

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



FULL FINDINGS

PREPARED FOR ST. DAVID'S FOUNDATION

2023



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Introduction.

In 2022, St. David's Foundation commissioned a statewide survey to better understand Texans' health care experiences, end-of-life priorities, and experiences and barriers around end-of-life care.



Methods.

The survey was conducted among n=2,181 Texas adults 18 and older from October 25 through November 15, 2022 using YouGov's online panel. An additional n=124 interviews from Travis and Williamson Counties were conducted August 5 through September 4, 2022 using SSRS' addressed based sampling. This combined total is n=2,305 Texas adults. If YouGov's panel were strictly a probability-based panel, the margin of sampling error would be $\underline{+}$ 3.1 percentage points for the total results.

The survey includes:

- N = 725 Latina/o/x Texans
- N = 284 Black Texans
- N = 194 Asian American / Pacific Islander Texans
- N = 902 adults who had a loved one die in Texas in the past two years



Summary.

A majority of Texans are on the same page when it comes to their end-life-life preferences. Respondents say they want:

- To die at home (76%)
- To die a natural death (61% v. 16% preferring to prolong life as long as possible)
- To be sure their family is not burdened financially or by making tough decisions about their care (77% rate 6 or 7 on a 1-7 importance scale)
- To be comfortable and without pain (75%)
- To be sure their family is not burdened by taking care of them (74%)
- To be able to afford the care at the end of their life (73%)
- Family members making end-of-life decisions for them if they aren't able to (89%)

These preferences are fairly consistent across demographic segments of the population.



Data suggest most Texans lack preparation for end-oflife care and decisions.

While a majority of respondents (87%) says 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).

The top barriers to putting wishes in writing include:

- Wishes may change based on the situation (49%)
- I trust family to make decisions (45%)
- I trust God to be in charge (42%)
- I've never thought of putting wishes in writing (42%)

A large majority of adults (83%) say they've never had a doctor ask them about their wishes for end-of-life medical treatment, including majorities of adults 60 and older (81%) and those with a serious illness (79%).

About 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.

Texans are most likely to turn to a doctor (51%) or family member (44%) for information about end-of-life care. Just (13%) say they'd turn to the internet for information.



902 respondents have had a loved one recently die in Texas. We asked them about their loved one's end-of-life experiences.

About a third (37%) say their loved one's end of life went the way the loved one wanted it to go.

The same proportion (37%) says the end of life did not go the way their loved one wanted it to go. These loved ones are more likely than others to:

- Be uninsured (48% say didn't go the way they wanted)
- Have died in a hospital (53%)
- Have not gotten hospice care (55%)

What could've gone better?

Data suggest a few gaps between patients' needs and experiences:

- While 70% say their loved one preferred to die at home, only 37% did so
- Just 23% of those who died from a serious illness say their loved one was "very prepared" to deal with their illness as it progressed
- Forty-two percent say their loved one's end-of-life wishes were not completely followed or honored
- Close to half (47%) say their loved one faced some type of challenge related to care, such as facing problems with insurance coverage, being uninsured, or encountering language or cultural barriers

Consistently, we find that loved ones who were receiving hospice care had better end-of-life care and experiences than those who did not.



Detailed findings.

SECTIONS

- 10 Texans' experiences with the health care system
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Texans' experiences with the health care system.

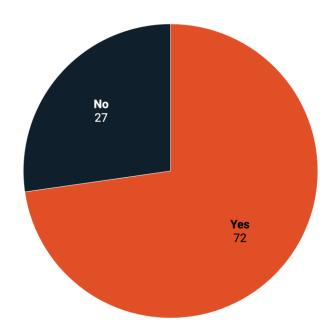
Most respondents say they have a main health care provider.

Those least likely to have primary provider include:

- · Uninsured respondents
- 18 to 44-year-olds
- Those under 100% FPL
- Men
- Respondents with less than a college degree

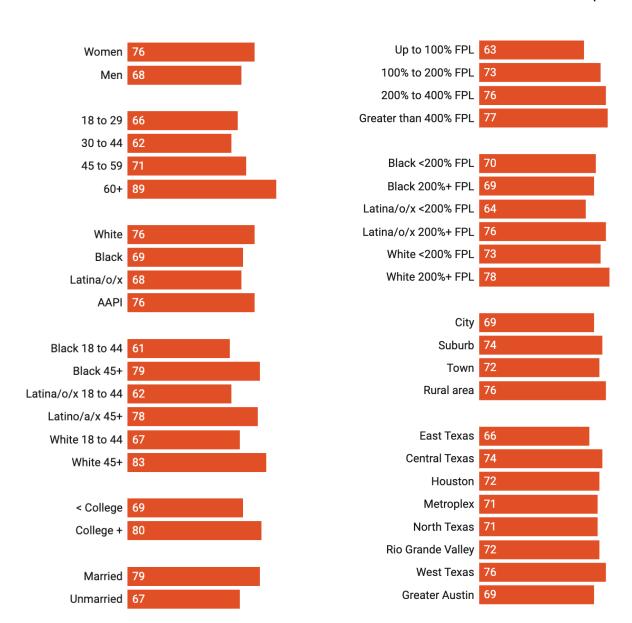
See next page.

First, do you have one person you think of as your main doctor or health care provider? (A "health care provider" could be a doctor, nurse practitioner, physician's assistant, or other type of provider.)





% Have a health care provider



Insured	83
Uninsured	44
Employer insurance	81
Private plan	75
Medicare only	88
Medicare and Medigap plan	93
Medicare and Texas Medicaid	84
Texas Medicaid only	83
Medicare + Other (VA/Employer, etc.)	96
VA benefits/Tri-Care (n = 95)	89



Generally speaking, how much effort would you say doctors, nurses, and other health professionals make to...

% A lot of effort / some effort

Most say their health care providers are making an effort to understand their needs.

That said, fewer than half say their providers are making "a lot" of effort.

85%

Help you understand your health issues

43% a lot of effort 42% some effort

84%

Listen to the things that matter most to you about your health issues

41% a lot of effort 43% some effort

84%

Include what matters most to you in making decisions about your care and treatments

40% a lot of effort 44% some effort



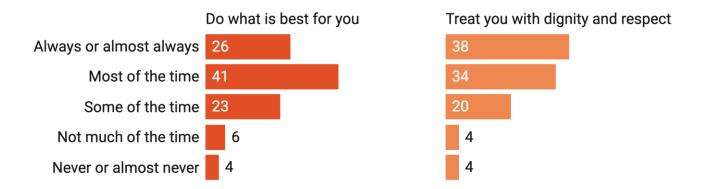
Two in three respondents trust their providers always or most of the time.

