



TO: Sean Crowley, Compassion and Choices

FROM: Amy Simon, John Whaley, and Sara Knight, Goodwin Simon Strategic Research

RE: Key Survey Findings: End-of-Life Care, Planning, and Preferences

DATE: November 30, 2023

This memo outlines key findings from a national survey fielded on behalf of Compassion & Choices in September/October 2023. Findings among Black, Hispanic, Asian, and Pacific Islander (API) subgroups include oversamples. Additional details on methodology can be found at the end of this memo.

In this survey, we explore attitudes, preferences, and experiences related to end-of-life care. There are notable differences by age for many attitudes, with younger people often reporting less familiarity and consideration of end-of-life care. We also see notable distinctions by race. For example, Black respondents report more confidence that they will receive quality of end of life health care compared to other respondents. At the same time, Black respondents also report more experiences of discrimination related to health care and more skepticism that written documents specifying end of life care preferences would be respected. Additionally, Black respondents are more likely to say they prioritize delaying death (rather than prioritizing comfort) and would choose to continue life-extending treatments at a higher percentage than others should they be diagnosed with dementia. Black respondents also show the lowest support for medical aid in dying, with Asian and Pacific Islanders showing the strongest support.

These and other key findings are outlined below.

High confidence in the quality of health care overall, with the lowest confidence in the quality of end-of-life care among Asian and Pacific Islanders.

Overall, more than eight in ten are confident that they will receive quality care when it comes to basic health care (89% overall confidence, 59% very confident), emergency medical care (87% overall, 53% very), and treatment for chronic illnesses (83% overall, 45% very). Confidence drops when it comes to treating a serious disease (76% overall, 40% very) and the quality of mental health care (76% overall, 38% very), with the lowest confidence overall in the quality of end-of-life care (71% overall, 34% very).

Those who have the most confidence in receiving quality end-of-life care include:

- Respondents aged 65 years and older (81% confident overall, 41% very confident);
- Men 45 and older (80% overall, 38% very);
- Black respondents (77% overall, 41% very); and
- Those with a four-year college degree (77% overall, 32% very).

Asian and Pacific Islander respondents are much less likely to have confidence in the quality of end-of-life care, with just 16 percent saying they are very confident (67% overall confidence).

More favor “wishes” or “preferences and priorities” when discussing end-of-life care.

When it comes to words and phrases describing end-of-life care, 80 percent overall favor (49% strongly) “wishes for end-of-life care,” 79 percent overall favor (48% strongly) “preferences and priorities for end-

of-life care,” 76 percent favor “values and priorities for end-of-life care” overall (42% strongly), and 67 percent overall favor (36% strongly) “goals for end-of-life care.”

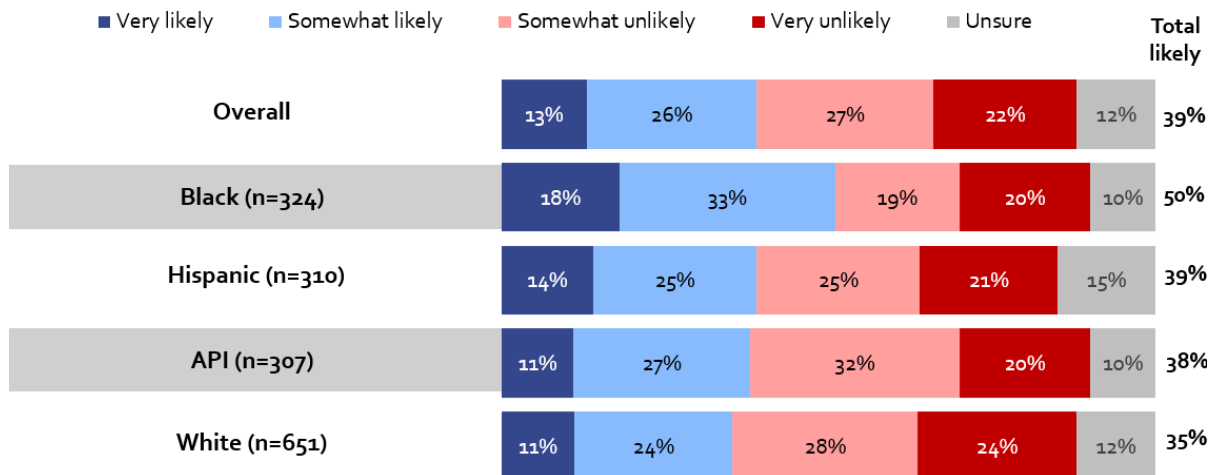
There are no significant distinctions by race or ethnicity, but those who are 65 and older favor “preferences and priorities” (84% overall) over “wishes” (78%)—and those with a four-year college degree favor “wishes” (86%) and “preference and priorities” (84%) more strongly than those without a college degree (76% for both options)

