

A BETTER DEATH

Texans' Views and Experiences with End-of-life Issues

Research Summary

June 2023

**PERRY
UNDEM**



**St David's
FOUNDATION**

Introduction

DYING IS A REALITY. Whether it is from the perspective as a patient, a caregiver, or as a family member or friend, the issue will touch each of us at some time in our lives. Yet, end-of-life discussions and planning are often the most overlooked areas of our lives. Many find these issues difficult to discuss or have not spent much time thinking about what they might need or want at the end of life. It is a topic that is not often talked about between family and friends, or even with those tasked with caring for us as we age or face serious illness. However, we know that end-of-life preparation can improve the quality of care and follow through on the wishes of the individuals in this phase of life.

What is end-of-life care? End-of-life care is the term used to describe the support and medical care given during the time surrounding death. This type of care does not happen only in the moments before breathing ceases and the heart stops beating but also with people who are aging or living with one or more chronic illnesses who need significant care for days, weeks, and even months before death.

St. David's Foundation commissioned PerryUndem to conduct a statewide survey to better understand Texan's experiences, end-of-life priorities, and barriers around end-of-life care. The survey took place August 10 through November 15, 2022, among 2,305 Texas adults from two samples, including 902 respondents who have had a loved one recently pass away in Texas. A full methodological report can be found [here](#).

This study uncovered that most Texans have similar preferences at the end of their lives - such as wanting to die at home and being free of financial burdens of care. However, only a third of Texans say their loved one's end-of-life experiences went the way they wanted it to go. **Data suggests that most Texans, even older adults, are unprepared for decisions about end-of-life care.**

PERRYUNDEM RESEARCH is a non-partisan public opinion research firm based in Washington, DC, working on health care, gender and racial equity, and other public policy issues.

ST. DAVID'S FOUNDATION is a community-focused and equity-driven organization supporting health and wellness in five Central Texas counties. It is one of the largest health foundations in the United States, funding over \$85 million annually in a five-county area surrounding Austin, Texas.

To learn more, visit stdaidsfoundation.org.

Key Findings

KEY FINDING #1

A majority of Texans are on the same page when it comes to their end-of-life preferences.