About one in three respondents lack trust in providers (don't trust their providers always / almost always / most of the time).

Young respondents, uninsured adults, and those under 100% FPL are least likely to have trust in providers.

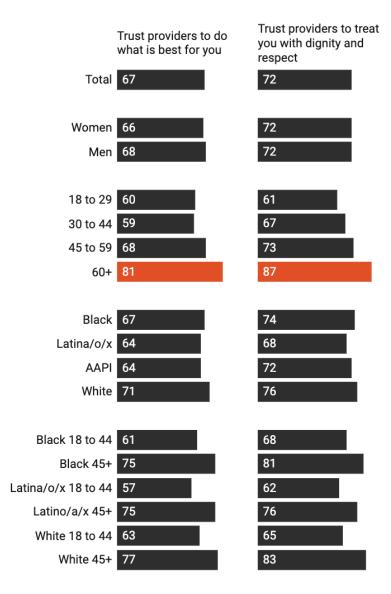
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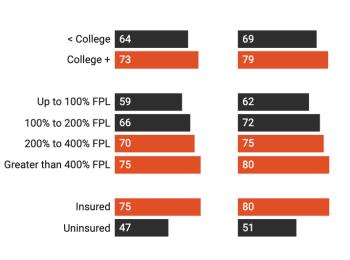
How often do you trust your health care providers to:





% Always / almost always or most of the time





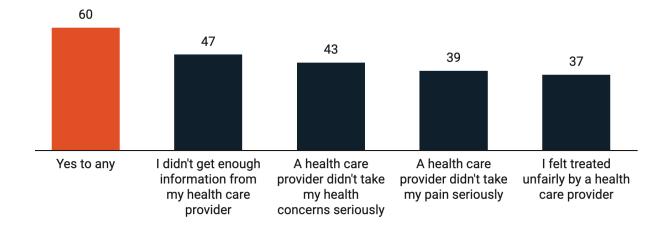


Here are things that can happen in the health care system. Has this ever happened to you?

% Yes

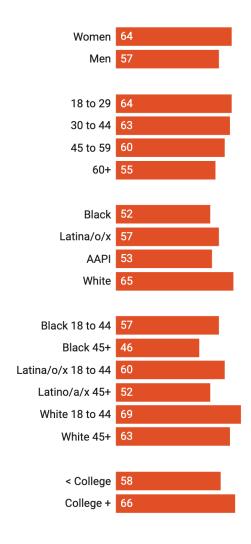
Six in ten (60%) have had one or more of these negative experiences with a health care provider.

There are not major differences by demographic variables (see next page).

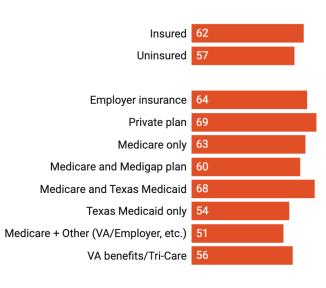




% Yes to any



Up to 200% FPL	60
Greater than 200% FPL	60
Black <200% FPL	48
Black 200%+ FPL	58
Latina/o/x <200% FPL	56
Latina/o/x 200%+ FPL	59
White <200% FPL	70
White 200%+ FPL	62
City	60
Suburb	61
Town	56
Rural area	62
East Texas	59
Central Texas	62
Houston	60
Metroplex	63
North Texas	51
Rio Grande Valley	58
West Texas	57
Greater Austin	57



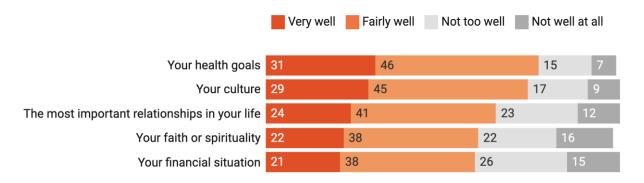


Most express confidence that providers understand their health goals.

Fewer say that providers understand their relationships, faith, and financial situation.

Black respondents are less likely than respondents overall to say their health care providers understand their culture "very well" or "fairly well" (67% among Black respondents vs. 74% among respondents overall).

In general, how well do you feel that health care providers understand....



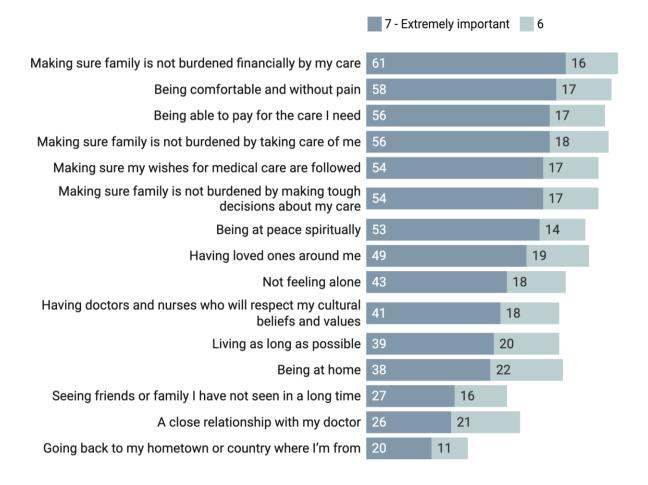


Preferences at end of life.

How important is each of the following to you at the end of your life?

1 to 7 scale, not at all to extremely important

The top end-of-life priorities include not burdening family, being without pain, and being able to afford care.





Women and older respondents are more likely than others to rate most priorities as important.

	Women	Men	18 to 29	30 to 44	45 to 59	60+
Family is not burdened financially	81	73	60	73	83	90
Being comfortable and without pain	80	69	63	70	79	86
Family is not burdened by taking care of me	78	69	58	68	83	86
Being able to pay for the care I need	78	68	60	69	82	81
Family is not burdened by making tough decisions	76	66	50	68	81	85
Making sure wishes for care are followed	76	65	54	65	80	85
Having loved ones around me	73	62	63	66	74	69
Being at peace spiritually	74	60	56	63	75	77
Not feeling alone	69	53	52	65	64	65
Being at home	61	60	50	59	66	67
Providers who will respect cultural beliefs and values	67	52	51	59	62	66
Living as long as possible	62	56	50	63	61	60
A close relationship with my doctor	51	43	37	46	47	56
Seeing friends / family I have not seen	45	41	46	44	43	39
Returning to my hometown / country where I'm from	31	31	37	35	29	23



Black respondents are more likely than others to prioritize being at peace spiritually and having providers that respect cultural beliefs and values.

