

AARP Family Caregiving Survey: Caregivers' Reflections on Changing Roles

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November 2017

<https://doi.org/10.26419/res.00175.001>

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The views expressed herein are for information, debate, and discussion, and do not necessarily represent official policies of AARP.

Acknowledgments

NORC conducted this survey for AARP using its nationally representative online panel, AmeriSpeak. This report was prepared by Laura Skufca in AARP Research. For additional information about the survey, contact Laura Skufca at Lskufca@aarp.org. Media inquiries should be directed to Greg Phillips at gphillips@aarp.org

Methodology

- This study was conducted with a nationally representative sample of 1,081 family caregivers age 18+ caring for an older adult (age 50+).
- The data was collected via NORC's AmeriSpeak® panel. Interviews were conducted both online and via telephone from August 31, 2017 - September 19, 2017. One hundred and forty four caregivers were of Hispanic/Latino descent. The survey was offered in both English and Spanish for both phone and online respondents.
- Four hundred and seventy nine care recipients age 50+ were also included in this study. These interviews were obtained from two sources: the AmeriSpeak® panel (n=435) and via caregiver nomination (n=44). It is important to note that due to the nature of the care recipient population, this sample of recipients is likely much healthier and more independent and not representative of the entire recipient population.
- The data for both caregivers and care recipients were adjusted to correct for potential non-response biases. For care recipients, additional adjustments were made to minimize the potential for nominated care recipients to differ systematically from randomly selected recipients obtained via the AmeriSpeak panel.
- The margin of error for the sample of caregivers is +/- 2.1 percentage points. The margin of error will be among subgroups (e.g., age cohorts, race/ethnicity, gender, etc.).
- Percentages may not equal 100% due to rounding.

Key Findings

Caregivers

- Four in ten caregivers say they were not prepared to take on the role of family caregiver. Among those who were prepared, only 16% say they were “very prepared”. Not surprisingly, older caregivers say they were more prepared to take on their role than younger caregivers.
- Caregivers experience a wide variety of emotions about their role as a family caregiver. Positive emotions such as being pleased they are able to help (91%) far outweigh the negative. However, over half are stressed (51%) or worried (51%) and many are overwhelmed (40%). Caregivers who felt prepared to take on their role report much more positive emotions than those who felt unprepared.
- Hispanic/Latino and African-American caregivers are more likely to feel happy, proud, and find satisfaction in helping their loved one. African-American caregivers also report less stress and worry and seem to be more comfortable in their role. Women and younger caregivers are also more likely to be proud and feel strong and brave, but at the same time, they are more likely to say they are stressed or overwhelmed.
- More than half of caregivers (54%) say they have experienced an unexpected joy in caregiving. This most commonly relates to a sense of satisfaction in helping their loved one as well as learning more about the person they are caring for. On the other hand, about one-quarter (24%) say they have regrets. Regrets ranged from wishing they spent more time with their loved one, being more compassionate to being better prepared both financially and emotionally.