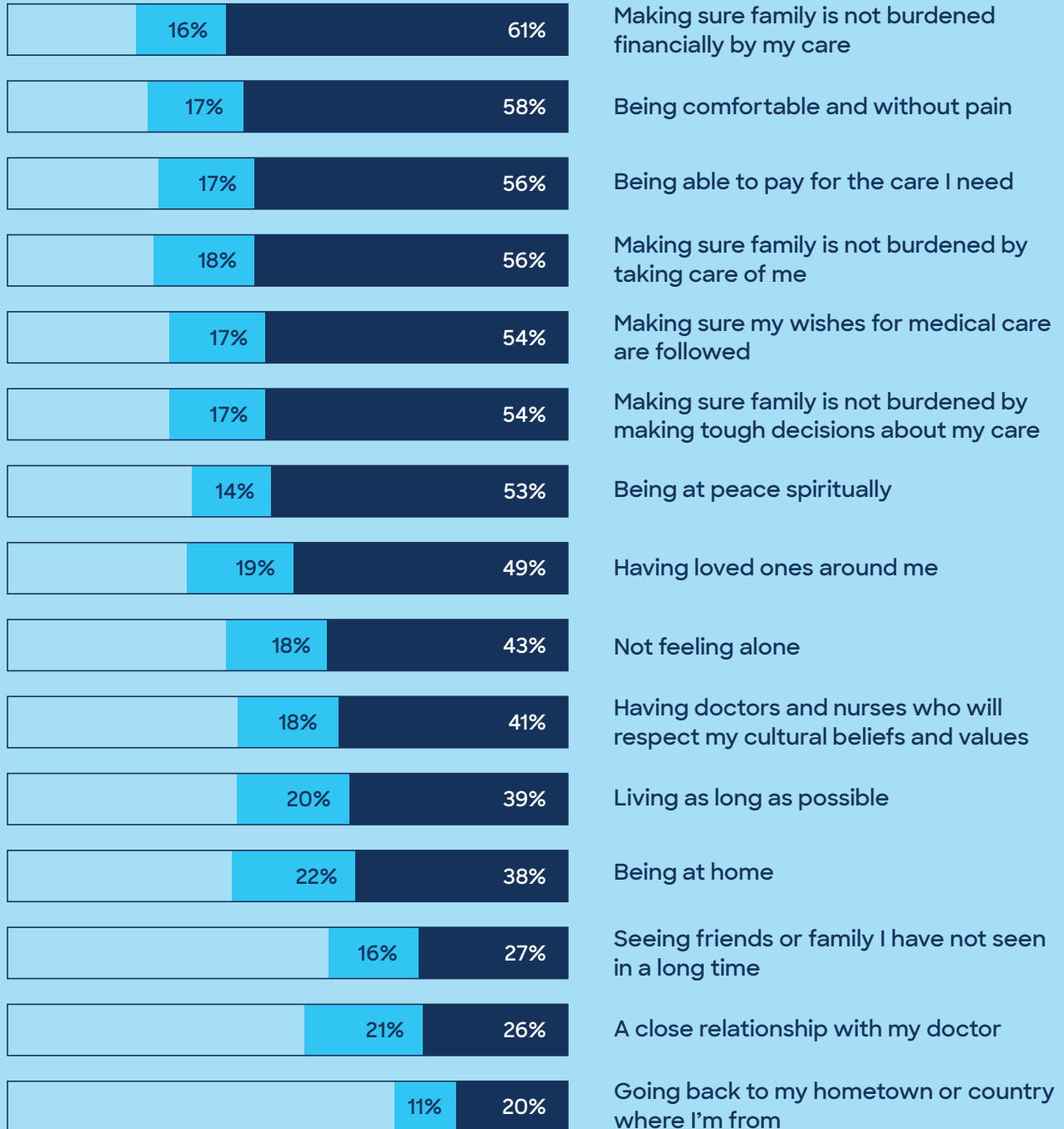
A large majority of respondents say they would want to die at home if they are able to (76%). Fewer than one in six say they'd want doctors and nurses doing everything possible to attempt to prolong their life. These preferences are fairly consistent across demographic segments of the population.

When asked about end-of-life priorities, Texans value not burdening their loved ones. Large majorities prioritize making sure their family isn't burdened by their care financially (77%), through caregiving responsibilities (71%), or by making tough decisions about their care (74%). Other top priorities include being comfortable and without pain (75%), being able to afford care (73%), and ensuring wishes for medical care are followed (71%). Fewer Texans say living as long as possible is among their top priorities (59%). Black Texans highly value being at peace spiritually and having providers respect their cultural beliefs and values.

How Important Is Each of the Following to You at the End of Your Life?

On a scale of 1 to 7, with 7 being extremely important

■ Rating of 6
 ■ Rating of 7, extremely important



KEY FINDING #2

Just a third of Texans (37%) say their loved one's end-of-life experience went the way they wanted it to go.¹

The gaps between patients' needs and wishes as compared to their experiences were uncovered throughout the survey:

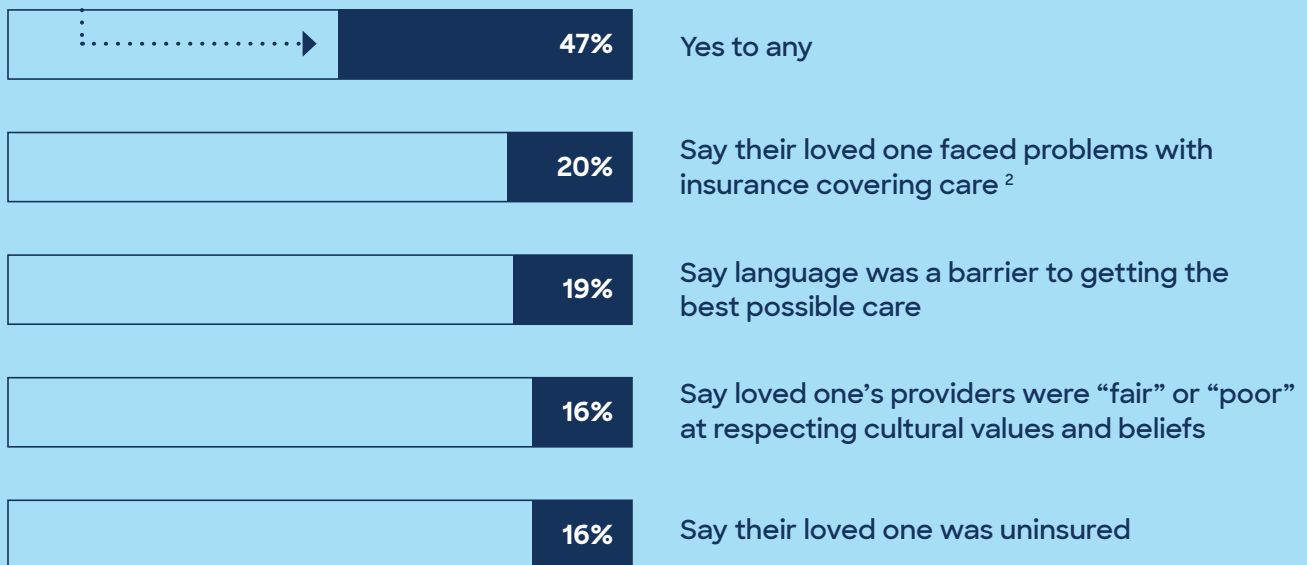
- While 70% say their loved one preferred to die at home, only 37% did so.
- While nearly all respondents (75%) say “being comfortable and without pain” is important to them toward the end of their life, just half (55%) say their loved one's providers did everything possible to help with pain and side effects.
- Texans also prioritize having wishes for medical care followed at the end of life (71%). Yet, just half (50%) of Texans say their loved one's providers took their concerns seriously.