Black respondents are more likely to think aggressive medical treatments will be given to a dying person against expert guidance or stated preferences.

Half of Black respondents (50%) say it is likely that “*the dying person would be given aggressive medical treatments—even though professional medical societies, such as the American Medical Association, have determined those aggressive treatments are not beneficial.*” Fewer white (35%), API (38%), and Hispanic (39%) respondents say it is likely.

Likelihood of Aggressive Medical Treatment (by Race)

The dying person would be given aggressive medical treatments—even though professional medical societies, such as the American Medical Association, have determined those aggressive treatments are not beneficial.



Ranked by Total likely; Black, Hispanic, API subgroups include oversamples.

Forty-five percent (45%) of Black respondents also say it is likely overall that “*the dying person would receive aggressive treatments even though they had a written document specifying their preference for non-aggressive comfort care,*” – with others saying the likelihood is lower:

- Hispanic (37% likely overall)
- Asian and Pacific Islander (35%)
- Overall (33%)
- White (29%)

A higher percentage of Black respondents (44%) than other subgroups also say it is likely that “*the dying person would be resuscitated and brought back—even though they had signed a document specifying they did not want to be resuscitated,*” including:

- Hispanic (37% likely overall)
- Asian and Pacific Islander (35%)
- Overall (31%)
- White (27%)

Black and younger respondents are most likely to prioritize extending life over dying with minimal pain/discomfort.

When asked to prioritize “delaying death and extending life as long as possible” or “helping people die with minimal pain, discomfort, and stress,” almost a quarter of Black respondents (24%) and men from the ages of 18-44 (23%) say delaying death is more important, compared to 13 percent overall.

Older respondents—specifically women over 45 years old (82%) and all 65 and older (80%)—are among those most likely to say “helping people die with minimal pain, discomfort, and stress” is important, compared to 74 percent overall. Almost eight in ten Asian and Pacific Islander respondents (79%), women (78%), and white respondents (78%) also say this is important.

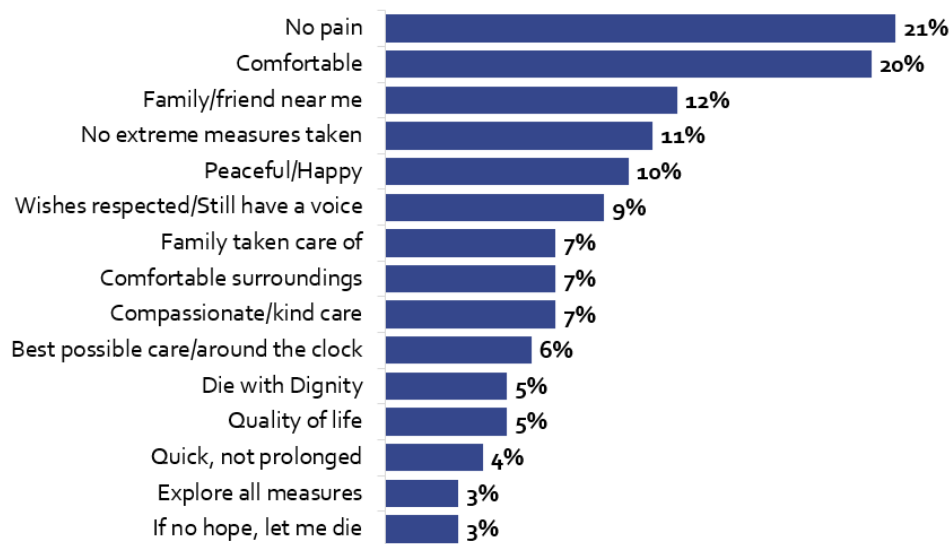
Except for white respondents, for whom education level has minimal impact, there are notable differences across race and education. Those with a college degree prioritize helping people die with minimal comfort in higher numbers than those who do not have a four-year college degree—with college-educated API and Hispanic respondents saying it is most important:

- API college+: 82%
- Hispanic college+: 80%
- White college+: 79%
- White non-college: 78%
- API non-college: 74%
- Hispanic non-college: 71%
- Black college+: 67%
- Black non-college: 59%

When asked to share in their own words what is most important about the kind of care they would receive at the end of their life, respondents say the absence of pain and being comfortable are top priorities:

Verbatims: End-of-Life Care Preferences + Priorities

What is most important when you think about the kind of care you would like to receive at the end of your life? What are your personal preferences and priorities for your own end-of-life care—should you ever need it someday?



There is strong agreement with Compassion & Choices' vision statement, with the least agreement among Black respondents.

Overall, 81 percent agree (55% strongly) with Compassion & Choices' vision statement, *"We should live in a society that affirms life and accepts the inevitability of death, embraces expanded options for compassionate dying, and empowers everyone to choose end-of-life care that reflects their values, priorities, and beliefs."*

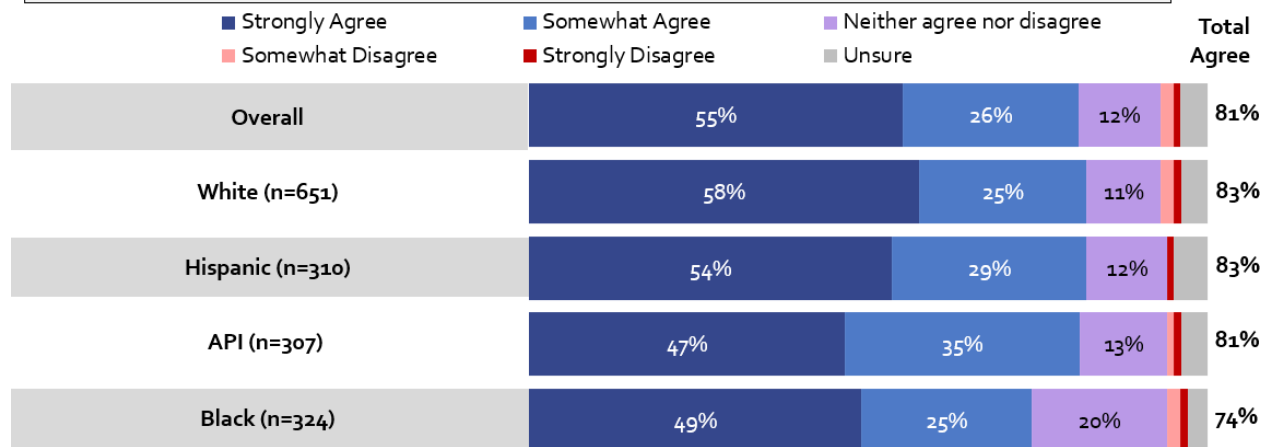
Those who are older agree even more, with 87 percent of those 65 and older saying they agree (62% strongly). Those with a college degree (84% overall, 58% strongly), particularly women (86% overall, 62% strongly), are also among those most likely to agree.

Black respondents (74% agree, 49% strongly) and those who are 18-34 (76% overall, 47% strongly) are less likely to agree.

Vision Statement: Agree or Disagree

Please read the following statement and indicate whether you agree or disagree with the statement.

We should live in a society that affirms life and accepts the inevitability of death, embraces expanded options for compassionate dying, and empowers everyone to choose end-of-life care that reflects their values, priorities, and beliefs.



Ranked by Total Agree; Black, Hispanic, API subgroups include oversamples.

Those who are the oldest have given the most thought to their end-of-life care.

Sixty-nine percent (69%) of respondents ages 65 and older report having given some (36%) or a great deal (33%) of thought to the kind of care they would like to receive at the end of their life. Those who are ages 18-34 have given their end-of-life care the least amount of thought (57% overall, 24% a great deal).