Key Findings

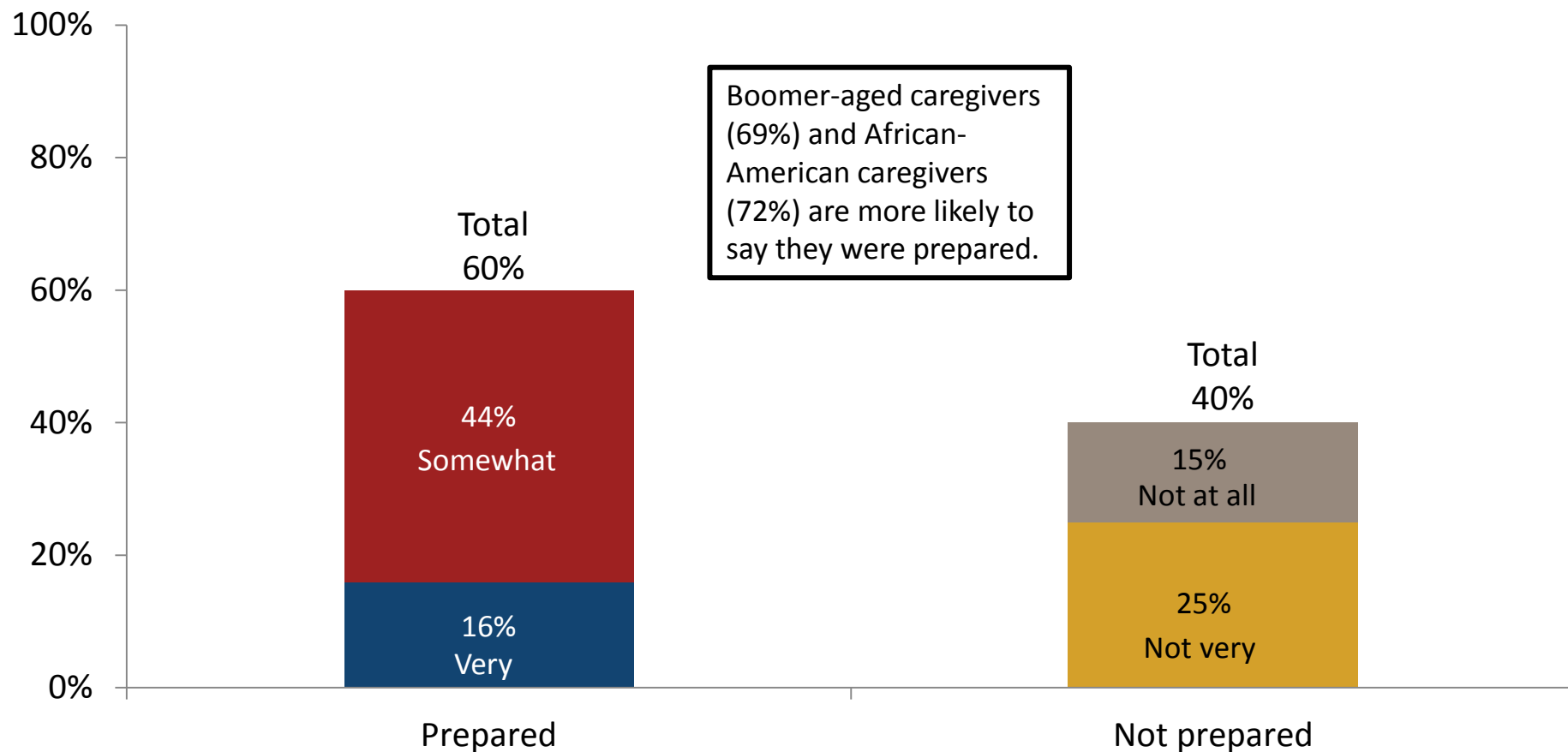
- Caregivers are also experiencing challenges such as difficulty taking care of their household (52%) or their own health (41%) and having to reduce the amount of money they save (40%). This suggests the importance of providing information and support to caregivers to help them maintain their own health and financial security while taking care of a loved one.

Care Recipients

- Like caregivers, care recipients also report more positive emotions than negative emotions. Most feel pleased (91%) or have a sense of gratitude (89%). However, nearly six in ten (59%) say they feel less independent since their loved one began providing assistance.
- Like caregivers, about half of recipients (51%) said they experienced an unexpected joy or positive experience they had not expected when accepting care from their loved one. Most feel a sense of companionship and enjoy the increased time spent together.
- On the other hand, one-quarter (26%) say they have regrets or things they wish they had done differently. Most of the regrets center around living a healthier lifestyle at a younger age. There is a perception healthier lifestyles would reduce the need for care and reliance on loved ones.
- Similar percentages of care recipients (compared to caregivers) say they felt prepared to accept help or assistance from their loved one (56%).

