerned about pain.
- A quarter of Californians (27%) believe their health care system does only a fair (19%) or poor (8%) job of making sure dying people are as pain free and comfortable as possible.
  - African-American (37%) and Latino (33%) Californians are more likely than other groups to feel the state's health care system does an inadequate job of pain control.



## Summary of Findings IX: Pain and pain control (continued)

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- Among those who lost a loved one in the past year, six in ten (60%) say their loved one was in some physical pain; a third (33%) say their loved one was in *a great deal* of pain.
  - African-American (67% were in some amount of pain, including 45% in a great deal of pain) and Latino (63%, 36%) Californians report their loved ones experienced higher levels of pain. (Percentages reflect only those who answered the question, not the total population surveyed.)
- Most respondents (81%) say their loved one's health care providers did all they could to alleviate pain.



## Summary of Findings X: Low levels of knowledge, but positive opinions of hospice

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- Though the majority of Californians (71%) have heard of hospice care, only a quarter (32%) know *a lot* about it.
  - Older Californians, Whites, and those of higher economic levels report more familiarity with hospice than others.
- Among those who have heard of hospice care, the majority (81%) have a positive opinion of it, including 51% who are very positive.
  - White Californians have the most positive views of hospice. Minority Californians have positive views of hospice, but are less likely to characterize their views as *very positive*.



## Summary of Findings XI: Over a third of Californians report their loved one received hospice care

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- Over a third of Californians (37%) report their loved one received hospice care.
  - This number is likely to be inflated due to lack of knowledge about hospice care.
  - Whites, and those of higher socio-economic status, are more likely to report that their loved one received hospice care.
- Ninety percent of those whose loved one received hospice care report positive views of hospice; 74% say their views are *very* positive.
- Those whose loved one received hospice care gave higher ratings than others to many aspects of their loved one's care.



## Summary of Findings XII: Minorities have special concerns

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- Half (51%) of African-American and 46% of Latino Californians give the state's health care system a rating of fair or poor in terms of the treatment it provides to dying people. By comparison, a third (34%) of White Californians give such a low rating.
- Two-thirds (65%) of African-American and 60% of Mandarin or Cantonese-speaking Chinese Californians are very concerned about "finding health care providers who will understand and respect their cultural beliefs and values."
- African-American Californians were more likely than Whites to report that their loved one died in the hospital (65% vs. 43%).
- White Californians (41%) are more likely than Latino (32%) or African-American (21%) Californians to say their loved one received hospice care.





## Summary of Findings XIII: Minorities have special concerns (continued)

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- African-American and Latino Californians give slightly lower ratings to their loved one's overall care, and the cultural sensitivity of their providers. They are also more likely to report communication and language barriers.
- 45% of African-American Californians report that their loved one died in a great deal of pain, compared to 28% of Whites.
- A quarter (27%) of Latino Californians feel that their loved one's provider did not do everything they could to alleviate their loved one's pain, compared to 15% of White Californians.
- African-American Californians are less likely than Whites to feel that their loved one's EOL wishes were followed (62% vs. 83%).

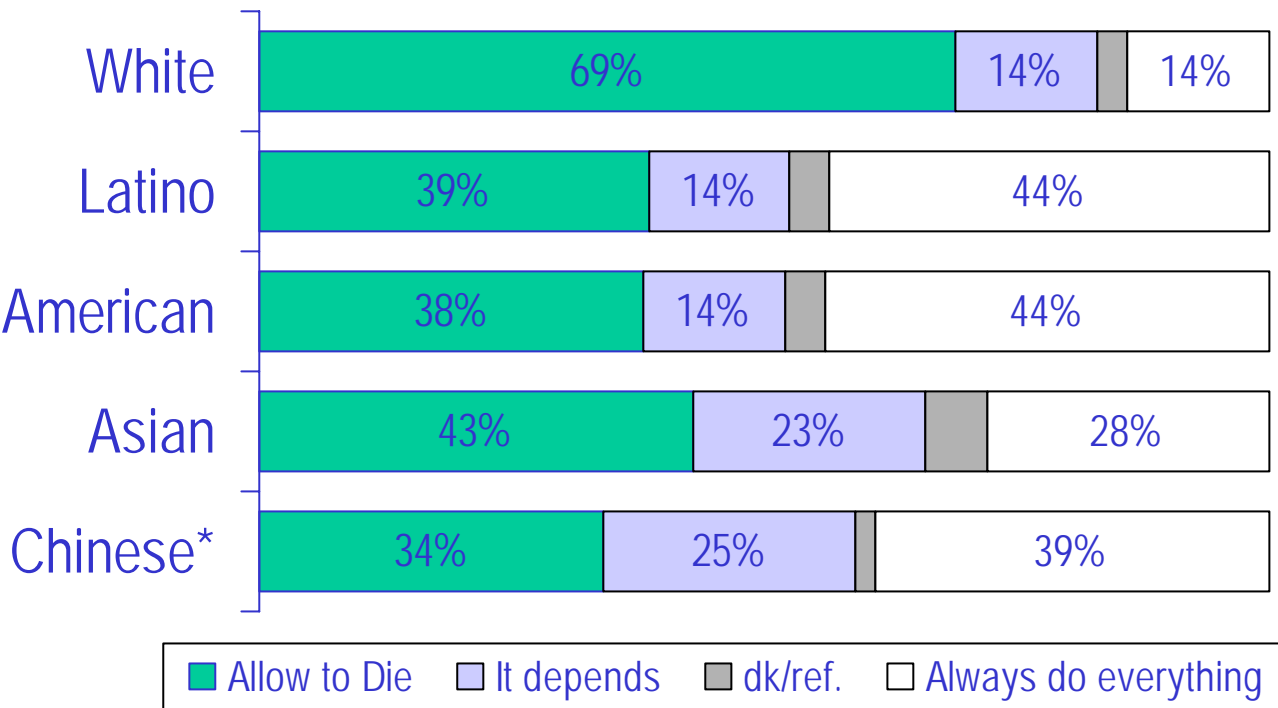


# General Knowledge and Attitudes



# Attitudes about Allowing Patients to Die Vary Widely by Race/Ethnicity

Feelings about Letting Patients Die vs. Doing Everything to Save a Life

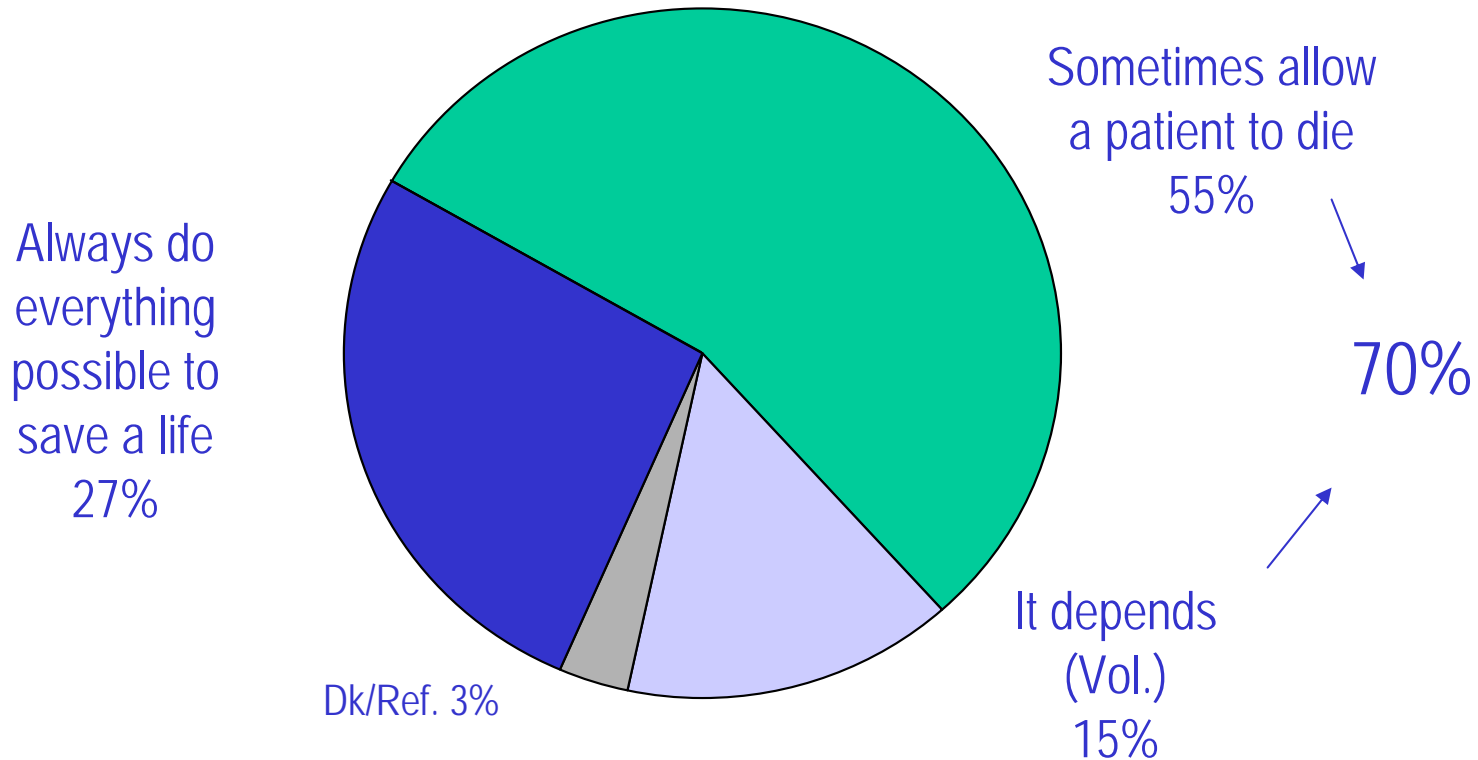


\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# Most Californians Believe Patients Should Be Allowed to Die in Certain Circumstances

Which comes closer to your view?



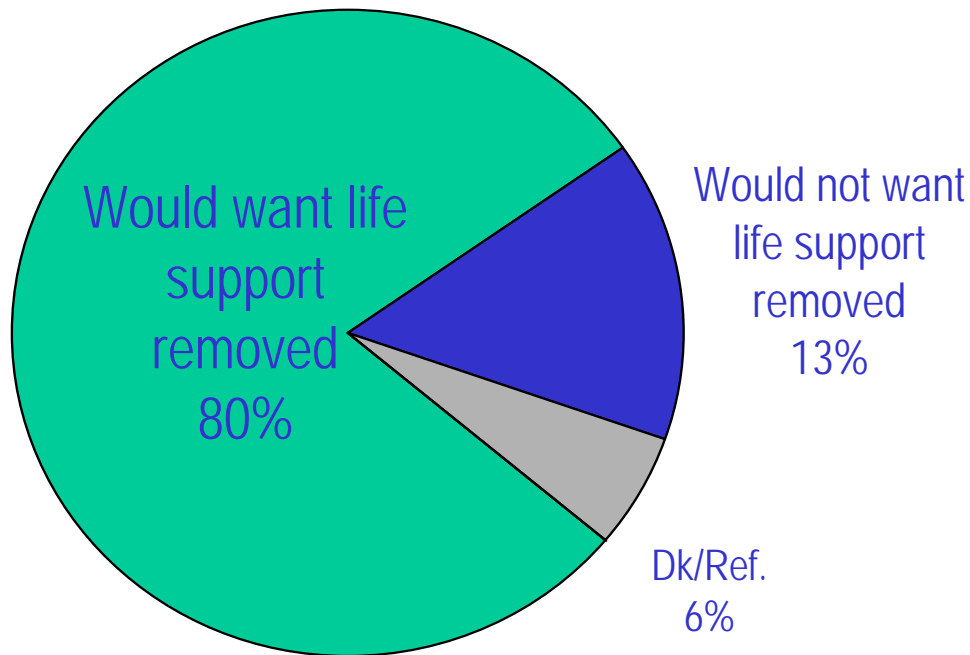


# Most Would Prefer Life Support Be Removed if No Hope for Significant Recovery

*My husband and I talked, and I told him that I don't want to be put on a machine if I'm going to die. If I'm going to die let me go. Don't try and save me for a reason that's ridiculous because you want me there, because that isn't fair to me, and I want to die with dignity. Just let me go in peace.*

-White Caregiver  
(focus group)

If you were in a persistent coma with no hope for significant recovery....

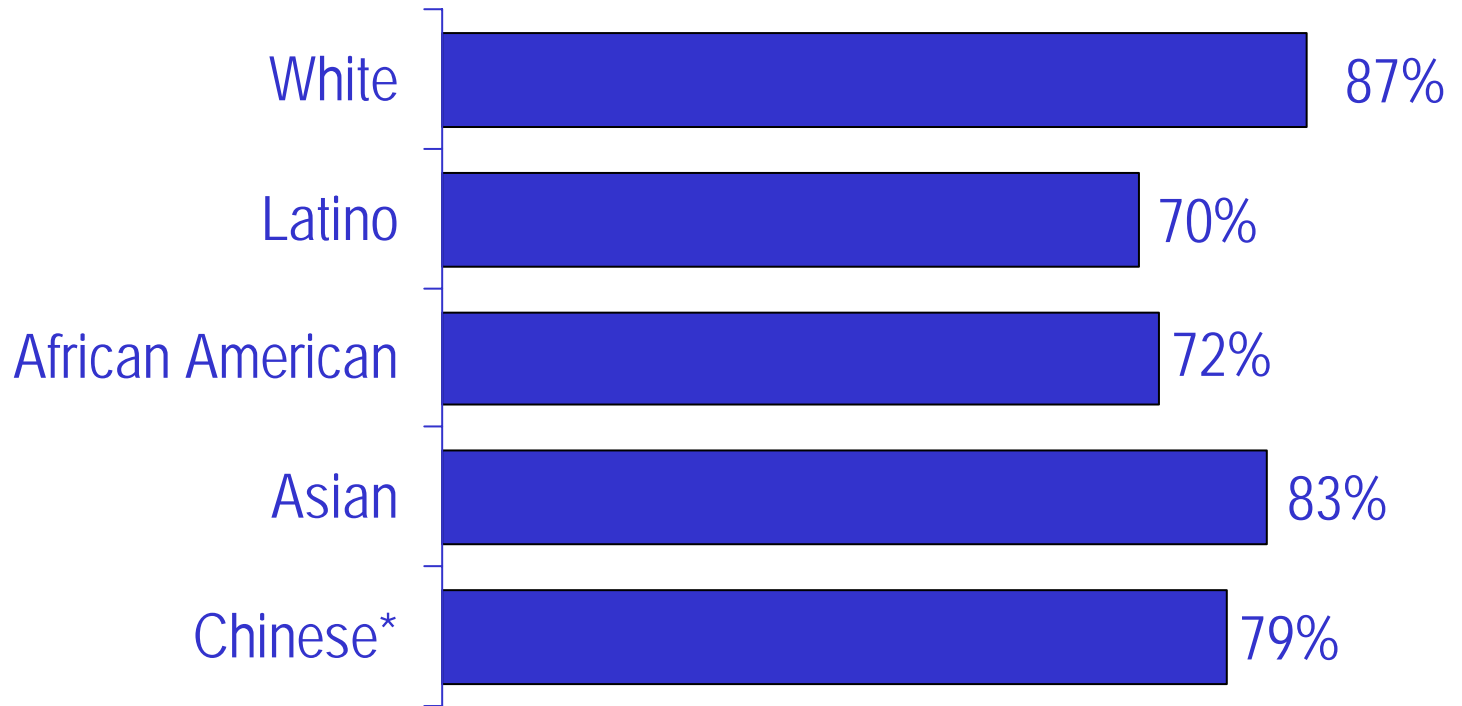




# Attitudes about Life Support Removal Vary by Race/Ethnicity

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## Would Want Life Support Removed



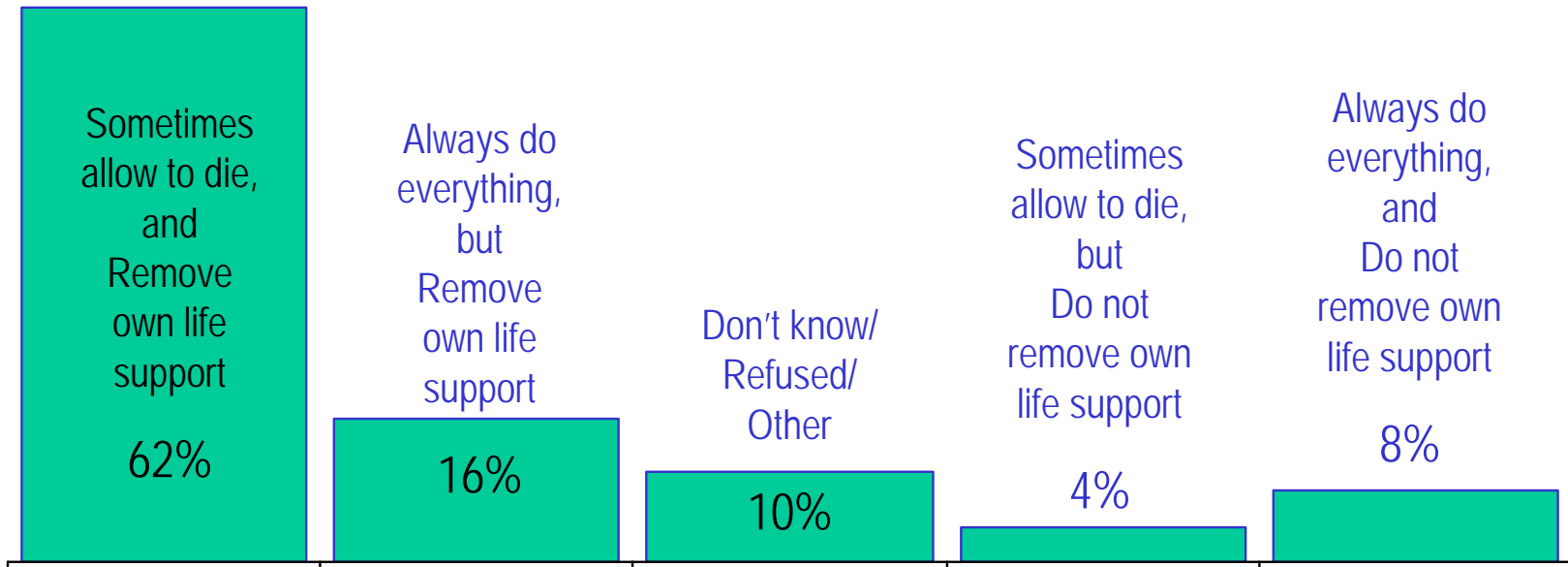
\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# Difference Between Personal Choice and Choice for Others

Q: Which comes closer to your view? In all circumstances, doctors and nurses should do everything possible to save the life of a patient. OR, sometimes there are circumstances where a patient should be allowed to die?

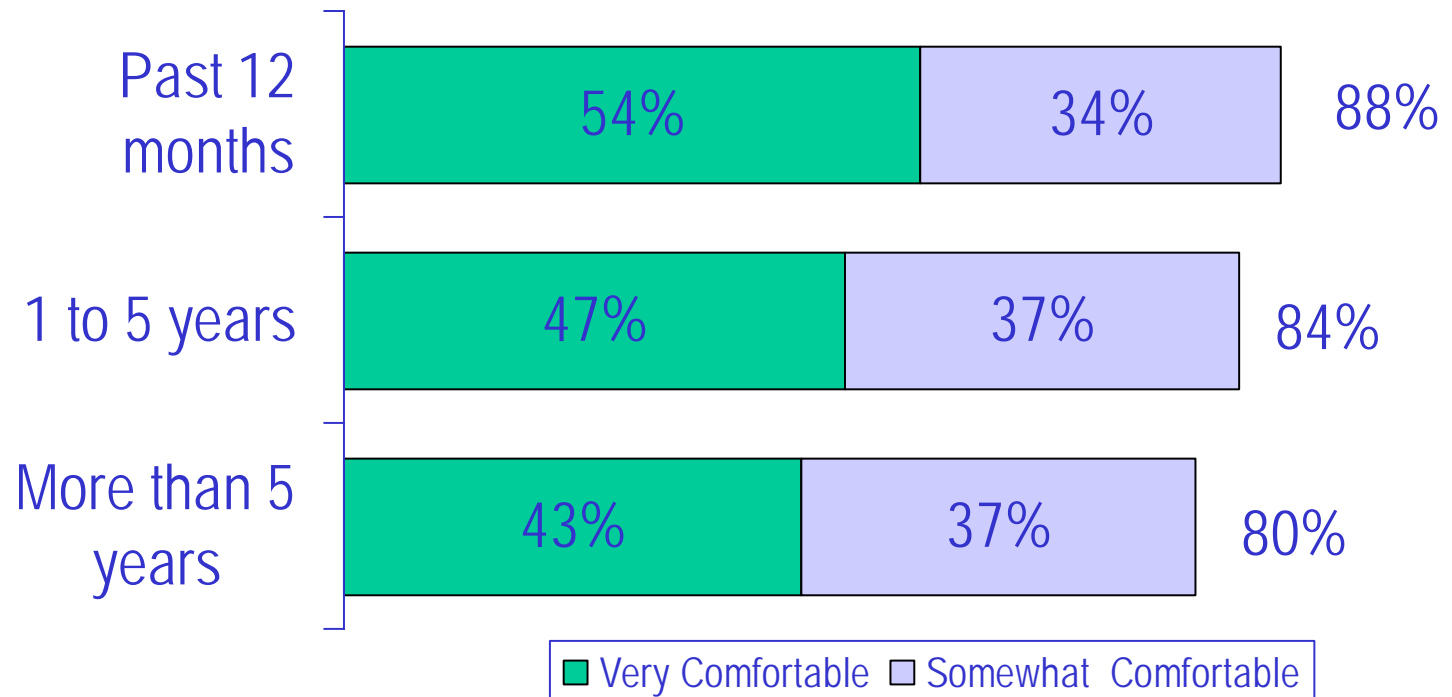
Q: If you, personally, were in a persistent vegetative state or a coma with no hope for significant recovery, would you want to have your life support removed or not?





# Experience Increases Comfort with Talking about Death and Dying

Comfort Level with Talking about Death,  
by Most Recent Loss of a Loved One

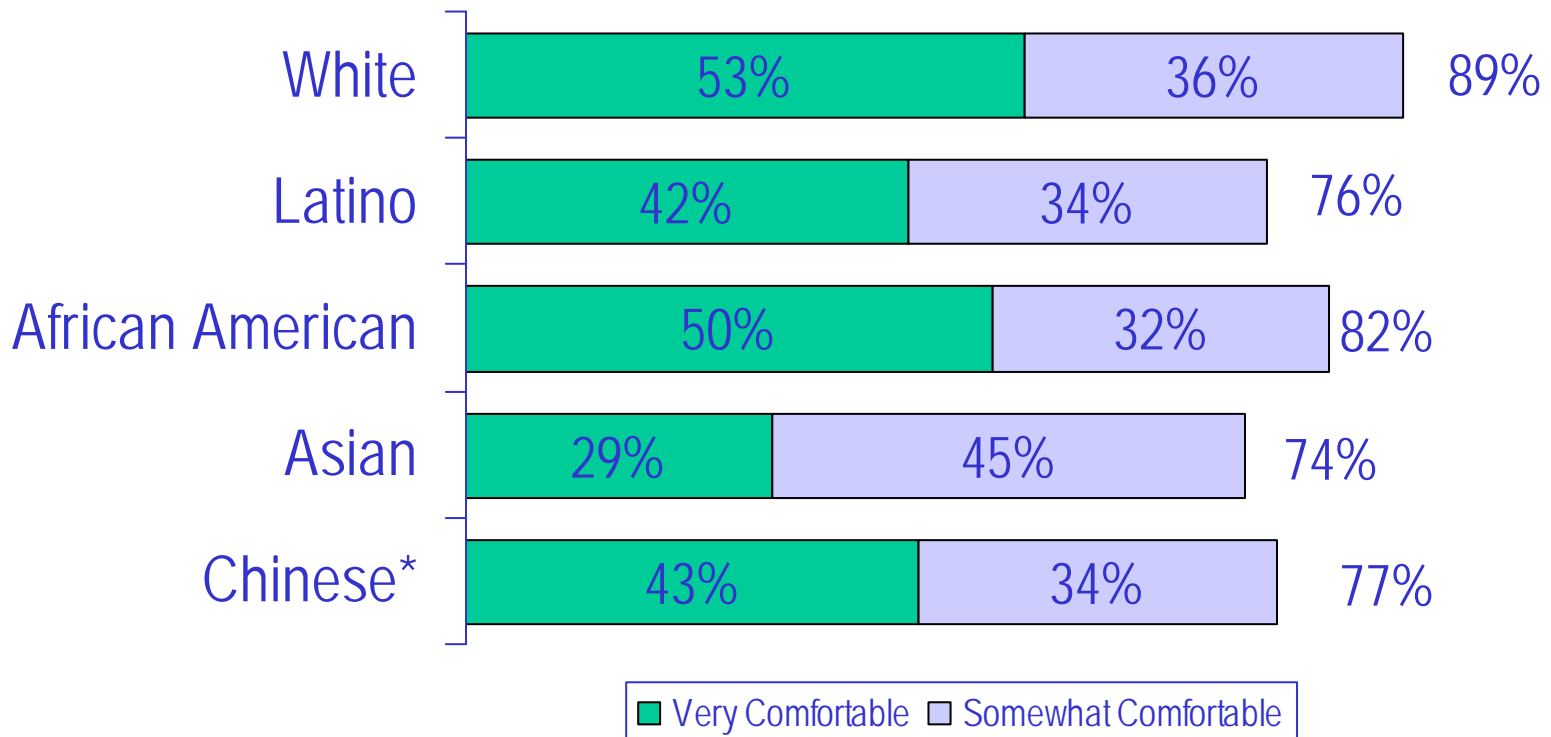






# White and African-American Californians Are Most Comfortable Talking about Death and Dying

Comfort Level with Talking about Death,  
by Race/Ethnicity

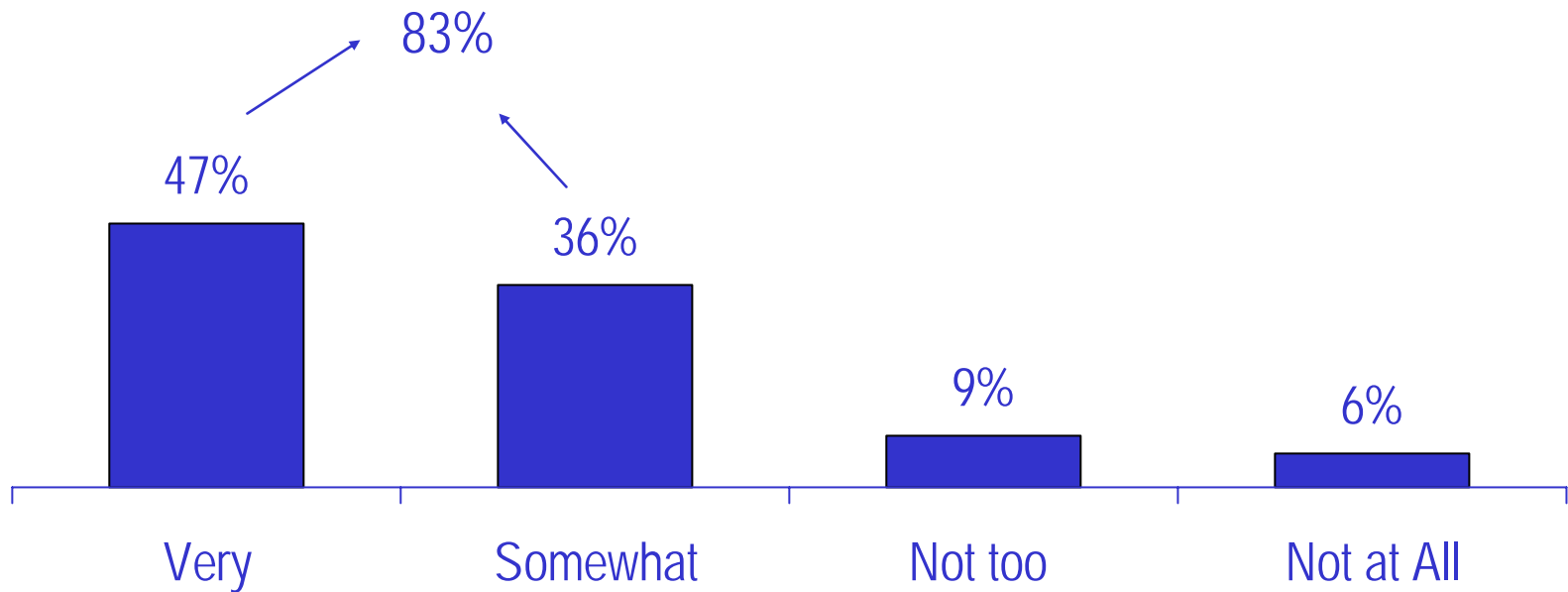


\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# Majority Says They Are at Least Somewhat Comfortable Talking About Death and Dying

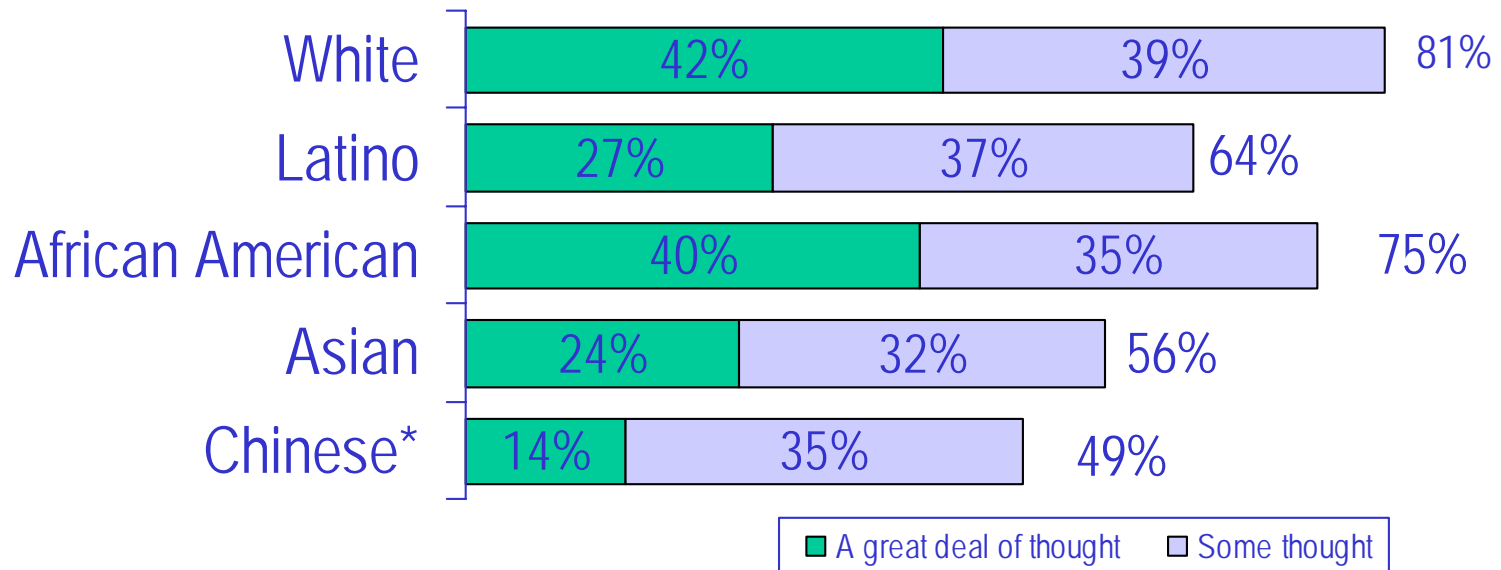
How comfortable are you talking about death and dying?





