



MASSACHUSETTS COALITION FOR  
**SERIOUS ILLNESS CARE**

**#WriteYourScript**

## Research Partners:



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# Methodological Overview

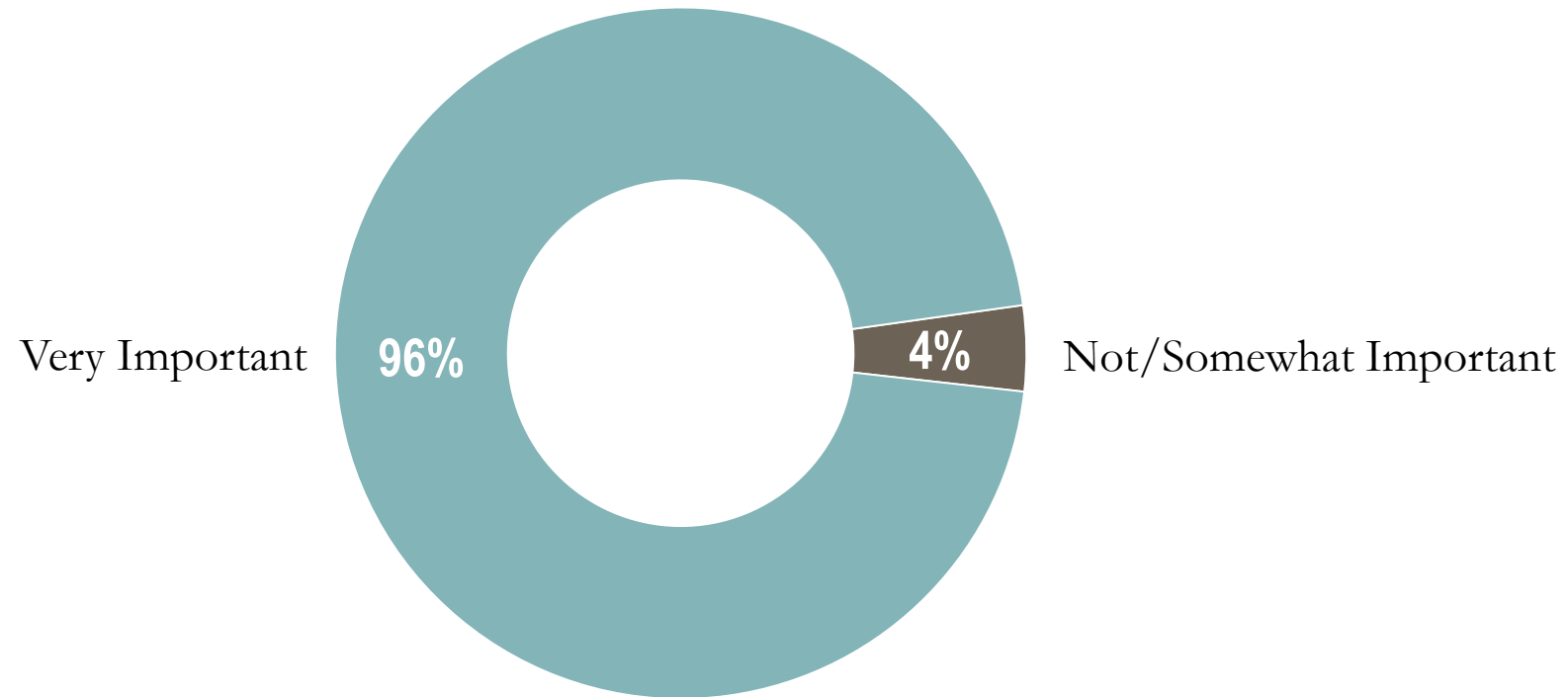
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- Who?** Individuals 18 years of age or older who agreed to be re-contacted after participating in the 2016 survey. For the 2016 survey, telephone numbers were randomly generated for the State of Massachusetts and individuals were randomly selected within households.
- When?** February 22 – March 19, 2017
- How?** Telephone interviews were conducted by SSRS, Inc. using Computer Assisted Telephone Interviewing (CATI). Each non-responsive number was contacted multiple times, varying the times of day, and the days of the week using a programmed differential call rule. Interviews were conducted in English or Spanish.
- Results?** During the 2016 survey, 860 respondents agreed to be re-contacted (46% of the sample). A total of 346 respondents completed the 2017 re-contact survey. Using AAPOR RR3, the overall response rate for the 2017 survey is 51%. When combined with the response rate from the 2016 survey (25%), the overall combined response rate is 13%. The design effect is 2.44 with a margin of sampling error of +/-8.23%.
- Participants?** Participants in the 2017 survey differed from the 2016 sample in meaningful ways. The average age was higher, as was income and educational levels. 2017 participants were slightly more likely to be white, female and married. They were also more likely to have engaged in advance care planning.
- Data were weighted to produce representative estimates of population parameters based on both demographic factors and engagement in advance care planning. However, open ended or qualitative responses are ‘unweighted’.



Almost all participants believe it's very important for people to have conversations with loved ones and health care providers about wishes for care.

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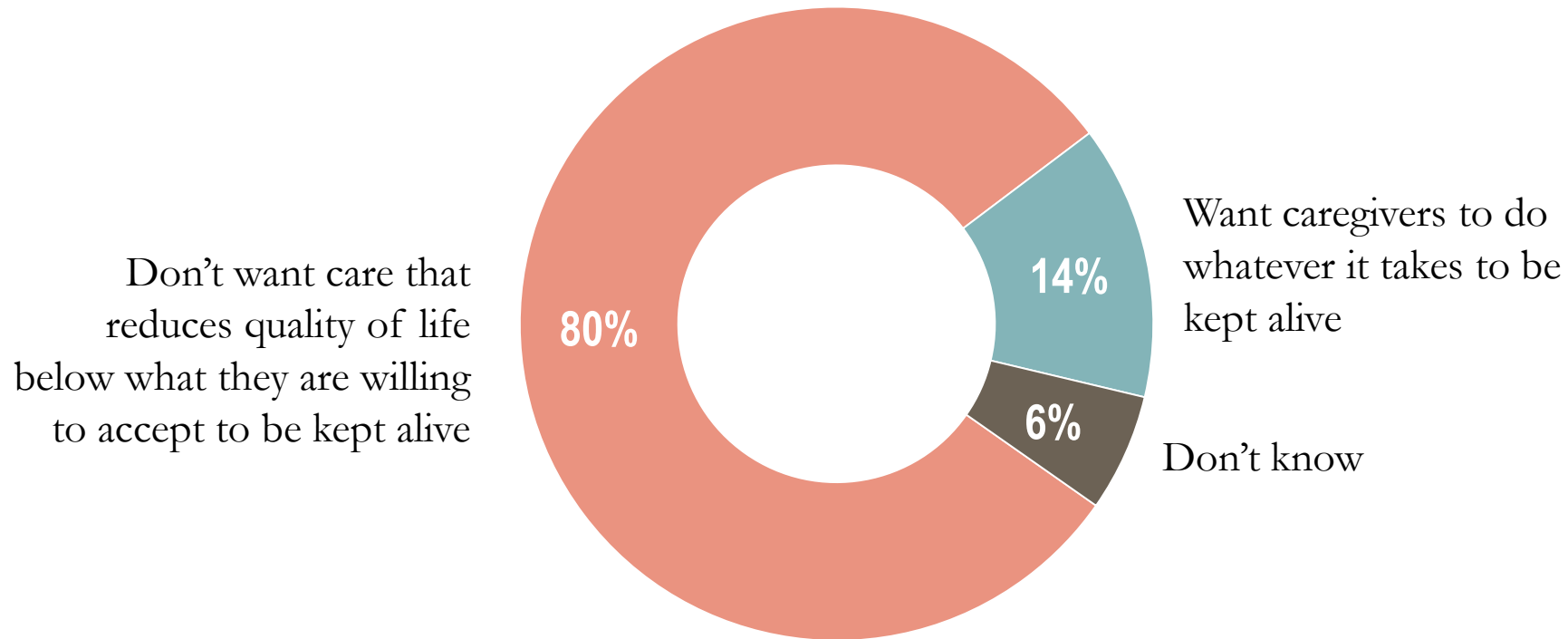


Q: How important do you believe it is for people to have conversations in advance with their loved ones and health care providers about their wishes for care if they were seriously ill or near the end of life?



# The majority of participants do not want care that reduces their quality of life below what they are willing to accept just to be kept alive.