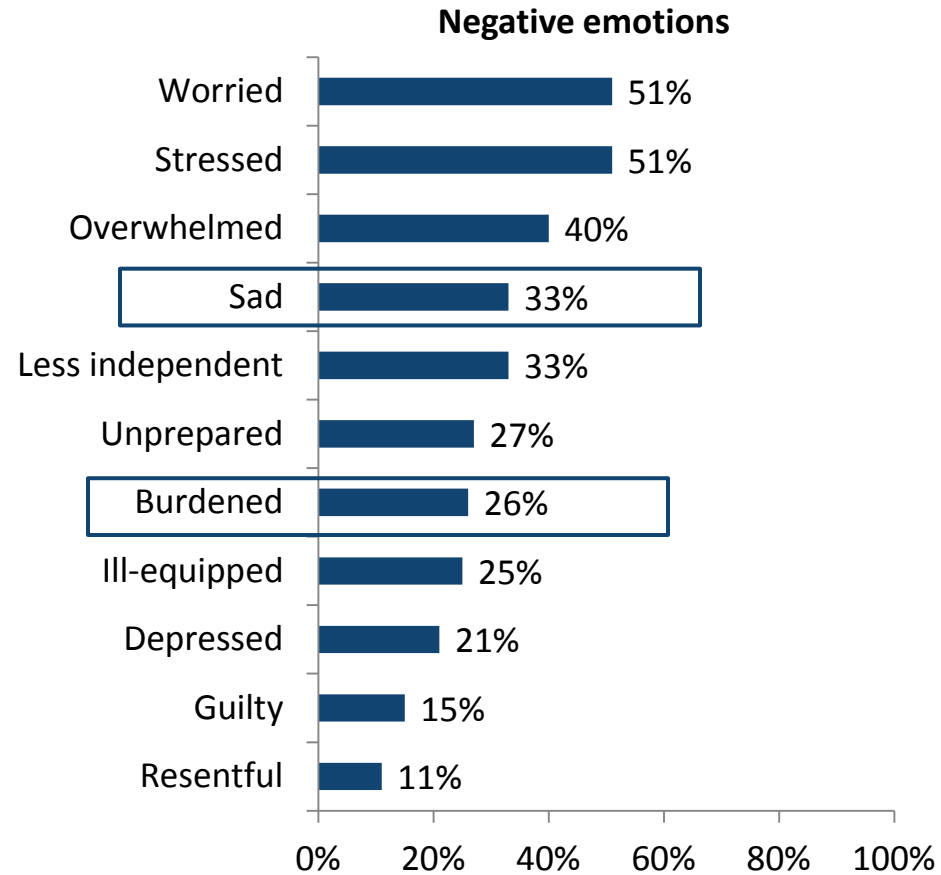
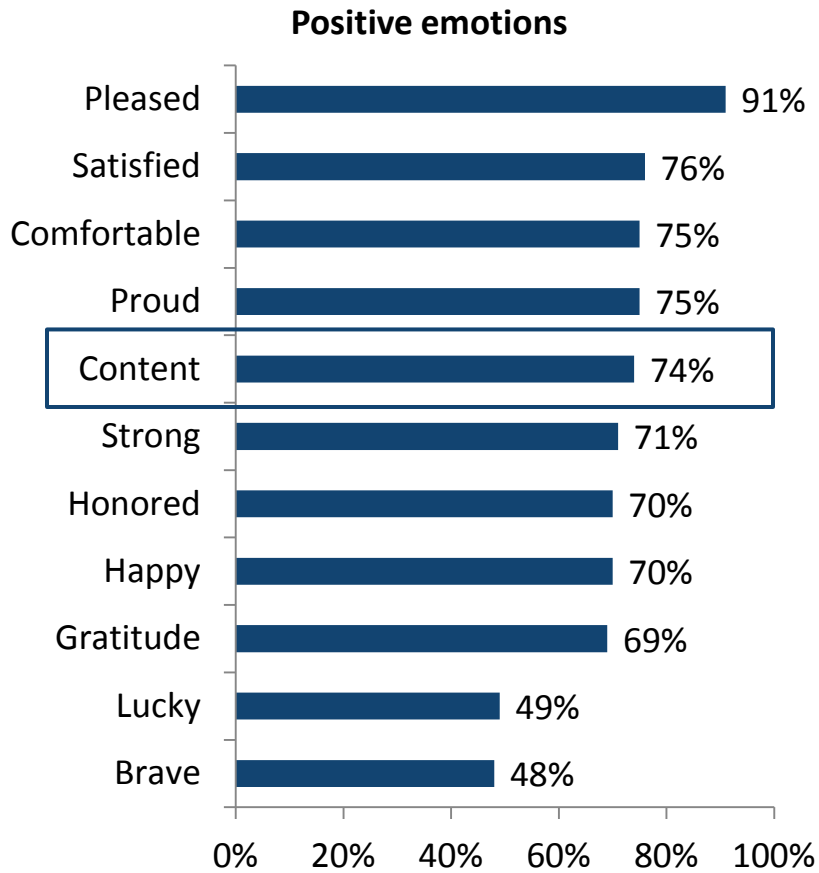
Caregivers' Perspective