	Black	Latina/o/x	AAPI	White	Married	Unmarried
Family is not burdened financially	79	76	72	78	81	74
Being comfortable and without pain	77	74	66	75	76	74
Family is not burdened by taking care of me	76	73	70	75	78	71
Being able to pay for the care I need	72	73	71	73	79	69
Family is not burdened by making tough decisions	76	71	66	72	76	68
Making sure wishes for care are followed	75	68	66	73	76	67
Having loved ones around me	71	70	64	66	71	66
Being at peace spiritually	78	67	66	65	70	66
Not feeling alone	64	63	58	60	65	59
Being at home	64	67	48	56	62	60
Providers who will respect cultural beliefs and values	73	62	56	56	62	58
Living as long as possible	70	63	53	53	60	58
A close relationship with my doctor	62	48	43	42	47	47
Seeing friends / family I have not seen	49	49	42	37	41	45
Returning to my hometown / country where I'm from	45	39	35	21	29	32



Uninsured respondents and those with the lowest incomes are slightly less likely than others to prioritize many of these issues.

	Up to 100% FPL	100% to 200% FPL	200% to 400% FPL	Greater than 400% FPL	Insured	Uninsured
Family is not burdened financially	72	74	79	82	81	67
Being comfortable and without pain	73	73	75	77	78	67
Family is not burdened by taking care of me	66	74	76	81	79	62
Being able to pay for the care I need	63	72	78	80	77	62
Family is not burdened by making tough decisions	64	71	72	79	77	58
Making sure wishes for care are followed	64	70	73	77	76	58
Having loved ones around me	63	70	69	69	70	61
Being at peace spiritually	66	67	69	69	71	58
Not feeling alone	57	64	60	65	64	54
Being at home	60	65	59	58	63	56
Providers who will respect cultural beliefs and values	57	61	60	62	63	51
Living as long as possible	62	62	59	52	60	55
A close relationship with my doctor	48	49	47	43	50	39
Seeing friends / family I have not seen	43	47	42	39	44	40
Returning to my hometown / country where I'm from	35	39	28	22	31	30



There are not significant differences by region.

	East Texas	Central Texas	Houston	Metroplex	North Texas	Rio Grande Valley	West Texas	Greater Austin
Family is not burdened financially	73	77	80	72	65	80	84	76
Being comfortable and without pain	80	77	79	67	59	78	77	74
Family is not burdened by taking care of me	74	75	76	66	70	77	80	74
Being able to pay for the care I need	70	75	75	72	62	73	80	75
Family is not burdened by making tough decisions	76	74	75	62	62	72	73	72
Making sure wishes for care are followed	72	74	74	64	56	74	79	73
Having loved ones around me	67	70	65	66	62	72	74	70
Being at peace spiritually	71	69	70	62	56	72	73	65
Not feeling alone	60	60	63	55	55	66	66	60
Being at home	64	56	64	55	56	69	68	51
Providers who will respect cultural beliefs and values	62	61	57	57	45	63	63	61
Living as long as possible	61	57	60	55	53	62	65	54
A close relationship with my doctor	49	41	46	43	40	50	58	35
Seeing friends / family I have not seen	43	37	45	41	36	47	52	35
Returning to my hometown / country where I'm from	30	25	31	27	29	40	43	22

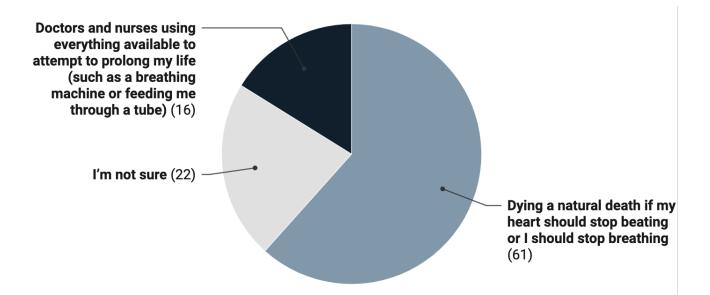


If you had an advanced, terminal illness, which would you prefer: ROTATE

Most Texans prefer dying a natural death.

Respondents who are most likely to want providers to prolong life include:

- Black adults ages 18 to 44 (32%)
- Young adults 18 to 29 (26%)
- All Black respondents (26%)



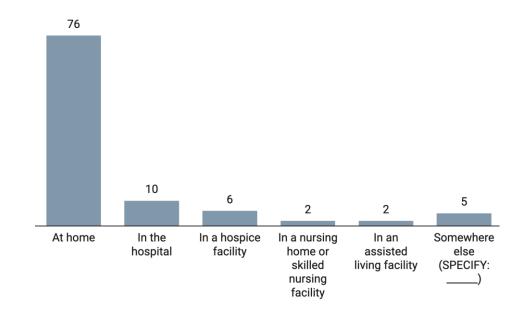


Most Texans say they prefer to die at home.

Black respondents are less likely than others to say they want to die at home.

See next slide.

If given a choice at the end of your life, where would you want to be when you die? RANDOMIZE





	Prefers natural death	Prefers to die at home
Total	61	76
Women	62	74
Men	60	77
18 to 29	44	75
30 to 44	56	75
45 to 59	64	75
60+	79	77
Black	46	69
Latina/o/x	58	79
AAPI	60	72
White	67	75
< College	58	77
College +	67	72
Married	69	78
Unmarried	55	74
Up to 100% FPL	49	75
100% to 200% FPL	52	74
200% to 400% FPL	71	80
Greater than 400% FPL	72	73

	Prefers natural death	Prefers to die at home
City	54	73
Suburb	68	79
Town	53	74
Rural area	64	76
East Texas	62	78
Central Texas	68	75
Houston	61	76
Metroplex	53	75
North Texas	54	74
Rio Grande Valley	62	80
West Texas	63	80
Greater Austin	68	73
Insured	65	75
Uninsured	51	78
Employer insurance	68	77
Private plan	63	71
Medicare only	63	78
Medicare and Medigap plan	83	76
Medicare and Texas Medicaid	46	62
Texas Medicaid only	48	75
Medicare + Other (VA/Employer, etc.)	70	66
VA benefits/Tri-Care	65	70

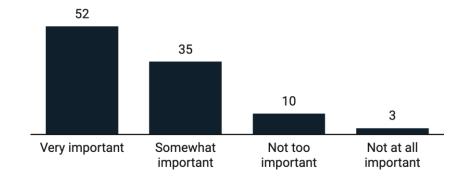
Planning for end-of-life care.