# White and African-American Californians Are More Likely Than Others to Have Thought about Own Medical Treatment Decisions

Thoughts About Treatment Wishes,  
by Race/Ethnicity



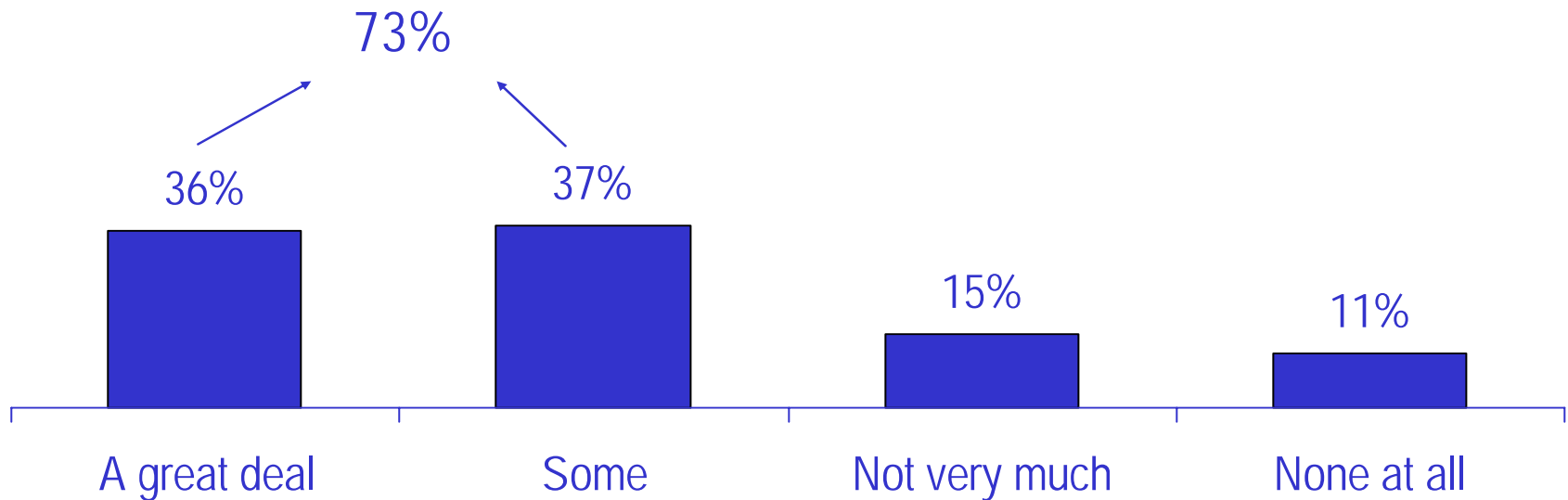
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## Three-quarters Have Given Thought to Their Wishes for Medical Treatment

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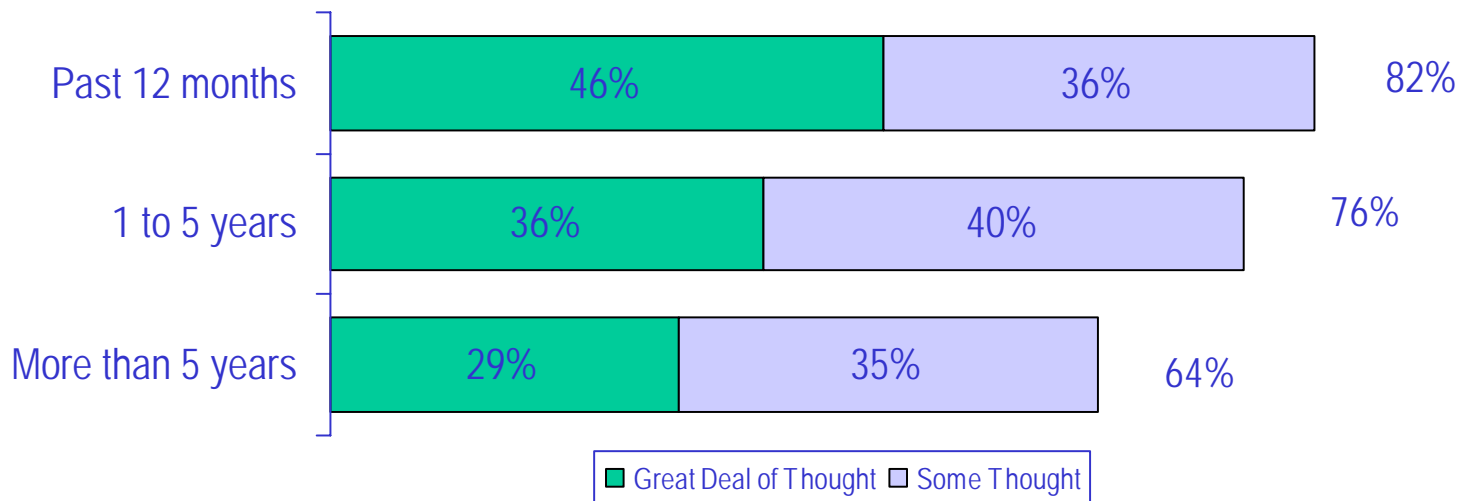
How much have you thought about your wishes for medical treatment?





# Those Who Have Lost a Loved One are More Likely to have Thought about Their Own EOL Wishes for Medical Treatment

Thought About Own Treatment Wishes,  
by Most Recent Loss of a Loved One





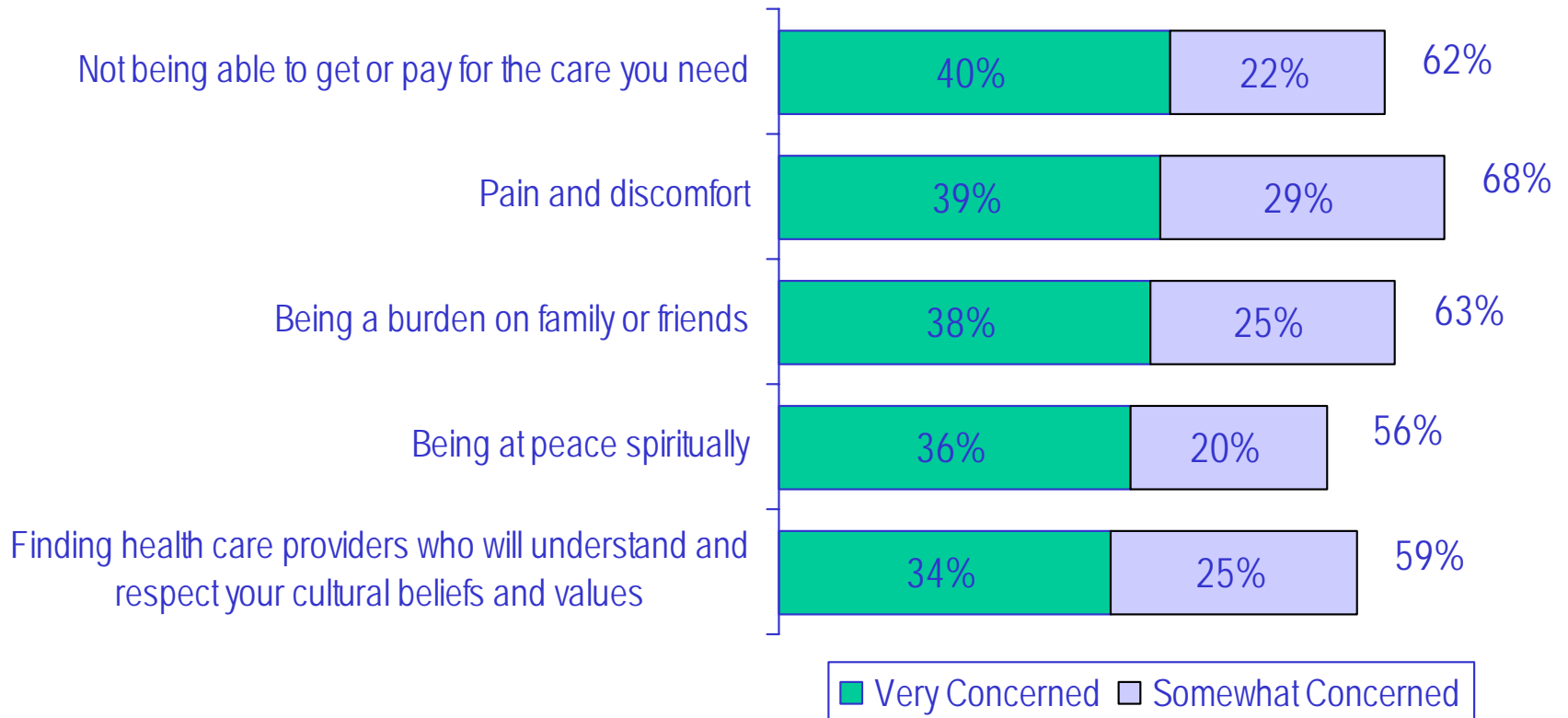
# Different Groups Have Different Concerns – and Levels of Concern – about Death and Dying

	White	Hispanic	African-American	Asian	Chinese*
1.	Pain and Discomfort 36%	Not Being Able to Afford the Care You Need 46%	Finding Providers who Respect Your Culture 62%	Not Being Able to Afford the Care You Need 50%	Not Being Able to Afford the Care You Need 72%
2.	Being a Burden on Family and Friends 35%	Being at Peace Spiritually 40%	Being at Peace Spiritually 60%	Pain and Discomfort 47%	Being a Burden on Family and Friends 68%
3.	Not Being Able to Afford the Care You Need 33%	Being a Burden on Family and Friends 39%	Not Being Able to Afford the Care You Need 59%	Being a Burden on Family and Friends 44%	Pain and Discomfort 61%
4.	Being at Peace Spiritually 32%	Pain and Discomfort 38%	Pain and Discomfort 56%	Finding Providers who Respect Your Culture 37%	Finding Providers who Respect Your Culture 60%
5.	Finding Providers who Respect Your Culture 30%	Finding Providers who Respect Your Culture 35%	Being a Burden on Family and Friends 54%	Being at Peace Spiritually 33%	Being at Peace Spiritually 40%

\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



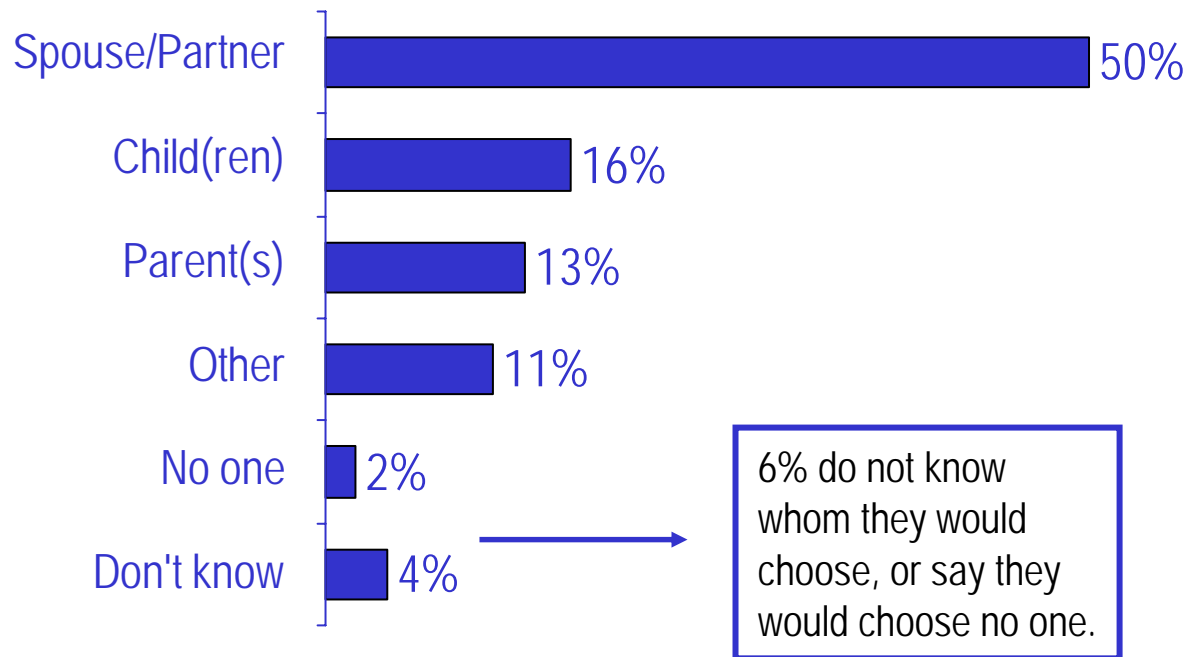
# Concerns about Death and Dying





# Half Would Want Their Spouse/Partner to Make Decisions on Their Behalf

Whom would you want to make decisions for you if you could not?

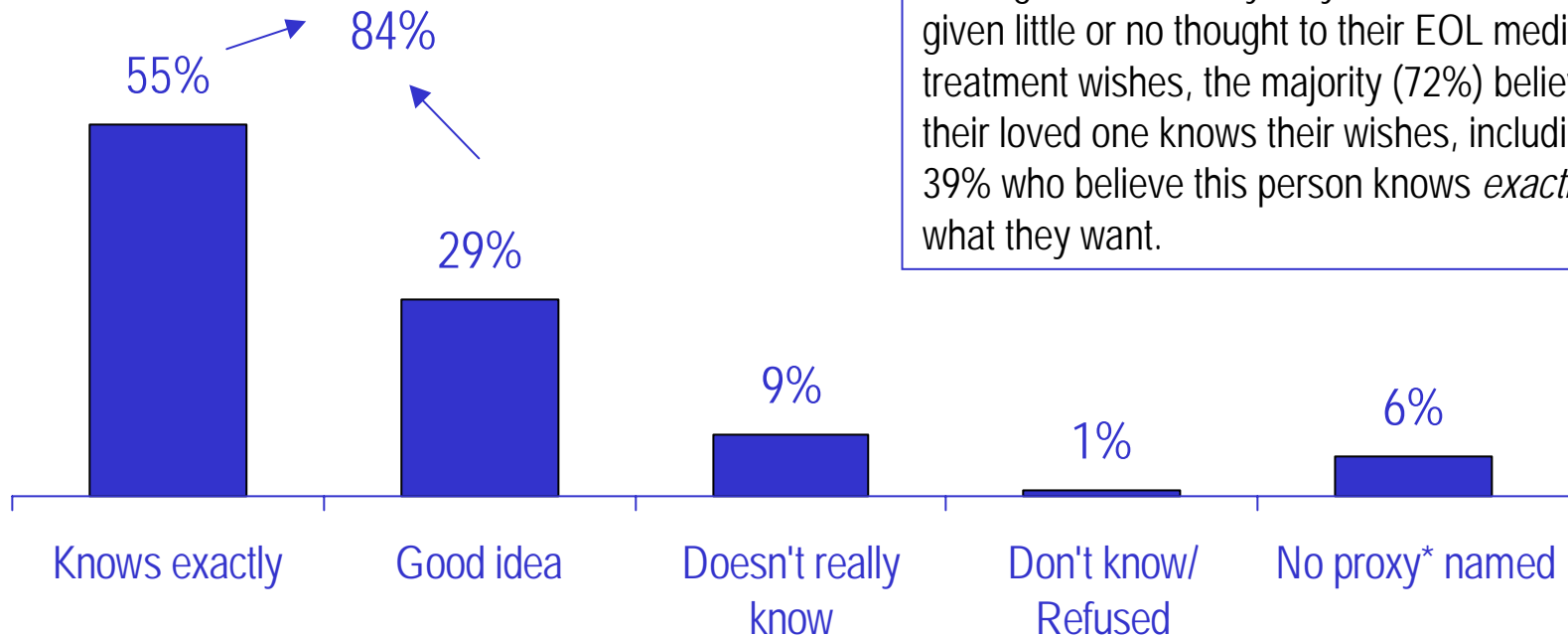






# Most Say Their EOL Treatment Wishes Are Known

How well does this person know your wishes for end-of-life treatment?

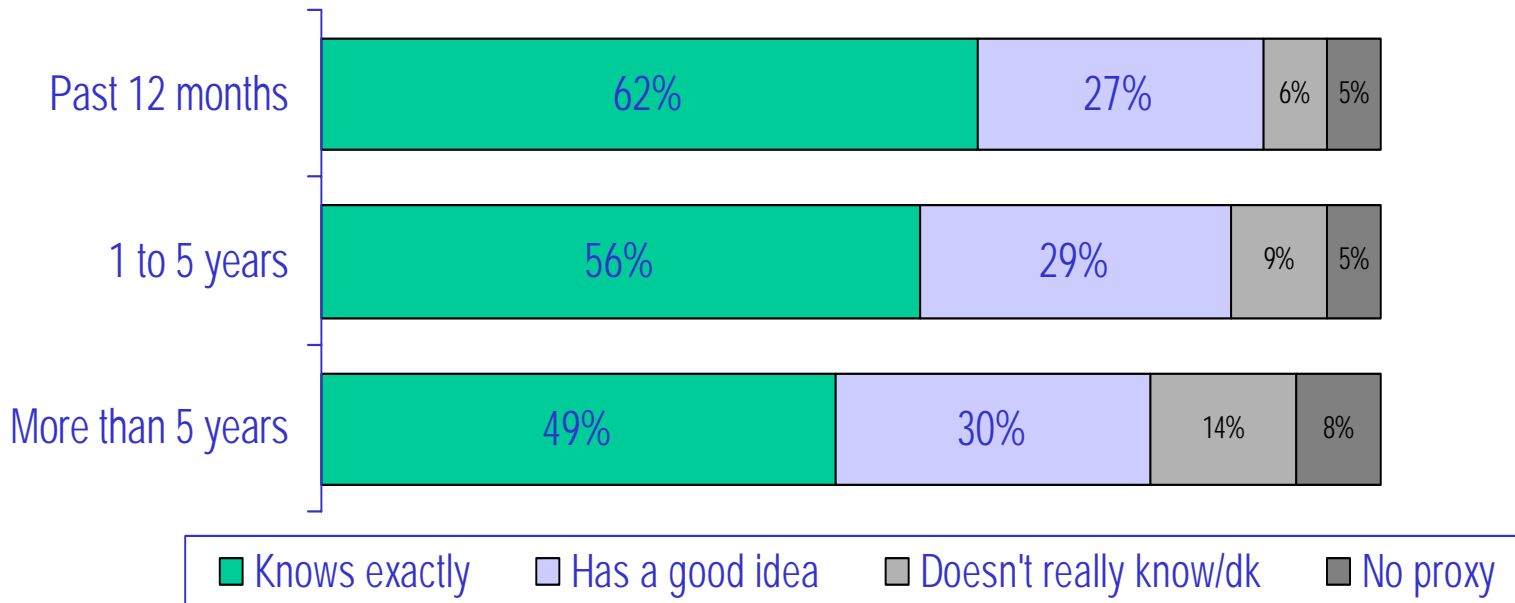


\*Proxy: Not used in the legal sense, it includes any relatives or friends named by respondents who would make medical decisions for them.



# Those with Recent EOL Experience Are More Likely to Say Their Wishes Are Known

## How Well Proxy\* Knows Wishes, by Most Recent Loss of a Loved One

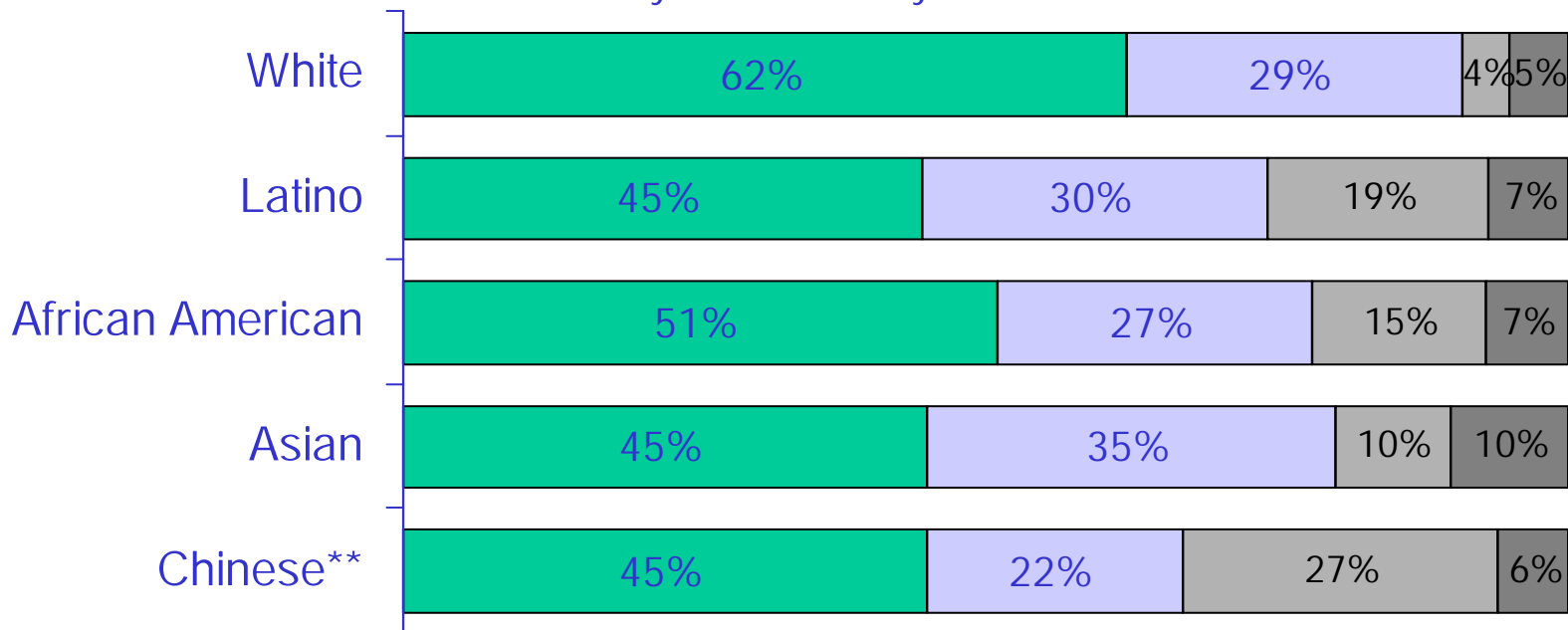


\*Proxy: Not used in the legal sense, it includes any relatives or friends named by respondents who would make medical decisions for them.



# White Californians Are More Likely to Say Their Wishes Are Known

## How Well Named Proxy\* Knows Wishes, by Race/Ethnicity



■ Knows exactly    ■ Has a good idea    ■ Doesn't really know/dk    ■ No proxy

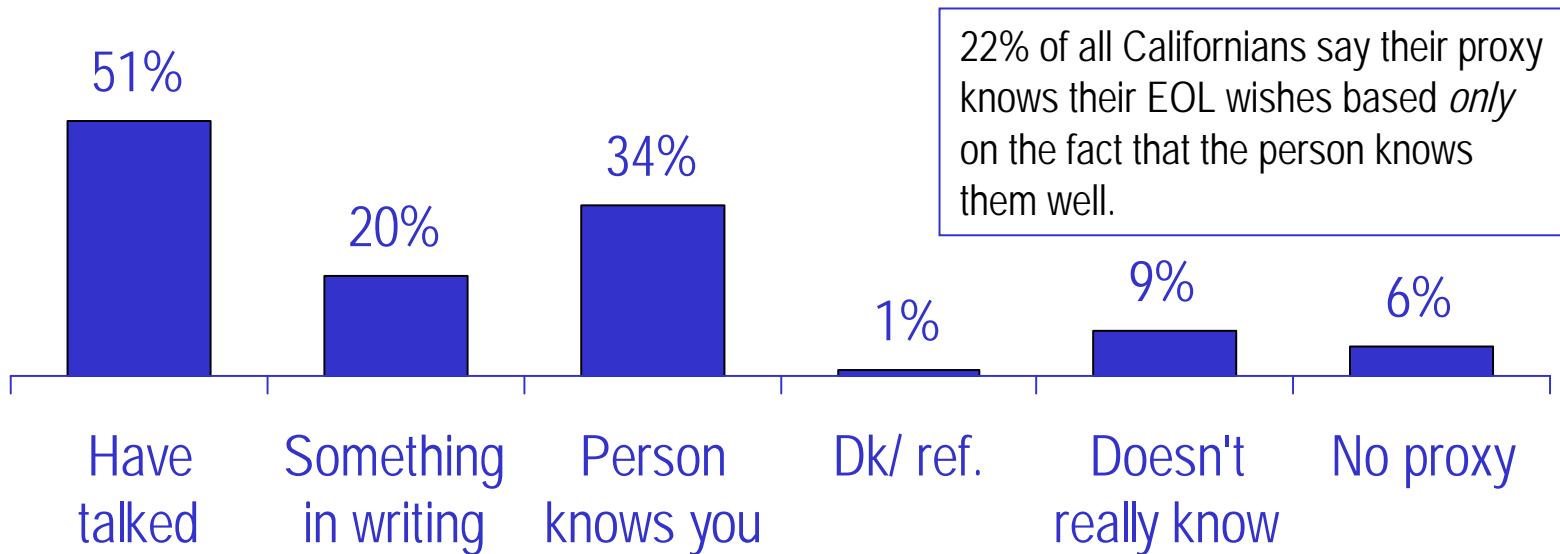
\*Proxy: Not used in the legal sense, it includes any relatives or friends named by respondents who would make medical decisions for them.