¹Among the n = 902 respondents who had a loved one recently die in Texas

We find that close to half (47%) say their loved one faced some type of challenge related to care, such as problems with insurance coverage, being uninsured, or encountering language or cultural barriers.

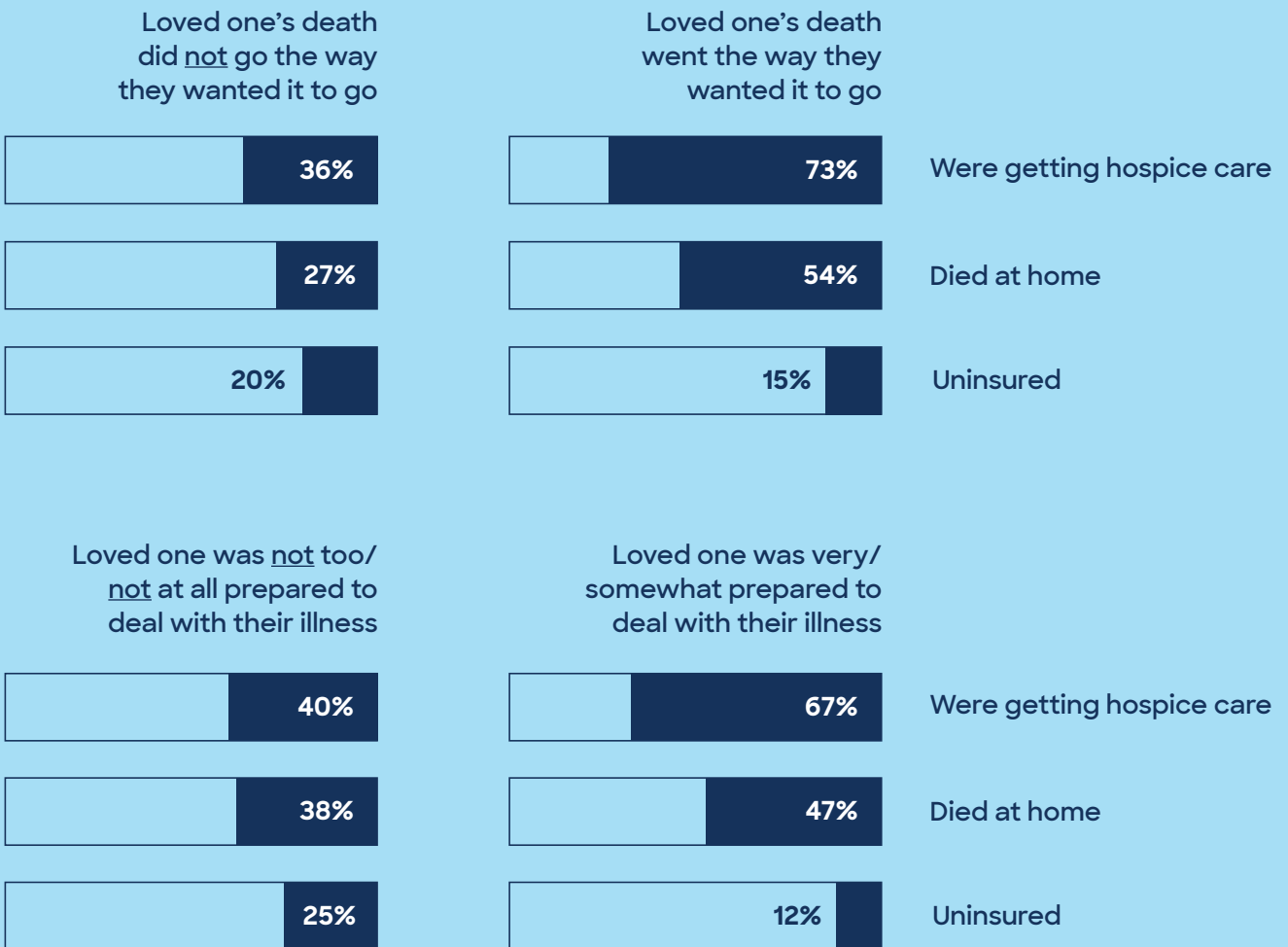
Across measures, we find that **having health insurance, receiving hospice care, and dying at home are associated with more positive end-of-life experiences.**