Women who are 45 and older (67% overall, 37% a great deal) also report thinking about their end-of-life care with more intensity than men in the same age range (66% overall, 27% a great deal).

Comfort, following preferences, and not burdening family are top priorities for end-of-life care.

When asked about the importance of being comfortable and without pain when it comes to end-of-life care, more than nine in ten respondents (94%) say that it is important—and 78 percent say it is *very important*. This pattern holds true across subgroups.

When it comes to *“making sure your preferences and priorities for medical care are followed”* in end-of-life care, 93 percent overall say it is important (73% very important). Those who are older ages 65+ place more importance on this (97% overall, 84% very)

“Making sure you or your family are not financially burdened” is also a top priority, with 93 percent saying it is important overall (76% very). This is also more important among those who are older, with 98 percent of respondents ages 65+ saying it is important (85% very). One hundred percent of college-educated Hispanic respondents say this is important (81% very), and 98 percent of 45+ women say it is important (84% very).

“Making sure your loved ones are not burdened by tough decisions about your care” is also important to 93 percent of respondents (72% very). Those who are 65 and older also prioritize this most strongly (97% overall, 81% very).

“Living as long as possible, even if your quality of life is poor” is the lowest priority overall (45% total important, 23% very), but 62 percent of Black respondents say this is important (38% very). Younger respondents also prioritize this more than others, with more than half of those 18-34 saying this is important for them (53% total, 28% very). Forty-nine percent of those without a college degree also say this is important (26% very).

Respondents are much more likely to report being familiar with hospice care than palliative care—but they like the idea of palliative care once they learn what it is.

When asked how familiar they are, 86 percent say they are familiar overall with hospice care (44% very familiar). Just 54 percent are familiar overall with palliative care (23% very). Those who are college-educated are more familiar with hospice (89% overall) and palliative care (62% overall).

Notably, Black respondents with a college degree are much more likely to be familiar with palliative care (75% overall, 30% very).

Favorability of hospice and palliative care follows patterns of familiarity, with 78 percent feeling favorable about hospice care (45% very) and 57 percent favorable about palliative care (28% very).

After hearing a description of palliative care, favorability increases significantly—by 23 points overall—to 80 percent (48% strongly). Those who increased their favorability most notably include:

- Non-college men: +32 points
- 45+ non-college: +30
- Some college: +29
- 65 and older: +28
- Republican men: +27
- Men: +26
- Conservative: +25

Increases in favorability by race/ethnicity are:

- Hispanic: +25
- Black: +24
- White: +22
- API: +19

Favorability of hospice care—which starts high—also increases by three points from 78% total favorable to 81% after respondents review a description. There is more movement in intensity, with very favorable increasing 8 points from 45% to 53%. Subgroups with notable increases in “very favorable” responses include:

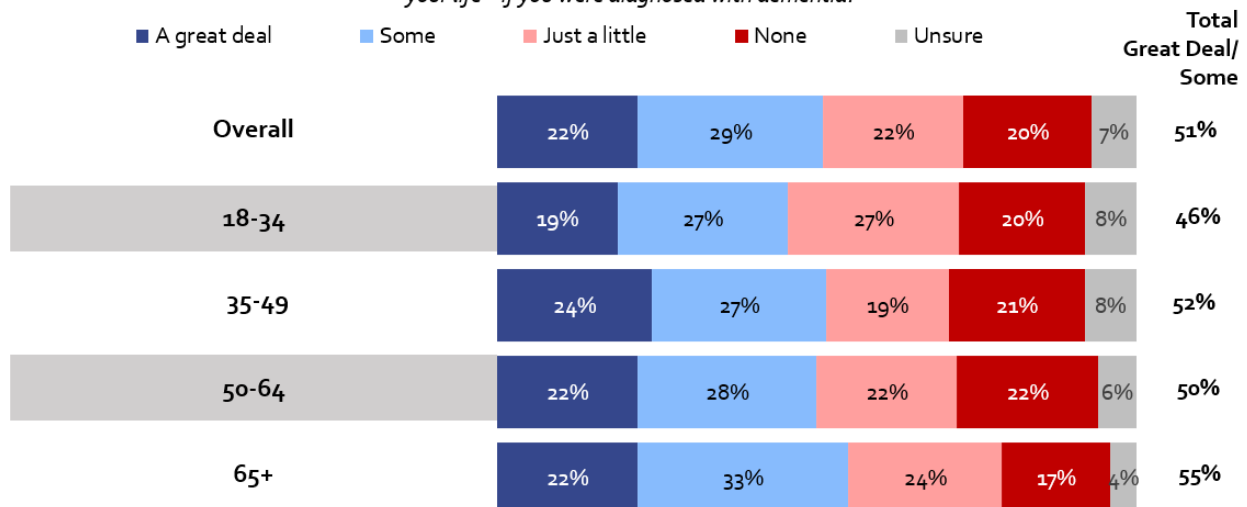
- Hispanic: +15 points
- No religion: +15
- Women college+: +12
- Women 45 and older: +11
- API: +10
- Moderate: +10
- Catholic: +10
- 65 and older: +10
- Non-college: +10
- Non-college men: +10