\*\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# Half Say EOL Wishes Are Known Through Conversation, Some Feel Just Knowing a Person Is Enough

How does your proxy\* know your wishes for end-of-life medical treatment?  
(multiple responses accepted)

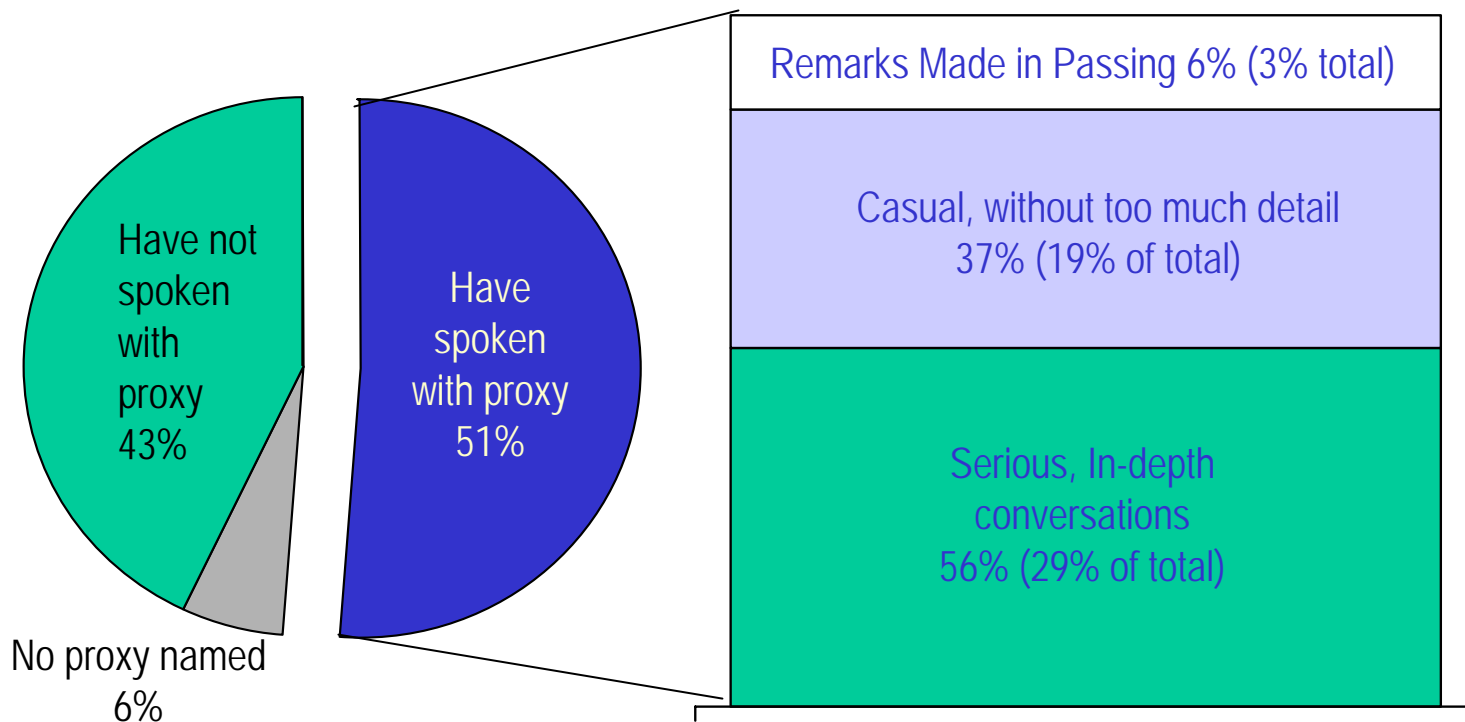


\*Proxy: Not used in the legal sense, it includes any relatives or friends named by respondents who would make medical decisions for them.



# Conversations about EOL Treatment Are Sometimes Informal

How would you describe these conversations? (with proxy\*)

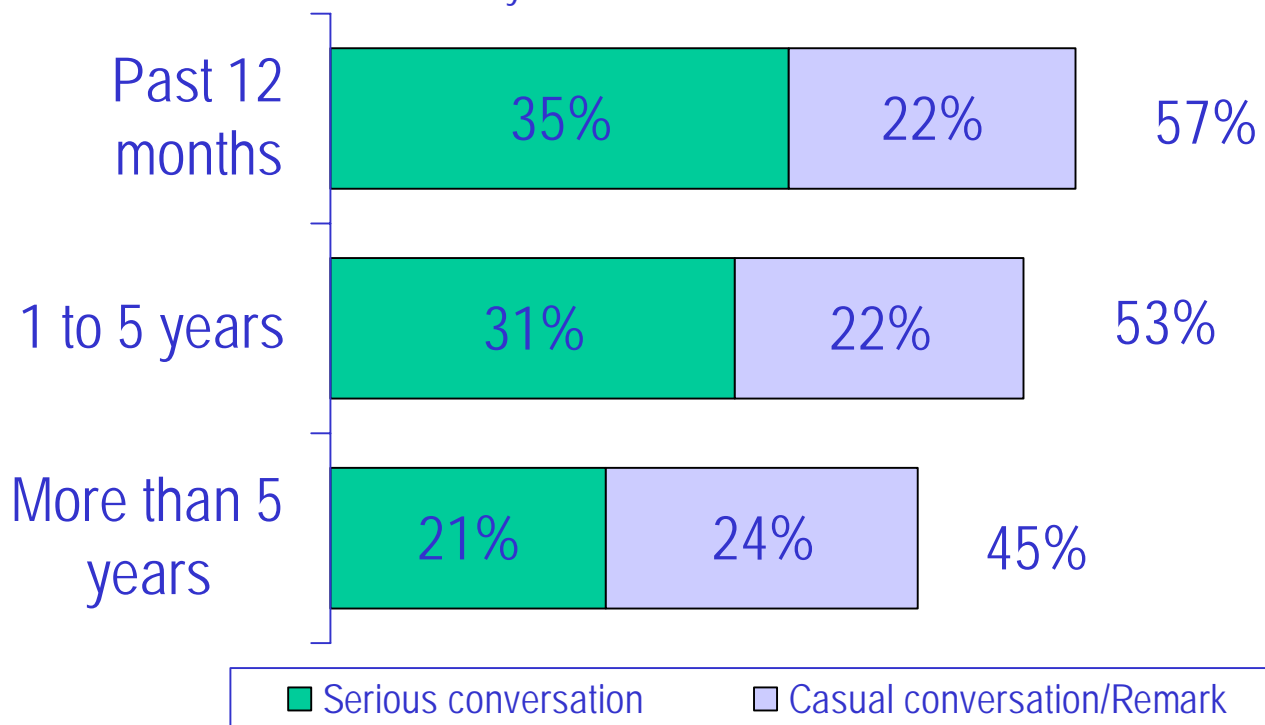


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# Loss of Loved One May Trigger Respondents' EOL Conversations with Others

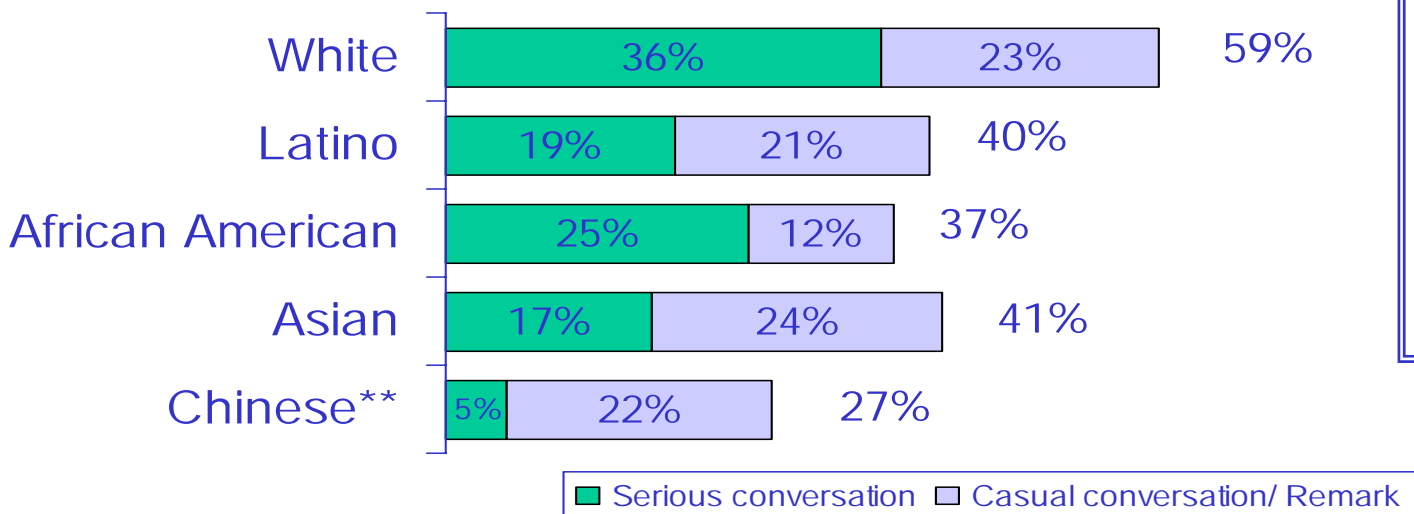
Conversations about EOL Wishes,  
by Most Recent Loss of a Loved One





# White Californians Are More Likely Than Others to Have Discussed EOL Medical Treatment Decisions with Their Proxy\*

Conversations about EOL Wishes,  
by Race/Ethnicity



*I make a joke of it, because I just don't want to accept it.*

-Latino Caregiver (focus group)

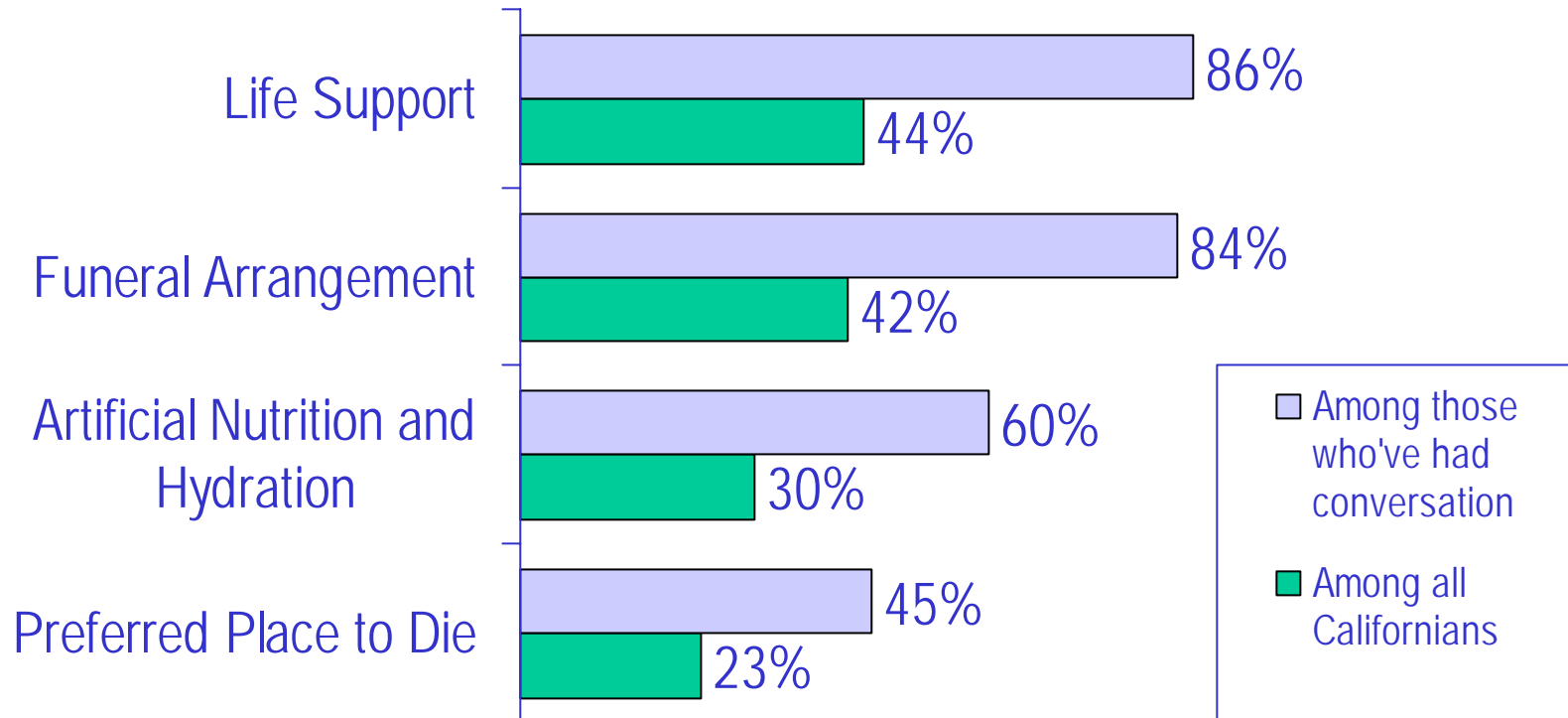
\*Proxy: Not used in the legal sense, it includes any relatives or friends named by respondents who would make medical decisions for them.

\*\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# EOL Conversations Cover Some Topics More Than Others

Topics Covered in EOL Conversations





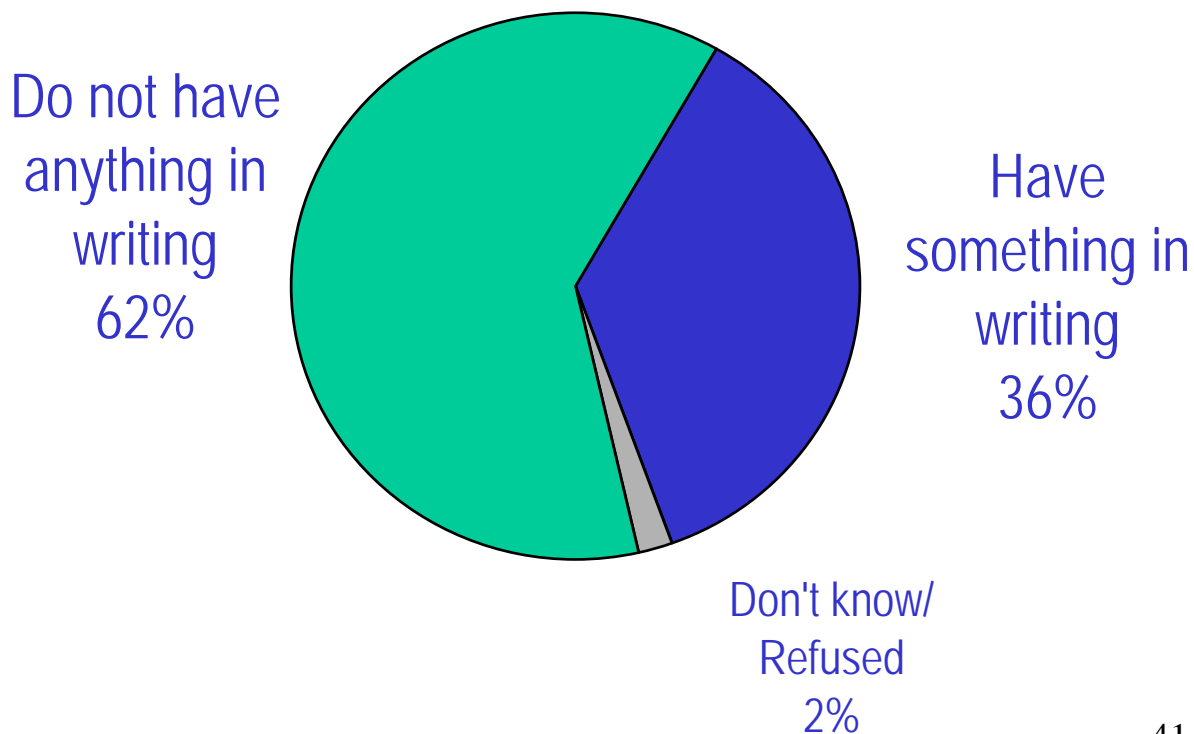


# Just Over a Third Have Their EOL Wishes in Writing

Do you have your end-of-life wishes for medical treatment in a written document?

*I still tell people all the time [to fill out an advance directive]. And interestingly enough, I haven't signed one myself. I take them to other people.*

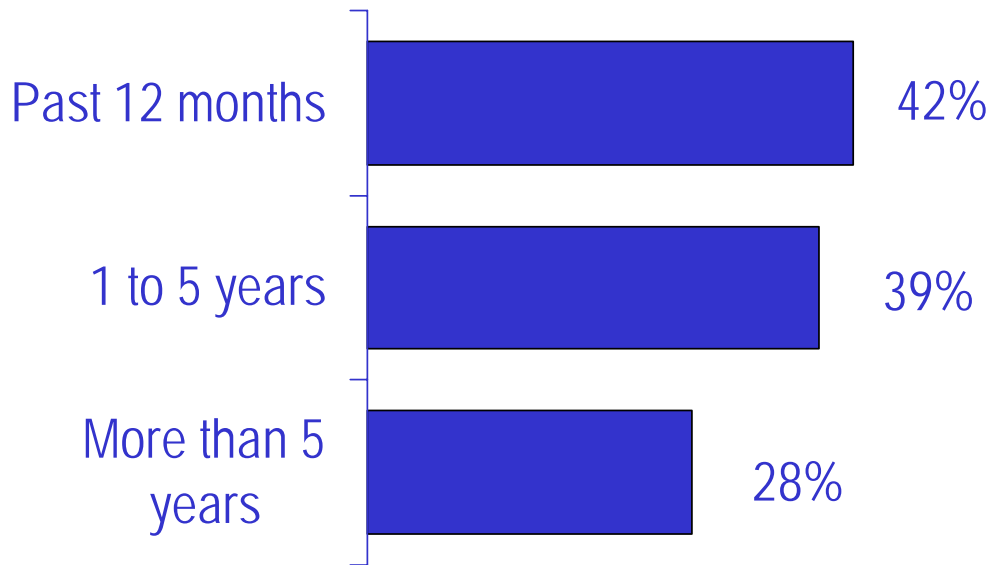
-African-American Caregiver (focus group)





# Those with Recent EOL Experience Are Somewhat More Likely to Have Something in Writing, Although Less than Half Do

Have EOL Wishes in Writing,  
by Most Recent Loss of a Loved One



*You just don't want to do it. You keep putting it off.*

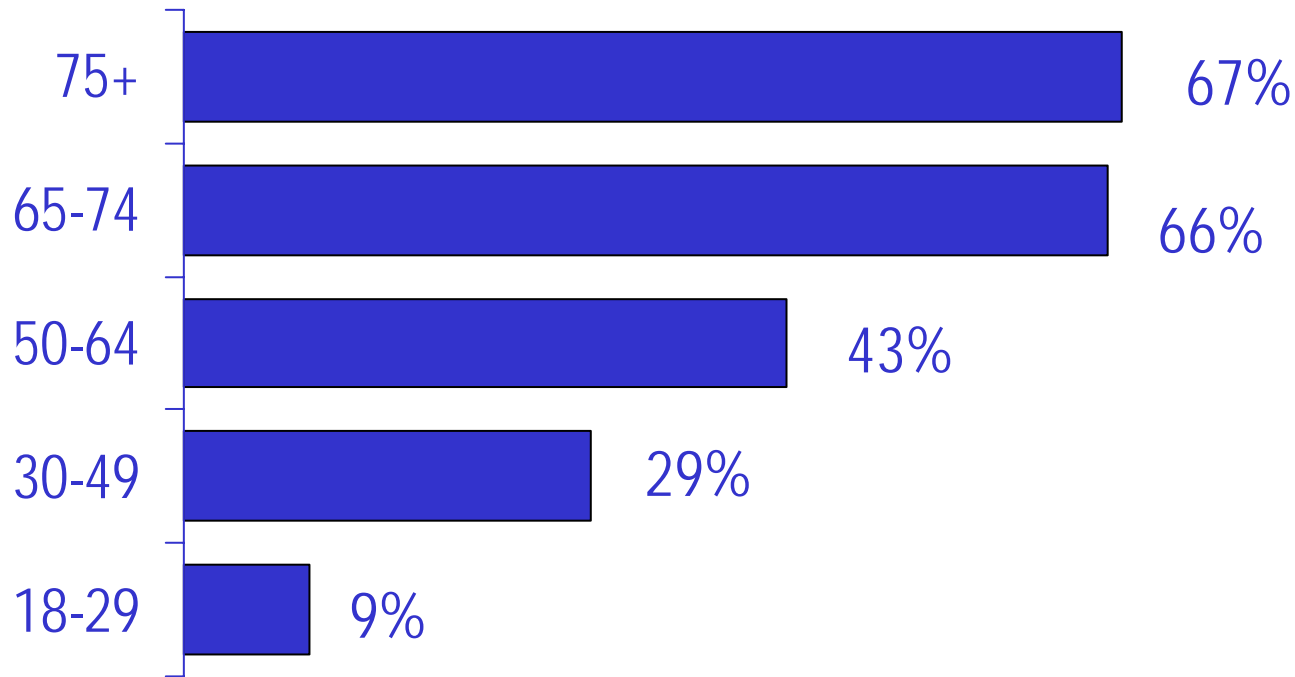
-African-American Caregiver (focus group)



# Likelihood of Having EOL Wishes in Writing Differs Widely by Age

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Have EOL Wishes in Writing,  
by Age

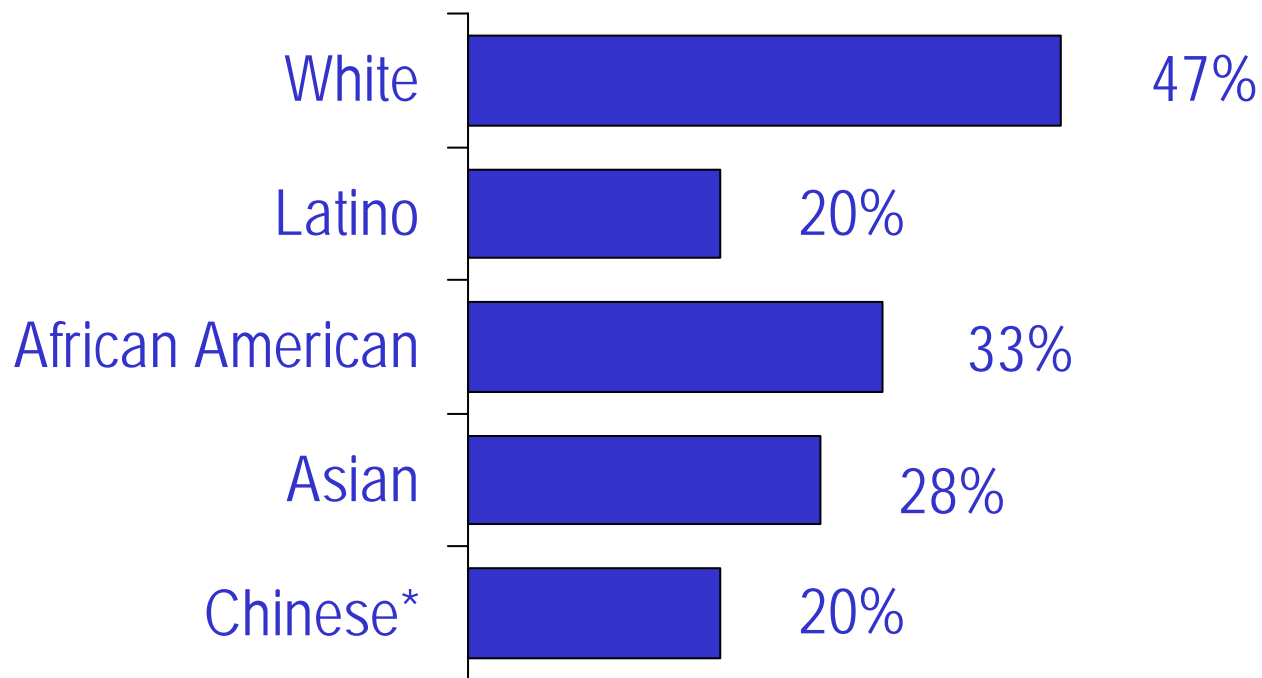




# Whites Are More Likely Than Others to Have Something in Writing

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Have EOL Wishes in Writing,  
by Race/Ethnicity

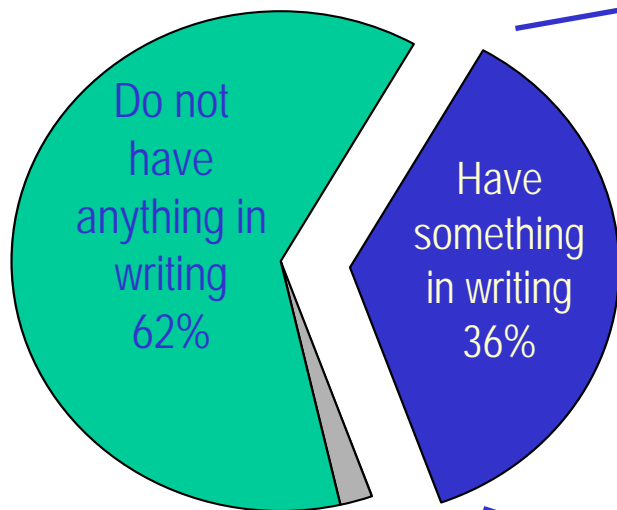


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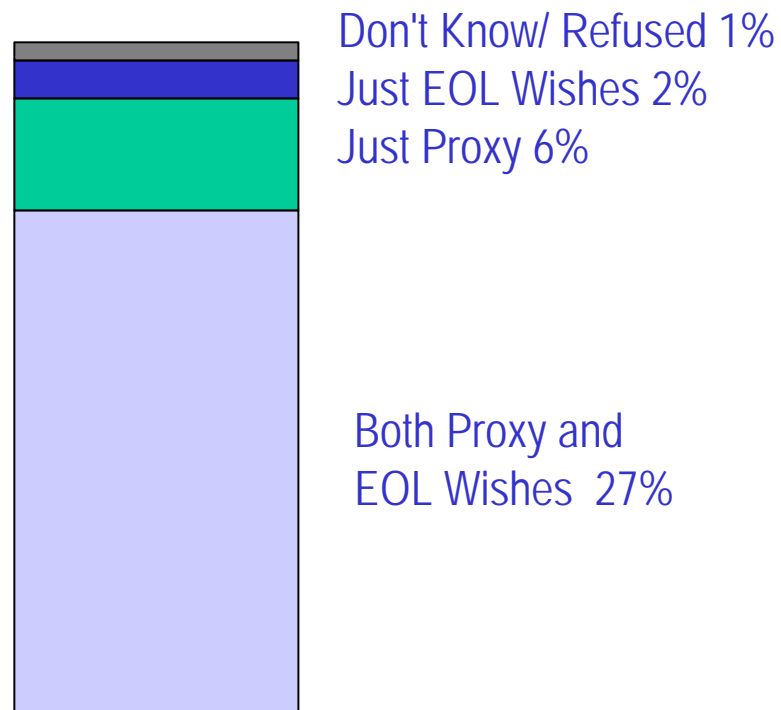


# Most Advance Directives Cover Both Proxy\* and EOL Wishes

EOL Wishes in Writing



Document Covers

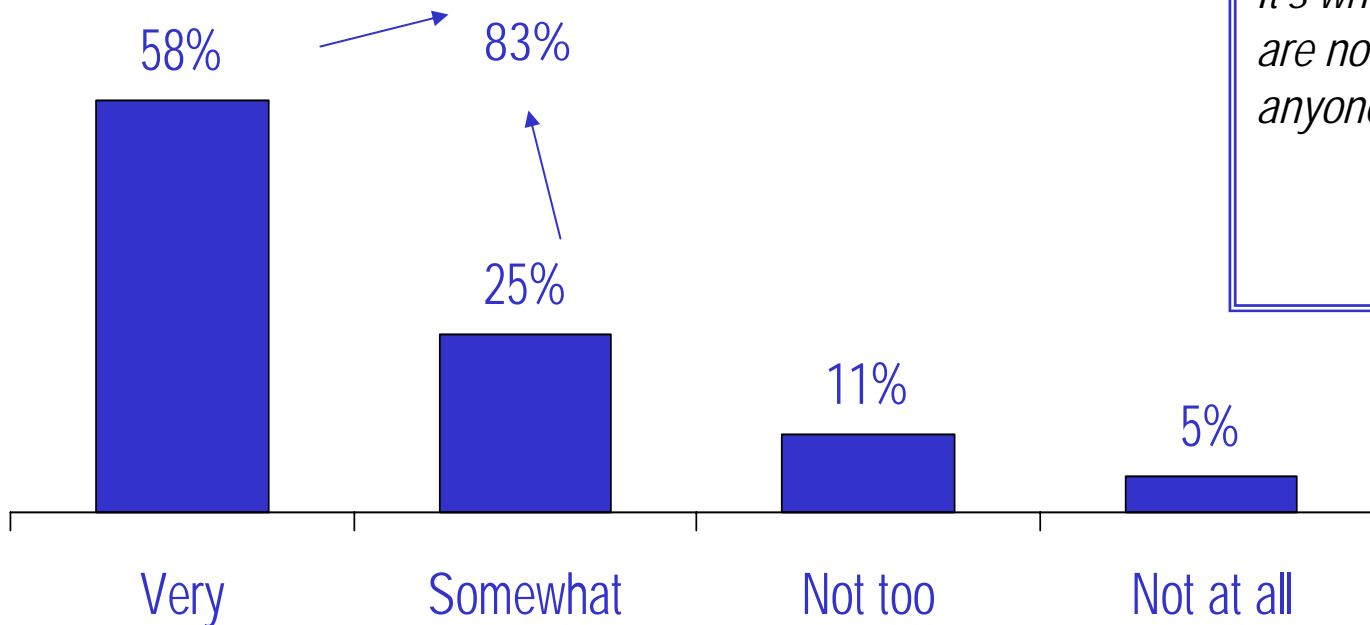


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# Most Believe Having Something in Writing Is Important

How important is it for you to have something in writing?