Loved-One Experienced Barriers to Accessing End-of-Life Care



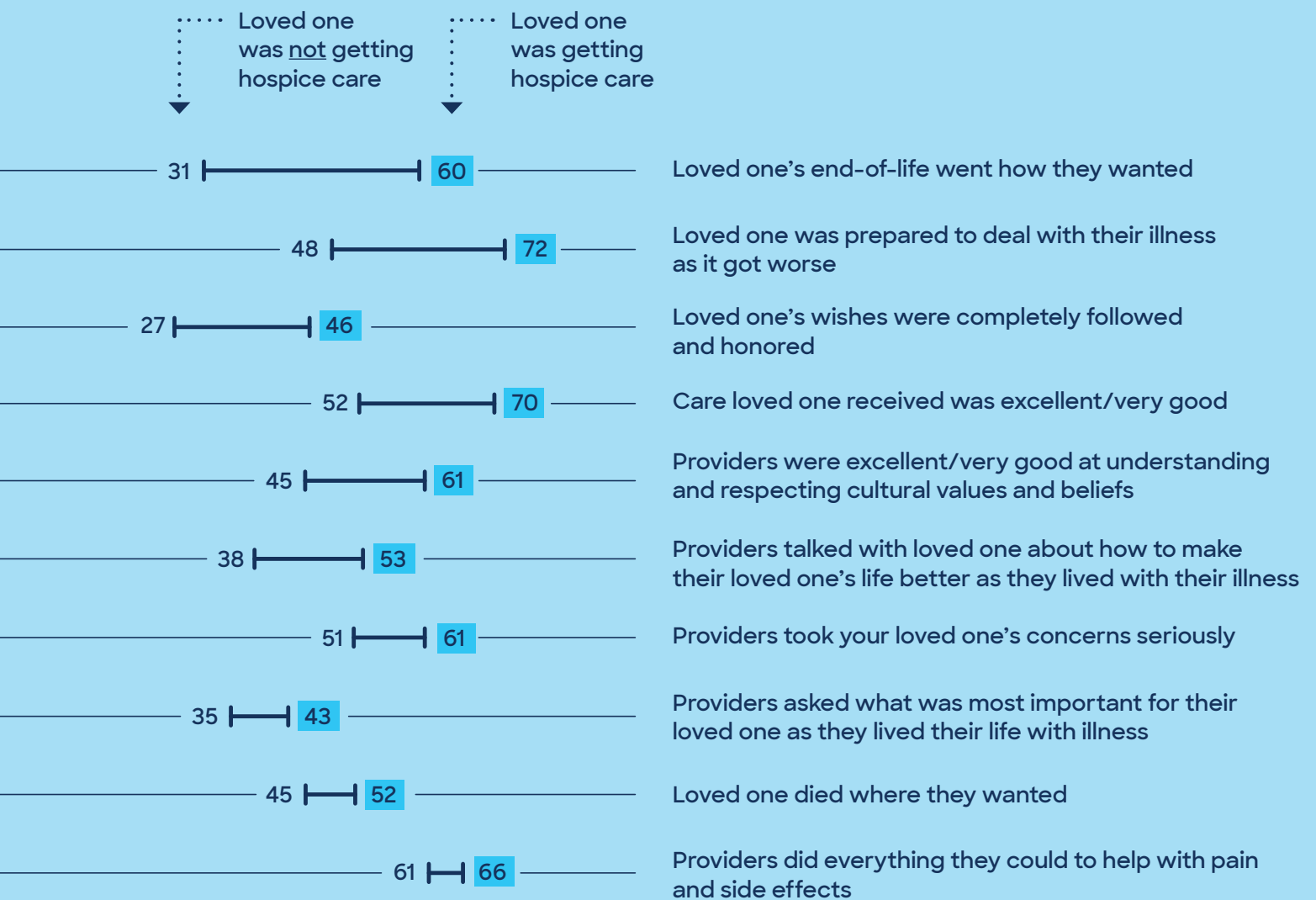
² Among the n = 589 respondents whose loved one was insured