More than 8 in 10 say it is important to have their wishes for end-of-life medical treatment in writing.

About half of respondents (52%) say this is "very" important. Older respondents, women, college-educated respondents, and insured respondents are more likely than others to say it's "very" important.

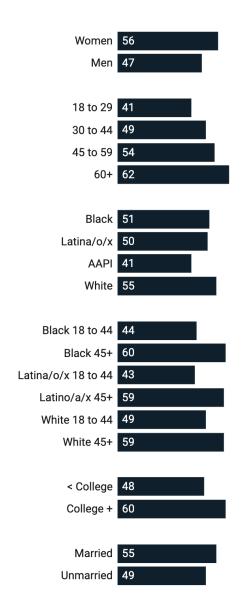
See next slide.

How important do you feel it is to have your wishes in writing?

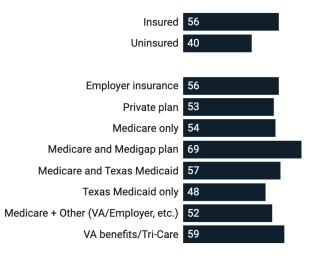




% Very important to have wishes in writing



Up to 100% FPL	48
100% to 200% FPL	50
200% to 400% FPL	53
Greater than 400% FPL	57
Black <200% FPL	50
Black 200%+ FPL	53
Latina/o/x <200% FPL	49
Latina/o/x 200%+ FPL	50
White <200% FPL	49
White 200%+ FPL	58
City	51
Suburb	57
Town	43
Rural area	47
East Texas	54
Central Texas	53
Houston	52
Metroplex	49
North Texas	40
Rio Grande Valley	51
West Texas	52
Greater Austin	49



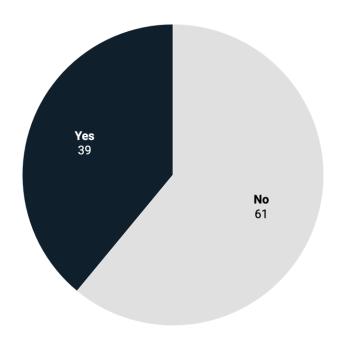


Despite perceived importance, most respondents do not have their wishes in writing.

White, older, higher-income adults are among the most likely to have wishes in writing.

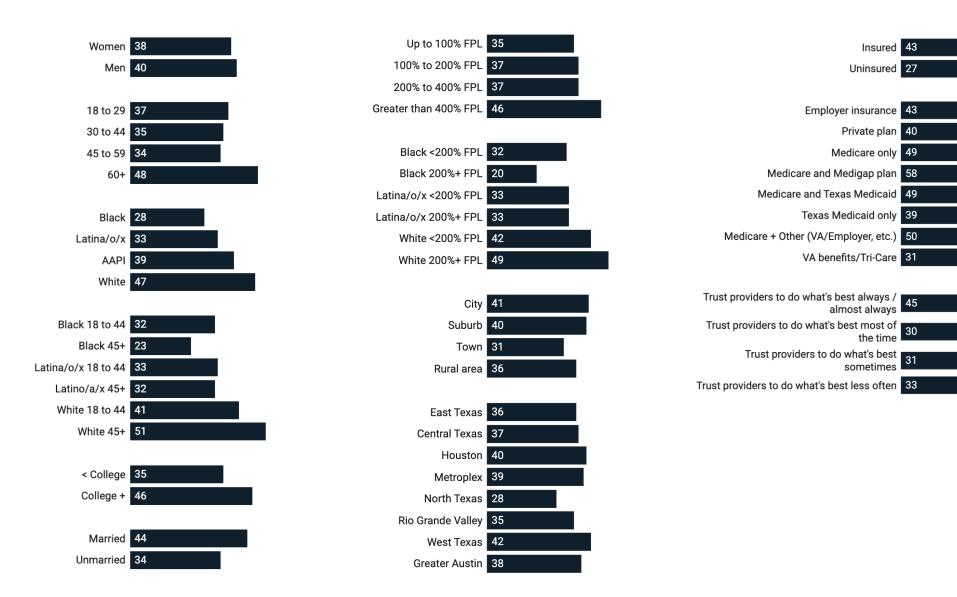
Do you have any of your wishes regarding the medical treatment you would want in a written document?

ROTATE





% Have wishes in writing





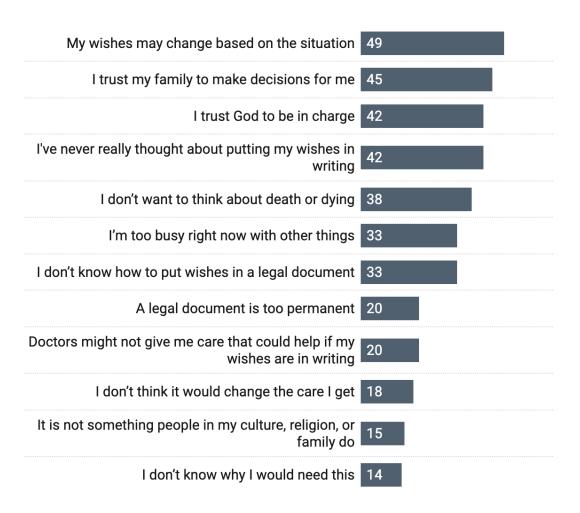
Here are reasons why some people do not have their wishes in writing. Are any of these a reason you do not have your wishes in writing?

RANDOMIZE | N = 1,369 Texans who don't have their wishes in writing

Here are the barriers to putting wishes in writing.

See the next few pages for top barriers by demographic segment.

Yes, a reason I don't have wishes in writing





Yes, a reason I don't have wishes in writing

	Women	Men	18 to 29	30 to 44	45 to 59	60+	Black	Latina/o/ x	AAPI	White	< College	College +
My wishes may change based on the situation	54	44	47	47	50	54	49	47	50	53	49	51
I trust my family to make decisions for me	50	41	38	43	47	55	44	43	39	50	45	47
I've never really thought about putting my wishes in writing	46	39	42	42	43	43	35	44	48	43	44	39
I trust God to be in charge	45	38	36	36	47	49	58	43	34	35	45	32
I don't want to think about death or dying	44	31	40	38	42	31	37	37	42	39	38	37
I'm too busy right now with other things	34	33	39	36	32	27	20	31	43	39	28	48
I don't know how to put wishes in a legal document	37	29	33	37	31	31	22	37	33	34	33	32

Numbers reflect percent who say given reason (in row) is a reason they don't have wishes in writing. For instance, 54% of women say "my wishes may change" is a reason they don't have wishes in writing.