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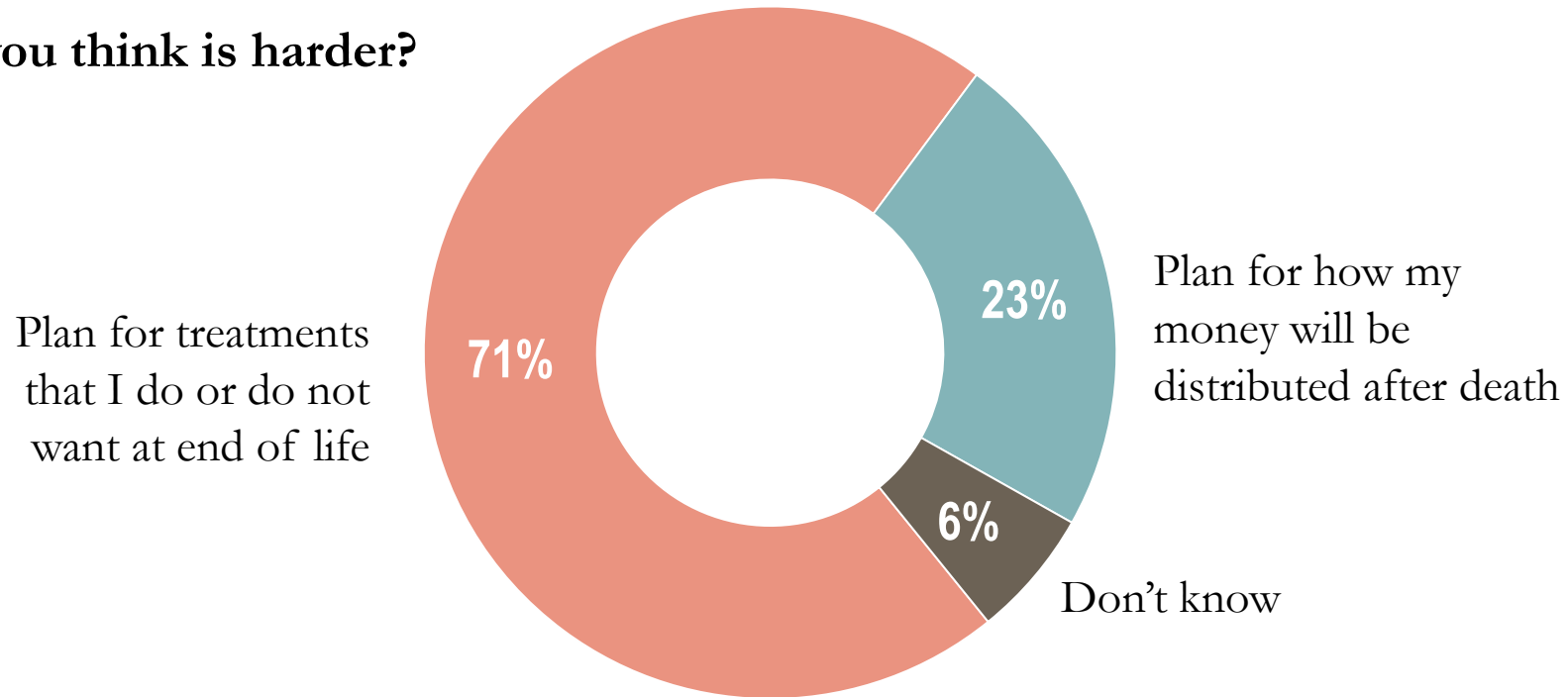
Q: Which comes closer to describing your own views on end-of-life care? Would you say I want my caregivers to do whatever it takes to keep me alive or I don't want care that reduces my quality of life below what I am willing to accept just to keep me alive.



# The majority of participants say it's harder to plan for end-of-life care than to plan for distributing their money after death.

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Which do you think is harder?

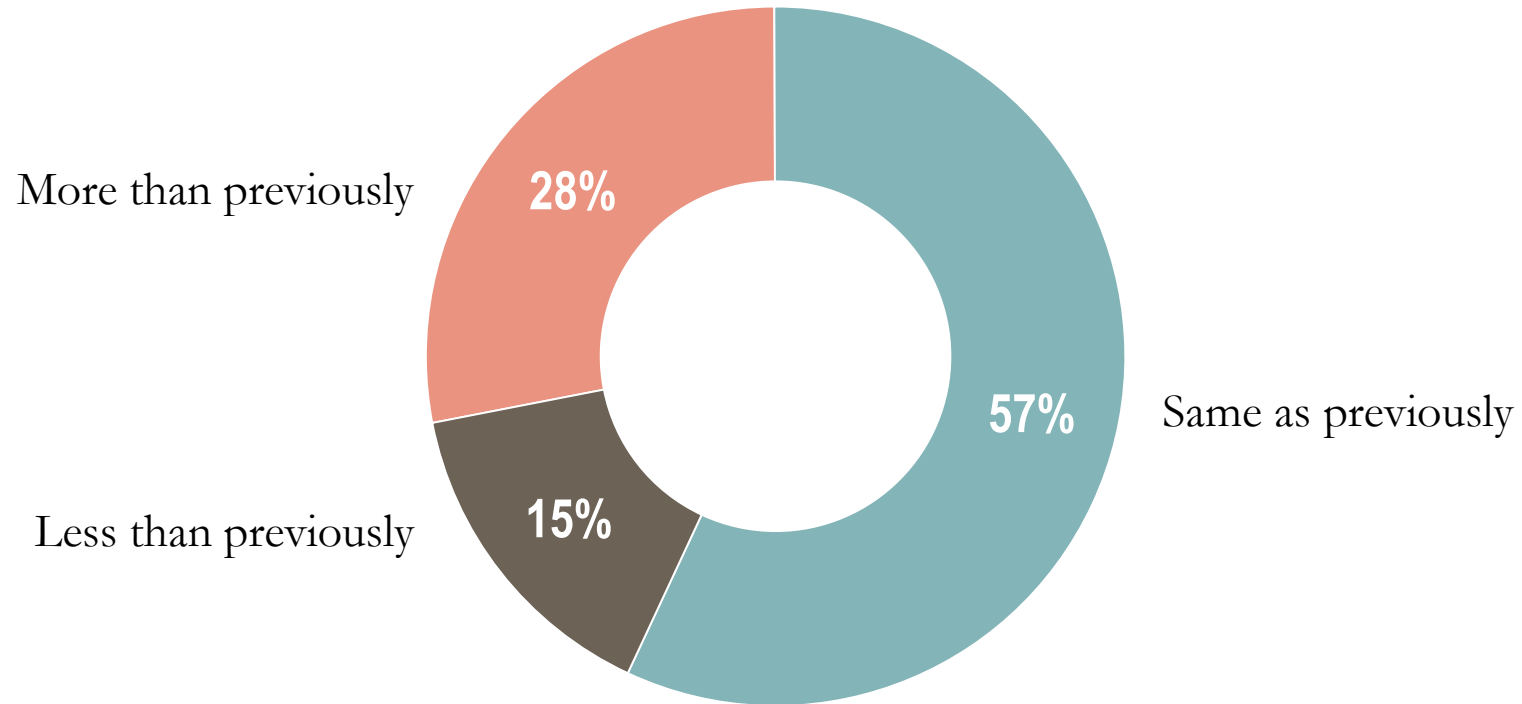


Q: Which do you think is harder to do? Would you say plan for how you want your money to be distributed after you die or plan for the treatments you do or do not want at the end of life?



# Almost 30% indicate that they have seen or heard more about end-of-life care issues in the past 12 months.

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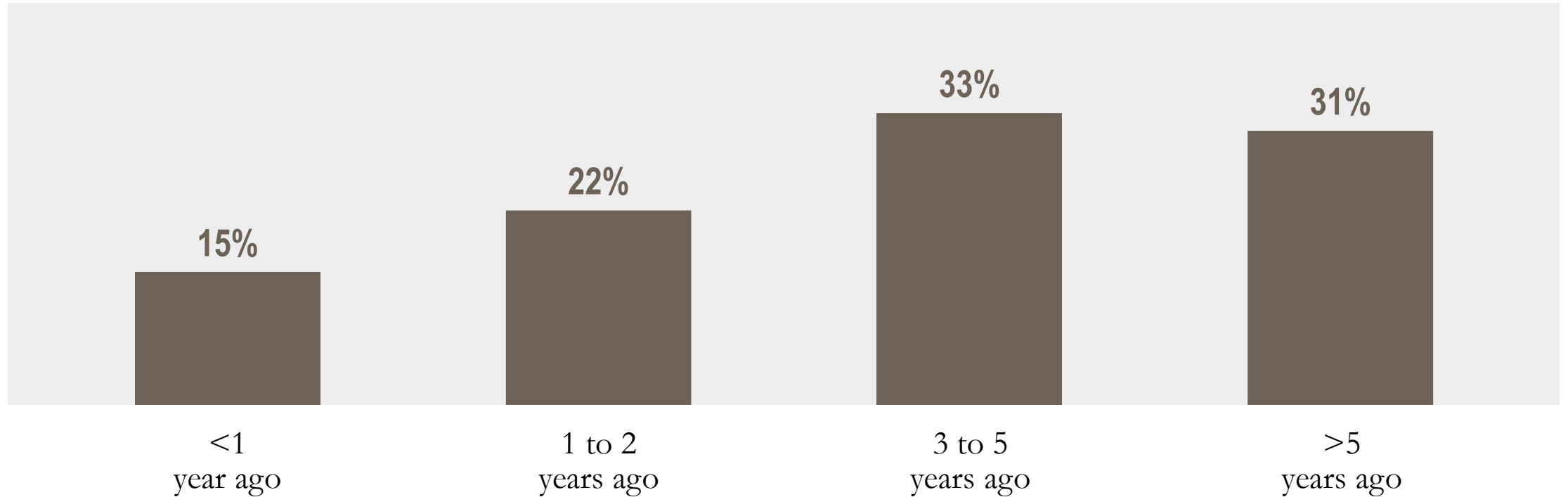


Q: In the past 12 months, would you say that you have seen or heard more about end-of-life care issues than you did previously, less about end-of-life care issues than you did previously, or about the same amount as you did previously?