When it comes to dementia care, those who are older have given it more thought—and Black respondents are less likely to halt life-sustaining interventions.

Perhaps not surprisingly, older respondents report having given more thought to the care they would like to receive if they are diagnosed with dementia. Fifty-five percent (55%) who are 65 or older have given it some thought (22% a great deal of thought). However, the differences by age may be less than expected, with 46 percent of those who are 18-34 saying they have considered this scenario.

End-of-Life Care for Dementia by Age

How much thought have you given to the kind of care you would like to receive at the end of your life—if you were diagnosed with dementia?



When asked to consider the treatment they would want to receive if they were in a state of advanced dementia, half (50%) say they would want to “*stop receiving life-sustaining treatments at some point in my physical and mental decline from dementia.*”

Twenty-three percent (23%) would want to “*stop receiving food or fluids at some point in my physical and mental decline from dementia.*”

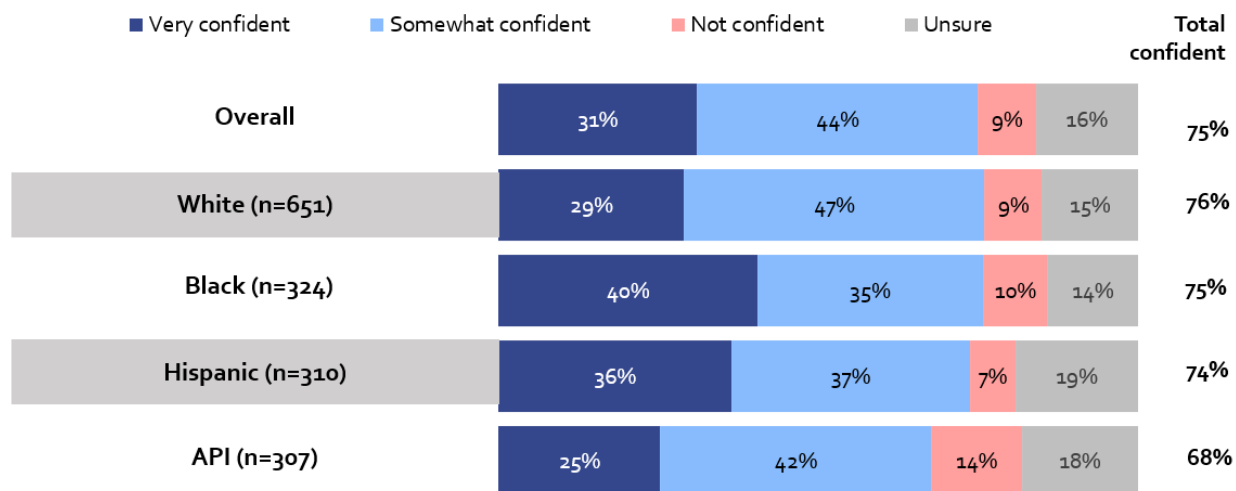
Nineteen percent (19%) would want to “*continue both life-sustaining treatments and food and fluids so I could live as long as possible—despite my physical and mental decline from dementia.*” Twenty-one percent (21%) are unsure.