Yes, a reason I don't have wishes in writing

	Married	Unmarried	<= 100% FPL	100% to 200% FPL	200% to 400% FPL	>= 400% FPL	City	Suburb	Town	Rural area
My wishes may change based on the situation	50	49	46	50	54	48	47	50	47	55
I trust my family to make decisions for me	52	42	46	37	51	47	39	50	45	49
I've never really thought about putting my wishes in writing	42	43	46	35	46	43	37	45	54	41
I trust God to be in charge	41	42	49	44	40	30	44	40	38	41
I don't want to think about death or dying	38	38	39	38	38	37	38	39	34	38
I'm too busy right now with other things	35	32	28	29	33	47	34	35	31	33
I don't know how to put wishes in a legal document	31	34	39	30	29	32	32	34	35	33



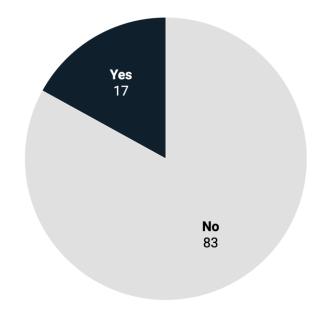
Yes, a reason I don't have wishes in writing

	East Texas	Central Texas	Houston	Metro- plex	North Texas	Rio Grande Valley	West Texas (n = 60)	Greater Austin	Insured	Un- insured	Employ. ins.	Private plan	Medi- care
My wishes may change based on the situation	50	49	52	50	40	54	40	48	53	42	52	57	56
I trust my family to make decisions for me	47	41	48	46	49	43	47	27	50	37	48	49	56
I've never really thought about putting my wishes in writing	45	37	49	40	41	43	35	41	46	36	45	49	43
I trust God to be in charge	42	35	45	42	40	49	35	28	43	39	35	48	55
I don't want to think about death or dying	40	34	39	41	34	38	43	34	40	34	39	50	31
I'm too busy right now with other things	29	32	34	35	29	31	49	30	37	25	46	44	25
I don't know how to put wishes in a legal document	39	25	33	29	23	39	36	25	34	31	34	46	28



Most say their provider has not asked them about their end-of-life care wishes. Have you ever had a doctor ask you about your wishes for medical treatment at the end of your life?

ROTATE



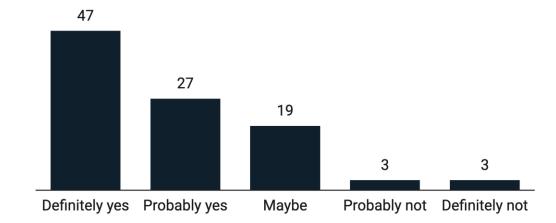


If facing a serious illness, most respondents would want to talk to their doctor about end-of-life wishes.

Respondents most interested in these conversations include:

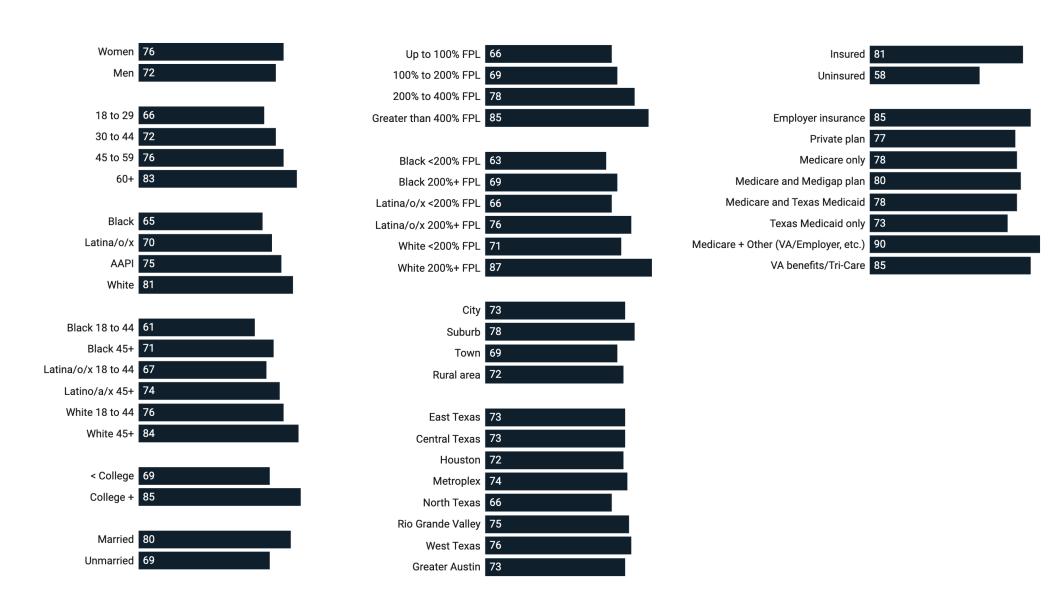
- 400%+ FPL
- White 200%+ FPL
- College +
- 60+
- White
- Insured

If you were seriously ill, would you like to talk with your doctor about your wishes for medical treatment towards the end of your life?





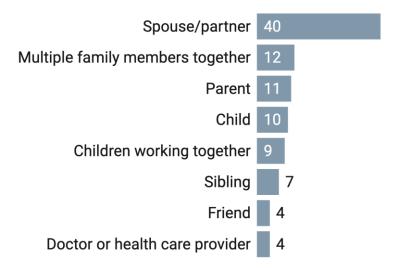
% Would definitely / probably like to talk with their doctor about their wishes for medical treatment





A plurality of Texans say they'd want their spouse / partner to make decisions for their end-of-life care. Let's say you were not able to make decisions about your care near the end of your life. Your doctor says there are different options. Someone has to decide for you. Who would you want to make decisions about your care?

RANDOMIZE



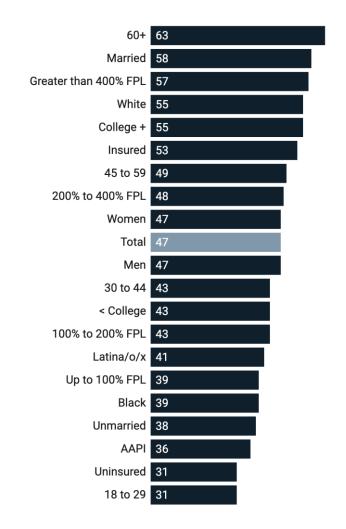


About half of respondents (47%) say they've talked with this person.