For instance, loved ones whose deaths went the way they wanted were twice as likely to have died at home and twice as likely to have been receiving hospice care as those whose deaths did not go the way they wanted.³



³ Among n = 485 respondents who had a loved one recently die in Texas of a serious illness

These differences in outcomes are especially stark among those who received hospice care. These loved ones were reported to have been more prepared to deal with their illness as it progressed, have had their wishes completely followed and honored, and have had better provider relationships around respecting cultural values, managing pain, taking their concerns seriously, and overall better care.⁴

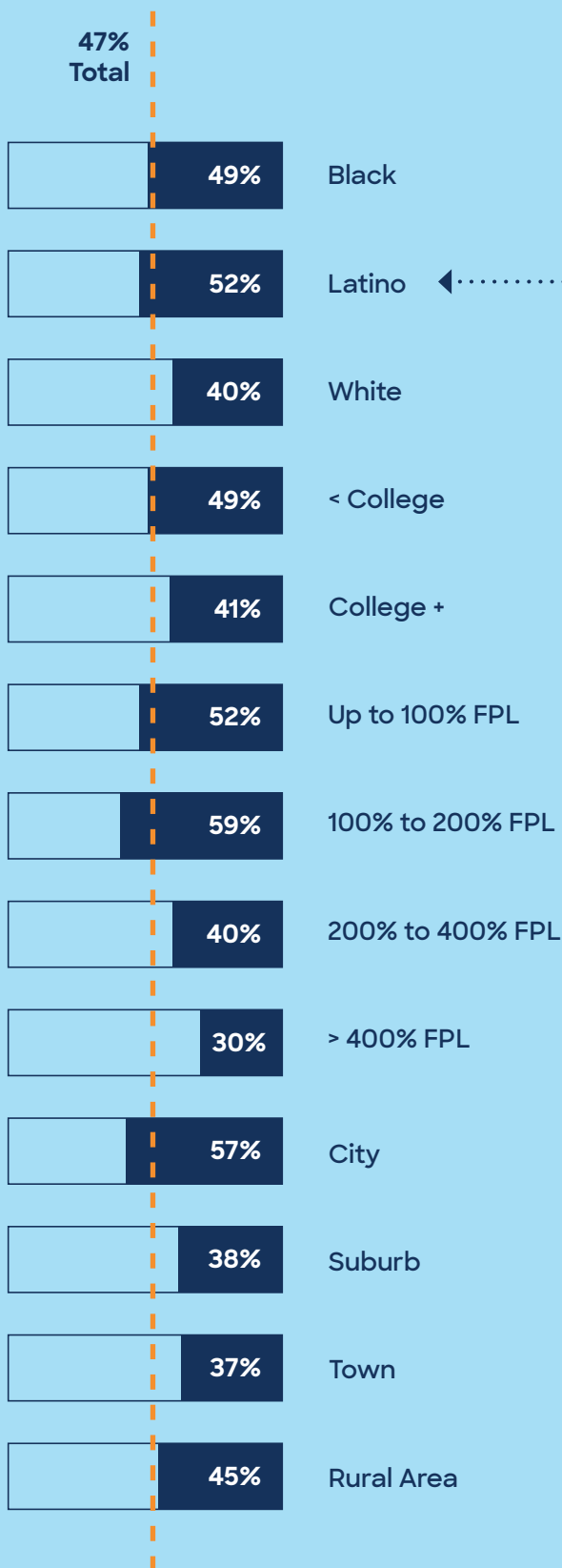


⁴ Among n = 485 respondents who had a loved one recently die in Texas of a serious illness

Black and Latino respondents report more challenges related to end-of-life care. Both Black and Latino respondents are less likely (34%) to say their loved ones received hospice care than their white counterparts (47%). Given the impact of hospice care on end-of-life experiences, these gaps likely translate into more adverse end-of-life experiences for Black and Latino Texans. Black Texans are also less likely (47%) than white respondents (58%) to say their loved one’s wishes were followed and honored “completely” or “for the most part.”



% Who Say Their Loved One Faced Some Type of Challenge Related to End-of-Life Care



These disparities are especially prominent around challenges in accessing end-of-life care.

Black respondents, Latino respondents, respondents with lower incomes, and urban respondents are more likely to say their loved ones faced barriers related to end-of-life care.⁵

Among Black respondents the most common challenge was getting insurance to cover care (24%) and providers not understanding and respecting cultural values and beliefs (22%). For Latino respondents language barriers (24%) and being uninsured (20%) were the largest challenges. Low-income Texans reported the most difficulties with insurance not covering care (27%) and being uninsured (20%).

⁵ Facing a barrier to end-of-life care is defined as either facing problems with insurance covering care, being uninsured, having providers who were “fair” or “poor” at respecting cultural values and beliefs, and facing a language barrier to receiving care