There are notable differences in how respondents answer this question across race and ethnicity. Black respondents are less likely to say they would stop life-sustaining treatments (33%)—and more likely to say they would want to continue life-sustaining treatments, food, and fluids (34%)

When considering how confident they are that they would receive the dementia care they would prefer, three-quarters are confident overall—and those who are older are more confident. Those who are API are less confident than other subgroups by race/ethnicity, with 68 percent saying they are confident (25% very)

Confidence in Receiving Preferred Dementia Care by Race

Think again about your answer to the previous question. If you were in that situation, how confident are you that you will get the care that you would want?



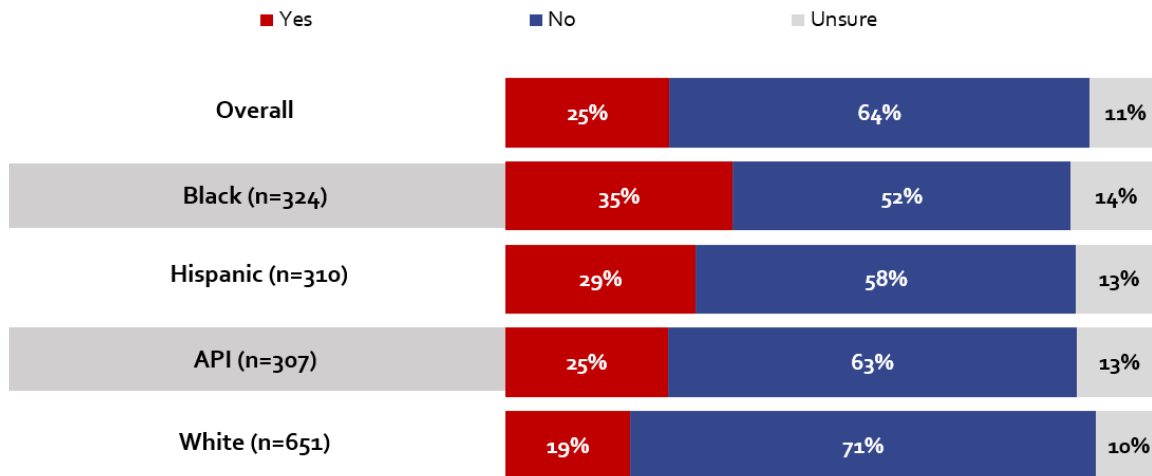
Black, Hispanic, API subgroups include oversamples.

Black respondents are more likely to report experiencing discrimination in health care than others.

Thirty-five percent (35%) of Black respondents say they have personally experienced or witnessed discrimination in their overall healthcare experiences, compared to 29 percent of Hispanic respondents, 25 percent of API respondents, and 19 percent of white respondents. Younger respondents, those ages 18-34, also report experiencing or witnessing discrimination at higher rates (34%).

Has Personally Experienced or Witnessed Discrimination: Overall Health

Thinking about discrimination in health care due to race, ethnicity, gender, disability, religion, or sexual orientation—do you feel that you personally have experienced or witnessed discrimination in your overall health care experiences (not including end-of-life care)?