Older, married, higher-income, and white respondents are most likely to have had these conversations.

Have you talked with this person about the kind of medical care you would want near the end of your life?

% Yes



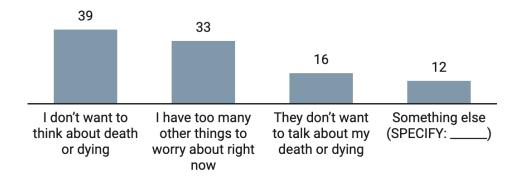


A top barrier to talking is not wanting to think about death or dying.

Barriers are fairly consistent across demographic groups (see next page).

What would you say is the main reason you have <u>not</u> talked with them about this?

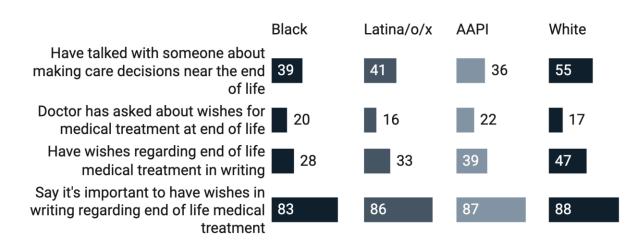
RANDOMIZE | N = 1,157





Total	I don't want to think about death	Too many other things	They don't want to talk about death	Up to 100% FPL	I don't want to think about death	Too many other things	They don't want to talk about death
Women	42	30	15	100% to 200% FPL		35	22
Men	36	36	17	200% to 400% FPL		30	15
				Greater than 400% FPL	_ 30	39	10
18 to 29	39	34	15		40		**
30 to 44	43	29	15		42	32	16
45 to 59	36	34	18	Suburb		33	17
60+	34	37	15	Towr		39	16
				Rural area	39	34	13
Black	37	41	13		0.7	00	16
Latina/o/x	44	26	19	Insured		33	16
AAPI	33	41	19	Uninsured	41	33	16
White	36	36	12		40	24	
				Employer insurance		34	11
< College	39	32	17	Medicare plar	1 32	30	23
College +	38	35	12				
Married	46	28	16				
Unmarried	35	35	16				PERRY

Fewer respondents of color have wishes in writing or have talked about end-of-life care.

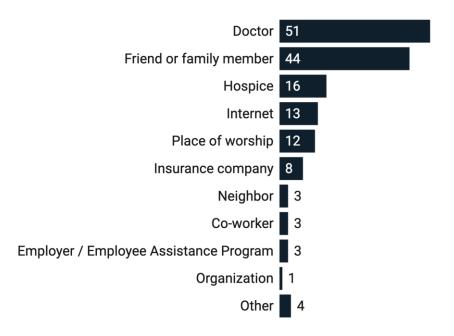




To learn about end-of-life care, most would turn to doctors or friends and family.

If you wanted to learn more about end-of-life care, where would you turn?

SELECT ALL THAT APPLY

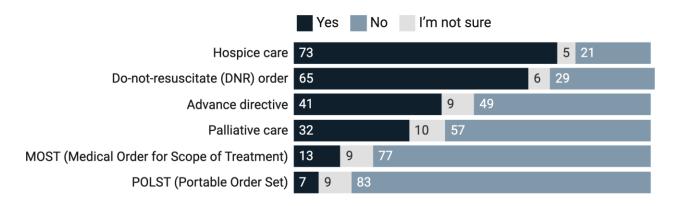




Three in four have heard the term "hospice care," while one in three have heard the term "palliative care."

Few have heard of the terms "MOST" or "POLST."

Have you ever heard of any of the following terms? RANDOMIZE





Experiences with end of life.

We explored experiences with end-of-life care through the eyes of loved ones. Roughly four in ten respondents (39%) say they had a close friend or family member pass away in Texas in the past two years.

We explored these respondents' views and impressions of their loved one's end-of -life experiences and care.

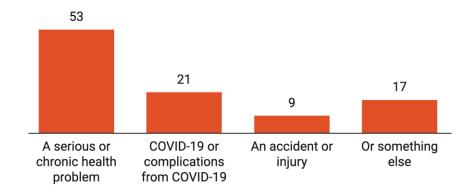
Unless otherwise noted, the base sample for the following charts is n = 902 respondents who had a loved one pass away in Texas in the past two years.



About half says their loved one died from a serious illness.

Twenty-one percent of those who lost a loved one say COVID-19 was the cause of death.

Did your loved one die from:



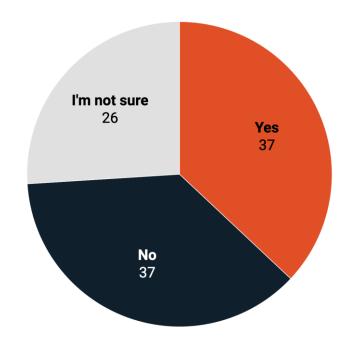


About a third said their loved one's end of life went the way they wanted it to go.

The same proportion (37%) says the end of life did not go the way their loved one wanted it to go. These loved ones are more likely than others to:

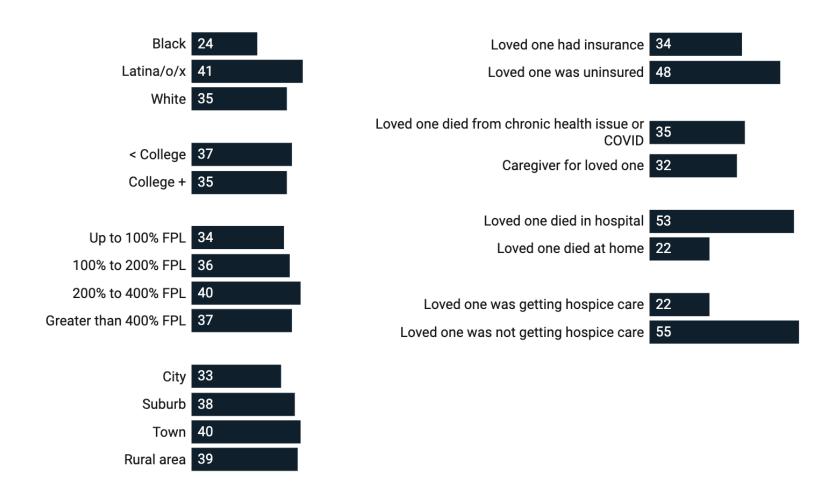
- Be uninsured (48% say didn't go the way they wanted)
- Have died in a hospital (53%)
- Have not gotten hospice care (55%)

Think about the very end of your loved one's life. Do you think the end went the way your loved one wanted it to go?