# Of those who completed a health care proxy, 15% named their agent within the past year.

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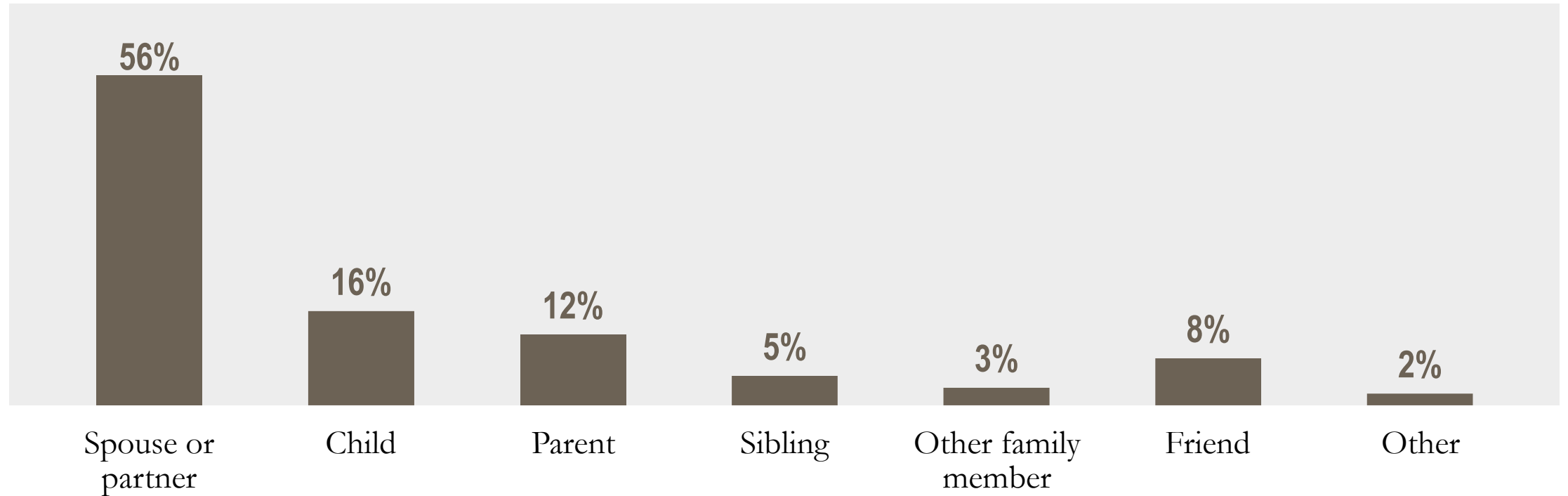
Q: Did you complete the form that named someone as your health care agent less than a year ago, between 1 to 2 years ago, between 3 to 5 years ago, or more than 5 years ago? *Base: Named a health care agent*





## Of those with an agent, over half named a spouse or partner.

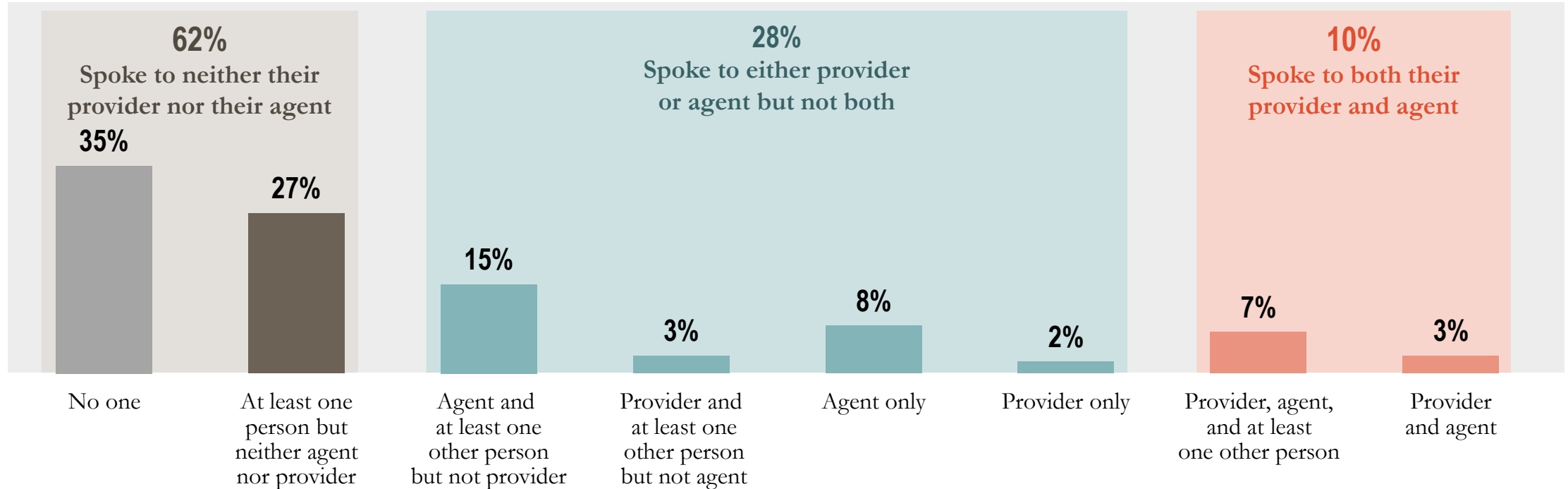
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Q: Who is your health care agent? Base: Named a health care agent



# Full circle conversations: Only a small minority had spoken to both their health care provider and their agent.



Q: Have you ever had a conversation with a doctor or other health care provider about your wishes for care if you were seriously ill or near the end of your life, or not?

Q: Have you had a conversation with at least one person other than a doctor or other health care provider about your wishes for care if you were seriously ill or near the end of your life, or not?

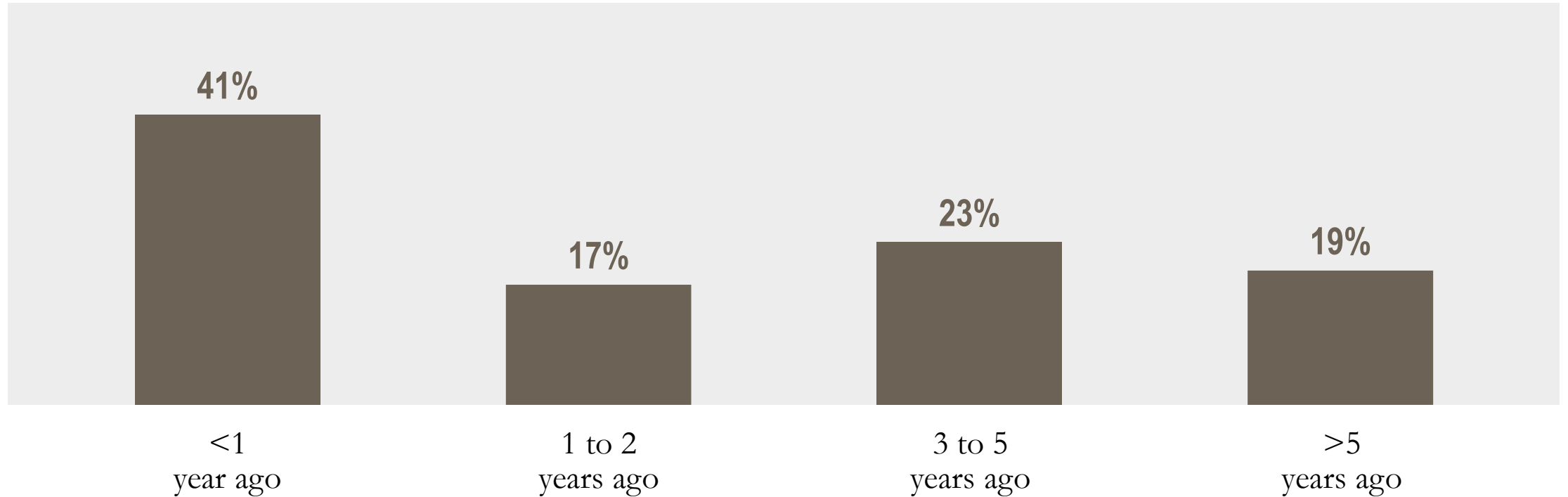
Q: With whom did you have this conversation about your wishes for care if you were seriously ill or near the end of life? *Base: Had conversation with at least one person other than health care provider*

Q: Is [response] your health care agent? *Base: Had conversation with at least one person other than health care provider*



## Of those who talked with a health care provider, about 40% of conversations occurred within the past year.

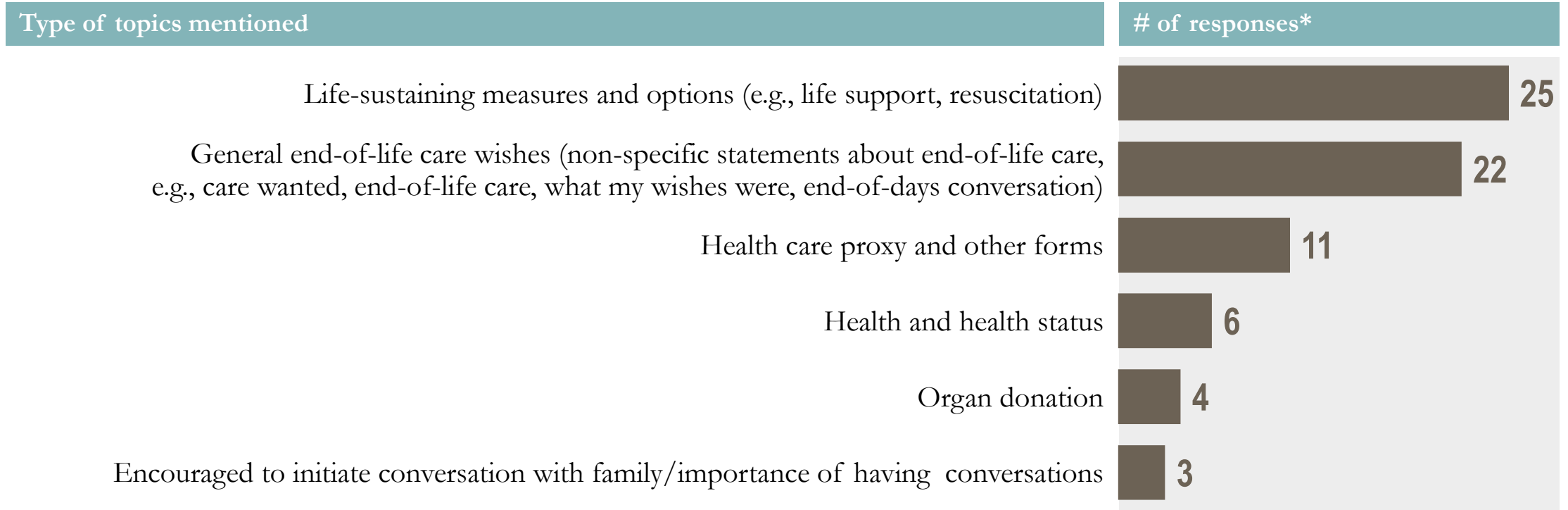
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Q: Did you have this conversation with a doctor or other health care provider about your wishes less than a year ago, between 1 to 2 years ago, between 3 to 5 years ago, or more than 5 years ago? Base: Had conversation with health care provider