While most caregivers say they were at least somewhat prepared to take on their role, four in ten (40%) say they were not prepared.



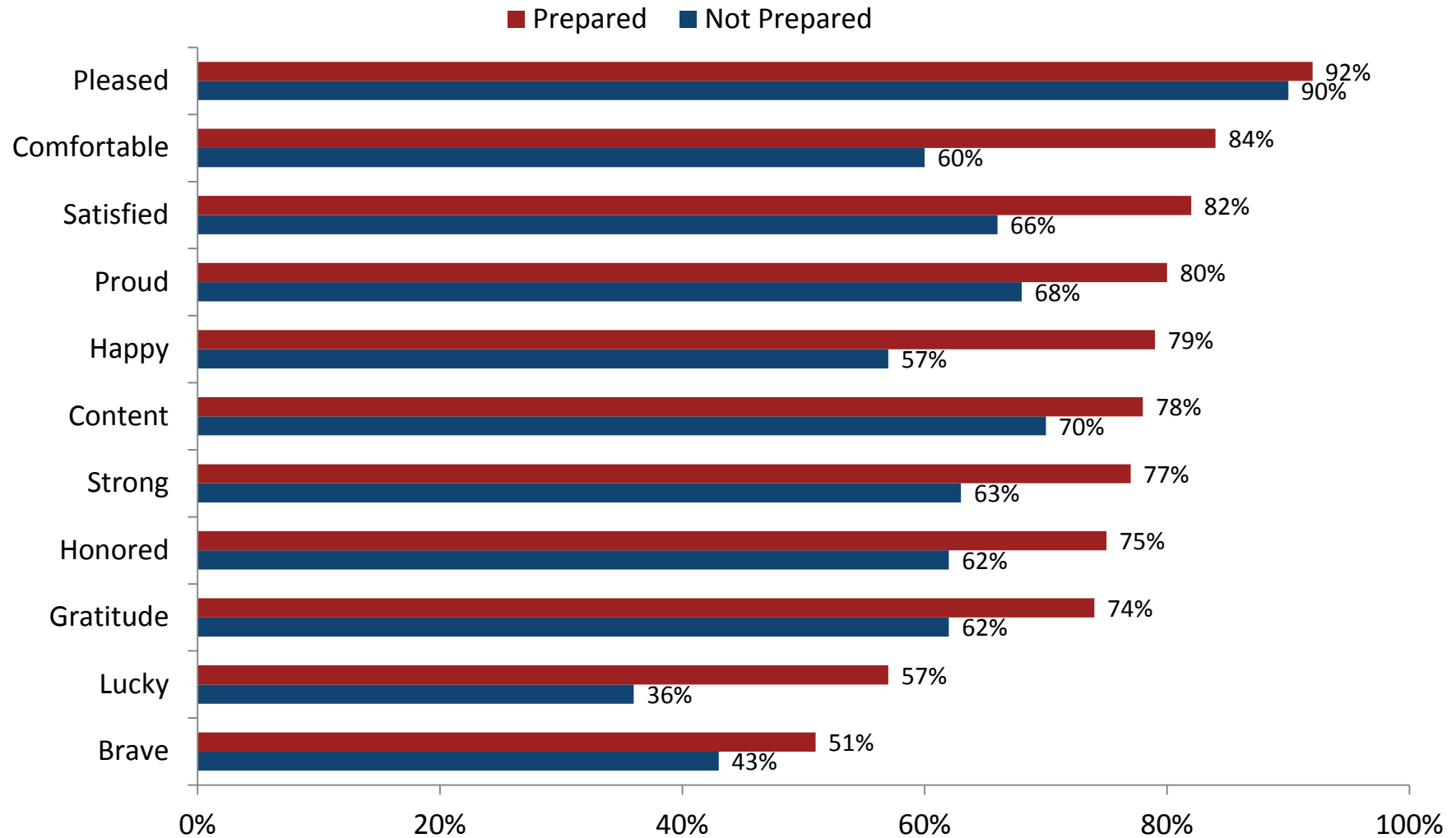
Q5. Thinking back to when you first began helping your loved one, how prepared would you say you were to take on this new role?