% Death did not go the way loved one wanted it to go



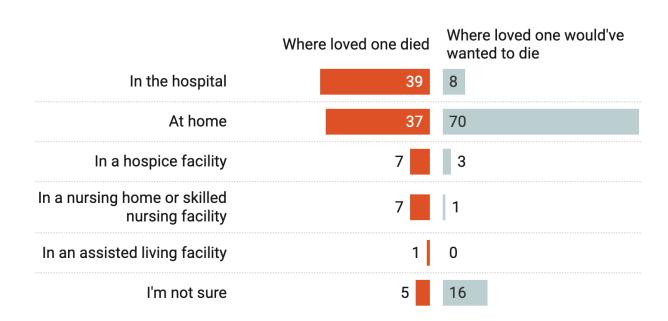


Data suggest most loved ones did not die where they wanted to.

While 39% of respondents say their loved one died in a hospital, just 8% say that's where they would've wanted to pass away. Most say the loved one would've preferred dying at home.

Respondents most likely to say their loved one died in the hospital include:

- Those not getting hospice care (51%)
- Black respondents (45%)
- Latina/o/x respondents (45%)



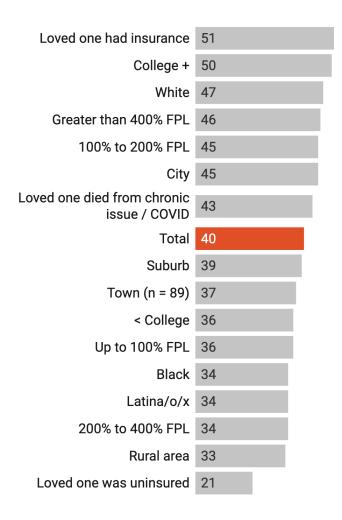


Four in ten say their loved one was receiving hospice care.

Data suggest that uninsured loved ones were 30 points less likely than insured to receive hospice care. Rural residents, respondents of color, and those with lower incomes are also less likely to report their loved one received hospice.

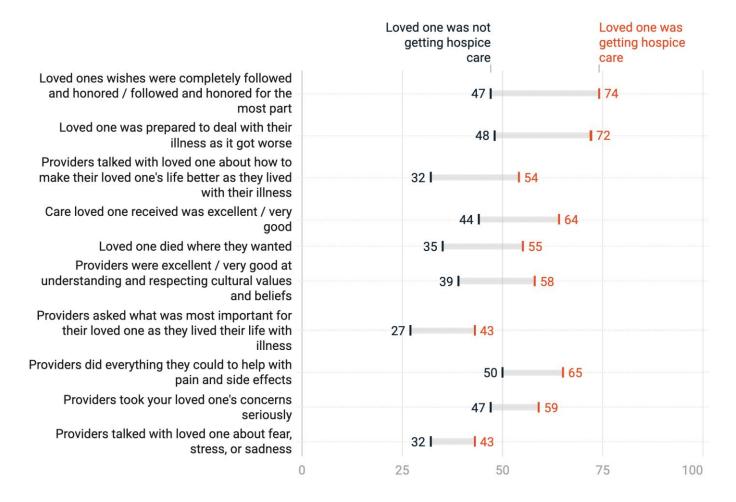
Was your loved one getting hospice care near the end of their life?

% Yes





Respondents with loved ones who received hospice care reported better care quality.

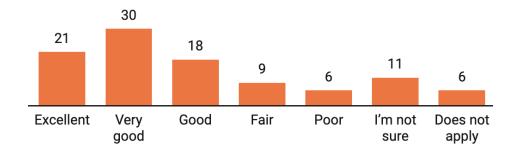




About half says their loved one received "excellent" or "very good" care in the last few months of their life.

Across demographics, respondents are similarly likely to feel positively about their care.

Overall, how would you rate the care your loved one received at the end of life, that is, in the last few months of their life?

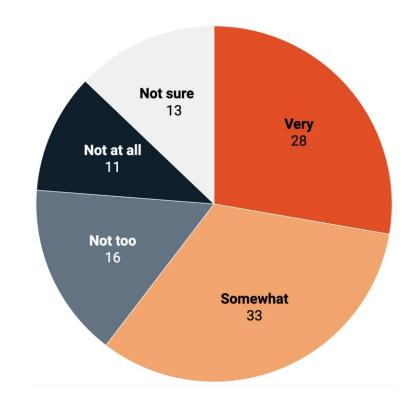




About one in four says their loved one was "very prepared" to deal with their illness as it got worse.

How prepared was your loved one to deal with their illness as it got worse? By prepared, we mean your loved one knew what was going on, they could plan for what was coming, and they felt ready.

N = 485 respondents who had a loved one die of a serious or chronic illness in Texas

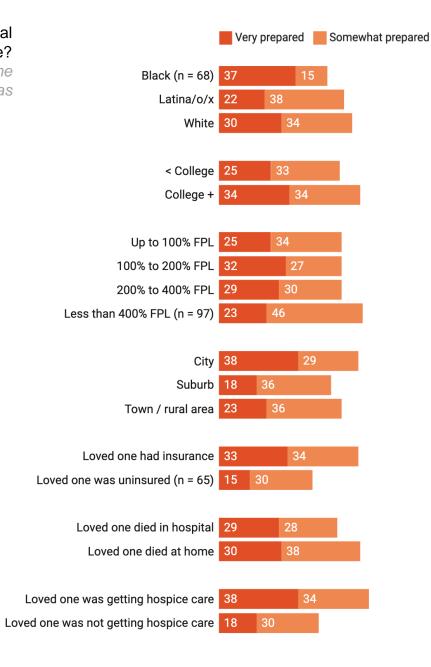




How prepared was your loved one to deal with their illness as it got worse?

N = 485 respondents who had a loved one die of a serious or chronic illness in Texas

Loved ones who were uninsured, died in the hospital, and weren't getting hospice care may have been less prepared to deal with their illness as it progressed.

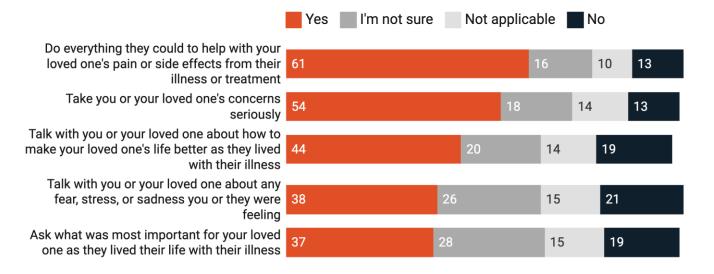




As far as you know, did your loved one's doctors or health care providers...