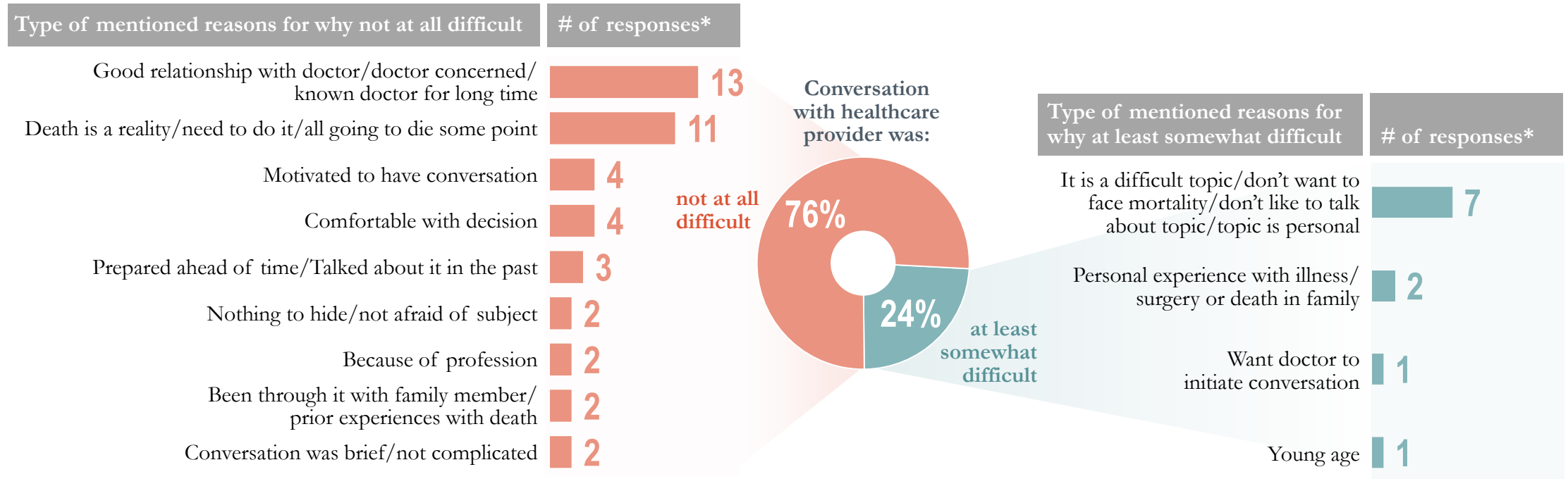
# The most common discussion topics with providers were life-sustaining measures and general wishes for end-of-life care.



\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
Q: In the conversation with a doctor or other health care provider, what did you talk about? Base: Conversation with health care provider ≤ 5 years



# More than three-quarters say that conversations with providers were not at all difficult. They cite their good relationships as the most common reason for ease.



\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.

Q: On a scale of 1 to 5 with 1 being not at all difficult and 5 being very difficult, how difficult was it for you to have a conversation with a doctor or other health care provider about your wishes for care? Base: Conversation with healthcare provider ≤ 5 years

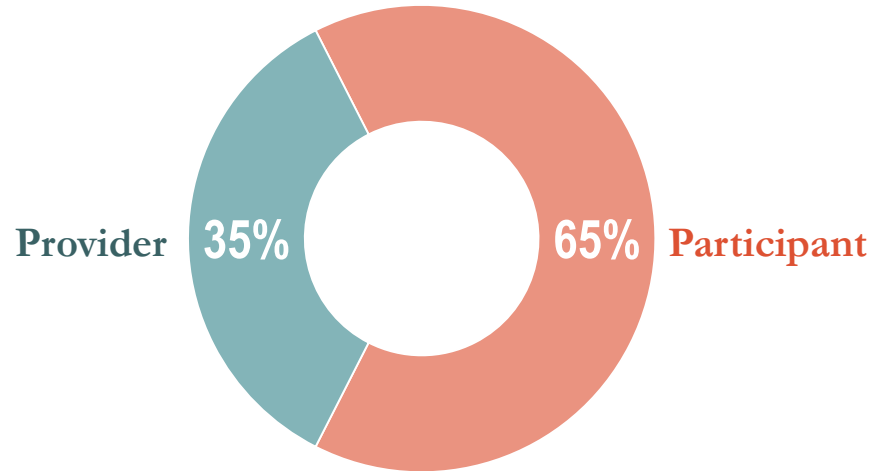
Q: Why did you give a rating of [answer] for how difficult it was for you to have a conversation about your wishes for care? Base: Conversation with health care provider ≤ 5 years



# The majority of participants had initiated the conversation with their provider themselves.

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Who initiated conversation?\*



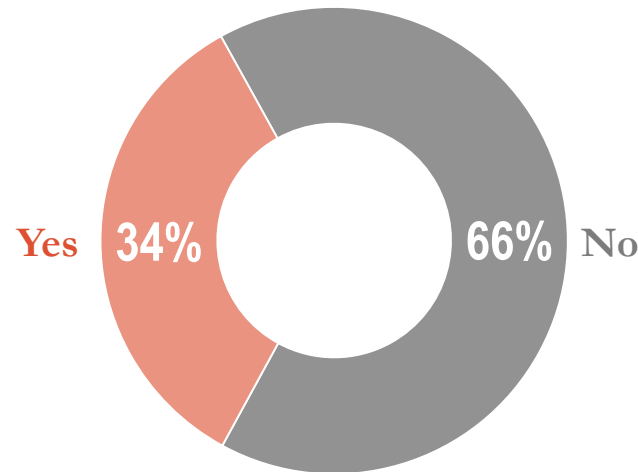
\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
Q: Who initiated the conversation about your wishes for care? Base: Conversation with health care provider ≤ 5 years



# About one-third of initiators prepared to have conversations by using some form of resource to help guide them.

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*Among participants who initiated conversation:*  
**Prepared to have conversation?\***

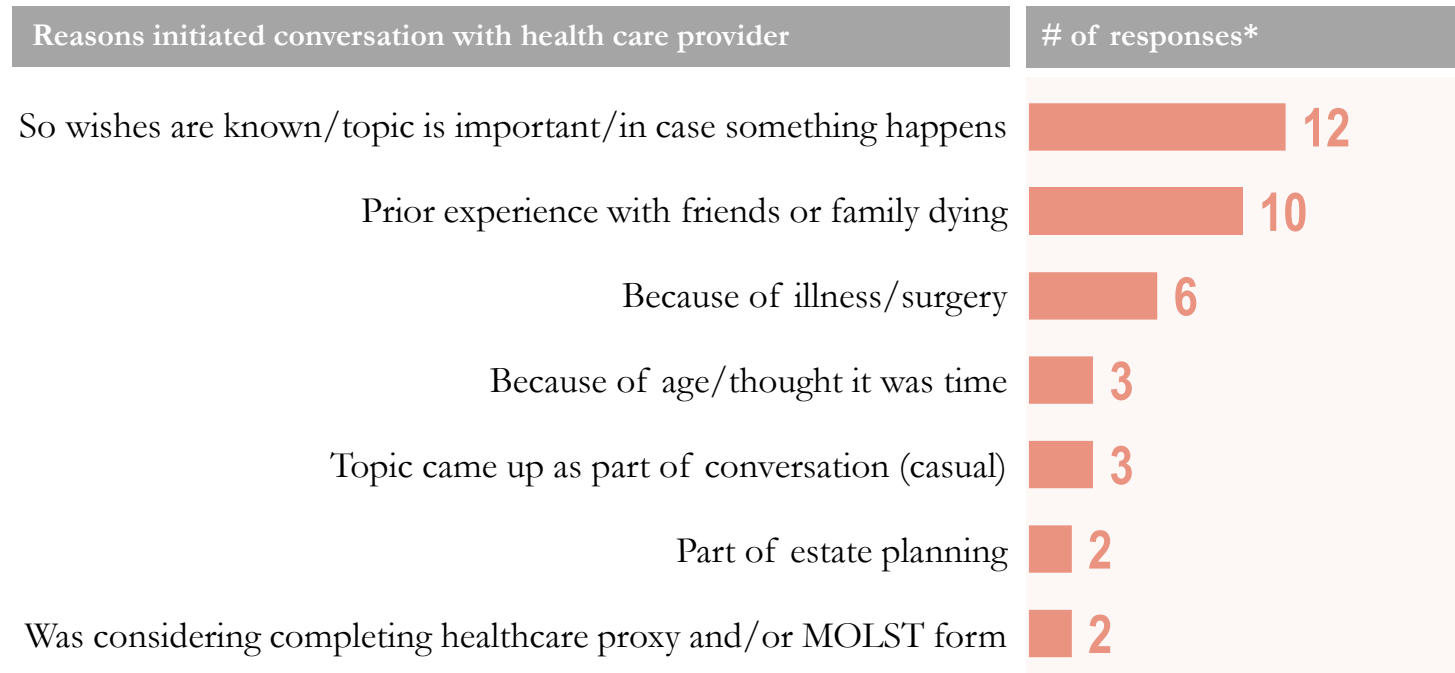


\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.