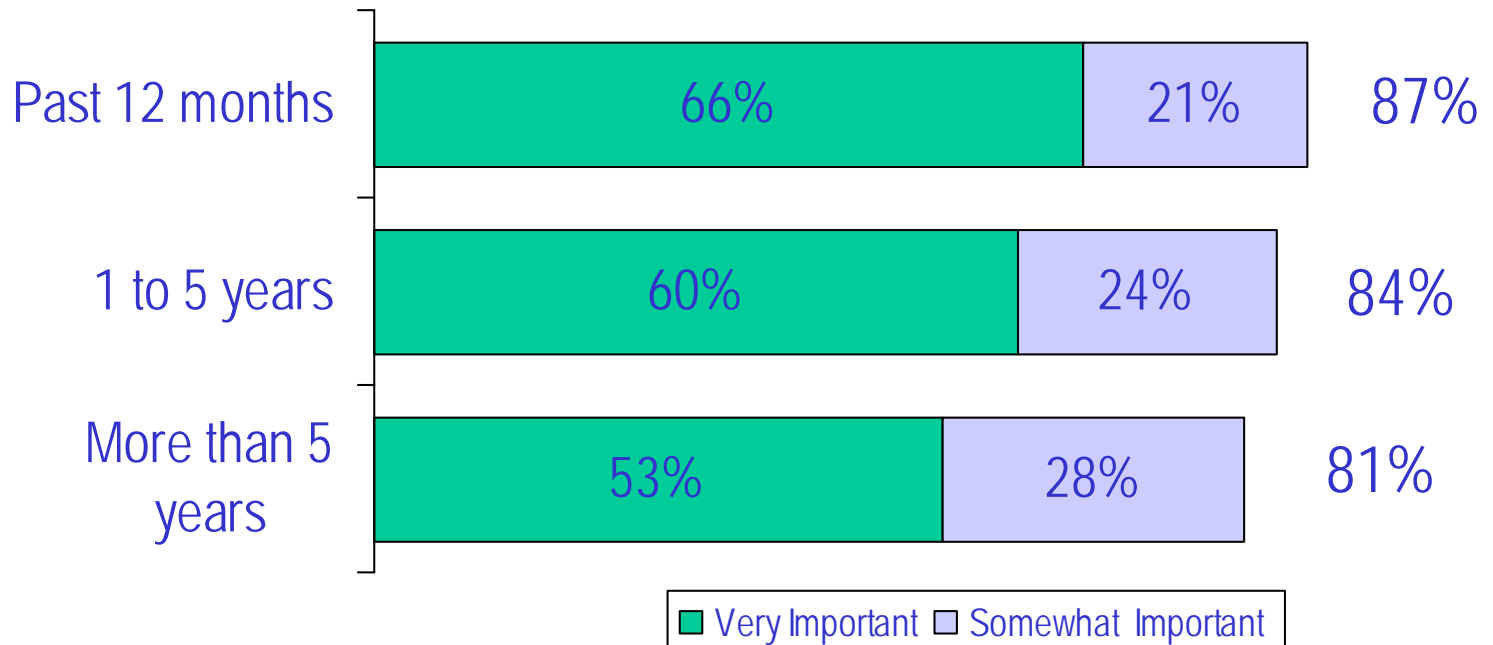
*I think that it's a good idea because this way, everything is in order. It's written and there are no problems with anyone.*

-Latino Caregiver  
(focus group)



# Recent Loss of a Loved One Affects Views on Having EOL Wishes in Writing

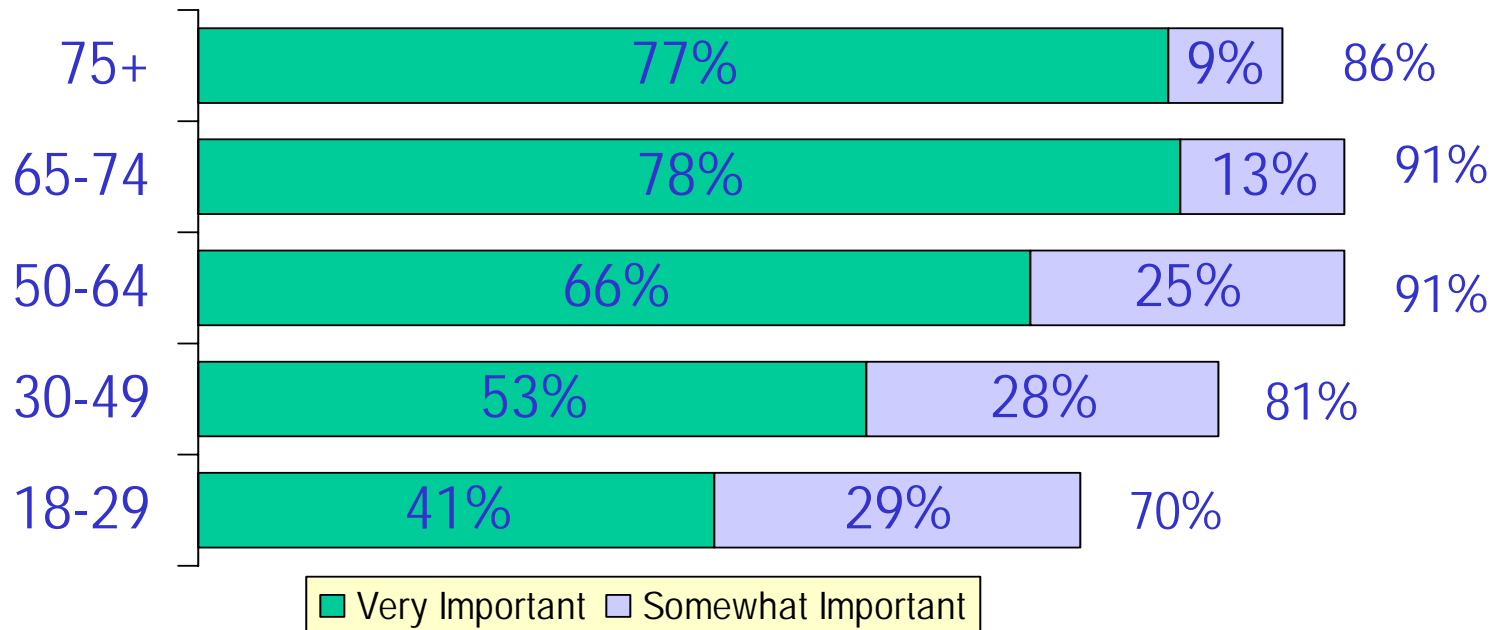
Importance of Having EOL Wishes in Writing,  
by Most Recent Loss of a Loved One





# Older Californians Feel More Strongly about Having EOL Wishes in Writing

Importance of Having EOL Wishes in Writing,  
by Age



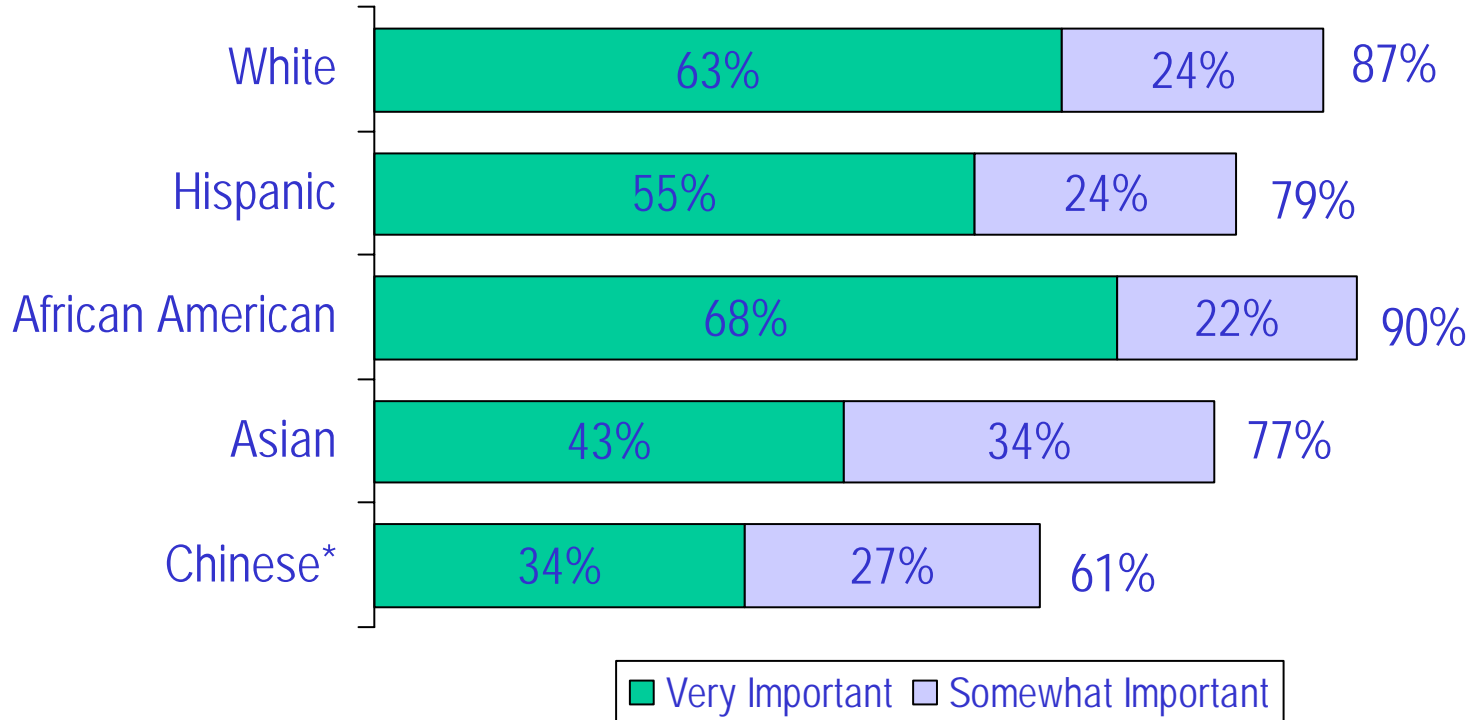




# African Americans and Whites Feel Most Strongly about Having EOL Wishes in Writing

*I am not going to have my daughter go through that, having to decide. I'm going to decide for her.*  
-African-American Caregiver (focus group)

### Importance of Having EOL Wishes in Writing, by Race/Ethnicity



\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



## Mixed Feelings about EOL Planning and Advance Directives (focus group comments)

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Last year I almost died. I was very close to death. I've always been a very happy person, always joking, and I feel I'm not going to be much of a planner. I think the day that God wants to gather me unto Himself, my only thought will be, don't let me be so, so old or leave me connected to anything. If He's going to take me, let Him take me straight. My wife and my children may decide, I will trust them.

- Latino Caregiver

I haven't had this conversation with anyone because I don't want it on record that I said one thing, and then I might change my mind. And frankly, I must admit I don't even think about it because the subject is depressing, and I know that's running away from reality. I just can't dwell on it. I don't know when I'm going to bring up the issue.

- Caucasian Caregiver

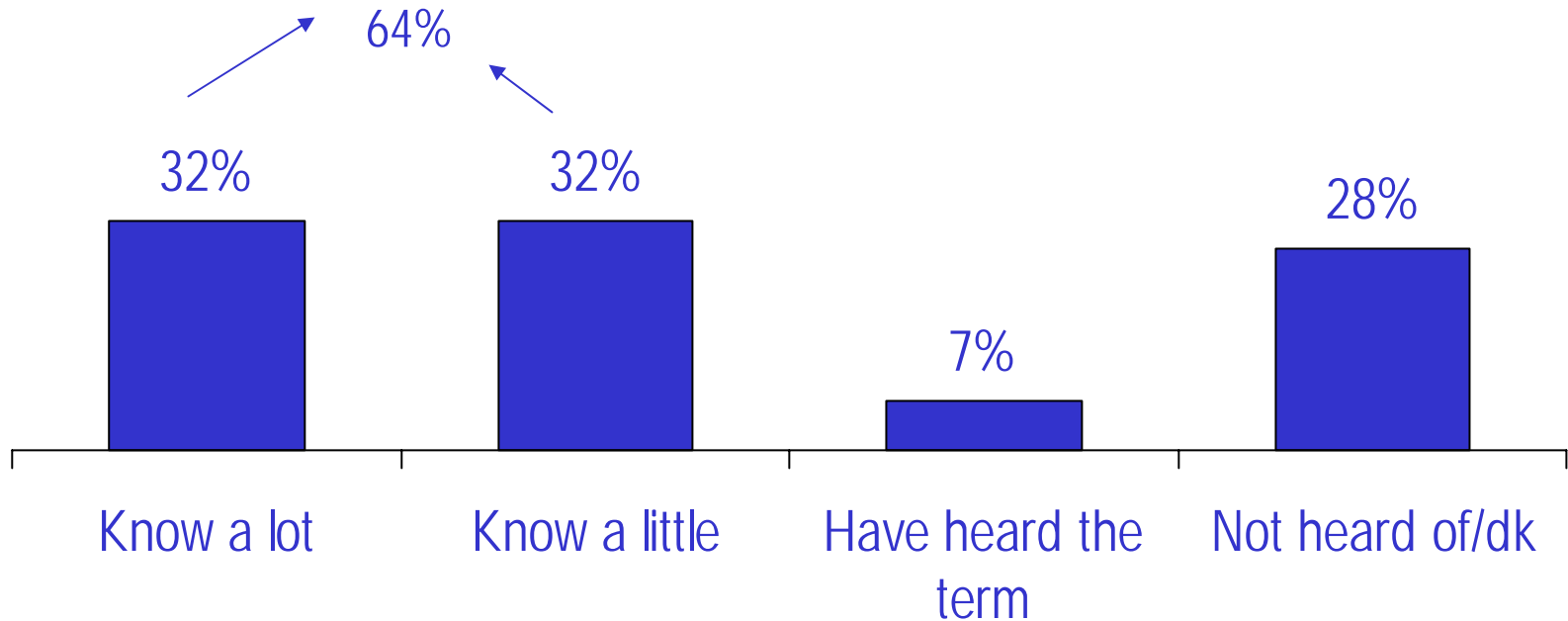
When you're actually in the situation you might just want to hold on to every last day that you have. That's where I would have a problem with the advance directive. That right there. It's the only issue that I would have with it because I think it's a wonderful idea. But what if that person as it [death] gets closer and they say, "I need to hang on a little bit longer for whatever reason."

- Caucasian Caregiver



# The Majority Have Heard of Hospice, but Only a Third “Know a Lot” about It

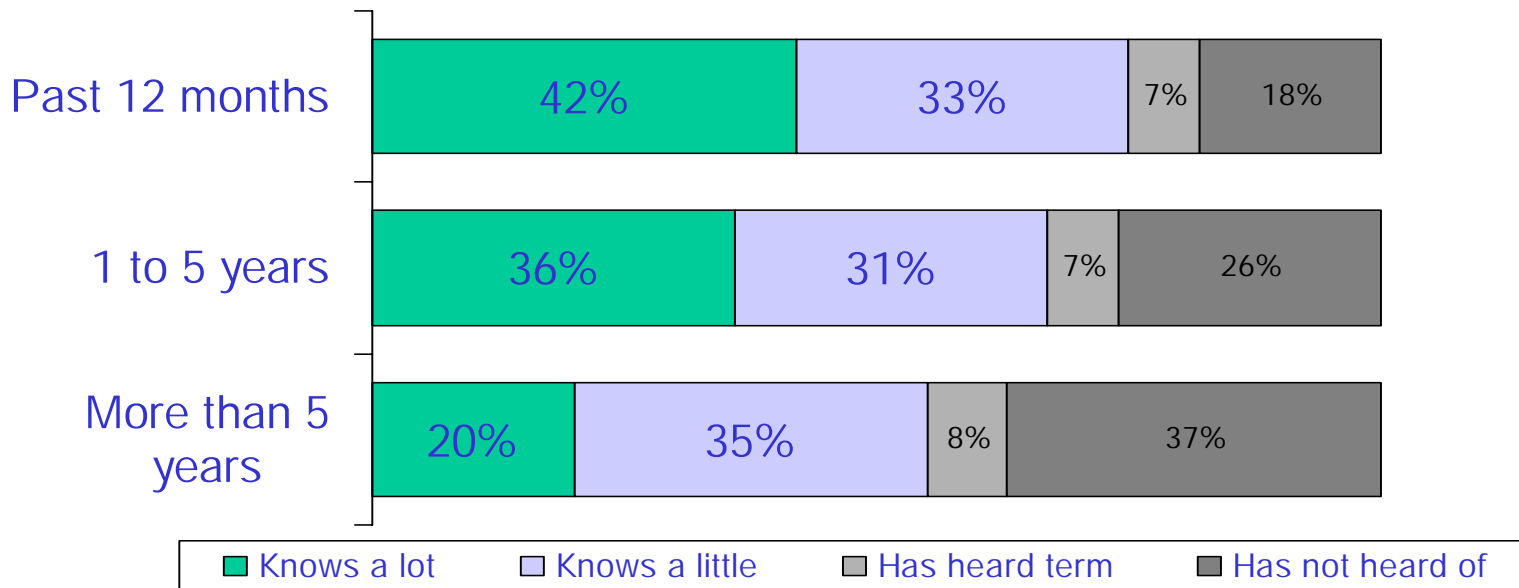
Have you heard of hospice care? How much do you know about it?





# Those with Recent EOL Experience Are More Familiar with Hospice

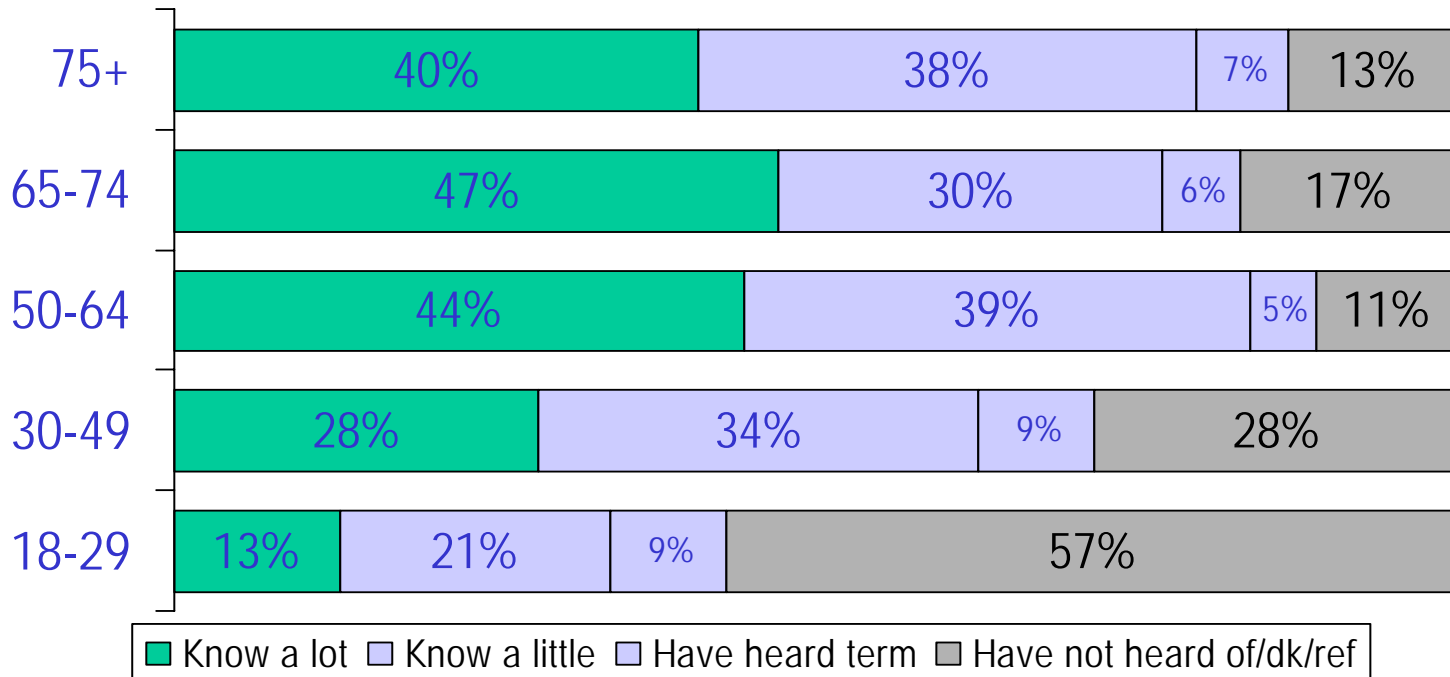
Familiarity with Hospice,  
by Most Recent Loss of a Loved One





# Older Californians Are More Well Informed About Hospice

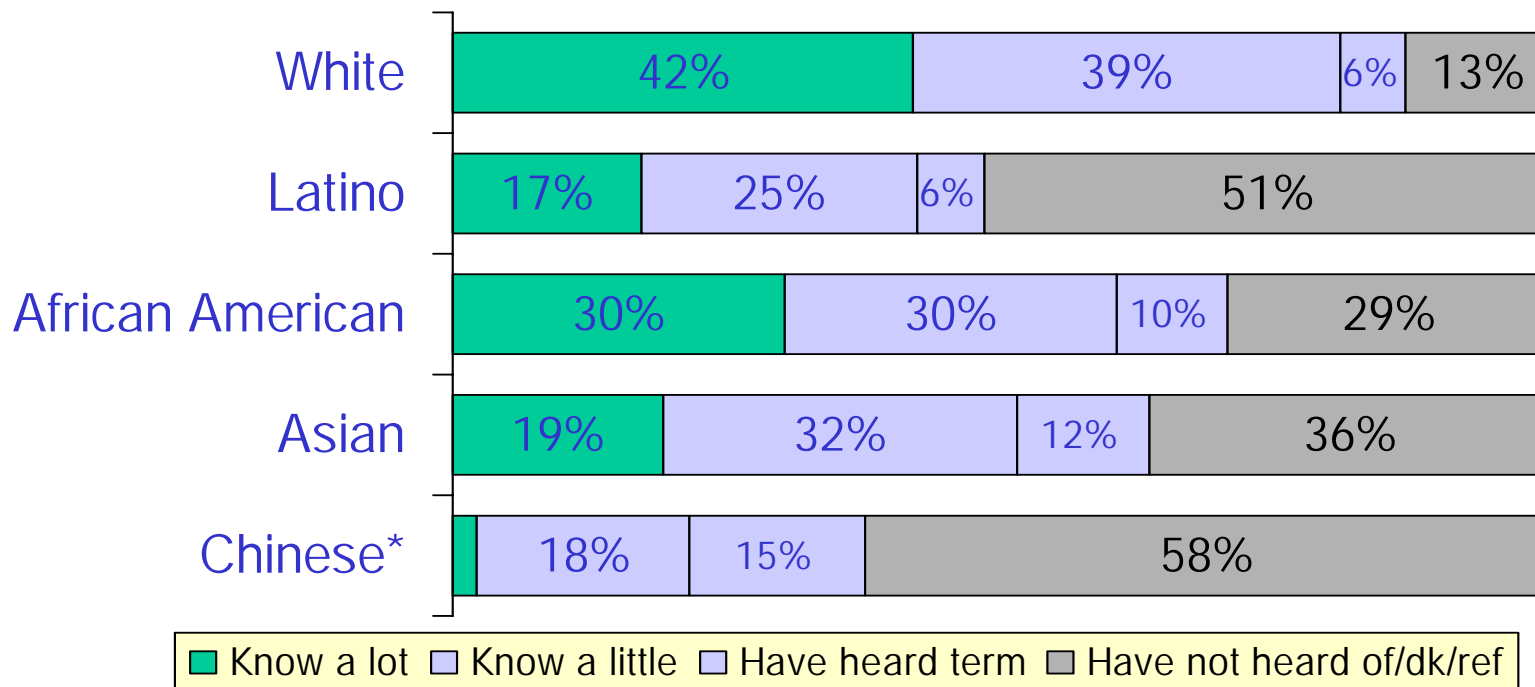
### Familiarity with Hospice by Age





# African-American and White Californians Are Most Familiar with Hospice

Familiarity with Hospice  
by Race/Ethnicity

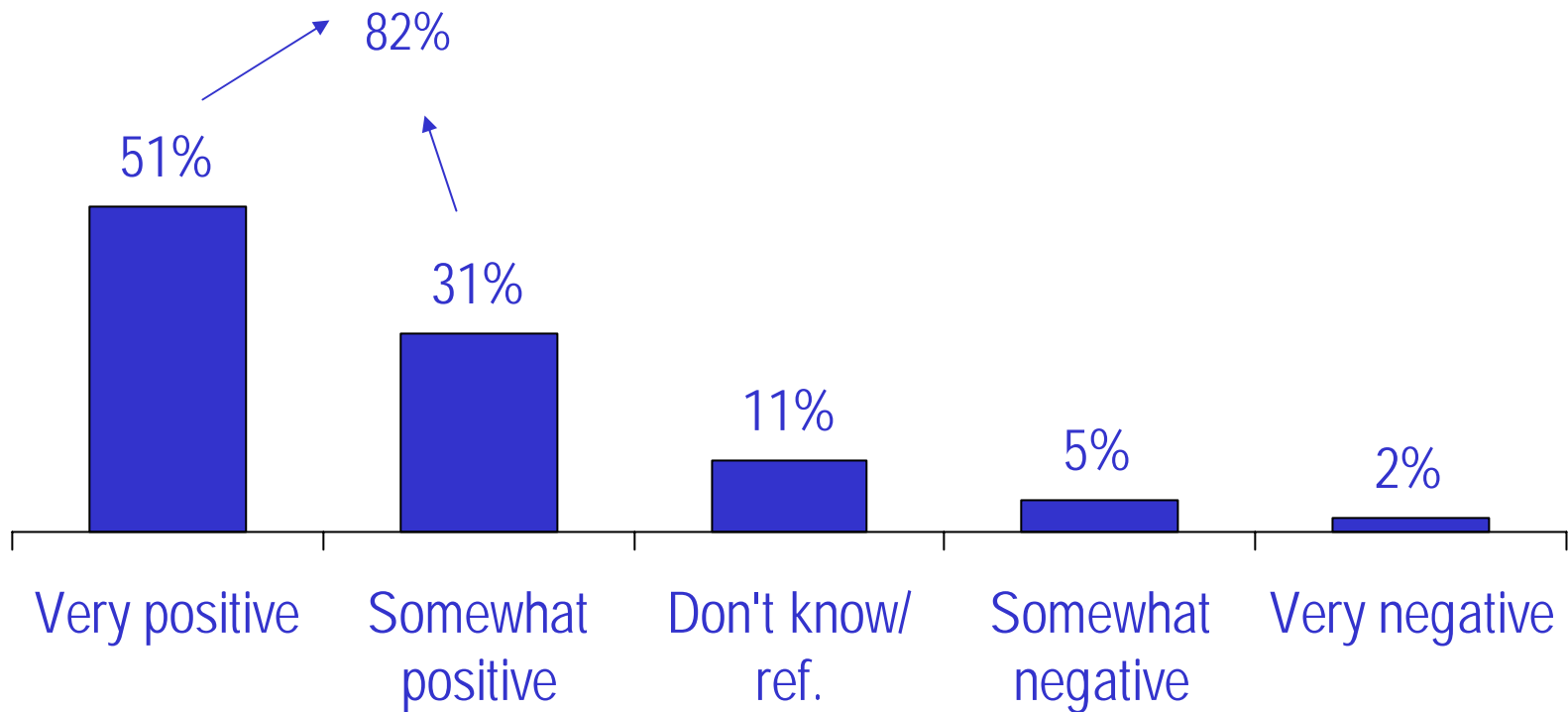


\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# Among Those Who Have Heard of Hospice, Most View It Positively