RANDOMIZE | N = 485 respondents who had a loved one die of a serious or chronic illness in Texas

Data indicate a gap in palliative care efforts – particularly around talking about stress and how to live with illnesses.





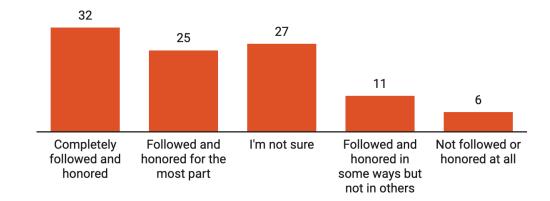
About one in three (32%) says their loved one's end-of-life wishes were completely followed and honored.

Respondents least likely to say their loved one's wishes were followed and honored include:

- Black respondents
- Loved ones who did not receive hospice care
- Loved ones who were uninsured
- Rural respondents

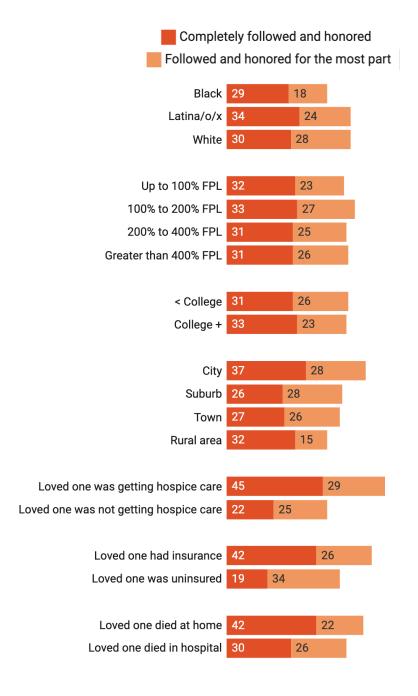
See next page.

To what extent do you feel your loved one's endof-life wishes were followed and honored by the doctors, nurses, and other health care providers who cared for them?





To what extent do you feel your loved one's end-of-life wishes were followed and honored by the doctors, nurses, and other health care providers who cared for them?





Half of respondents (47%) report some barrier related to accessing end-of-life care.

Yes to any 47

Say their loved one faced problems with insurance covering care (n = 589 respondents 20 whose loved one was insured)

Say language was a barrier to getting the best possible care

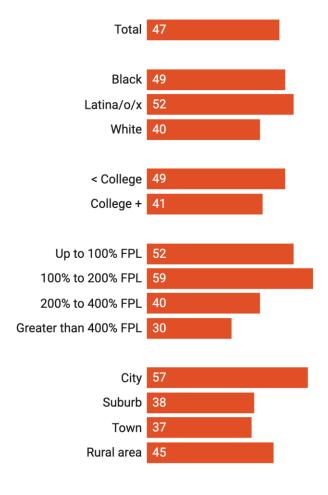
Say their loved one's providers were "fair" or "poor" at respecting cultural values and beliefs

Say their loved one was uninsured 16



Latina/o/x respondents (52%), respondents with lower incomes (55%), and urban respondents (57%) were among the most likely to report their loved one experiencing one of these barriers (see next page).

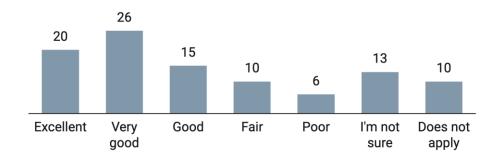
% Report their loved one facing a barrier related to accessing end-of-life care





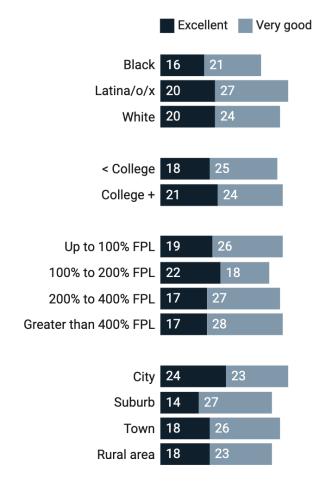
Close to half say their loved one's providers were excellent or very good at understanding and respecting their cultural beliefs and values.

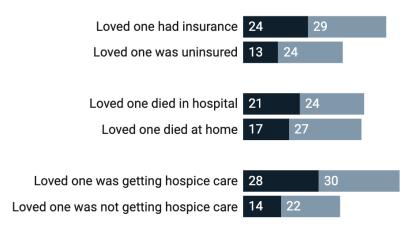
Black respondents were less likely than others to say their health care providers were excellent or very good. See next page. Overall, how would you rate the doctors and other health care providers in terms of how well they understood and respected the cultural values and beliefs of your loved one and their family members?





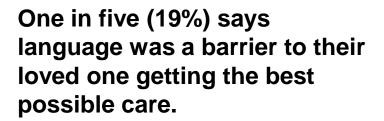
Overall, how would you rate the doctors and other health care providers in terms of how well they understood and respected the cultural values and beliefs of your loved one and their family members?





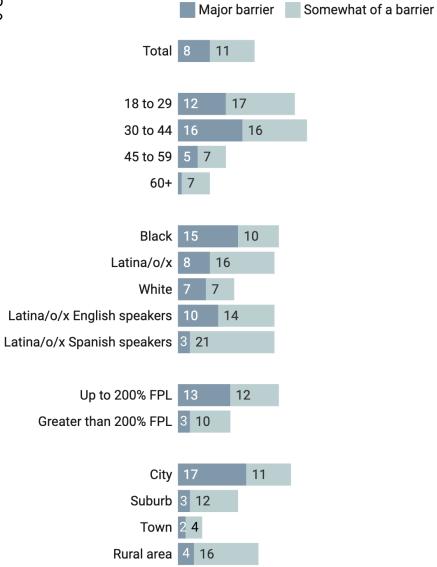


To what extent, if at all, was language a barrier to your loved one getting the best possible care?



Respondents most likely to say language was a barrier to receiving care include:

- Younger respondents
- Black respondents
- Latina/o/x respondents
- Those with lower incomes
- Texans who live in urban areas





Nearly three in ten (28%) say either their loved one was uninsured or they faced problems getting insurance to cover care.

16%

Say their loved one was uninsured at the end of their loved one's life

20%

Say their loved one was insured, but faced problems with their plan covering all of the care they needed

N = 589 respondents who had a loved one die in TX in the past two years who was insured



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.

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