Q: Did you prepare to have a conversation about your wishes for care with a doctor or other health care provider by using any books, forms, tools or other resources to help guide you? *Base: Initiated conversation with health care provider*



# Among those who initiated the conversation with their provider, the most common reason cited was to ensure their wishes were known.



\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
Q: Why did you initiate a conversation about your wishes for care with a doctor or other health care provider? Base: Initiated conversation





# When providers initiated conversations, participant reactions were largely neutral or positive.

| Reaction when health care provider initiated conversation:  | # of responses* |
|---|-----------------|
| <b>Neutral reactions</b>  |                 |
| It was fine, no big thing, normal question, comfortable, regularly asked by doctor, conversation everyone should have | 9               |
| Something new/wanted more explanation   | 2               |
| <b>Positive reactions</b>   |                 |
| Glad, happy, good or great idea, thought highly of doctor for doing it, showed concern                                | 7               |
| <b>Negative reactions</b>   |                 |
| Didn't want to hear it  | 1               |
| Not happy because was not usual doctor  | 1               |
| Irritated because doctor "danced around the subject"  | 1               |

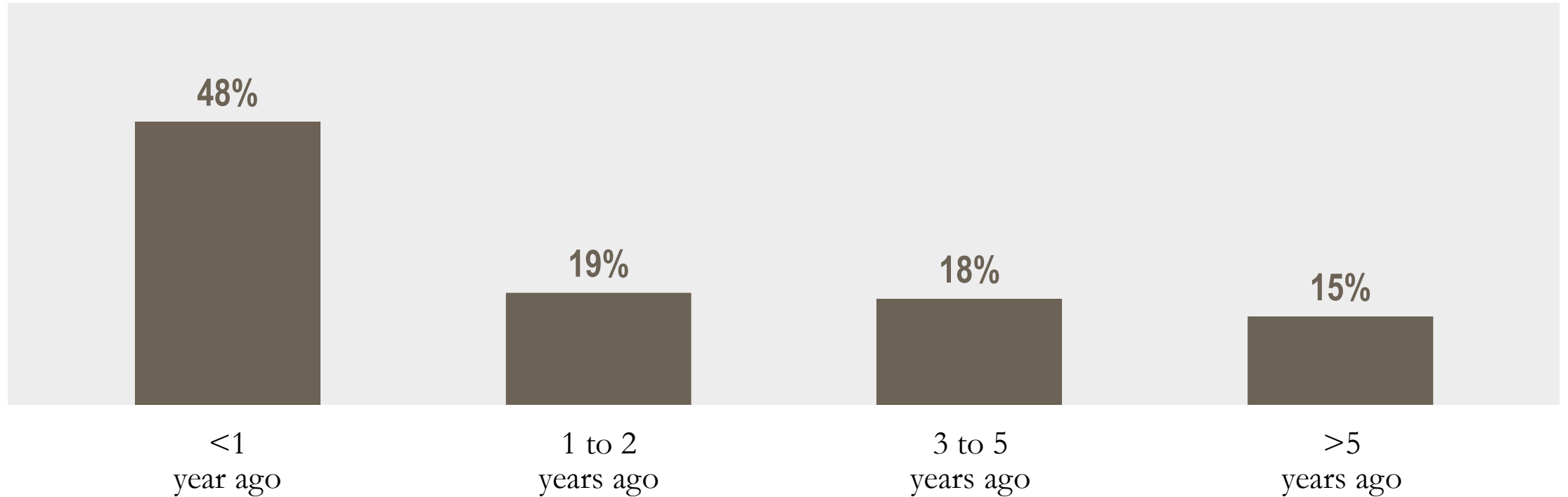
\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.

Q: What was your reaction when a doctor or other health care provider brought up the topic of your wishes for care if you were seriously ill or near the end of life? Base: Conversation with health care provider ≤ 5 years, health care provider initiated conversation



# Nearly half of those who had a conversation with someone other than a provider did so within the last year.

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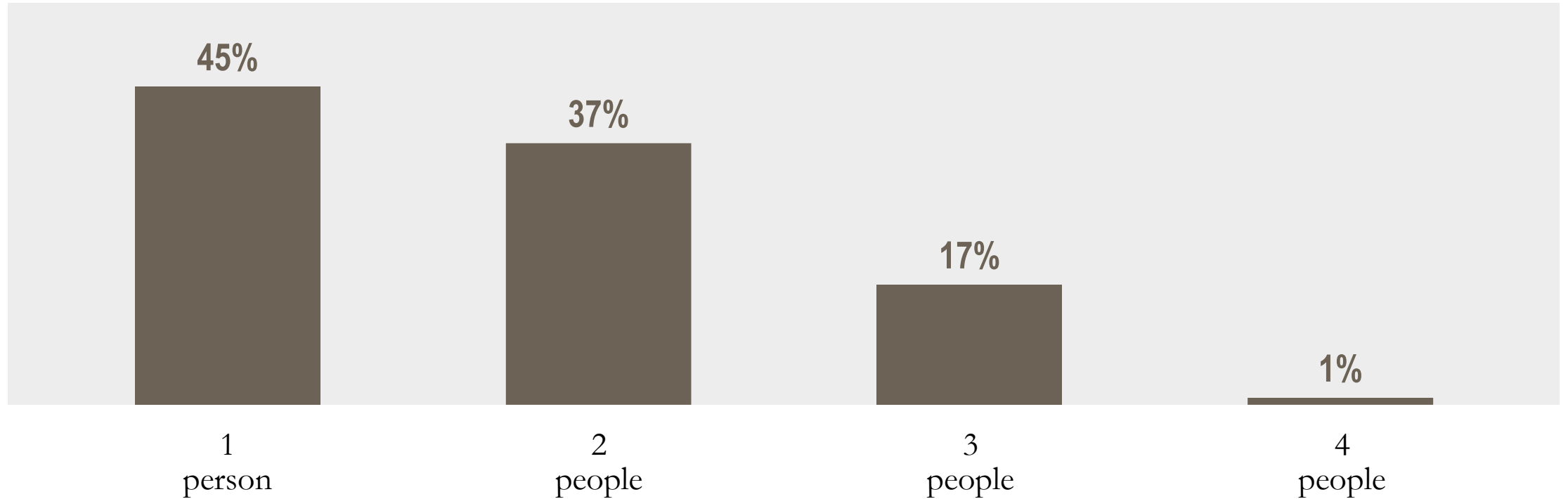


Q: Did you have this conversation about your wishes for care if you were seriously ill or near the end of life with [mentioned person] less than a year ago, between 1 to 2 years ago, between 3 to 5 years ago, or more than 5 years ago? Base: Had conversation with someone other than health care provider



Among those who had a conversation with someone other than a provider, almost half talked with one person, and almost one-fifth talked with three or more people.

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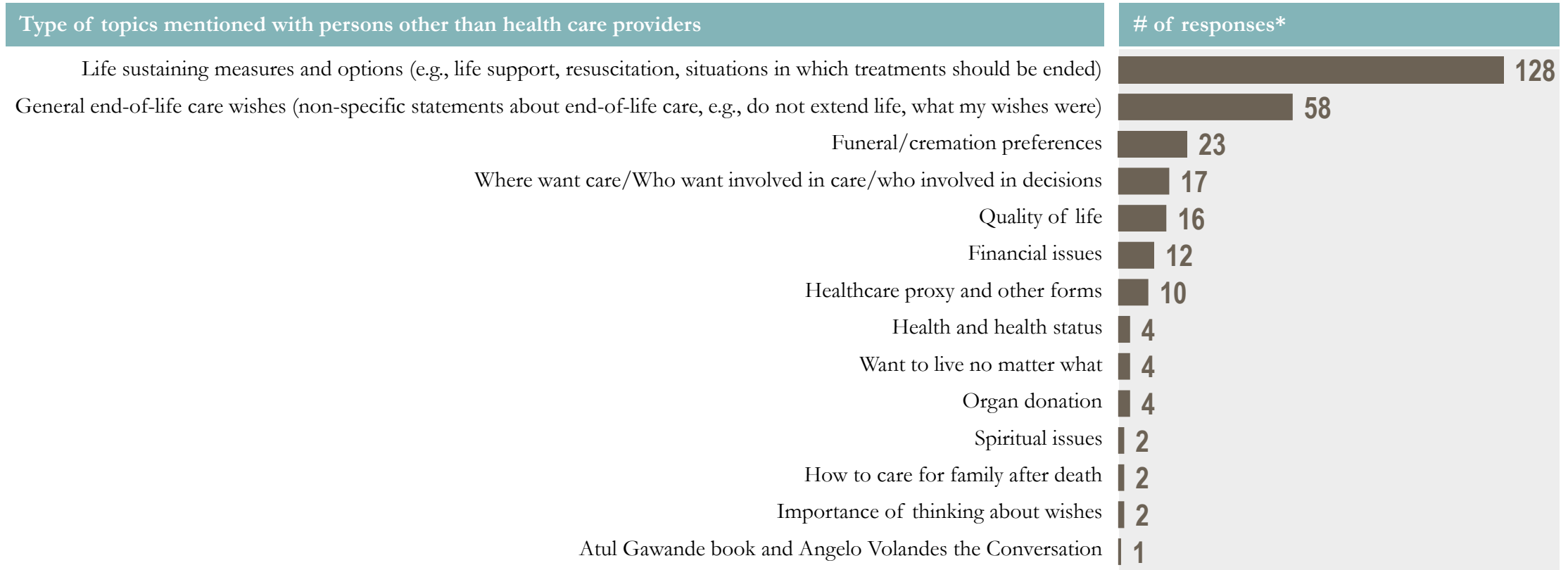


Q: Have you had a conversation with at least one person other than a doctor or other health care provider about your wishes for care if you were seriously ill or near the end of your life, or not?