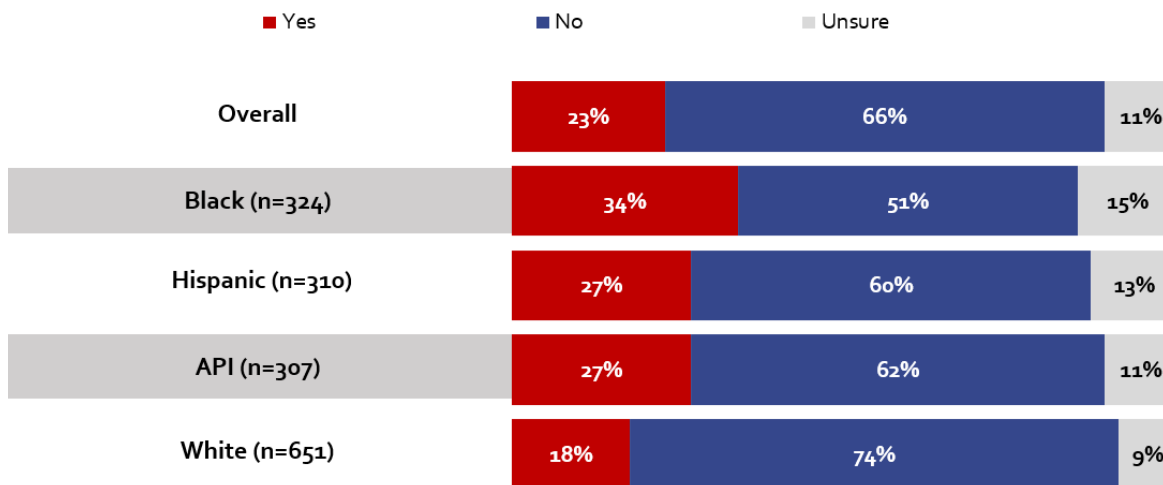


Black, Hispanic, API subgroups include oversamples.

This pattern holds true when respondents report witnessing or experiencing discrimination in end-of-life care for family or loved ones, with 34 percent of Black respondents reporting they have experienced this—with more Black respondents (43%) ages 18-44 saying they have had these experiences.

Has Personally Experienced or Witnessed Discrimination: Family or Loved One's End-of-Life Care

Thinking about discrimination in health care due to race, ethnicity, gender, disability, religion, or sexual orientation—do you feel that you personally have experienced or witnessed discrimination with your family or other loved ones related to end-of-life care?



Black, Hispanic, API subgroups include oversamples.

Strong support for medical aid in dying

Overall, 66 percent of respondents report being familiar with “*medical aid in dying*” (23% very familiar). Thirty-six percent (36%) report hearing or reading about people requesting medical aid in dying (51% have not), with Black respondents least likely to report hearing about this across race and ethnicity subgroups:

- White: 37%
- Hispanic: 35%
- API: 30%
- Black: 28%

Respondents report having heard about people requesting medical aid in dying at the same rate across most age groups (37-38%), higher percentage than other age groups, except for those ages 50-64, who report having heard about it at slightly lower rates (32%):

- 18-34: 38%
- 65+: 37%
- 35-49: 37%
- 50-64: 32%

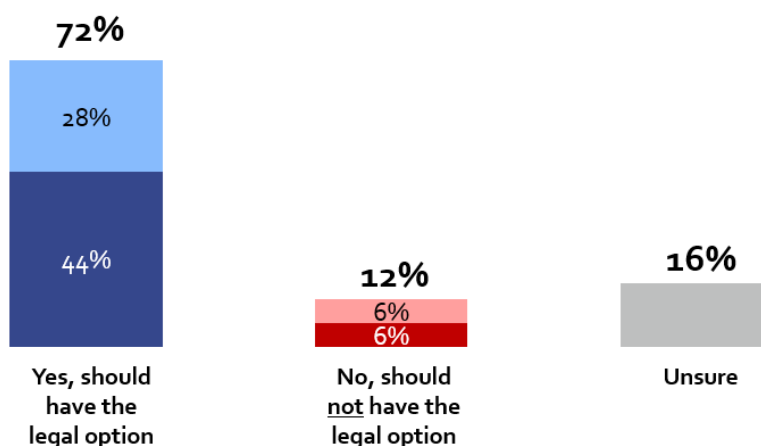
Of those who have heard about people requesting medical aid in dying, more than half of respondents (55%) say what they have heard or read makes them more inclined to support medical aid in dying, with 31 percent saying they are much more inclined. Seventeen percent (17%) say they are less inclined to support medical aid in dying based on what they have heard or read. Black and Hispanic respondents are more inclined to support medical aid in dying based on what they have heard or read—61% total inclined for both—than other race and ethnicity subgroups.

More than seven in ten (72%) support the legal option for medical aid in dying when asked the question, “Do you think a mentally sound adult with an incurable, terminal illness—who only has six months or less to live—should have the legal option of medical aid in dying to get prescription medication they may take to pass peacefully in their sleep?” This includes 44 percent who support it strongly.