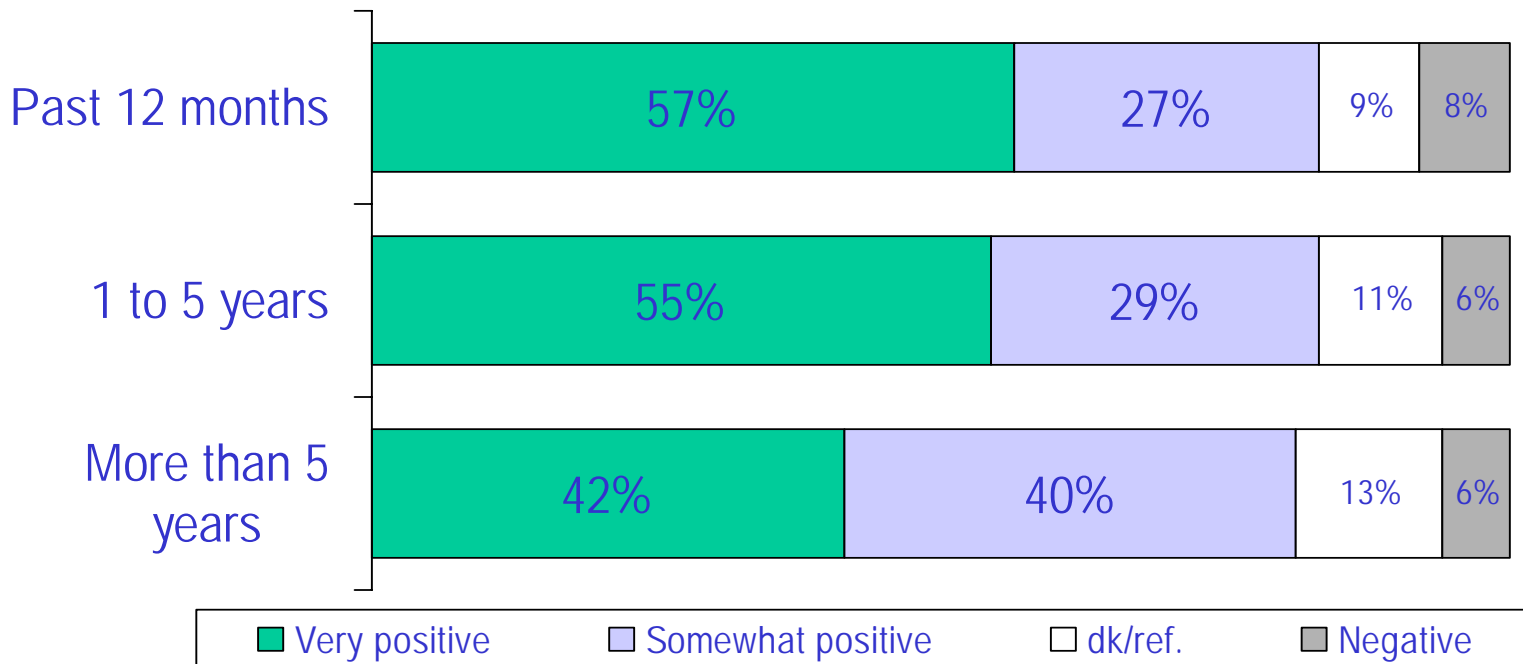
What is your opinion of hospice care?  
(among those who have heard of hospice)





# Those With Recent EOL Experience View Hospice Somewhat More Favorably

Opinion of Hospice  
(among those who have heard of hospice)  
by Most Recent Loss of a Loved One

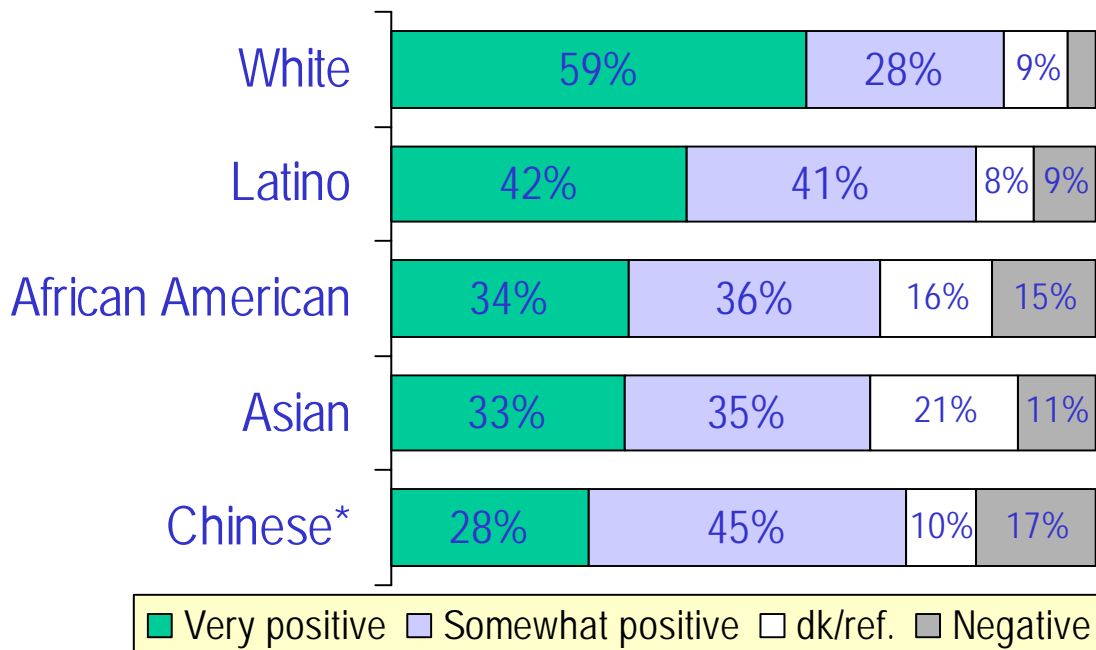






# White Californians Have Most Positive Views of Hospice

Opinion of Hospice  
(among those who have heard of hospice)  
by Race/Ethnicity



*In Latin America, there are different customs. There you have a person who is ill, you take care of them until they die. If the neighbor were to find out you took your mother to be taken care of somewhere else, they will think, this woman has no soul. We don't send people outside the home when they're ill.*

-Latino Caregiver  
(focus group)

\*\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



## Focus Group Results Suggest Many Believe Hospice is Unaffordable

---

I think the big decision has to do with, if you're going to a hospice, then I think you have to know who is going to pay for this.

- Latino Caregiver

Here it's very difficult to have a hospice house in your house if you don't have insurance. Whether it's the custom or the tradition, simply what speaks here is money.

- Latino Caregiver

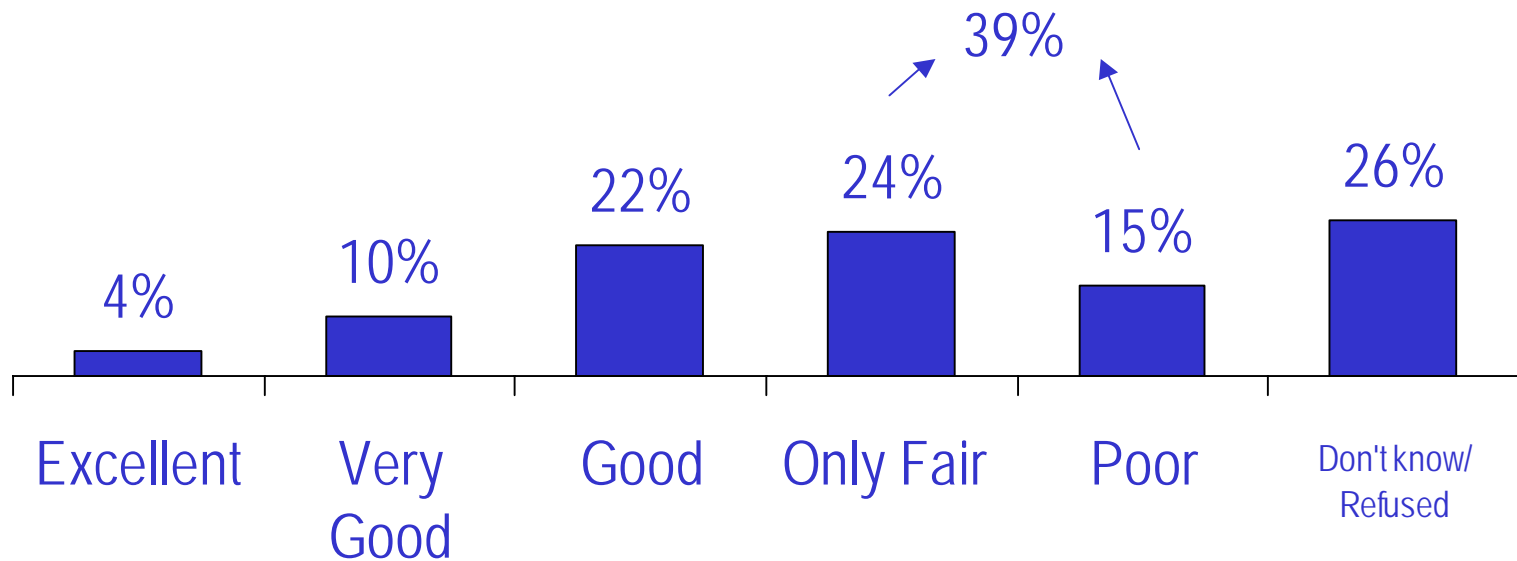
This is a good program for those who can pay for it, but those that can't...

- Latino Caregiver



# Many Californians Give the State's Health Care System Fair to Poor Marks, a Quarter Refuse to or Cannot Judge

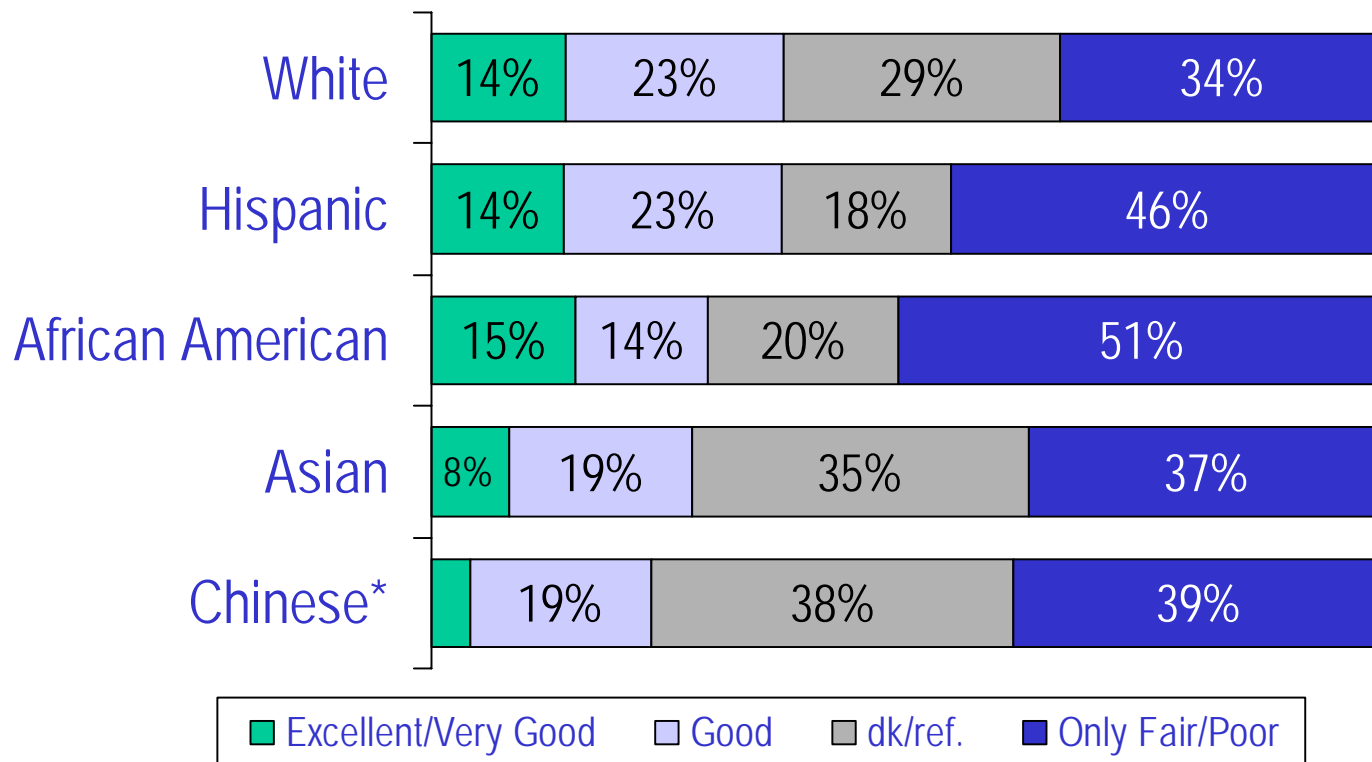
In general, how well do you think California's current health care system does in caring for dying people?





# African-American and Hispanic Californians Are Most Critical of State's EOL Care

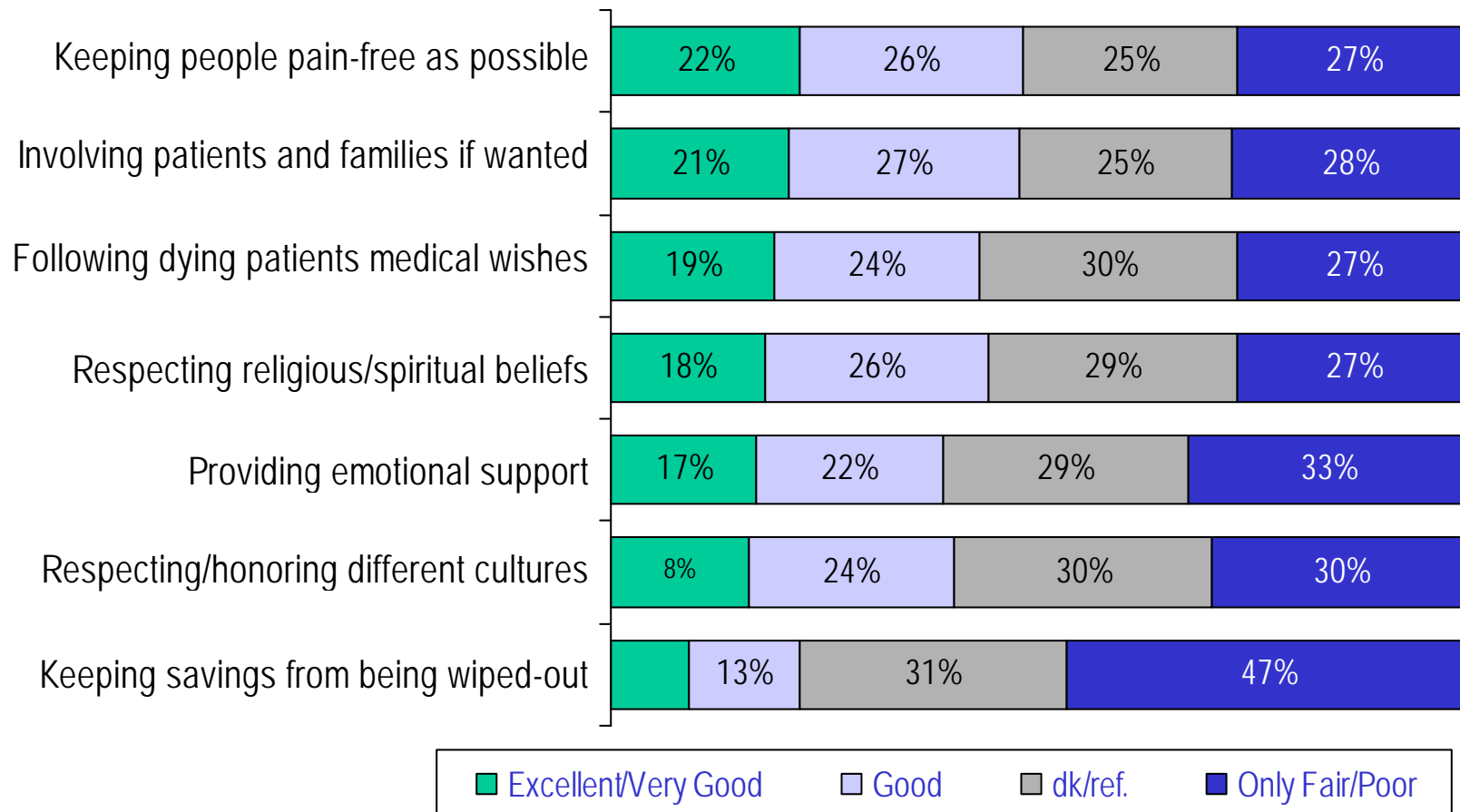
Rating of State's Health System for Dying People,  
by Race/Ethnicity



\*Chinese includes Mandarin and Cantonese-speaking subset of Asian population surveyed.



# Californians Rate Various Aspects of the State's Health Care System for EOL Care





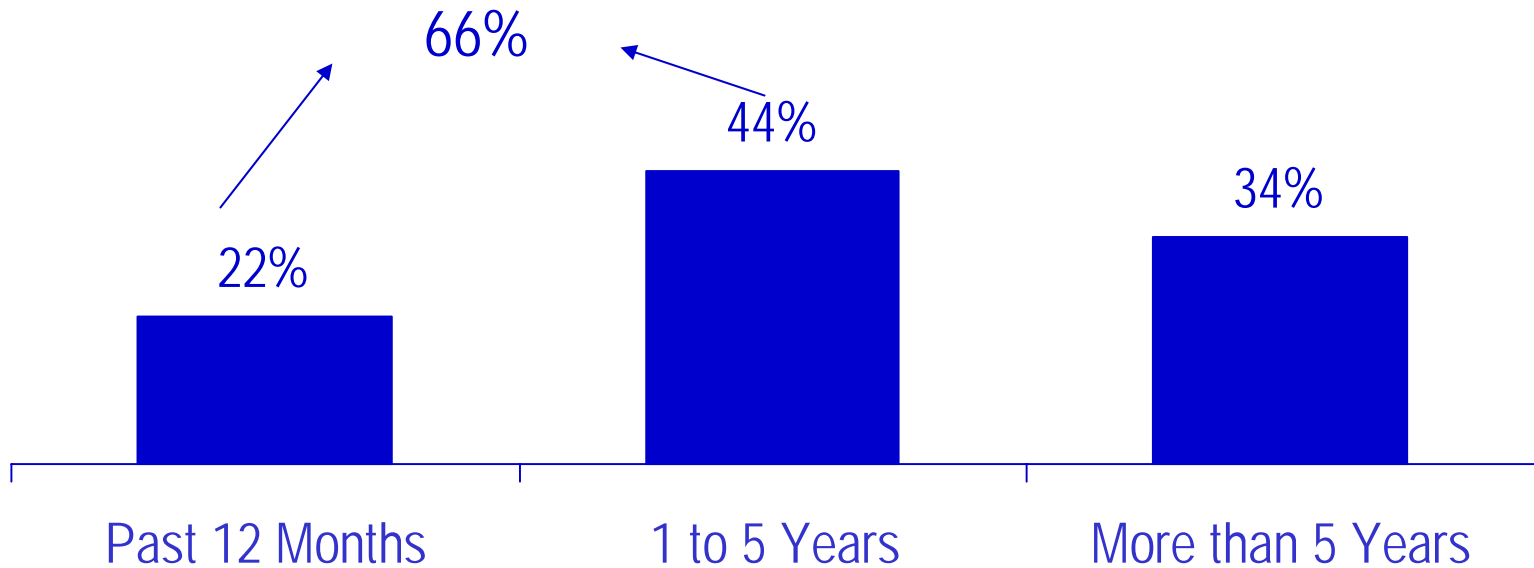
# *Firsthand Experience*

Those Who Have  
Lost a Loved One



# Two-thirds of Californians Have Lost a Loved One within the Past Five Years

Most Recent Loss of a Loved One



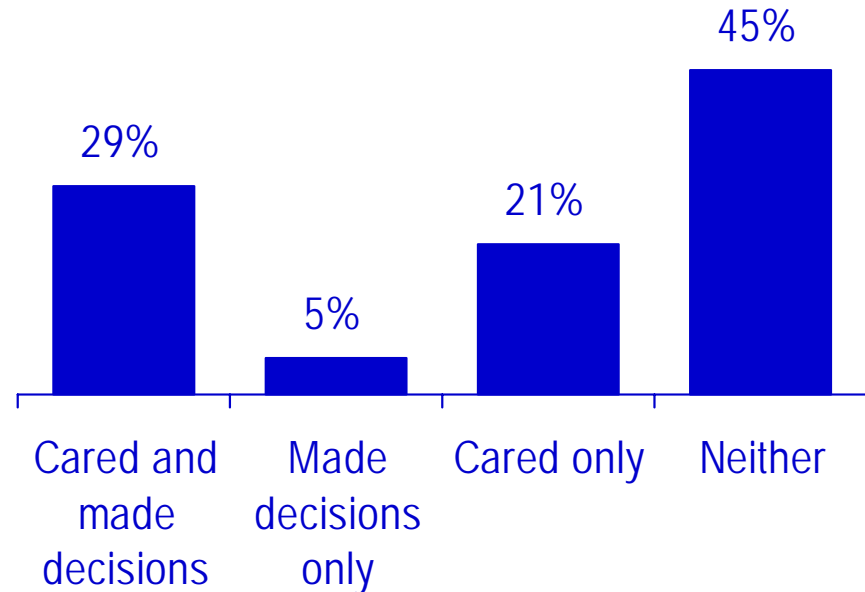


## Respondent's Role

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- Half (50%) say they helped care for their loved one.
- A third (34%) made or were involved in medical decisions.
- Twenty-nine percent were both caregivers and decision makers.
- Forty-five percent played neither of these roles.

Respondent's Role

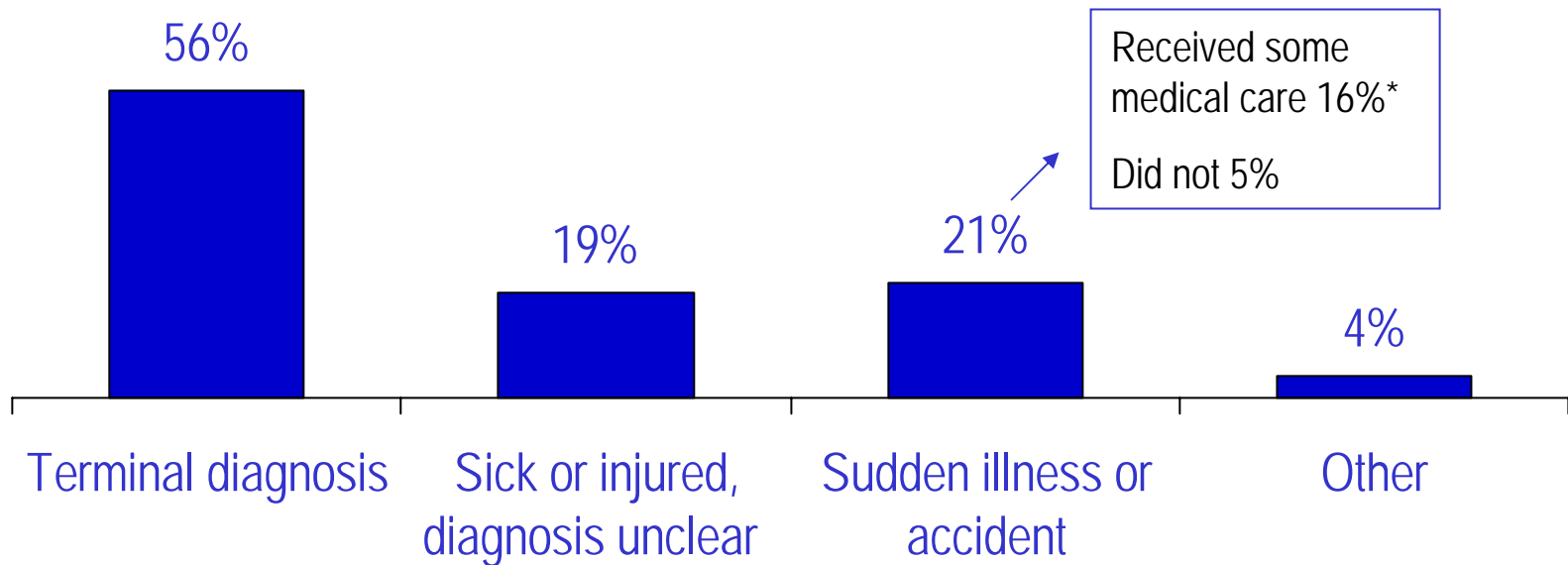






# Over Half Say Their Loved One Had a Terminal Diagnosis

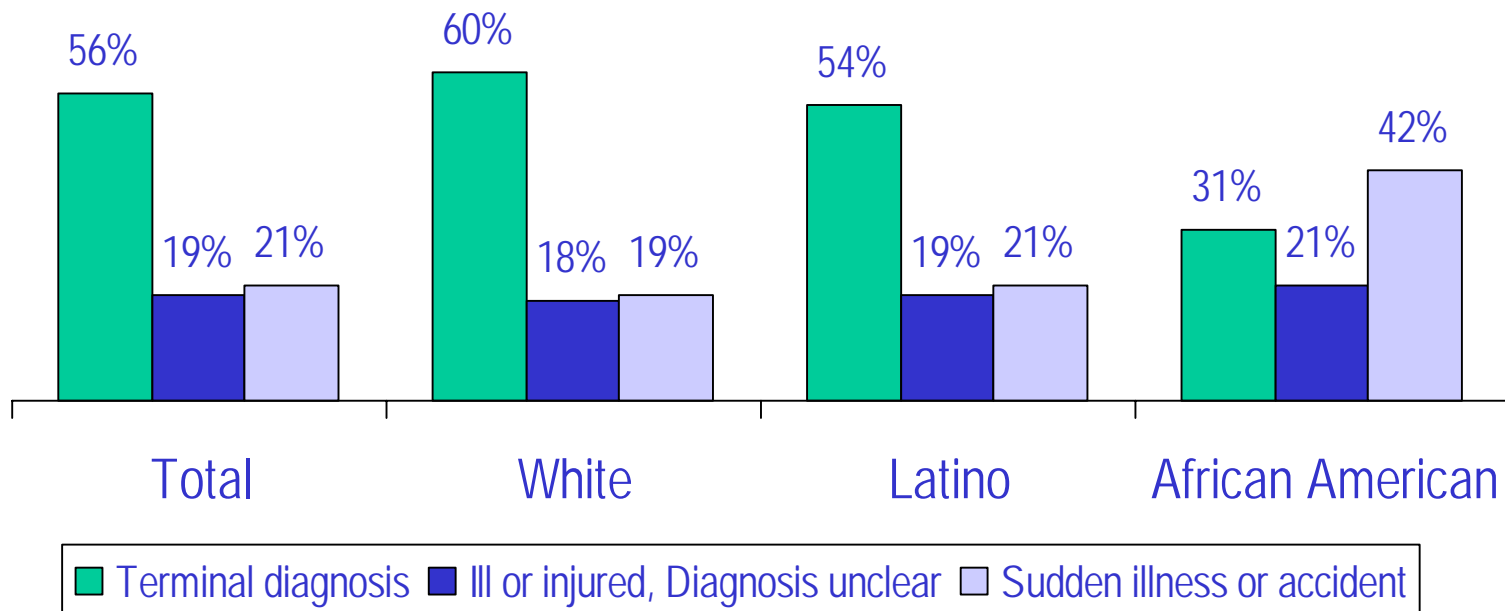
Which of the following best describes the circumstances of your loved one's death....