Q: With whom did you have this conversation about your wishes for care if you were seriously ill or near the end of life? *Base: Had conversation with at least one person*



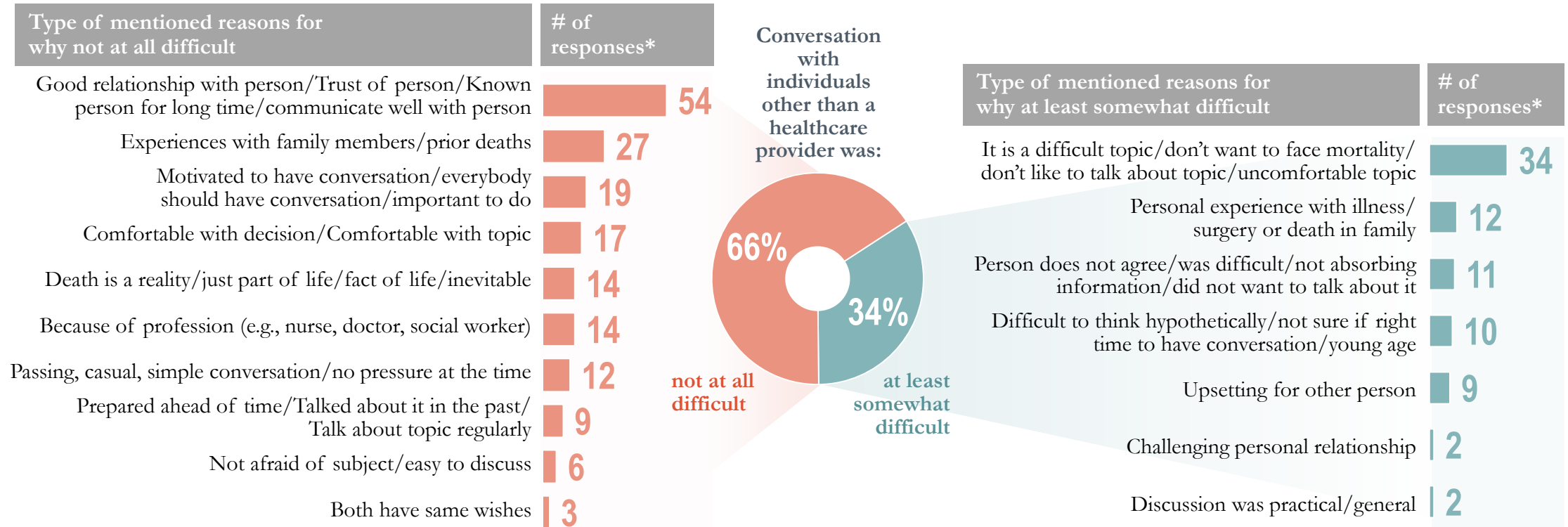
# The most common discussion topics in conversations with someone other than a provider were life-sustaining measures, general wishes for end-of-life care, and funeral/cremation preferences.



\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
 Q: In the conversation with [mentioned person], what did you talk about? Base: Conversation with someone other than health care provider ≤ 5 years



# Two-thirds say that conversations with someone other than a provider were not at all difficult.

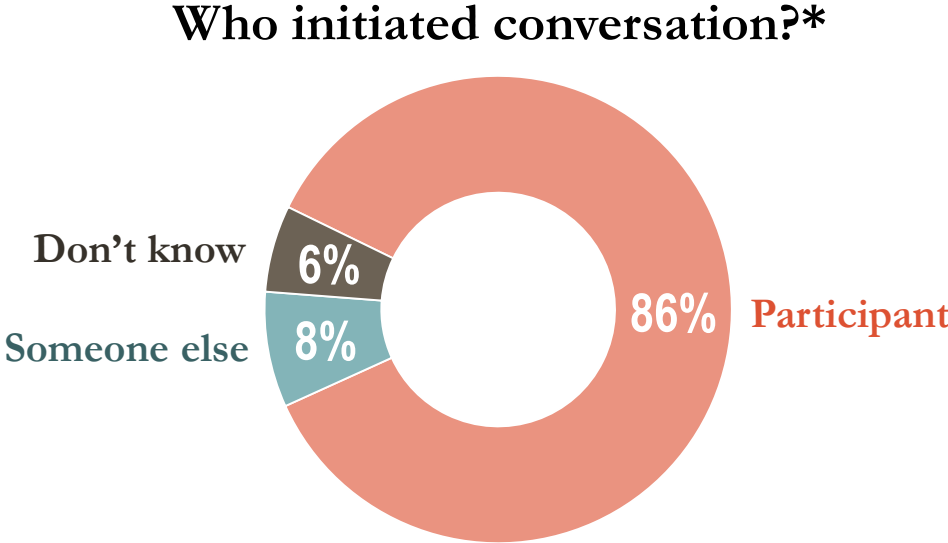


\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
 Q: On a scale of 1 to 5 with 1 being not at all difficult and 5 being very difficult, how difficult was it for you to have a conversation with [mentioned person] about your wishes for care? Base: Conversation with someone health care provider ≤ 5 years  
 Q: Why did you give a rating of [answer] for how difficult it was for you to have a conversation with [mentioned person] about your wishes for care? Base: Conversation with health care provider ≤ 5 years



Among those who had conversations with someone other than a provider, the large majority initiated the conversation.

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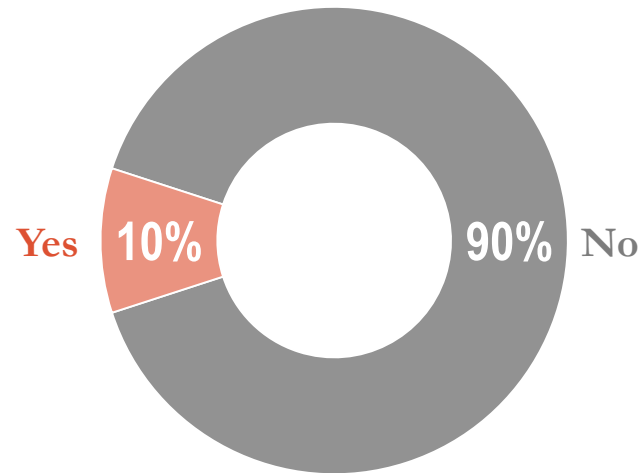
\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
Q: Who initiated the conversation about your wishes for care? Base: Conversation with someone other than health care provider ≤ 5 years



# Only a small percentage prepared to have conversations by using some form of resource to help guide them.

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*Among respondents who initiated conversation:*  
**Prepared to have conversation?\***

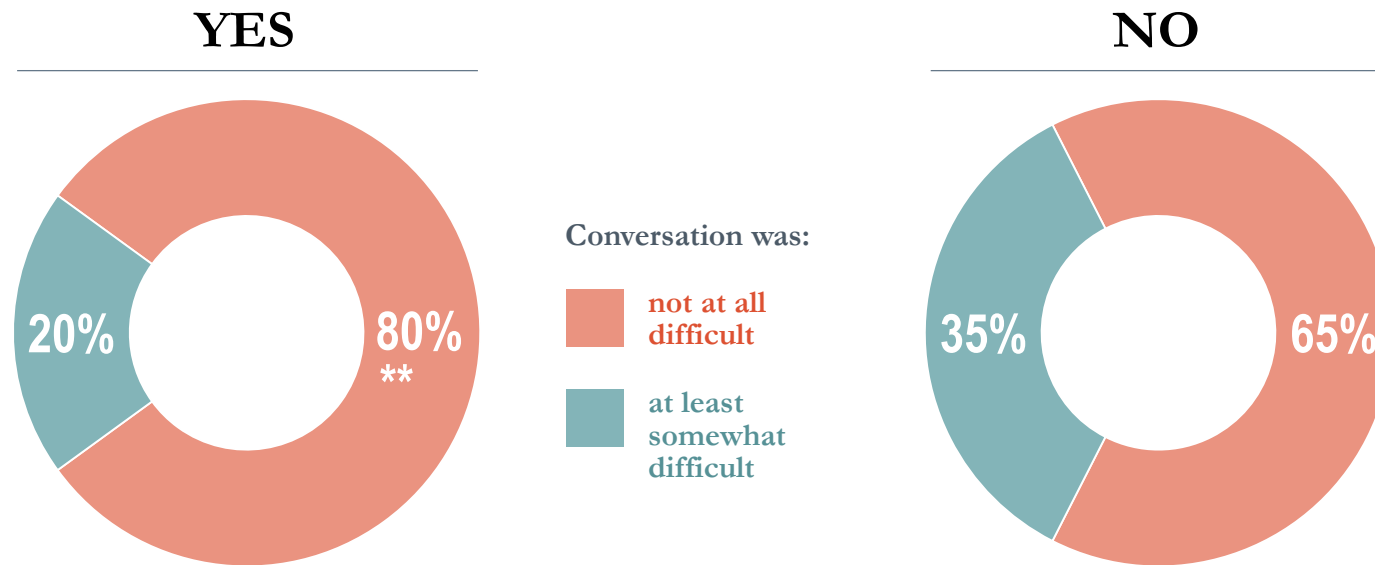


\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
Q: Did you prepare to have this conversation with [mentioned person] about your wishes for care by using any books, forms, tools or other resources to help guide you? Base: Initiated at least one conversation



# Those who prepared to have a conversation with someone other than a provider were more likely to report that the conversation was not at all difficult.

## Prepared to have conversation with at least one person other than a health care provider using some form of resource?\*



\*Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.

\*\*Significantly higher than comparison group at 95% confidence level.