KEY FINDING #3

**Most Texans lack preparation for end-of-life care
and decisions.**

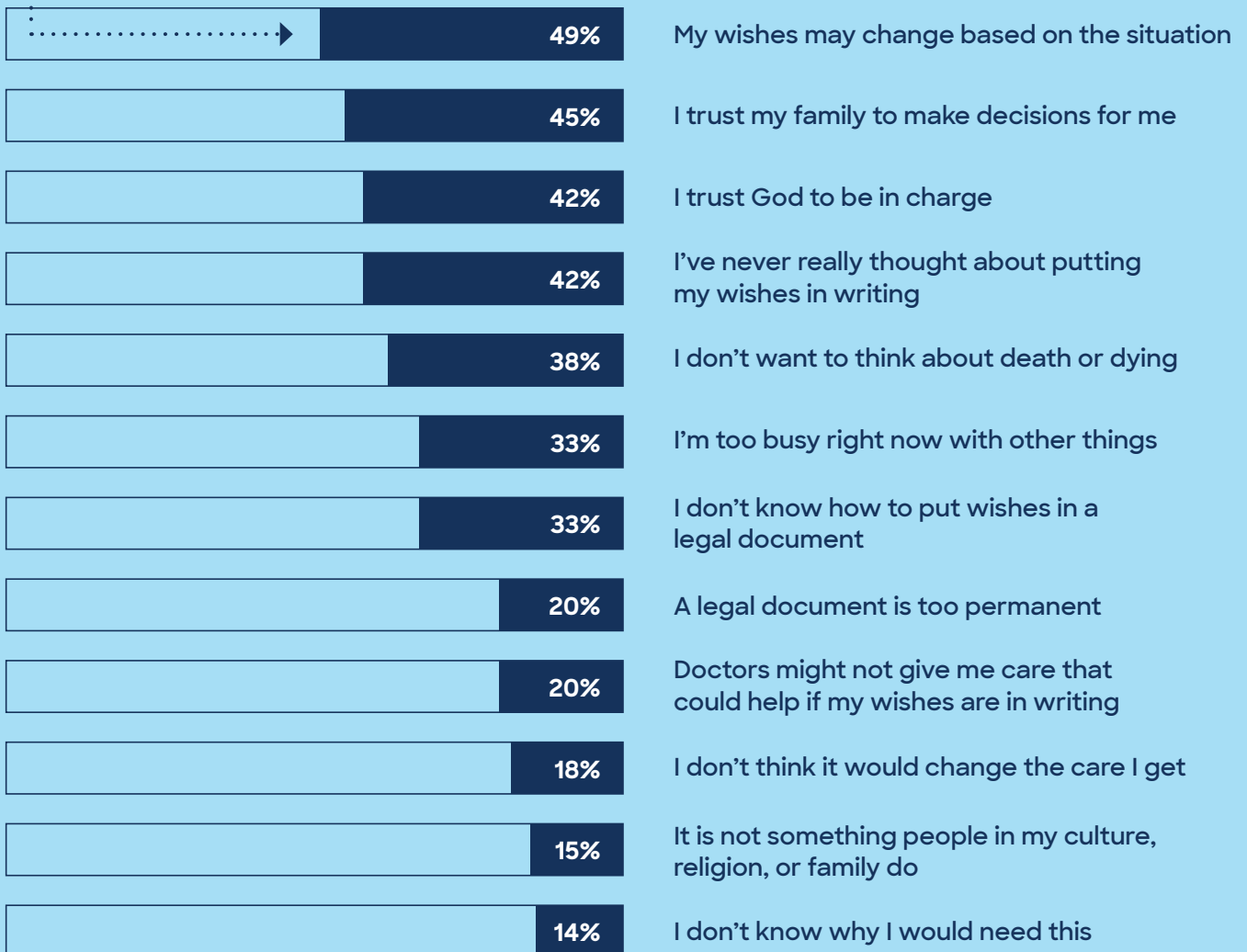
Just 25% of those who had a loved one die from a serious illness in Texas say their loved one was “very prepared” to deal with their illness as it progressed. We find similar themes when asking respondents about their own level of preparedness.



Texans recognize the importance of having their own wishes in writing, yet many do not. **While a majority of respondents (87%) say it's important to have wishes regarding end-of-life medical treatment in writing, fewer than half (39%) have done so** – including 48% of the oldest respondents (60 and older) and 46% of respondents with a serious illness. The top reasons for not having wishes in writing relate to changing wishes, trust in family or God, and never having thought to put wishes in writing.

N=1,369
Texans

% Who Say This Is a Reason Why They Don't Have Their Wishes in Writing



Texans are not having important conversations about end-of-life care. Three-quarters of respondents (74%) say they'd want to have a conversation with their doctor about end-of-life care if they were faced with a serious illness. However, doctors are not initiating these conversations. Just 17% say their doctor has asked them about end-of-life wishes for medical treatment – including just 21% of respondents with a serious illness and 19% of respondents ages 60+.

Similarly, respondents are not having these conversations with their loved ones. Half (53%) of respondents have not had a conversation about the kind of medical care they'd want at the end of their life. About four in ten (37%) respondents ages 60+ have not had these conversations. When asked about barriers to these conversations, most respondents mention not wanting to think about death or competing priorities.



What Would You Say Is the Main Reason You Have Not Talked With Loved Ones About This? ⁶

39%

I don't want to think about death or dying

33%

I have too many other things to worry about right now

16%

They don't want to talk about my death or dying

12%

Something else (specify)