\* Remaining questions in this section asked only of those whose loved-one received at least some medical care

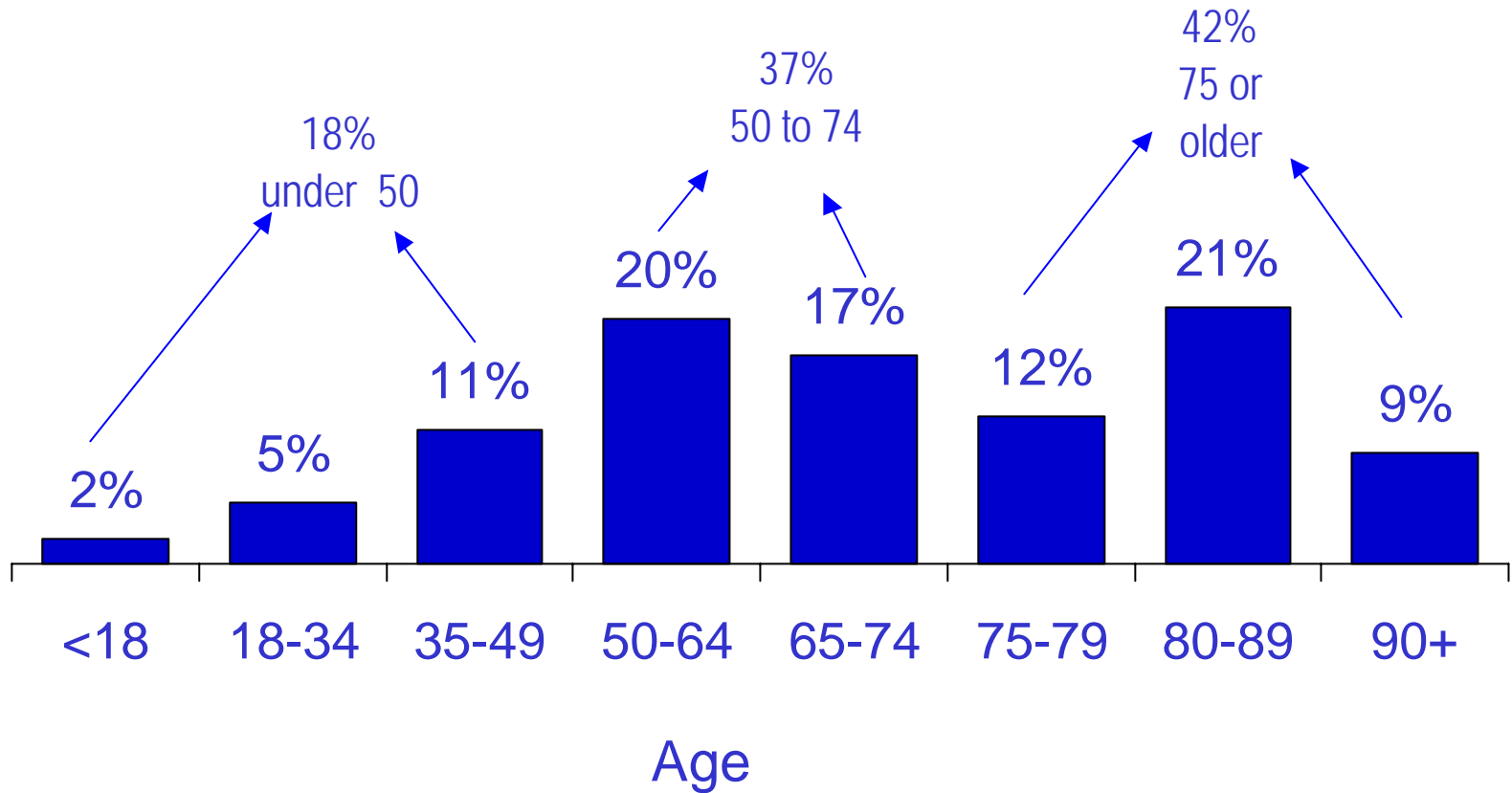


# Circumstances of Death (as Reported by Respondents) Differ by Race/Ethnicity





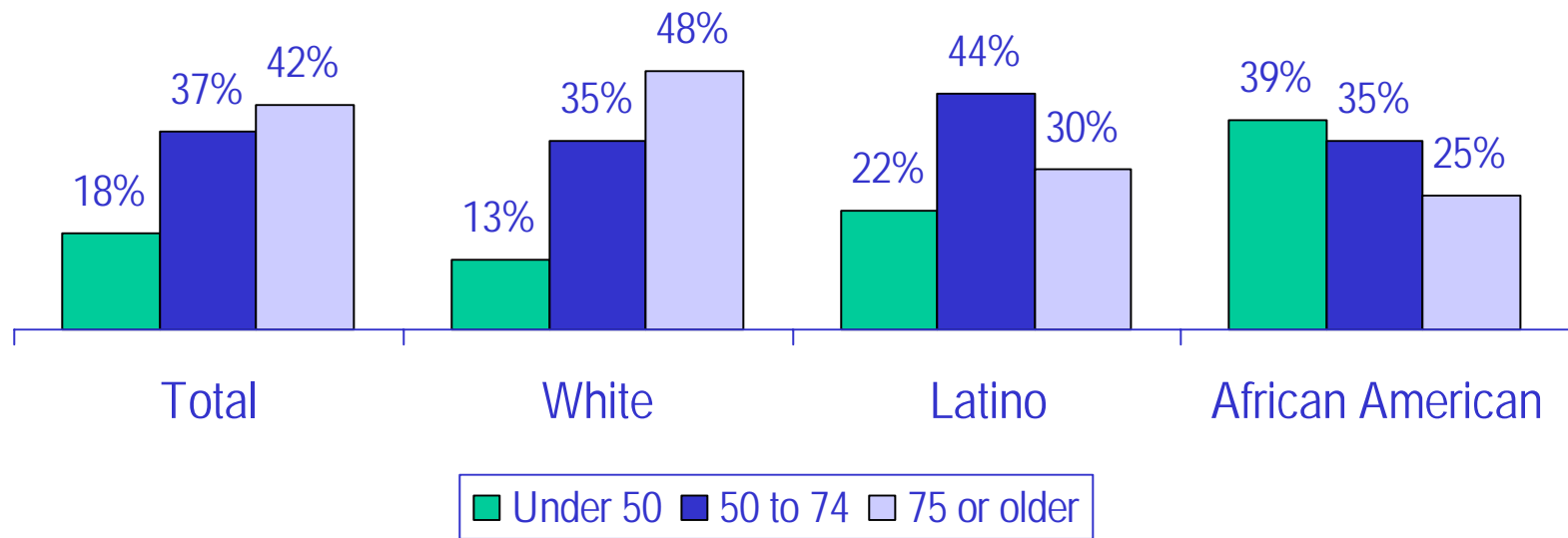
# Loved One's Age at Death





# African-American Californians Report Greater Number of Deaths at Younger Ages

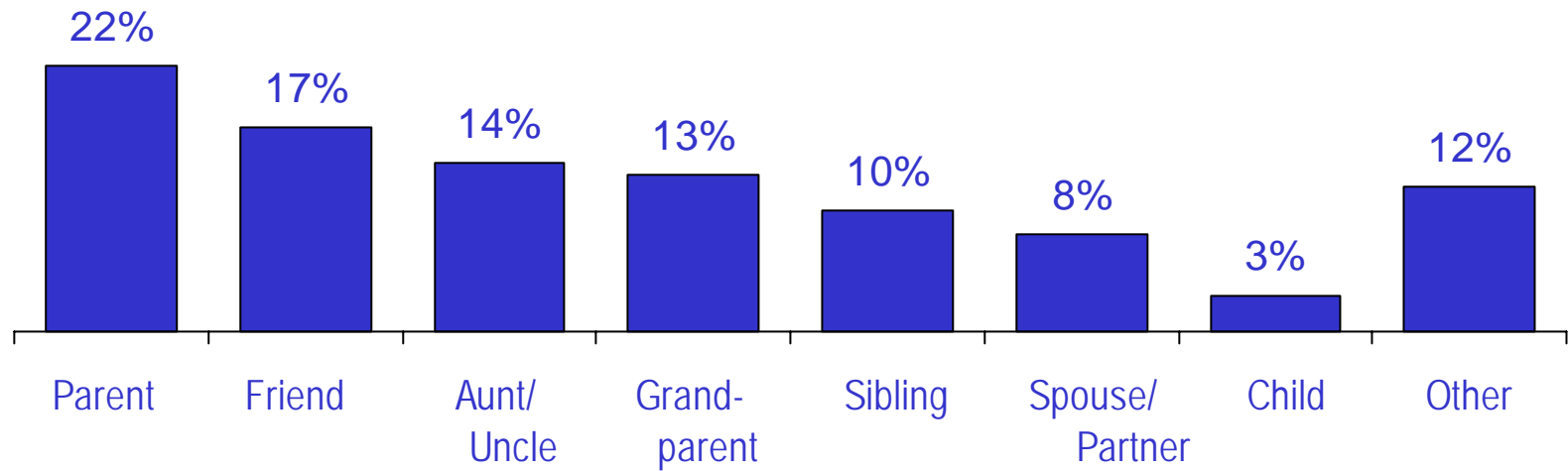
Loved One's Age at Death,  
by Race/Ethnicity





## Loved One's Relationship to Respondent

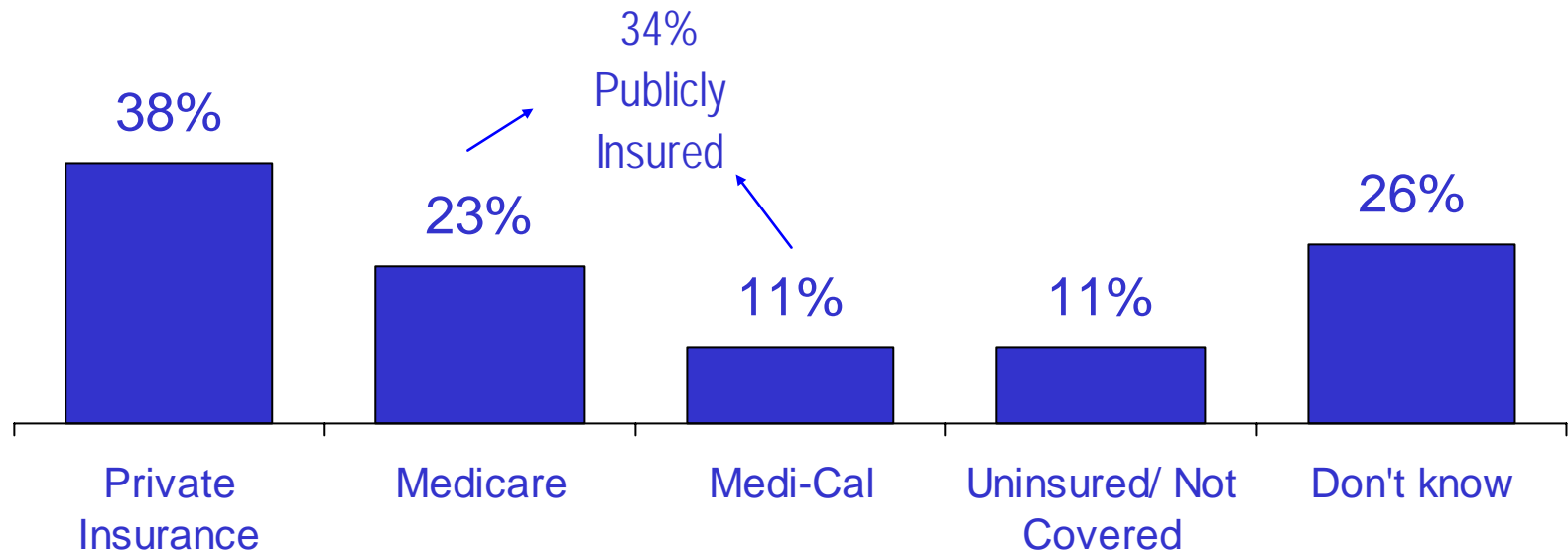
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# Loved One's Insurance Status at Death

Insurance Status at Death  
(multiple responses accepted)

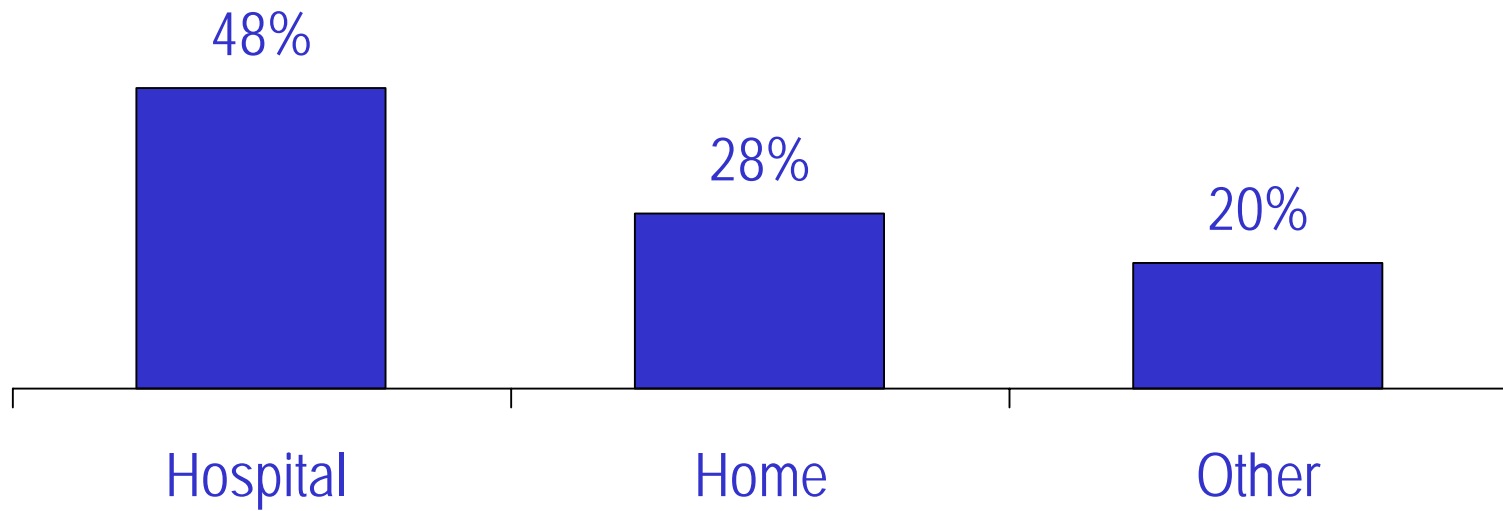




## More Say Their Loved One Died in the Hospital Than in Any Other Setting

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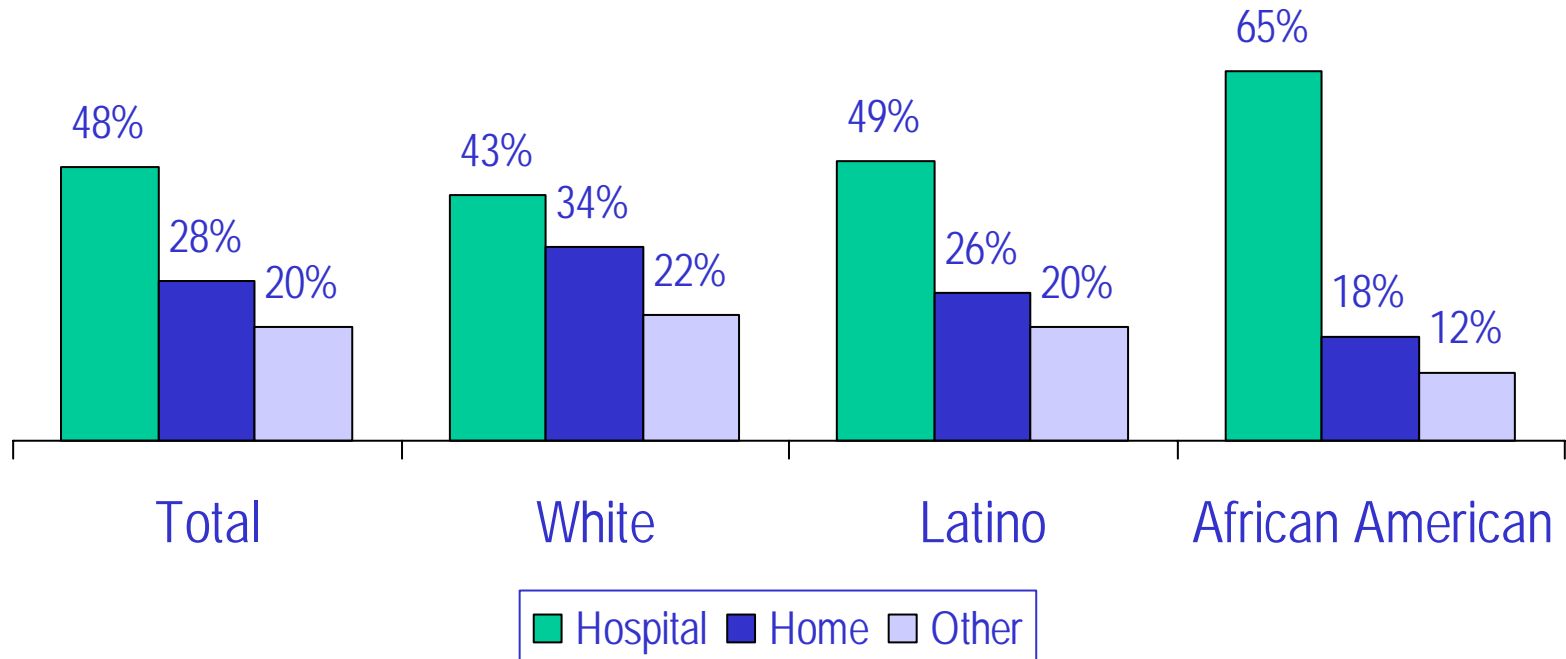
Where did your loved one die?





# Place of Death, by Race/Ethnicity

Where did your loved one die?



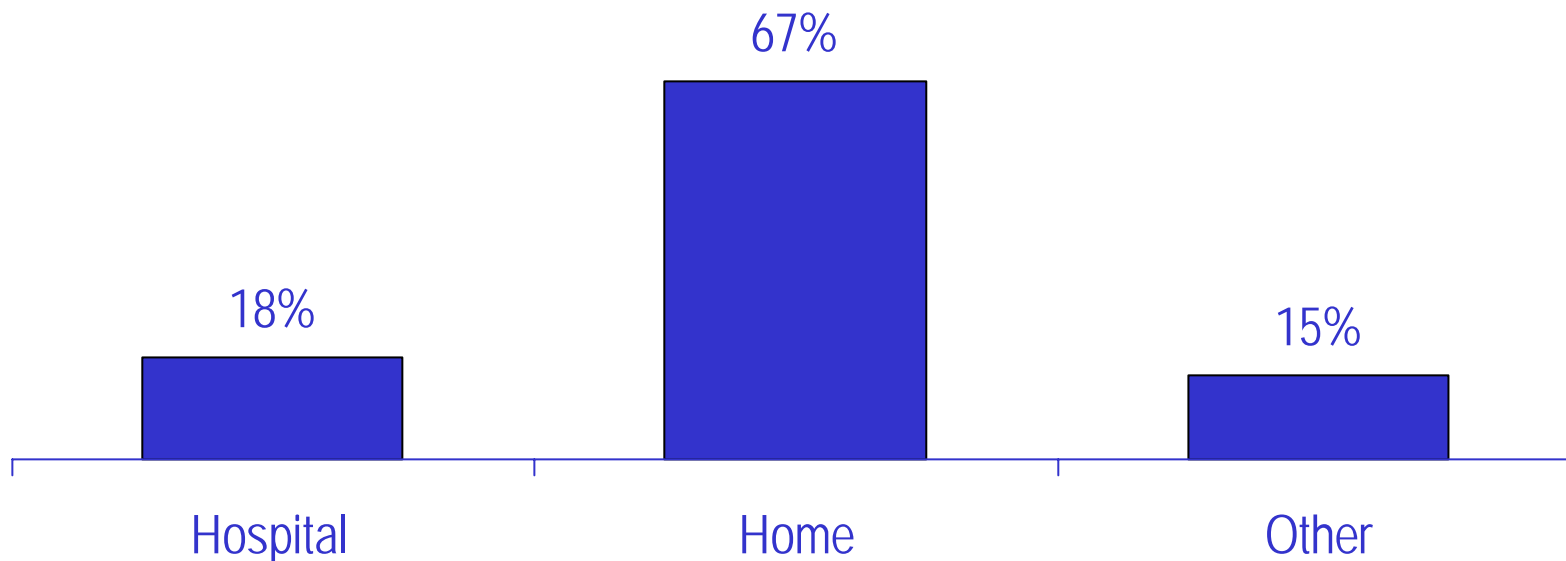




## Most Say Their Loved One Would Have Preferred to Die at Home

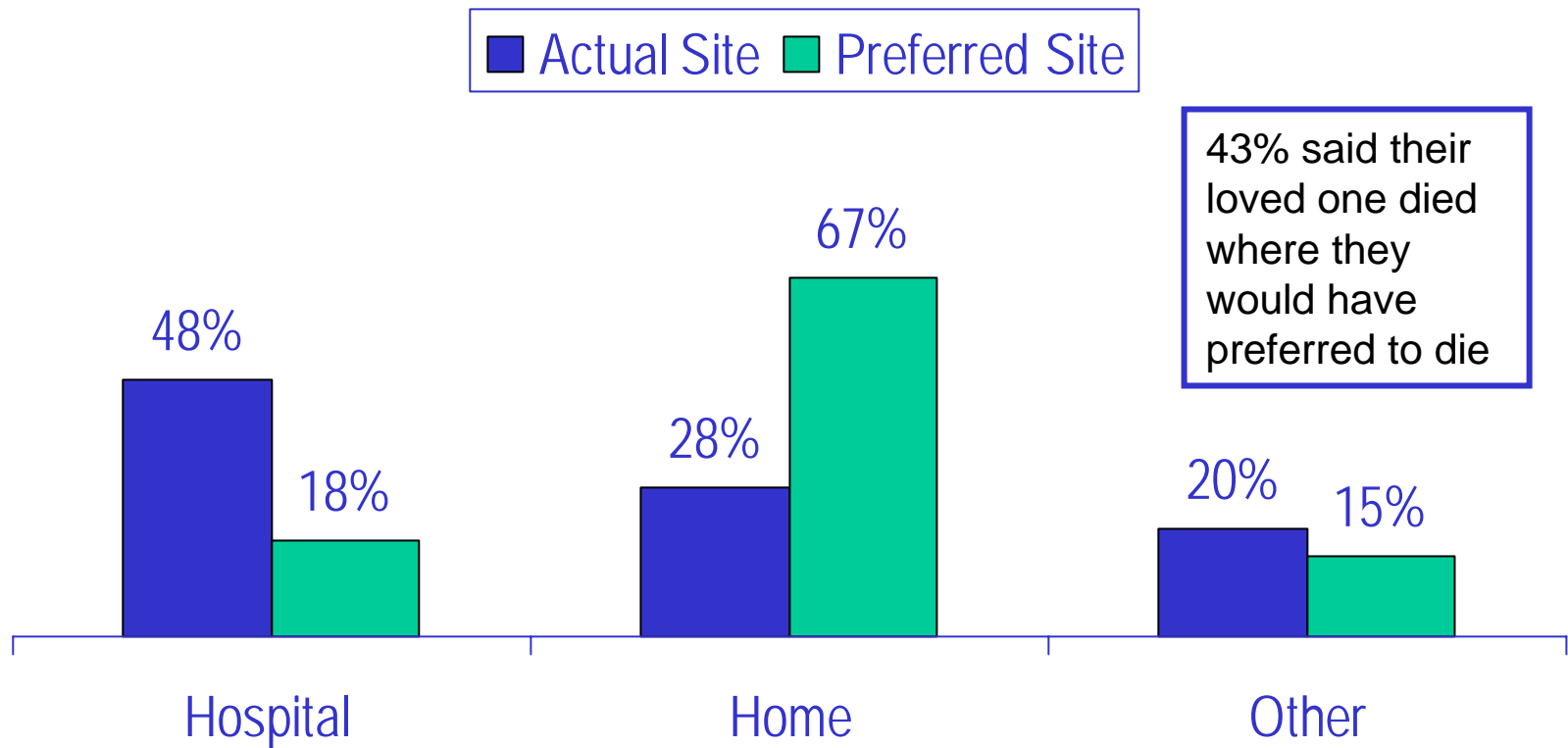
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Where would your loved one have preferred to die?  
(among those who knew loved one's preference)





# Actual Place of Death vs. Preferred Place of Death





## Those Most Likely to Say Their Loved One Died in Their Preferred Location

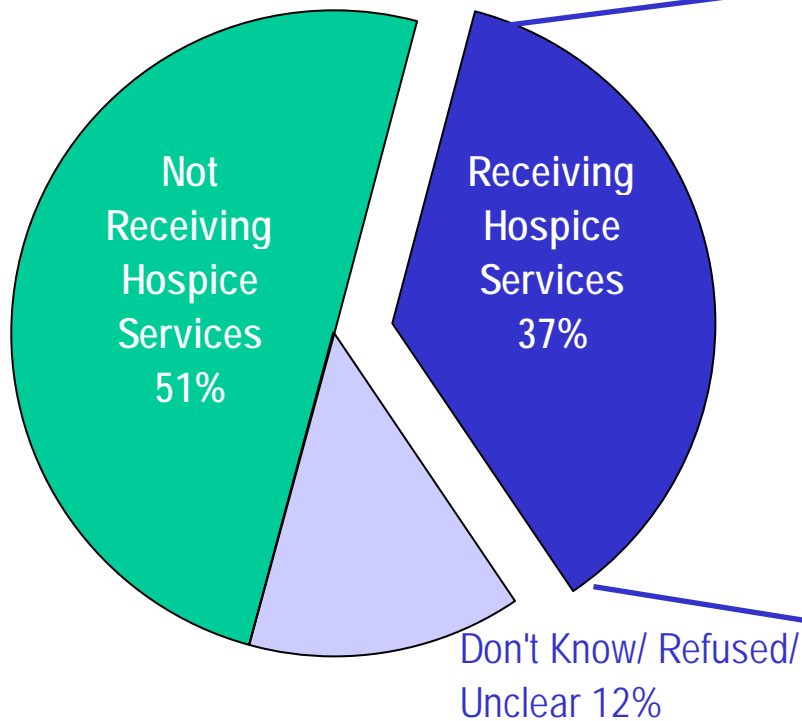
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- Those whose loved one died at home (91%)
- Those whose loved one received hospice services (66%)
- Those whose loved one had a terminal diagnosis (52%)
- Those who talked with their loved one about EOL wishes (51%)

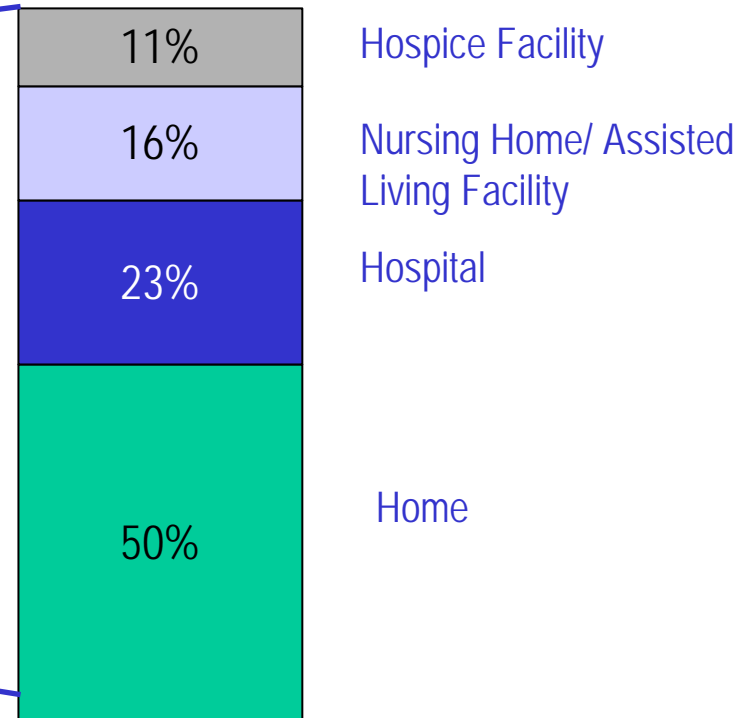


# Over a Third Report Their Loved One Was Receiving Hospice Care at Death, Most Often at Home

Was loved one receiving hospice care services at death?