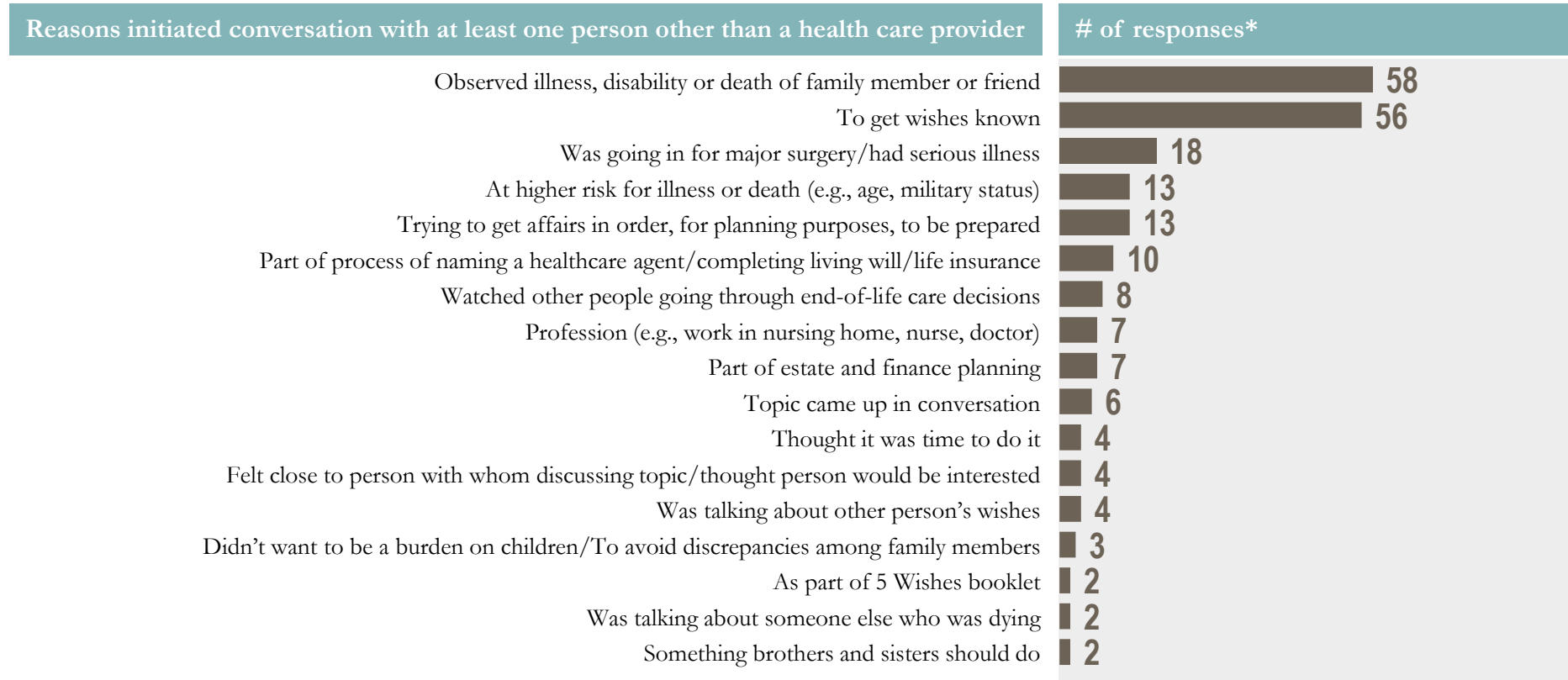
Q: Did you prepare to have this conversation with [mentioned person] about your wishes for care by using any books, forms, tools or other resources to help guide you? Base: Initiated at least one conversation

Q: On a scale of 1 to 5 with 1 being not at all difficult and 5 being very difficult, how difficult was it for you to have a conversation with [mentioned person] about your wishes for care? Base: Conversation with someone health care provider ≤ 5 years and prepared to have a conversation





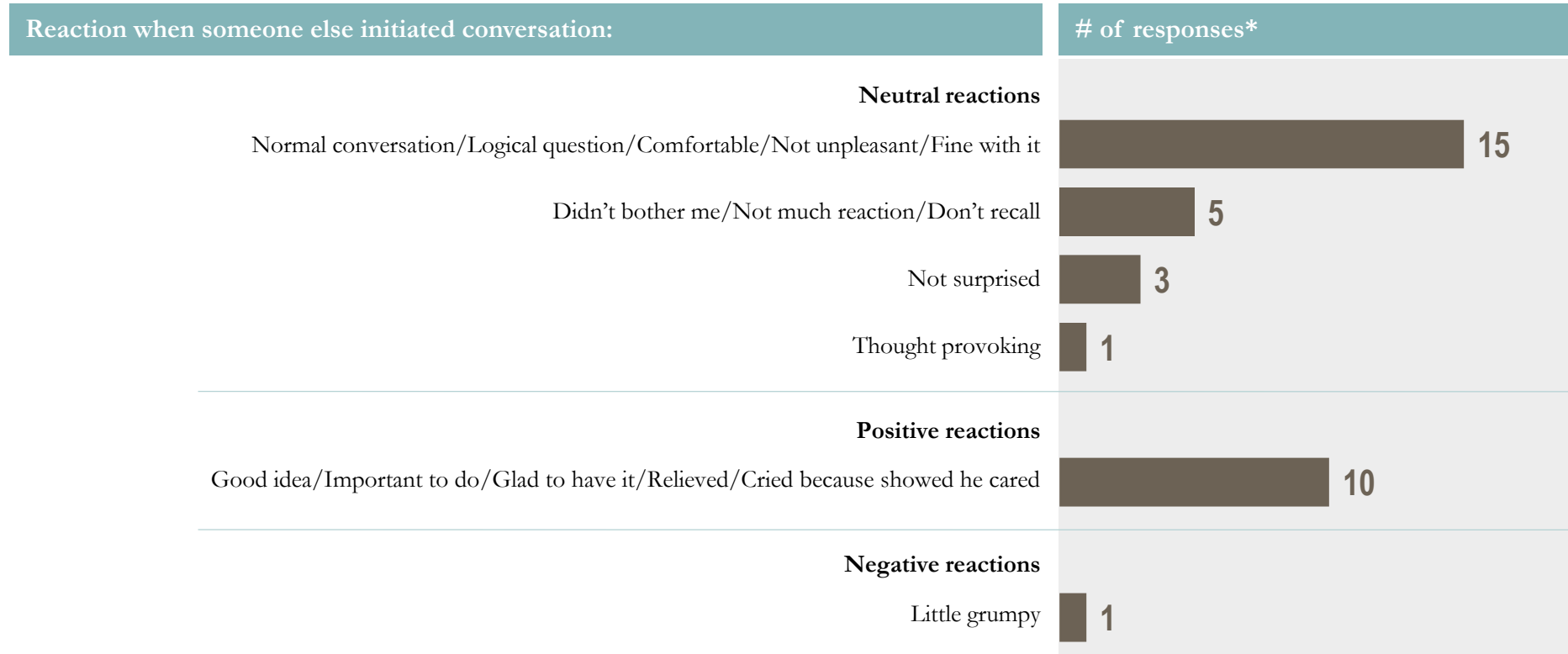
# For those who initiated conversations, the most common reasons were to make their wishes known and because of an experience with the illness, disability or a death of a family member or friend.



\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.  
 Q: Why did you initiate a conversation with [mentioned person] about your wishes for care? Base: Initiated at least one conversation



# For those who had someone else initiate the conversation, almost all reported having neutral or positive reactions.



\* Follow-up questions about conversations were asked only of participants who had conversations in the last five years to reduce the impact of recall bias.

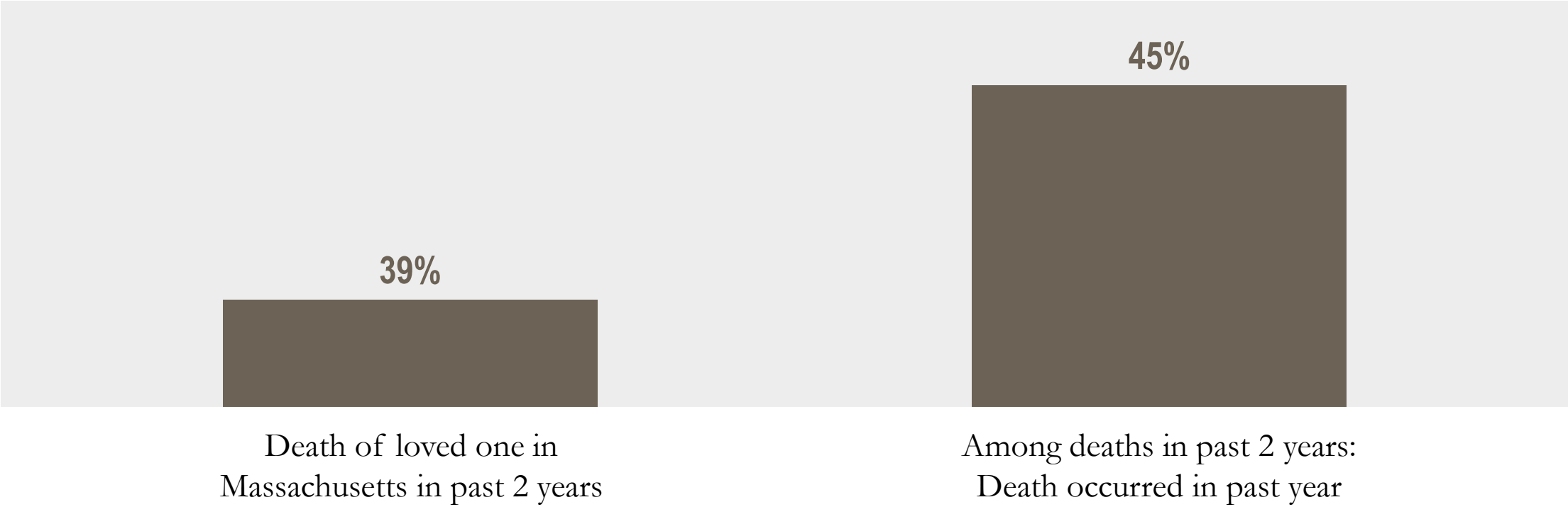
Q: What was your reaction when [other person] brought up the topic of your wishes for care if you were seriously ill or near the end of life?