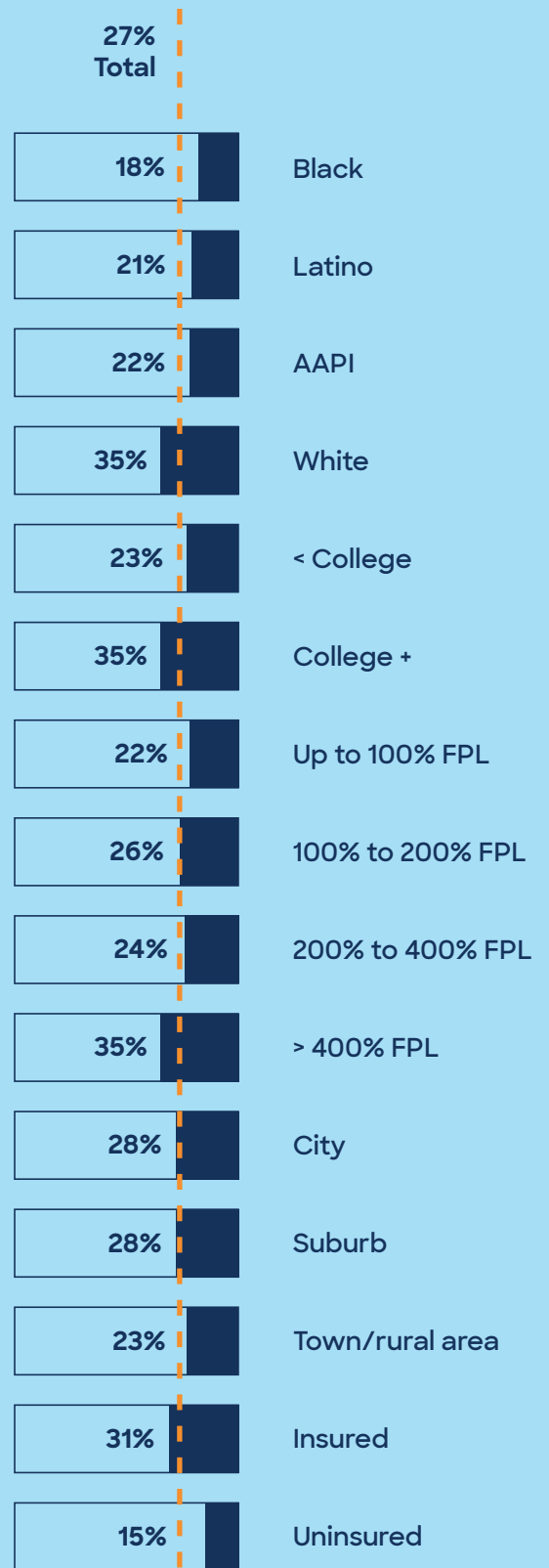
⁶ Randomize | N=1,157 respondents who have not talked with their preferred person about end-of-life care



End-of-life preparations vary across demographics. **Overall, one in four (27%) Texans have both their wishes in writing and have had conversations with their preferred person about end-of-life decision-making.**

However, Texans of color, non-college-educated Texans, Texans with lower incomes, and uninsured Texans are less likely to have taken these steps than Texans overall.

% Have Wishes Regarding Medical Treatment in Writing and Have Talked with Preferred Person About End-of-Life Decision-Making



These gaps in preparation for end-of-life care and decision-making are tied to trust in the health care system. The data shows that Texans are most likely to turn to a doctor (51%) or family member (44%) for information about end-of-life care. **Texans who say their providers treat them with dignity and respect are more interested in discussing end-of-life care with providers and more likely to turn to doctors to learn about end-of-life care.**

How Often Do You Trust Your Health Care Providers to Treat You with Dignity and Respect?

Always or almost always	Most of the time	Some of the time	Not much/never/ almost never
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Would definitely like to talk with health care provider about wishes around end-of-life care

86%	77%	59%	44%
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Would turn to health care provider to learn more about end-of-life care

59%	56%	41%	26%
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Conclusion

The study found that most Texans share end-of-life preferences, such as wanting to die at home and avoiding the financial burden of care. However, most Texans, including older adults and those with a serious illness, are unprepared for decisions around end-of-life care. Data suggests this lack of preparation may translate into worse end-of-life experiences. Just one-third of Texans said their loved one's end-of-life went the way they wanted it to go and Black and Latino respondents report more challenges related to end-of-life care.

These findings are shared to support individuals, families, communities, non-profit organizations, health care providers, and policy makers. They can help us advance efforts to ensure that end-of-life plans and wishes are known and acted upon. It is through our shared actions that we can improve end-of-life planning and help all Texans to have a better death.

For questions, please contact:

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