Where did loved one die?

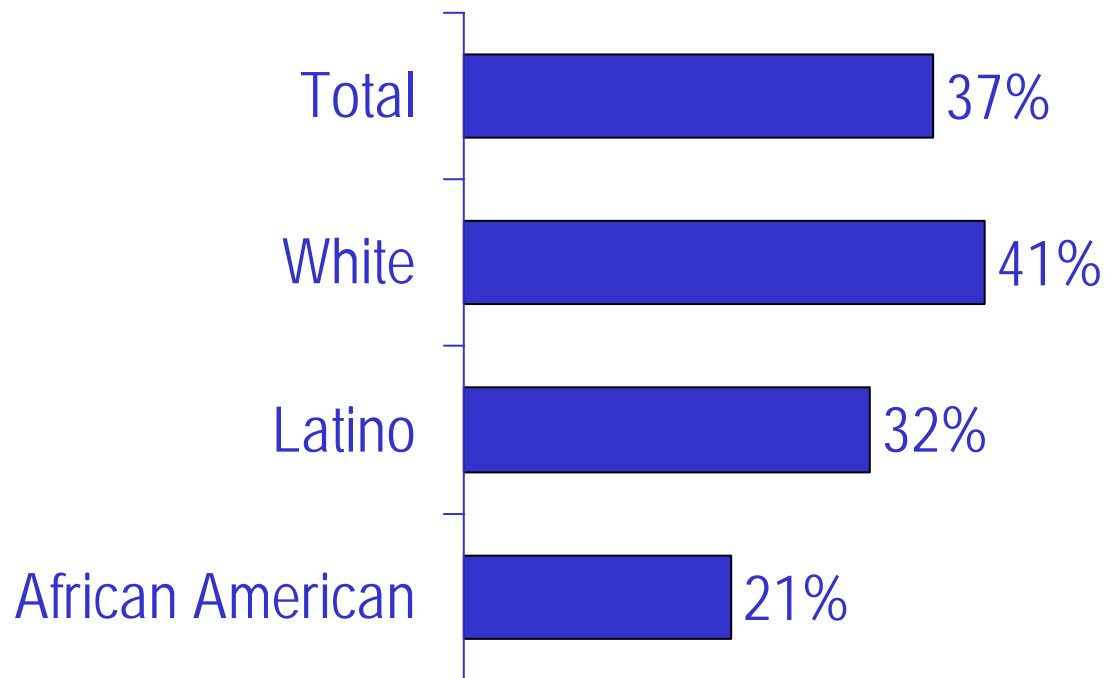




# White Californians Are More Likely than Others to Say Their Loved One Was Receiving Hospice Services

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Receiving Hospice Services,  
by Race/Ethnicity





## Hospice Care Rated Higher

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- Ninety percent of those whose loved one received hospice care have positive views of hospice; 74% say their views are *very positive*.
- Those whose loved one had hospice care were more likely than others to:
  - Rate care as excellent or very good (68% vs. 47%).
  - Rate doctors' communication skills as excellent or very good (51% vs. 40%).
  - Rate providers as excellent or very good on understanding and respecting an individual's culture (52% vs. 40%).
  - Say providers did all they could to alleviate pain (86% vs. 67%).
  - Say their loved one's wishes were completely honored and followed (61%. Vs. 47%).



## Focus Group Participants Report Positive Hospice Care Experiences

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As a matter of fact, hospice as a whole was very, very good. The medication, the instructions, the accessibility. [They said], “If you’ve got a problem, call me.” And when I called, they were there 24 hours. If I called and I needed something, they had it taken care of immediately. I would say that they were excellent. As a matter of fact, on a grading system, 98 percent.

- African-American Caregiver

My mother was treated with so much dignity. The nurses were so good to her. The doctors, everybody, they treated her like a queen.

-White Caregiver

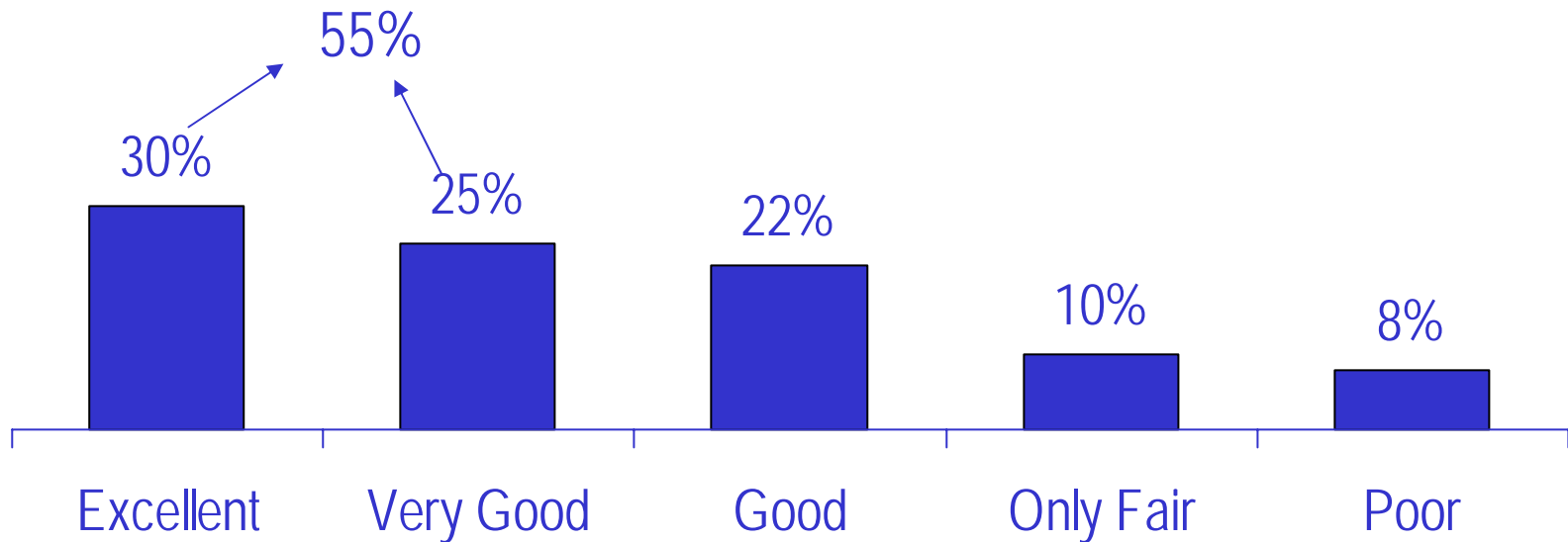
A+ and then some, because hospice [staff] are -- they are angels.

- White Caregiver



# Just Over Half Rate the Care Their Loved One Received as Excellent or Very Good

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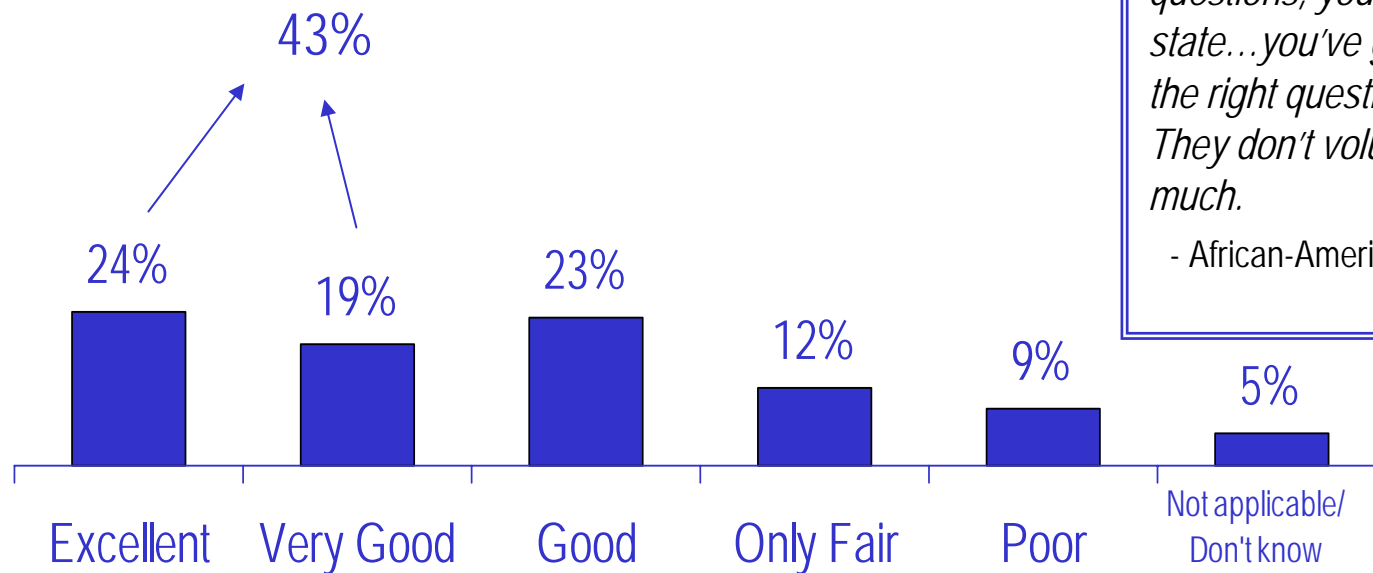






# Less than Half Say Their Loved One's Doctors Had Excellent or Very Good Communication Skills

Rating doctors in terms of how well they communicated



*If you don't have somebody with you that can speak up and ask questions, you're in a sorry state...you've got to know the right questions to ask. They don't volunteer much.*

- African-American Caregiver (focus group)

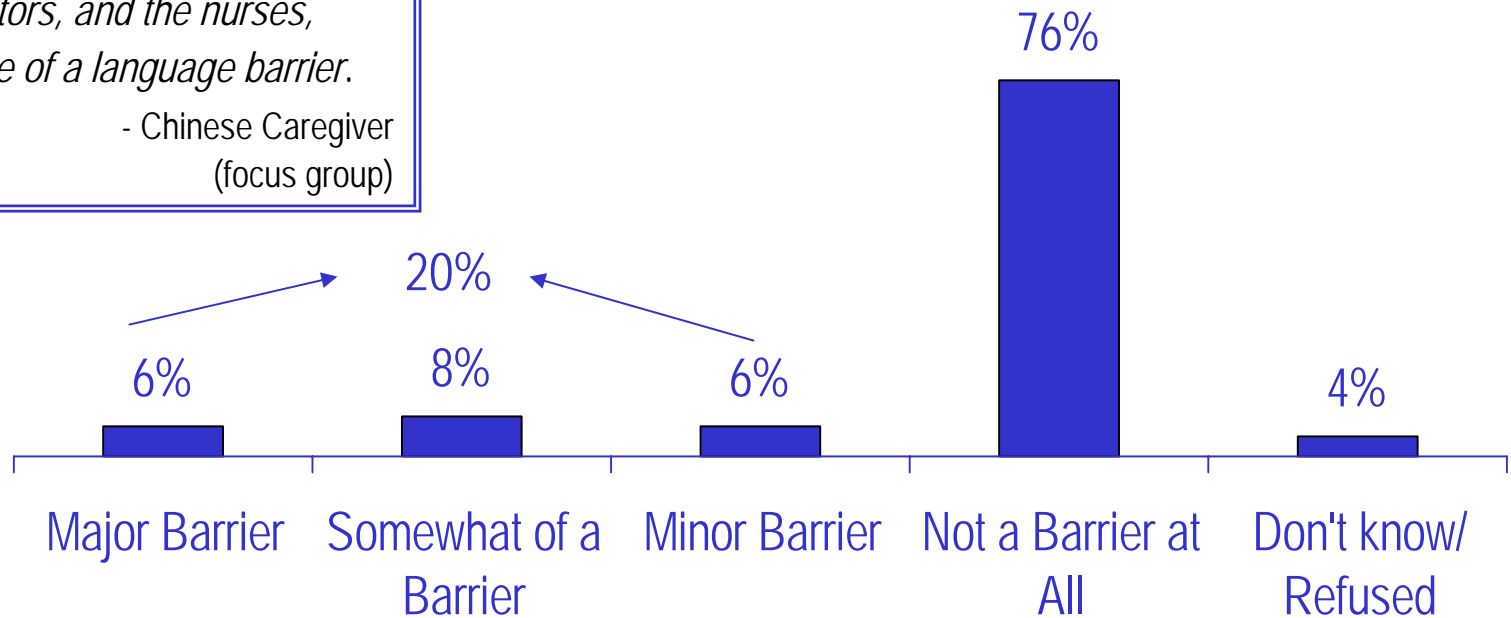


# Few Report Language Barriers

*He had to have friend to help out, and say which hospital, because his English was bad, so he could not communicate with the doctors, and the nurses, because of a language barrier.*

- Chinese Caregiver  
(focus group)

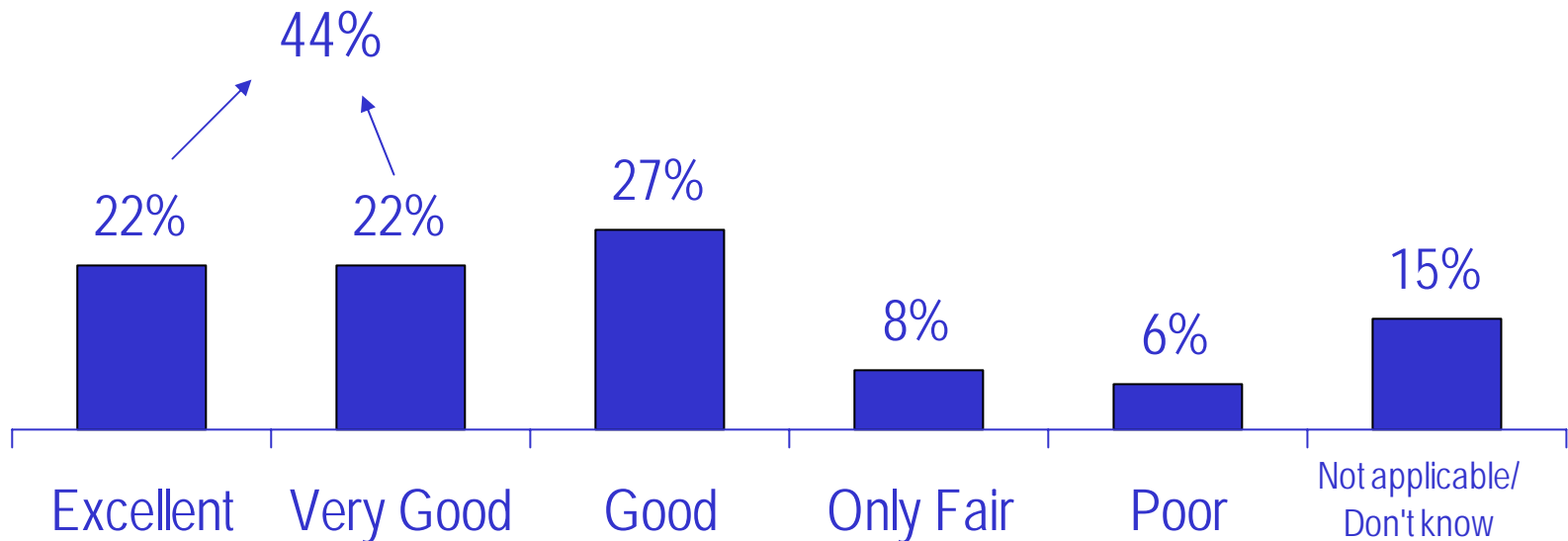
To what extent, if at all, was language a barrier to your loved one getting the best possible care?





# Less than Half Say Their Loved One's Health Care Providers Did an Excellent or Very Good Job of Being Culturally Competent

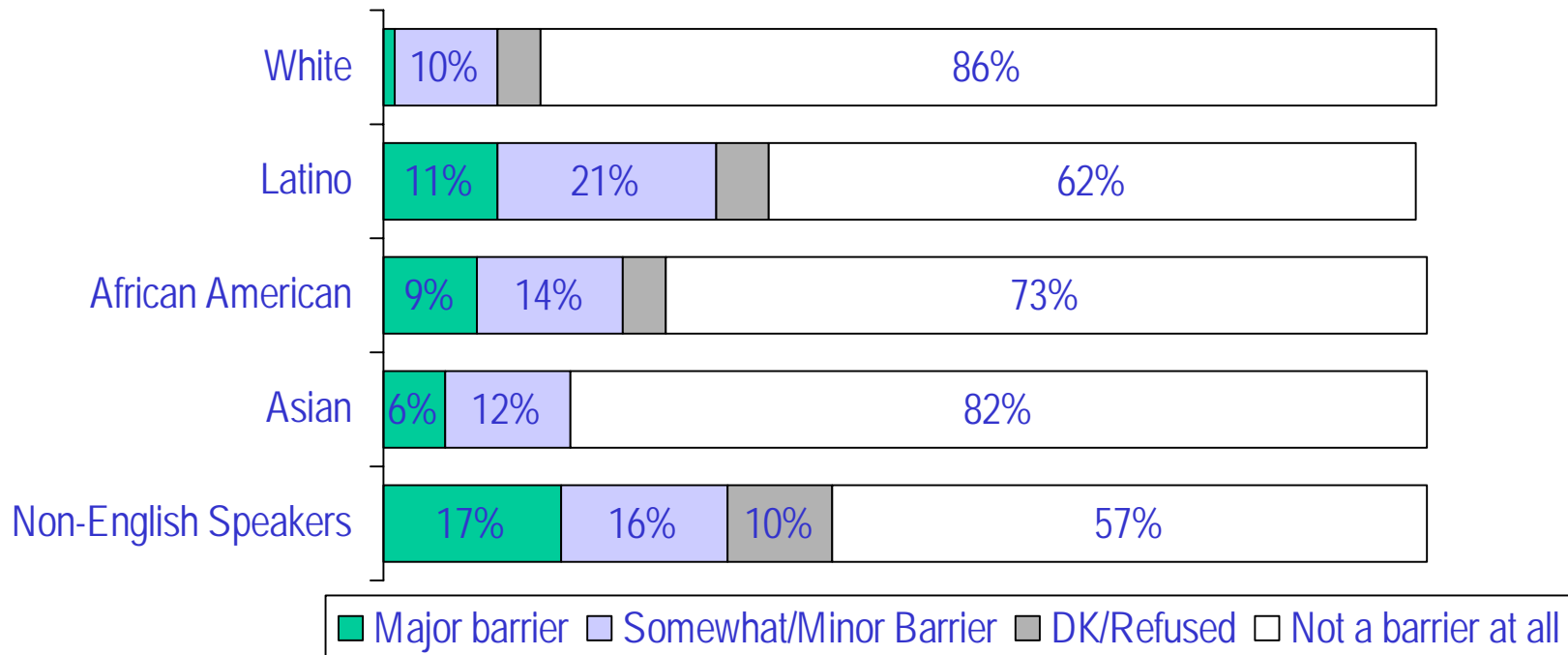
Rating providers in terms of understanding a respecting culture and beliefs of patient and family





# A Quarter of African Americans Report Language Barriers

Extent to Which Language Was Barrier To Best Possible Care  
by Race/Ethnicity and Language

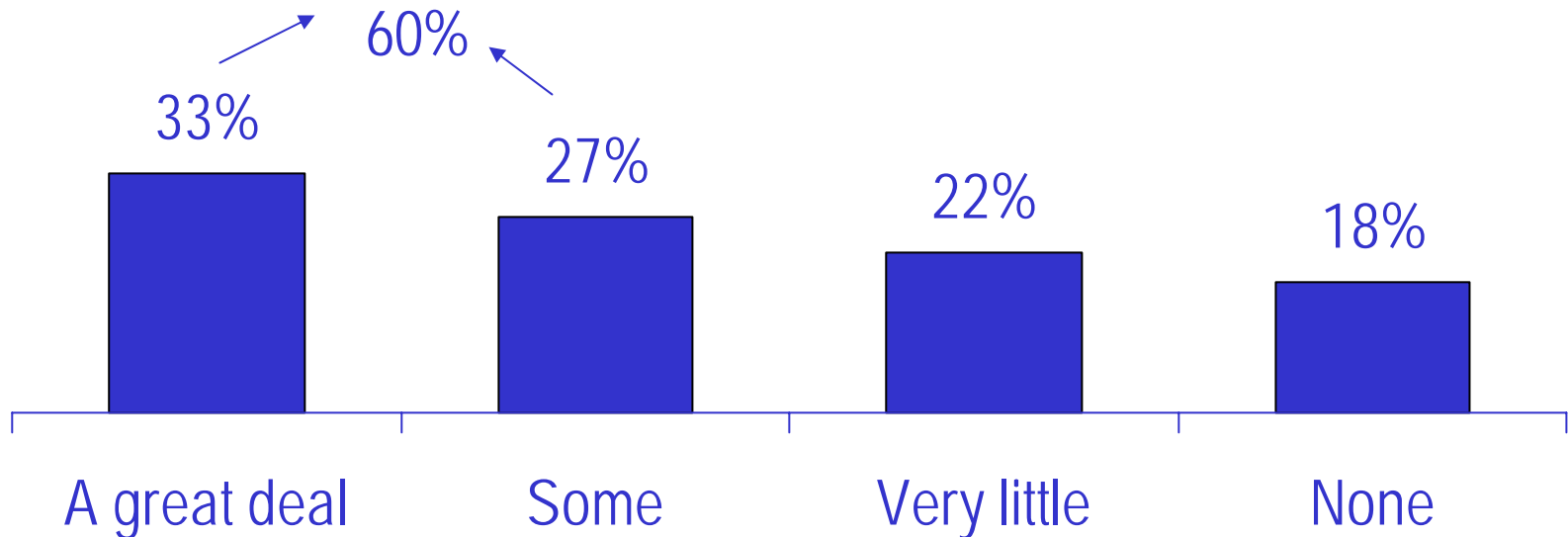




## A Majority Say Their Loved One Died in Pain

During your loved one's end of life, how much physical pain was he/she in?

(among those who could answer)



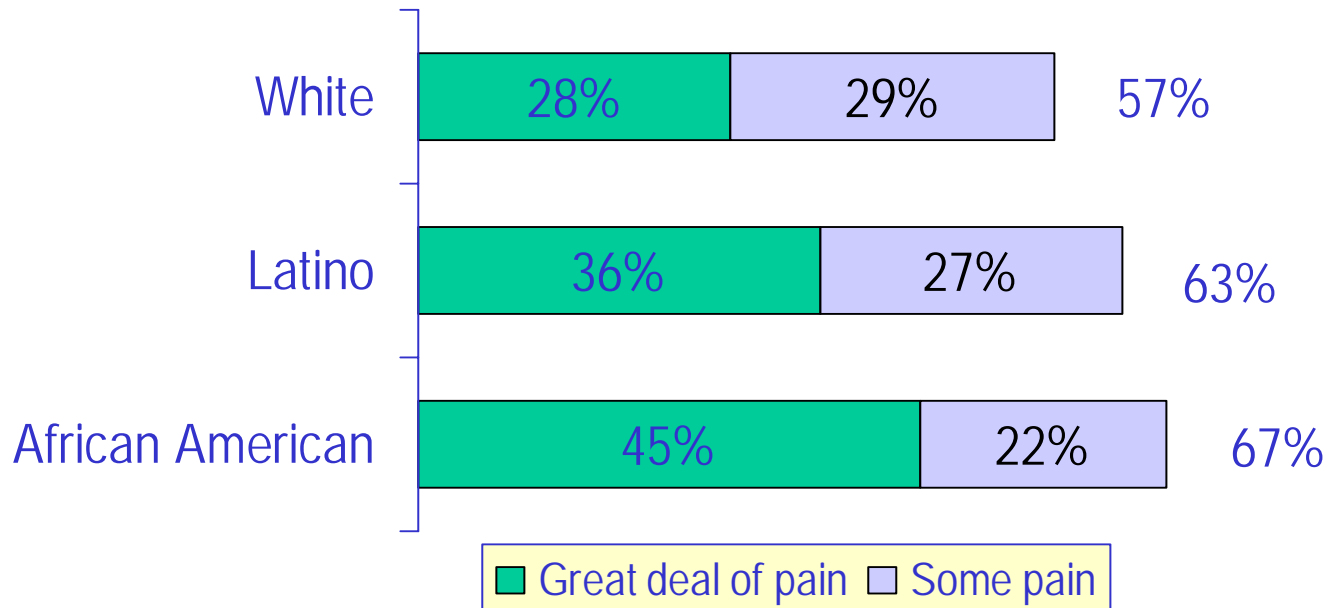


# Almost Half of African-Americans Report Their Loved One Was in a Great Deal of Pain

During your loved one's end of life, how much physical pain was he/she in?

(among those who could answer)

by Race/Ethnicity

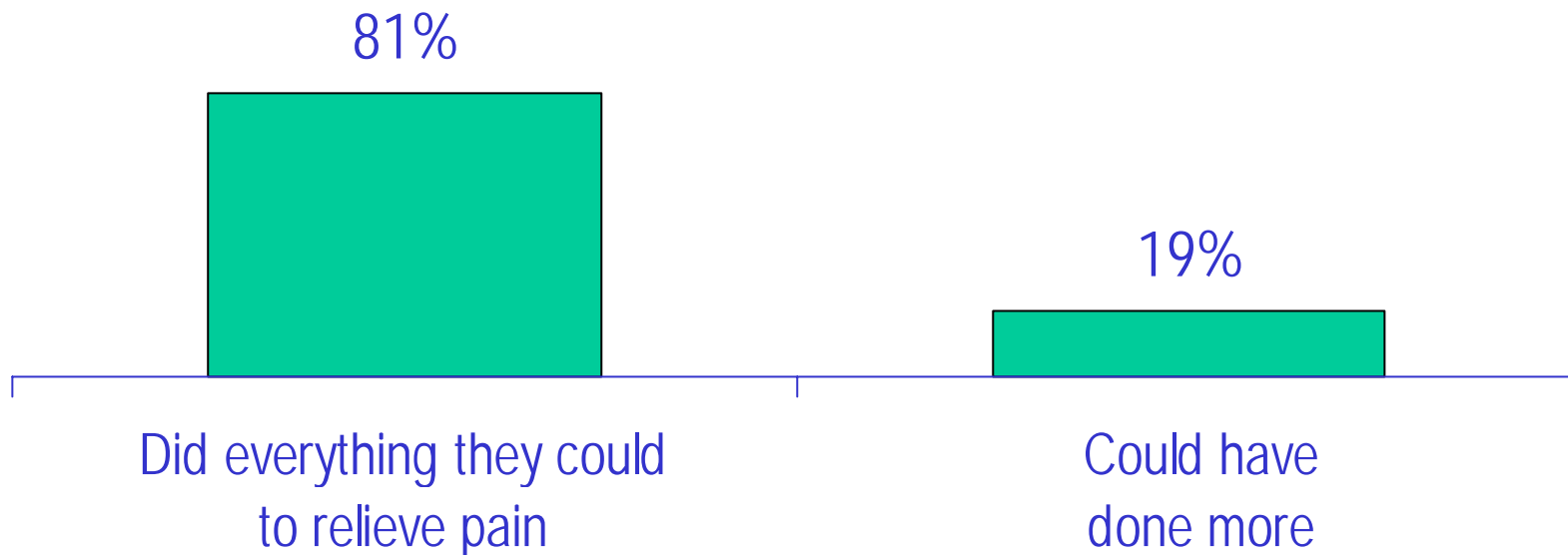




## Most Feel Providers Did All They Could to Relieve Pain

Did the health care providers do everything they could to alleviate your loved one's pain, or could they have done more?