Caregivers experience a wide variety of emotions about their role. Positive emotions such as being pleased they can help (91%) far outweigh the negative. However, over half are stressed or worried and many are overwhelmed. The feeling of contentment is most closely predictive of having other positive emotions. The feeling of sadness or burden is most predictive of having other negative emotions.

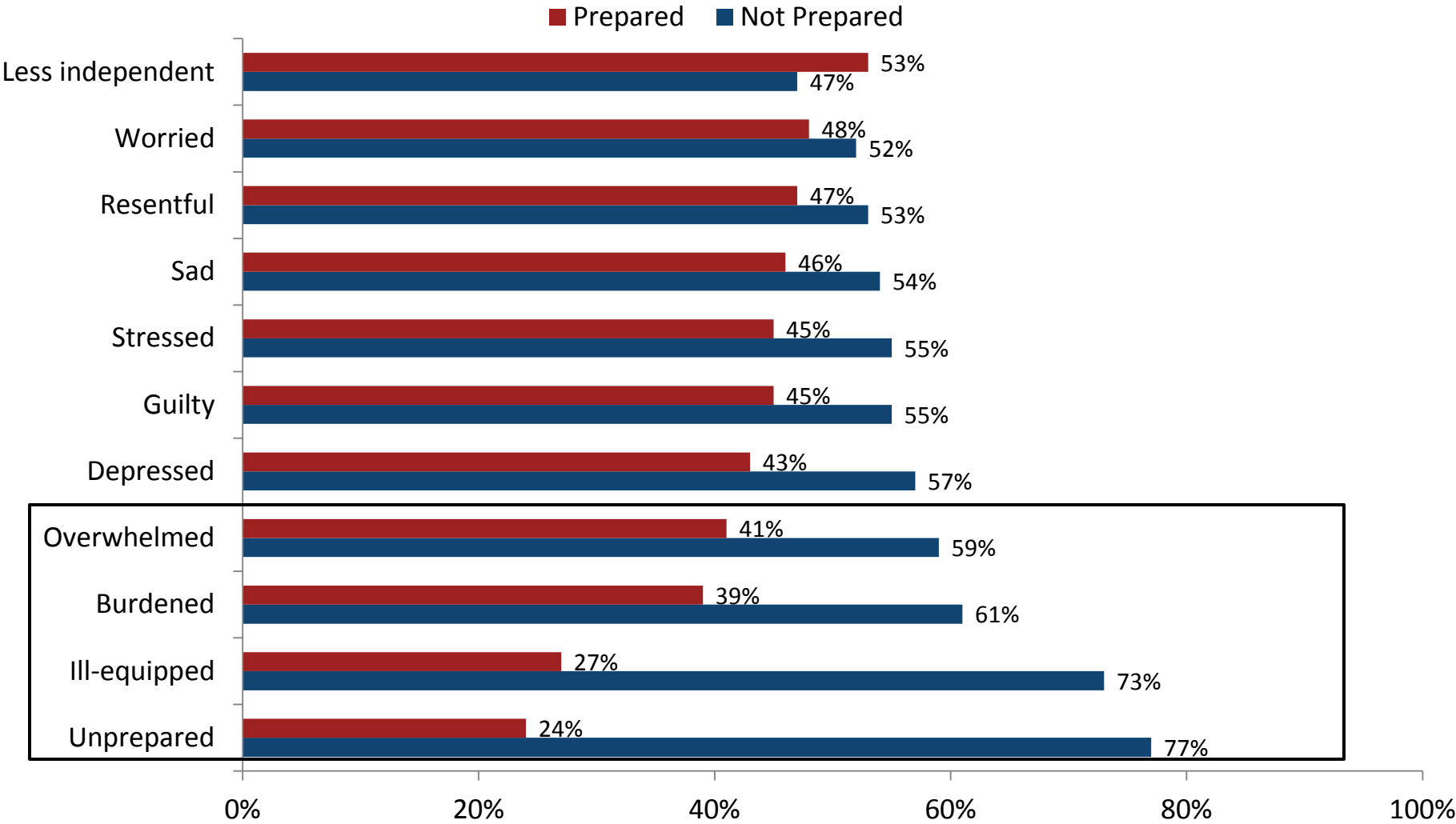


Division of emotions into positive and negative is justified by factor analysis. These yielded two dimensions (one positive, one negative) with content and burden loading highest on their respective dimensions. While they are not the most frequently cited emotion, they are the most indicative of positive and negative dimensions.

Caregivers who report they were prepared to take on caregiver duties are much more likely to experience positive emotions regarding their role as a family caregiver.



Caregivers who report they were prepared to take on caregiver duties are much less likely to experience negative emotions regarding their role as a family caregiver.



Younger caregivers, women, and multicultural populations tend to experience more positive emotions about their role as a family caregiver. However, they tend to be just as stressed, if not more, than other caregivers.

Age differences

Millennial and Gen X caregivers compared to Baby Boomers are more likely to experience feelings such as being proud (80%, 80% vs. 68%) or strong (73%, 78% vs. 65%) but at the same time, they are more likely to feel stressed (51%, 56% vs. 46%) and overwhelmed (46%, 46% vs. 31%).