Base: Conversation with someone other than health care provider ≤ 5 years, someone else initiated conversation



# Almost 40% of participants had a loved one die in the past two years, with 45% dying in the past year.

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Q: In the past 2 years, did you have a loved one die in Massachusetts?  
Q: Did your loved one die within the past year or within the past 2 years? Base: Death of loved one in past 2 years



# More than half of participants said their loved ones talked very much about their wishes for care with both providers and loved ones.



NOTE: Follow-up questions were only asked to participants who reported that they were involved in their loved one's care in the last weeks of their life

Q: To what extent did a health care team talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past 2 years and involved in loved one's care

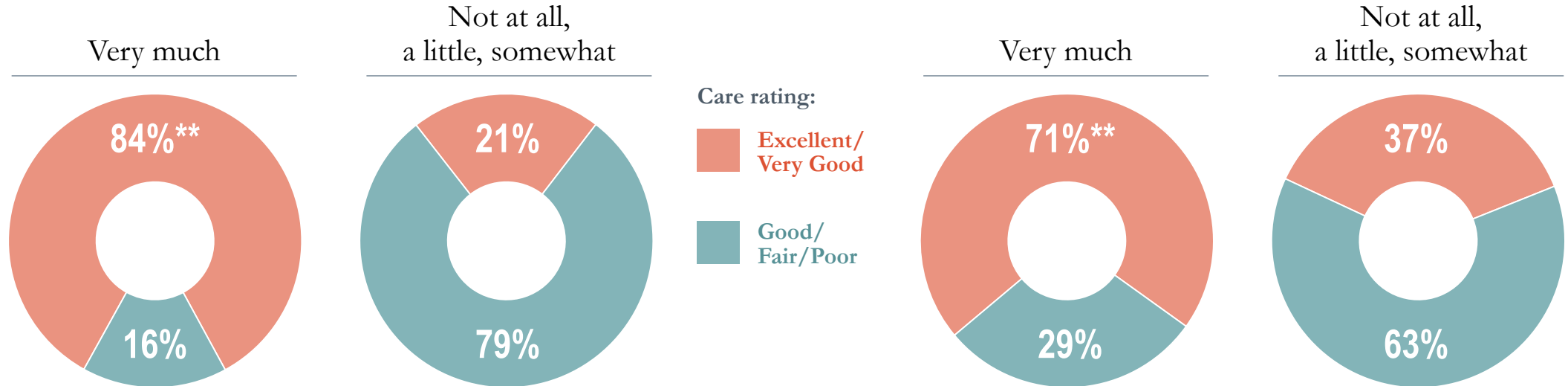
Q: To what extent did you or family members or friends talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past 2 years and involved in loved one's care



# Those who reported more conversations about their loved one's wishes were more likely to say that their loved one's care was very good or excellent.

Extent to which health care team talked to loved one about wishes\*

Extent to which respondent, family member, or friend talked to loved one about wishes\*



\*Follow-up questions were only asked to participants who reported that they were involved in their loved one's care in the last weeks of their life.

\*\*Significantly higher than comparison group at 95% confidence level.

Q: Overall, how would you rate the care your loved one received at the end of their life? Base: Death of a loved one in Massachusetts in past 2 years

Q: To what extent did a health care team talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past 2 years and involved in loved one's care

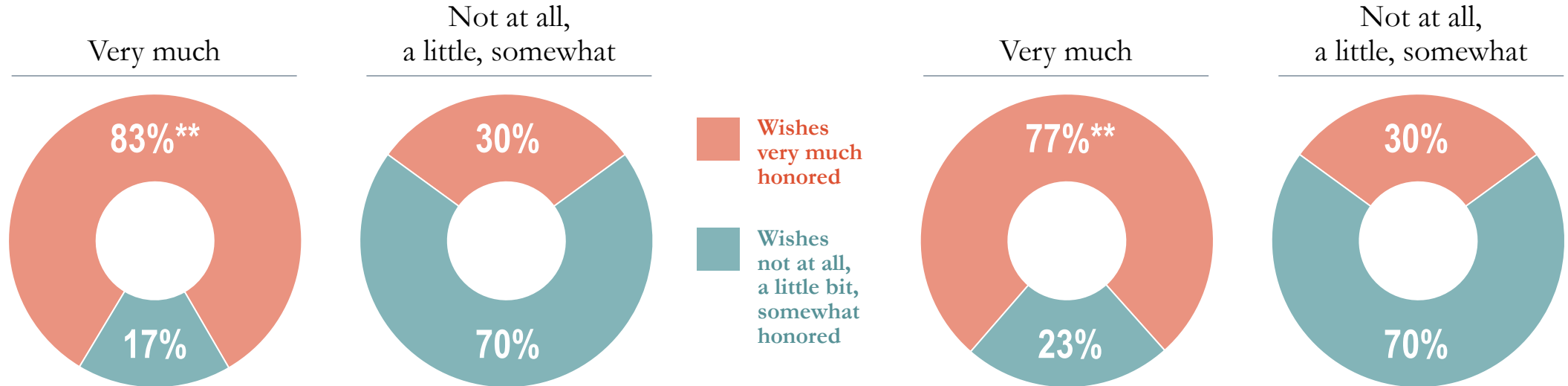
Q: To what extent did you or family members or friends talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past 2 years and involved in loved one's care



# Those who reported more conversations about their loved one's wishes were more likely to report that their loved one's wishes were very much honored.

Extent to which health care team talked to loved one about wishes\*

Extent to which respondent, family member, or friend talked to loved one about wishes\*



\*Follow-up questions were only asked to participants who reported that they were involved in their loved one's care in the last weeks of their life.

\*\*Significantly higher than comparison group at 95% confidence level.

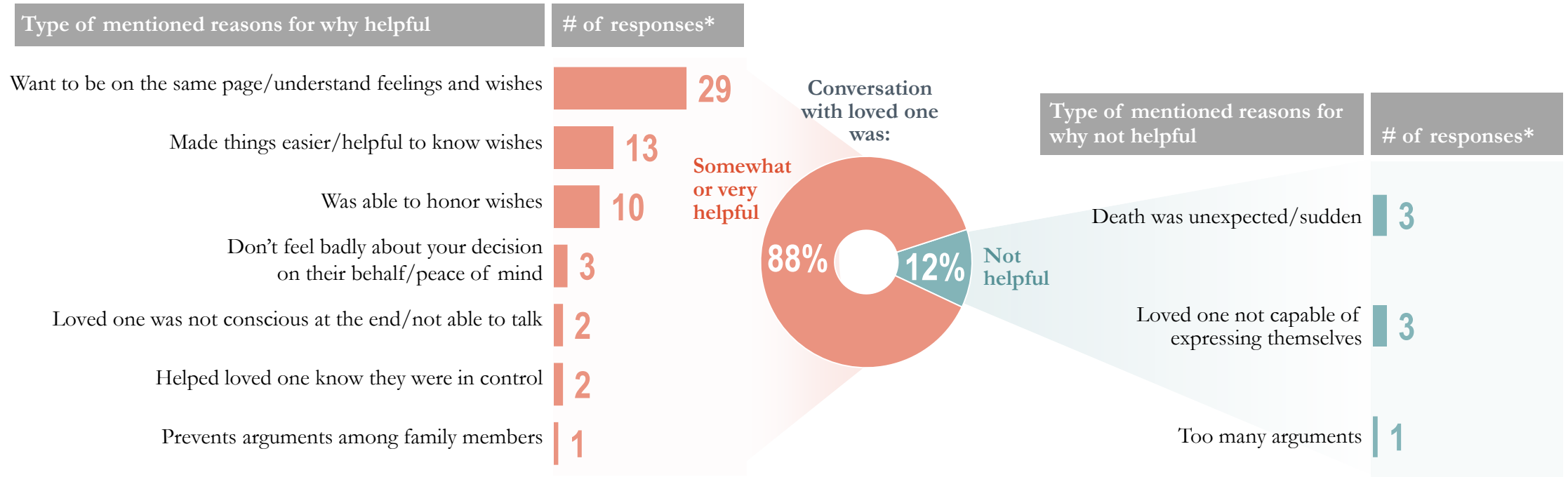
Q: To what extent would you say that your loved one's wishes were followed and honored by health care providers at the end of their life? Base: Death of a loved one in Massachusetts in past 2 years

Q: To what extent did a health care team talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past 2 years and involved in loved one's care

Q: To what extent did you or family members or friends talk to your loved one about his or her wishes for care near the end of life? Base: Death of a loved one in past 2 years and involved in loved one's care



# Nearly 90% indicated that the conversation with their loved one was somewhat or very helpful.



\*Follow-up questions were only asked to participants who reported that they were involved in their loved one's care in the last weeks of their life.

Q: How helpful was that conversation in making decisions about care for your loved one near the end of their life? Base: Talked to loved one about wishes

Q: Why was having a conversation with your loved one about their wishes not helpful in making care decisions for them? Base: Talked to loved one about wishes, conversation not helpful

Q: Why was having a conversation with your loved one about their wishes helpful in making care decisions for them? Base: Talked to loved one about wishes, conversation at least somewhat helpful