(among those who could answer)





## Views on Providers' Efforts to Alleviate Pain Vary Somewhat by Race/Ethnicity

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Yes, providers did all they could to alleviate pain

(among those who could answer)

by Race/Ethnicity

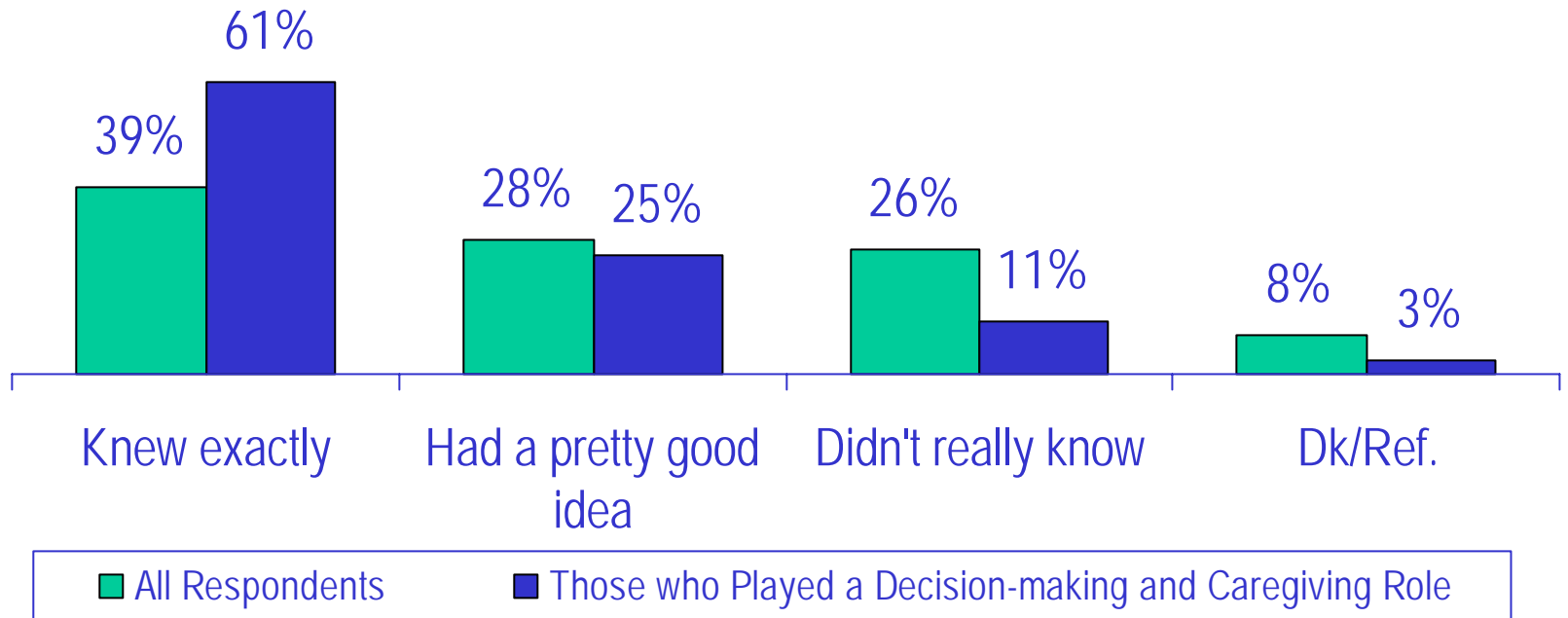






# Knowledge of Loved One's EOL Wishes Influenced by Respondent's Role

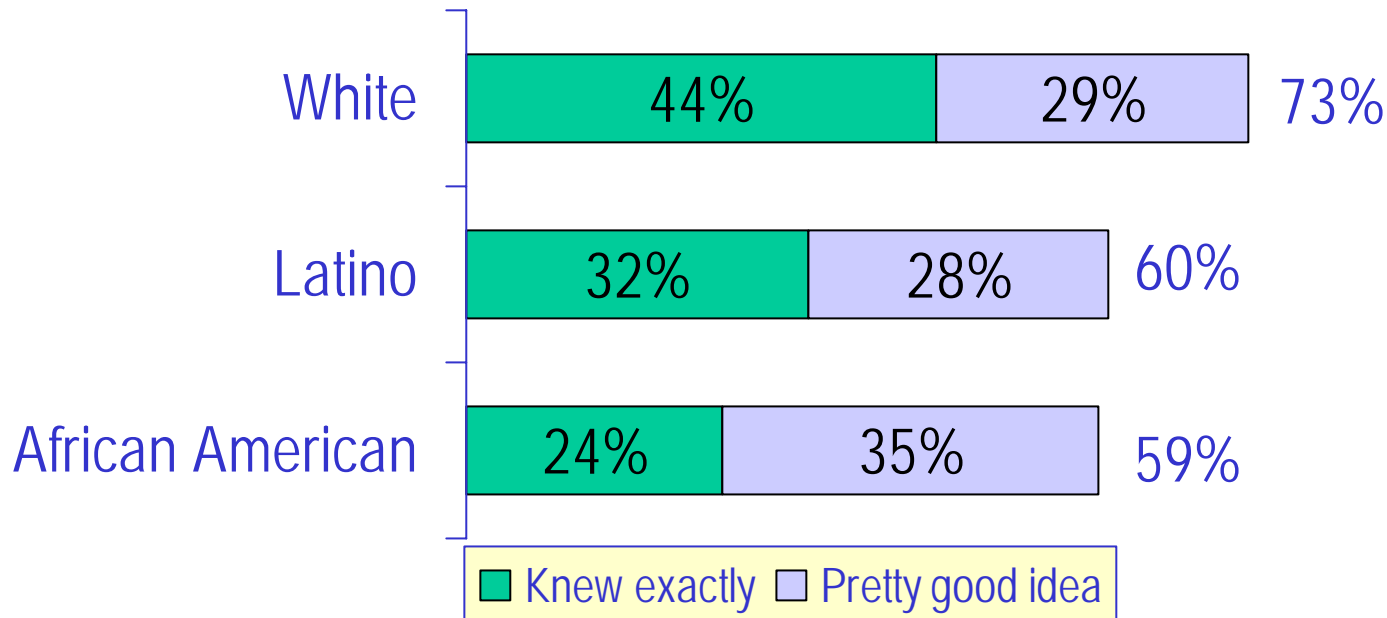
How well did you know your loved one's wishes for EOL treatment?





# White Californians More Likely than Others to Have Known Loved One's EOL Wishes

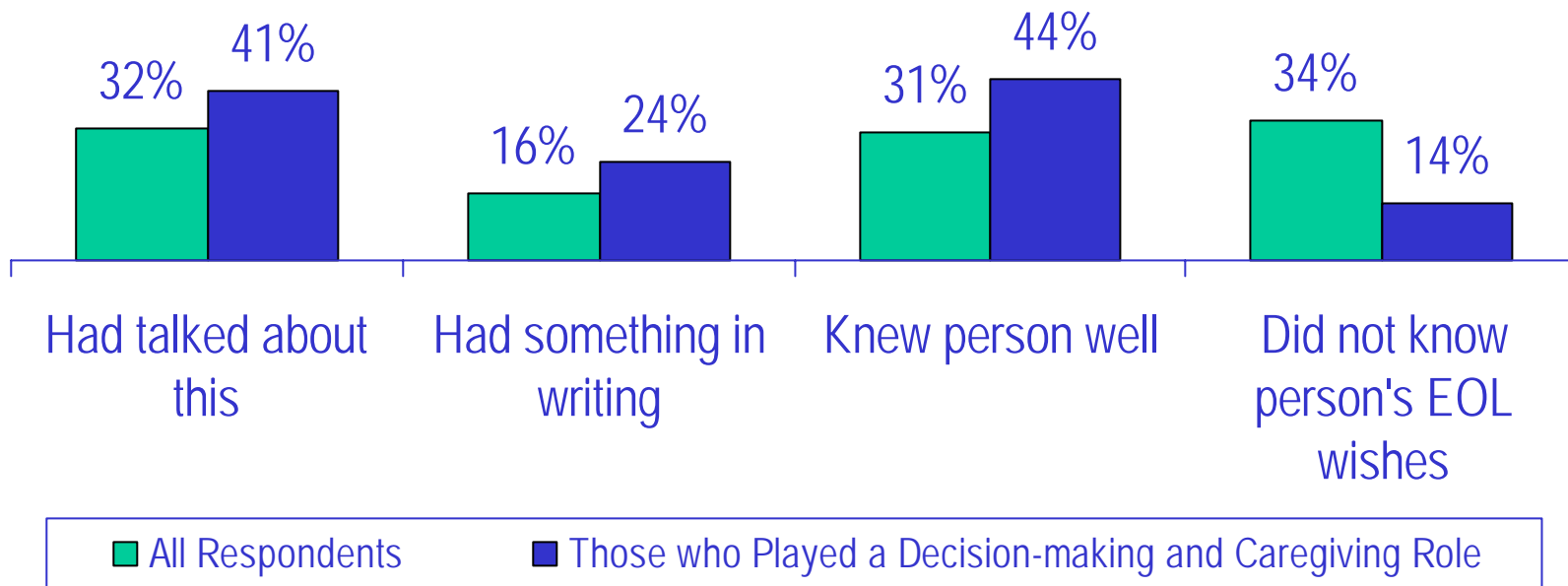
Knowledge of loved one's EOL wishes  
by Race/Ethnicity





# Respondent's Knowledge of Loved One's EOL Wishes Depends on Role Played

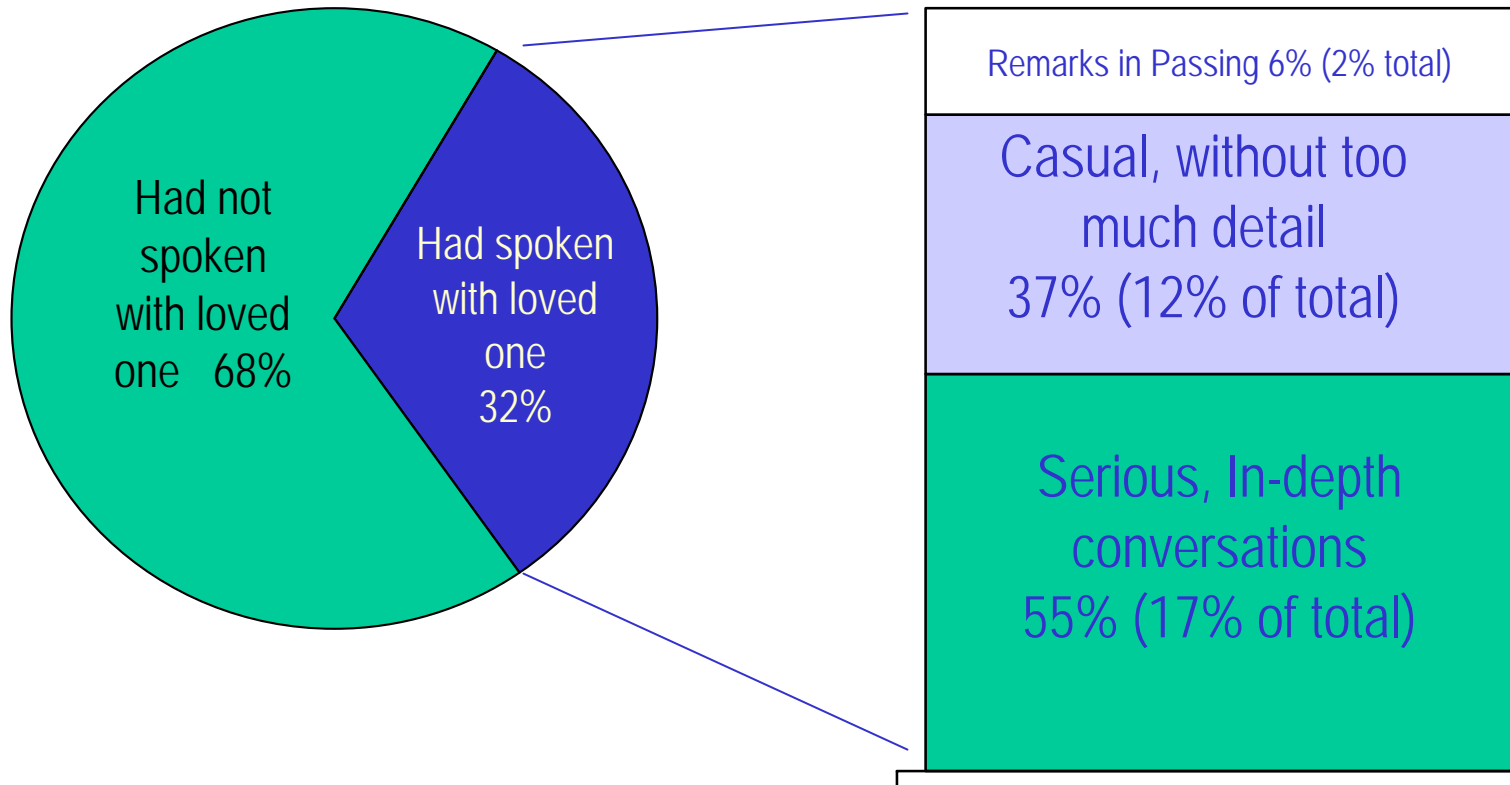
How did you know your loved one's wishes for EOL treatment?  
(Multiple responses allowed)





# Conversations about EOL Treatment Were Rare, and Some Were Casual

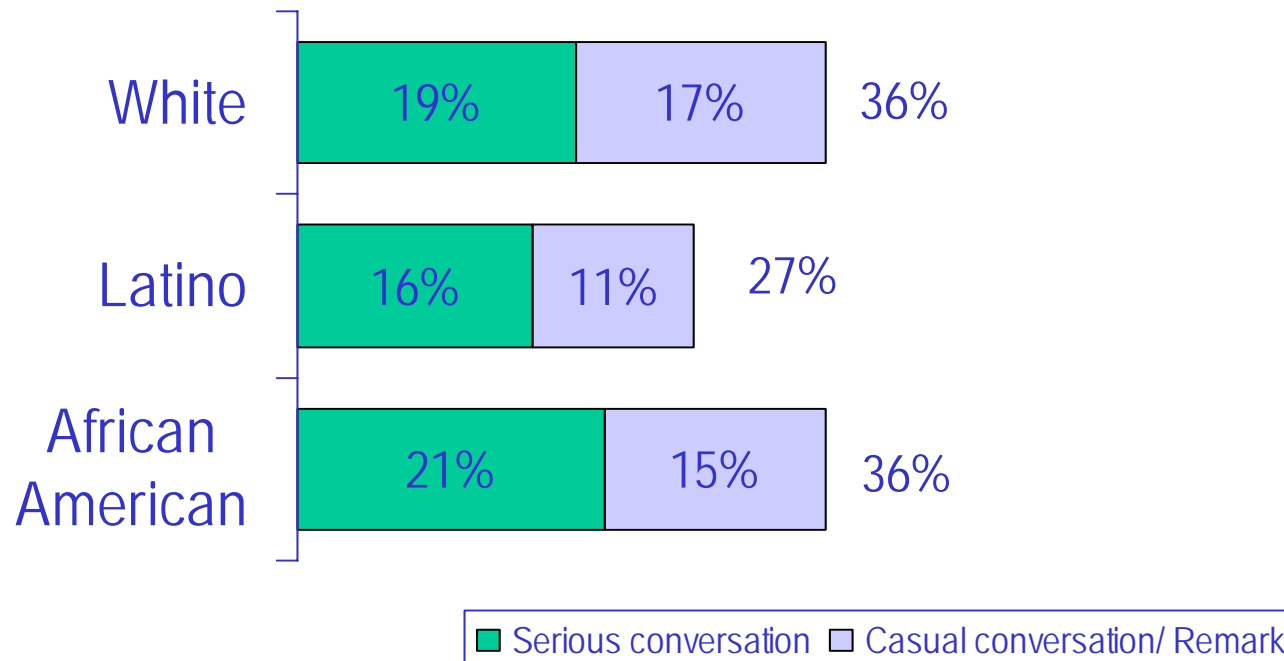
How would you describe these conversations?





# White and African-American Californians Were More Likely than Hispanics to Have Discussed EOL Issues with Their Loved One

Conversations about EOL Wishes,  
by Race/Ethnicity





## What Focus Group Participants Said About Conversations (or Lack Thereof)

---

He was not seriously ill or near death. It was just a conversation that we had because he had read the paper or something. So he said, "If this were to happen to me, I do not want to be revived. I'd just rather die." That was all. It was just a quick conversation.

- Latino Caregiver

She accepted the fact that I would make the right decisions for her.

- African-American Caregiver

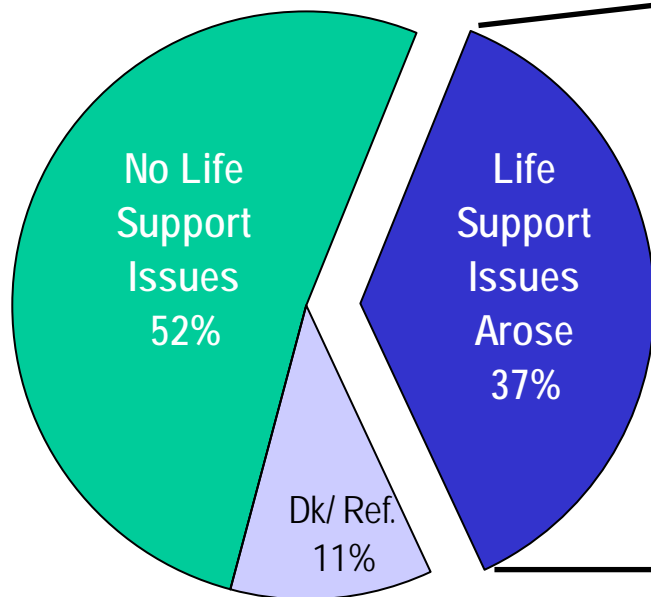
[When we asked her to sign the DNR], she got really upset. She said, "You want me to sign this, so you want me to die or what?"

- Chinese Caregiver

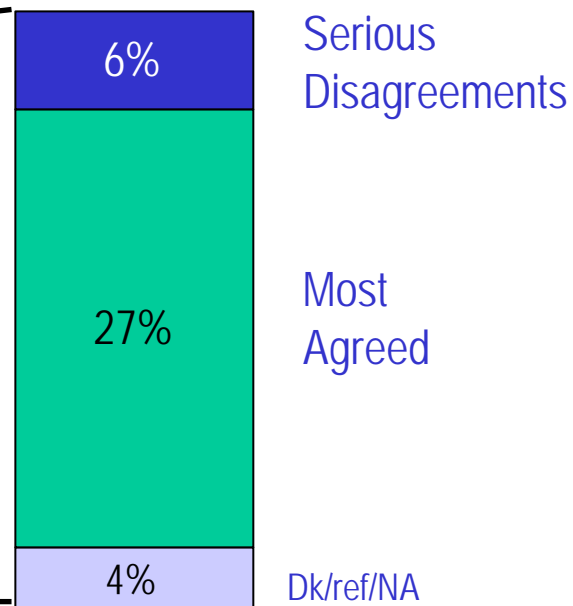


# A Third Say Life Support Issues Arose, and Serious Disagreements Arose for Some

Did life support issues come up?



Were there serious disagreements?





## Disagreements About EOL Choices

---

I have no regrets of anything I did for my father. I did exactly what my dad would have me do. And I've got a lot of people that actually despise me, and you know what, they weren't meant to be there anyway.

- White Caregiver

By the time I got back home, my mother had probably just passed away when I got there. She still had her color but she wasn't breathing. It was maybe five or six seconds after I got there, her whole color was wiped out.... Then it got all chaotic in my house, and everybody wanted to have her resuscitated, and we had already done a DNR. It was just a mess.

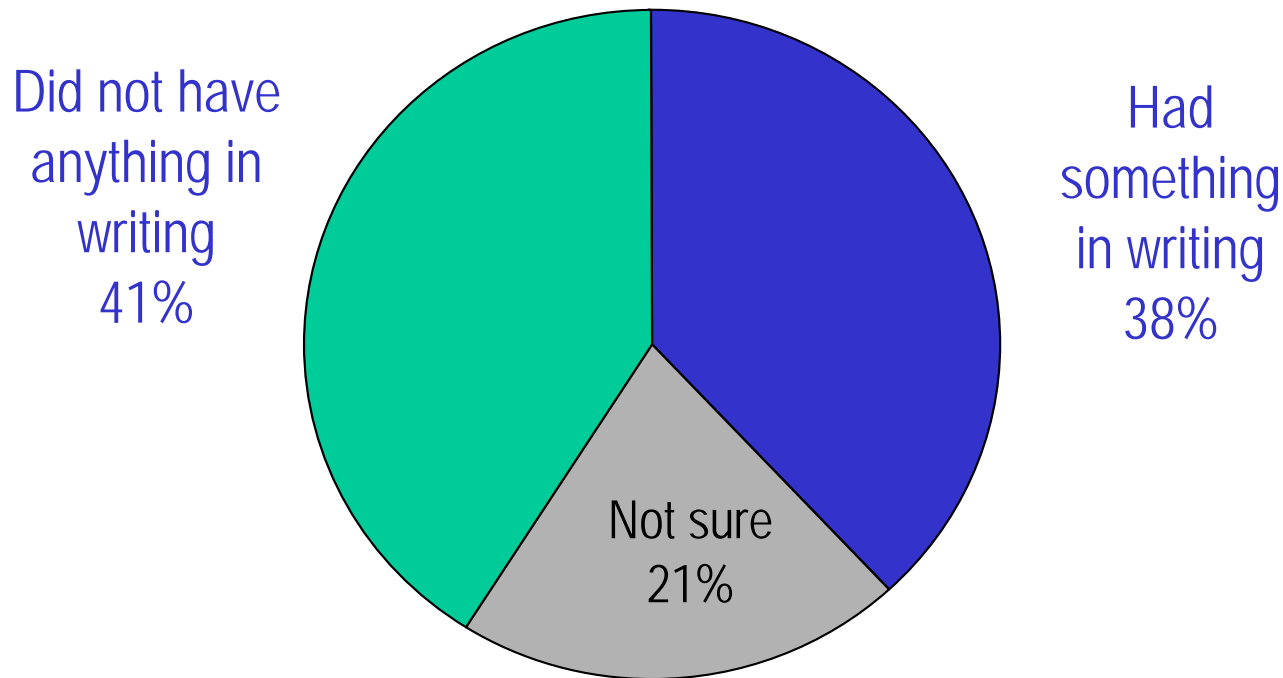
- African-American Caregiver





## Four in Ten Had Something in Writing

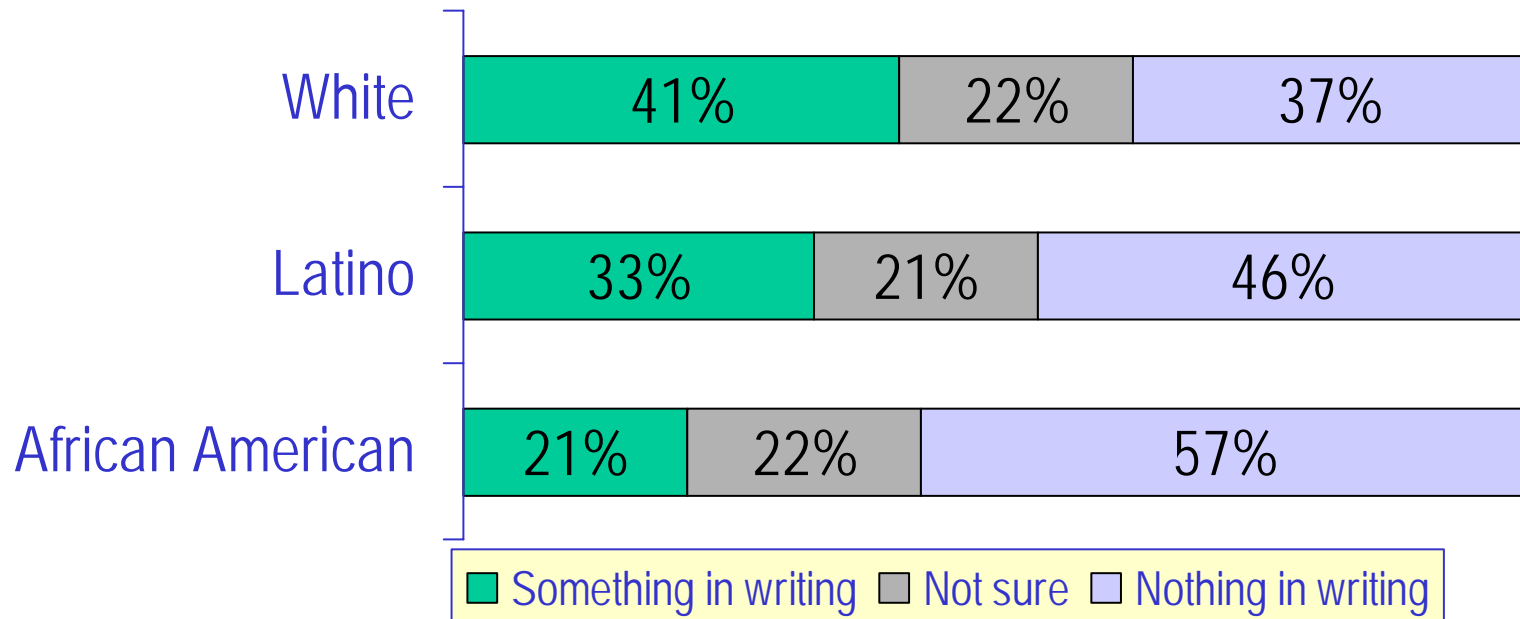
Did loved one have EOL wishes in writing?





# White Californians Are More Likely To Have Something in Writing

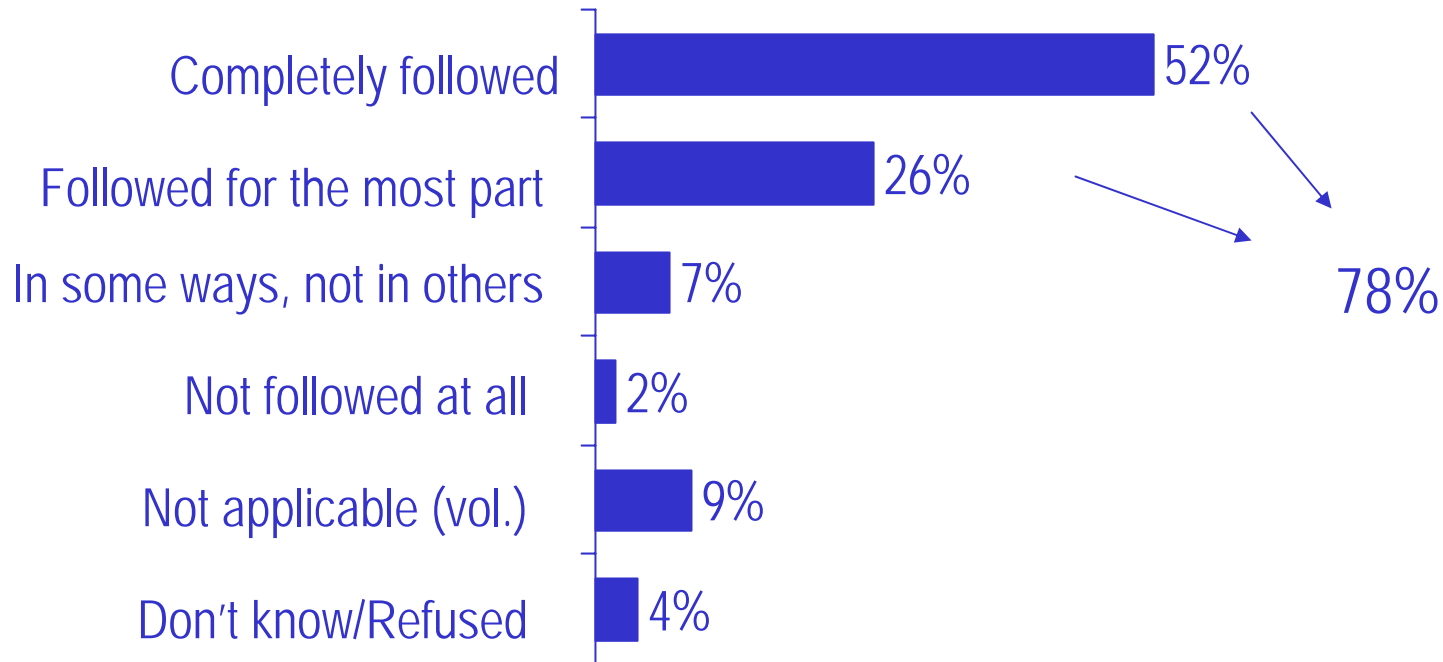
Did loved one have EOL wishes in writing?  
by Race/Ethnicity





# The Majority Say Their Loved One's Wishes Were Honored

To what extent were your loved one's EOL wishes followed and honored?





# Whites Are Most Likely to Report That Their Loved One's EOL Wishes Were Followed

Extent to Which Loved One's Wishes Were Honored  
by Race/Ethnicity