Gender differences

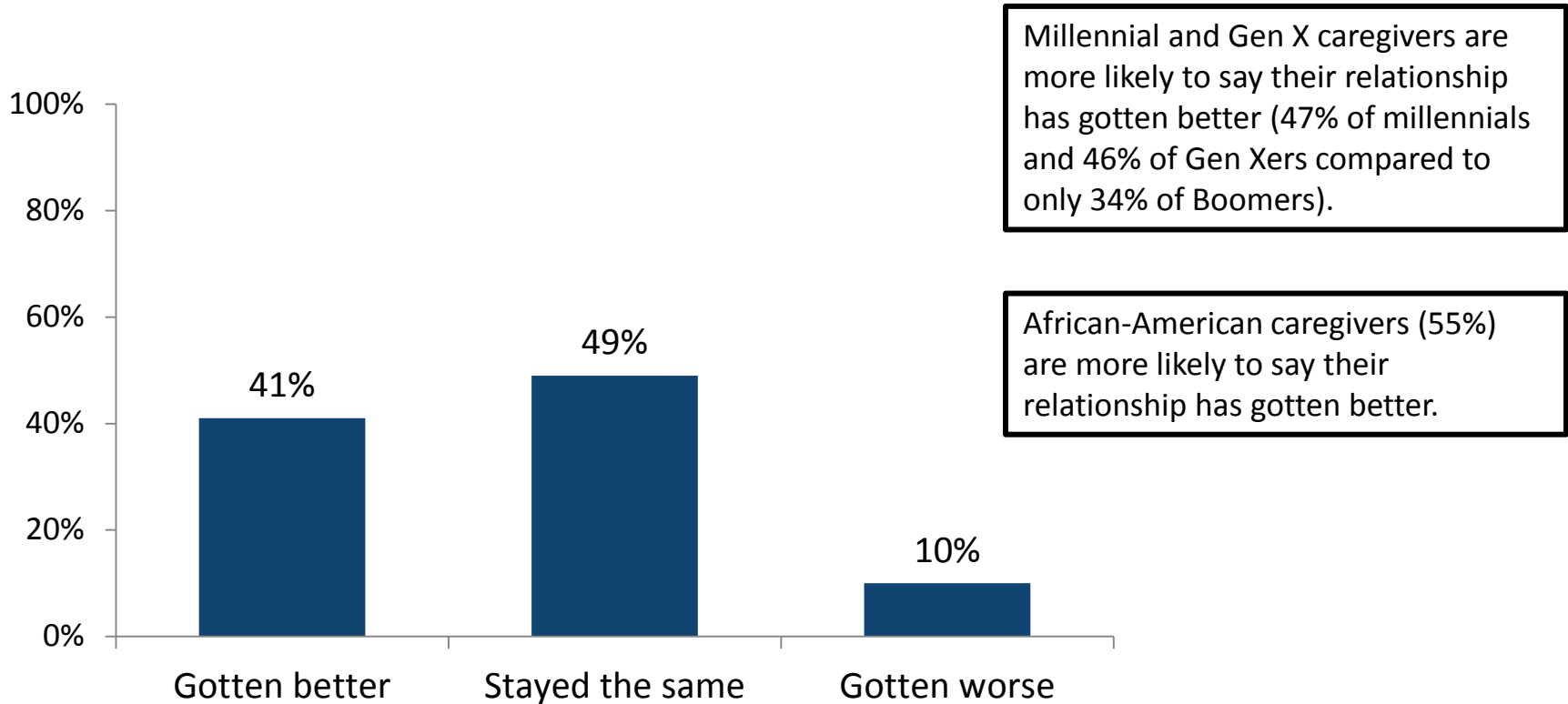
Women compared to men are feeling more stressed (55% vs. 46%) and overwhelmed (46% vs. 32%) but are also more likely to say they feel strong (75% vs. 67%), brave (54% vs. 40%), and proud (79% vs. 70%).

Race/ethnicity

African-American and Hispanic/Latino caregivers are more likely to experience positive emotions such as feeling happy (79%, 78%) or proud (85%, 82%). African-Americans are also much less likely to say they are stressed (33%).



Four in ten caregivers say their relationship with the person they help has gotten better since they began providing care. Among them, the most common reasons they feel the relationship has gotten better are that they feel closer to this person and now communicate more.



Q2. Would you say your relationship with the person you provide care or assistance for has gotten better, gotten worse, or stayed the same since you began helping them?

More than half of family caregivers say they experienced an unexpected joy. The most common being a sense of satisfaction out of helping as well as learning more about the person they are helping. Millennial caregivers (64%) and Hispanic/Latino caregivers (62%) are most likely to have experienced an unexpected joy or positive experience they had not expected.

“Getting to know more about my mom’s life before I was born” (48-year old, male caregiver)

“He is a role model and a friend to my 3 children. They love visiting with him.” (35-year old, female caregiver)

54%

of caregivers say they experienced an unexpected joy

“Giving back is a joy. My father fought in the 442nd battalion and earned a purple heart. He deserves all the care in the world.” (60-year old, male caregiver)

“I am learning how to be patient and how to appreciate the value of a relationship.” (68-year old, female caregiver)

Q3. Thinking about your role as a family caregiver, have you experienced any unexpected joys or positive experiences you had not expected?

While more than half have experienced an unexpected joy, less than one-quarter say they have regrets or things they wished they had done differently. The most common regrets are wishing they had been more compassionate, visited more often, and been more financially prepared.