Support for Legal Option to Pass Peacefully

Do you think a mentally sound adult with an incurable, terminal illness—who only has six months or less to live—should have the legal option of medical aid in dying to get prescription medication they may take to pass peacefully in their sleep?

■ Yes—feel strongly ■ Yes—feel somewhat ■ No—feel strongly ■ No—feel somewhat ■ Unsure



Among race and ethnicity subgroups, white, API and Hispanic respondents show the strongest support (72-73%), and Black respondents (66%) show the lowest:

- White: 73%
- API: 73%
- Hispanic: 72%

- Black: 66%

There is no statistically significant difference across age groups, which is notable given other distinctions by age in the survey:

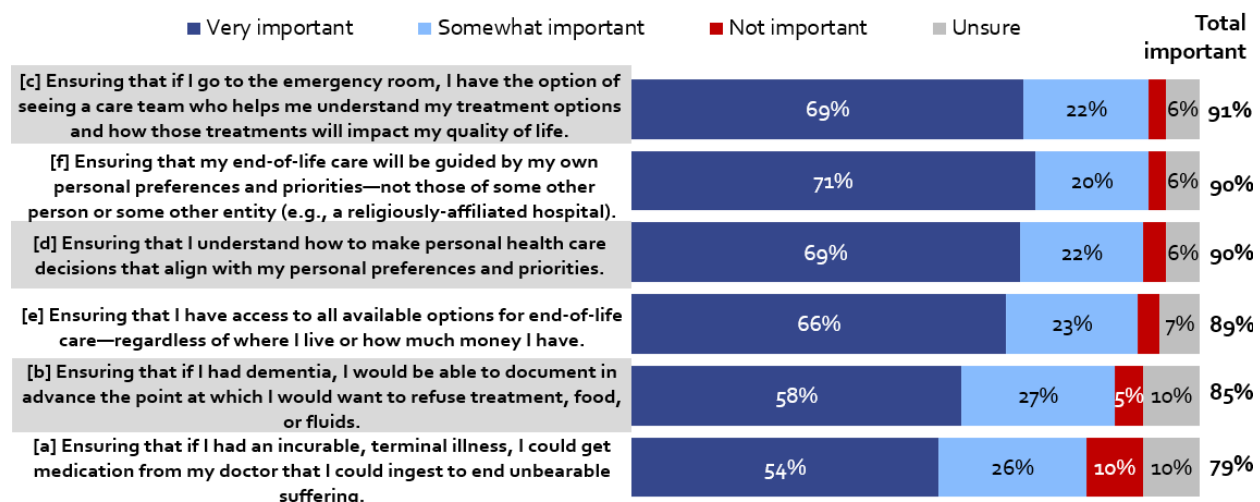
- 65+: 73%
- 35-49: 73%
- 18-34: 71%
- 50-64: 70%

While support for medical aid in dying is strong—79 percent important overall, 54 percent very important—it is a lower priority for respondents than the other aspects of end-of-life care that were asked, as outlined in the chart below.

API and Hispanic respondents say medical aid in dying (item [a] below) is important at a higher percentage (84% and 82%, respectively) than those of other race or ethnic groups.

Importance of Aspects of Personal End-of-Life Care

Thinking again about the kind of care you would like to receive at the end of your life, how important are each of the following for you personally?



Ranked by Total important

Conclusion

The survey shows clear insights into people's perspectives, experiences, and attitudes about end-of-life care and considerations—including honoring personal preferences and wishes, which is deeply important across the board.

If you have questions about the survey findings or would like more information, please contact Amy Simon (amys@goodwinsimon.com).

Methodology

- *National online survey of n=1,648 registered voters conducted on behalf of Compassion & Choices between September 22 – October 4, 2023, including oversamples among Black (n=324), Asian and Pacific Islander (API) (n=307), and Hispanic respondents (n=310).*
- *Oversamples were weighted down to reflect the national electorate in the overall sample; the weighted nationally representative sample size is n=1,002.*
- *Due to rounding, a sum of percentages may appear to be one point more or less than its parts.*
- *Susquehanna Polling & Research advised on questionnaire development and provided input on initial analysis of key findings.*