“How I was towards that person in the past.” (28-year old, male caregiver)

“Do more with him when he was more able-bodied.” (47-year old, female caregiver)

24%

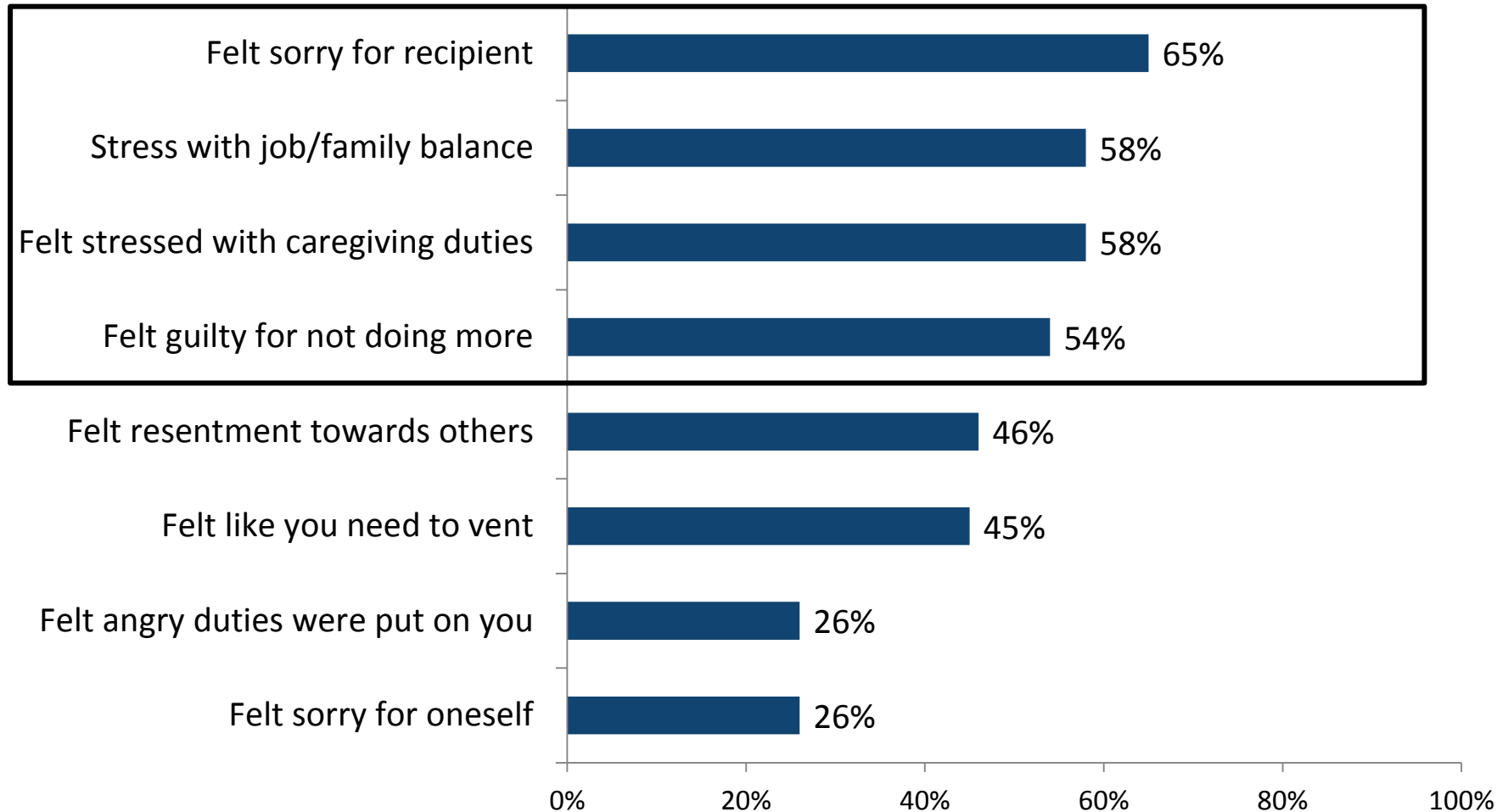
of caregivers say they have regrets

“Sometimes I feel that I'm not doing enough or when I'm enjoying activities outside of caregiving that I should be doing something for the person I am caring for.” (25-year old, female caregiver)

“I wish I was better prepared and more able to cope with the medical needs. I should have sought out more professional medical help sooner.” (42-year old, male caregiver)

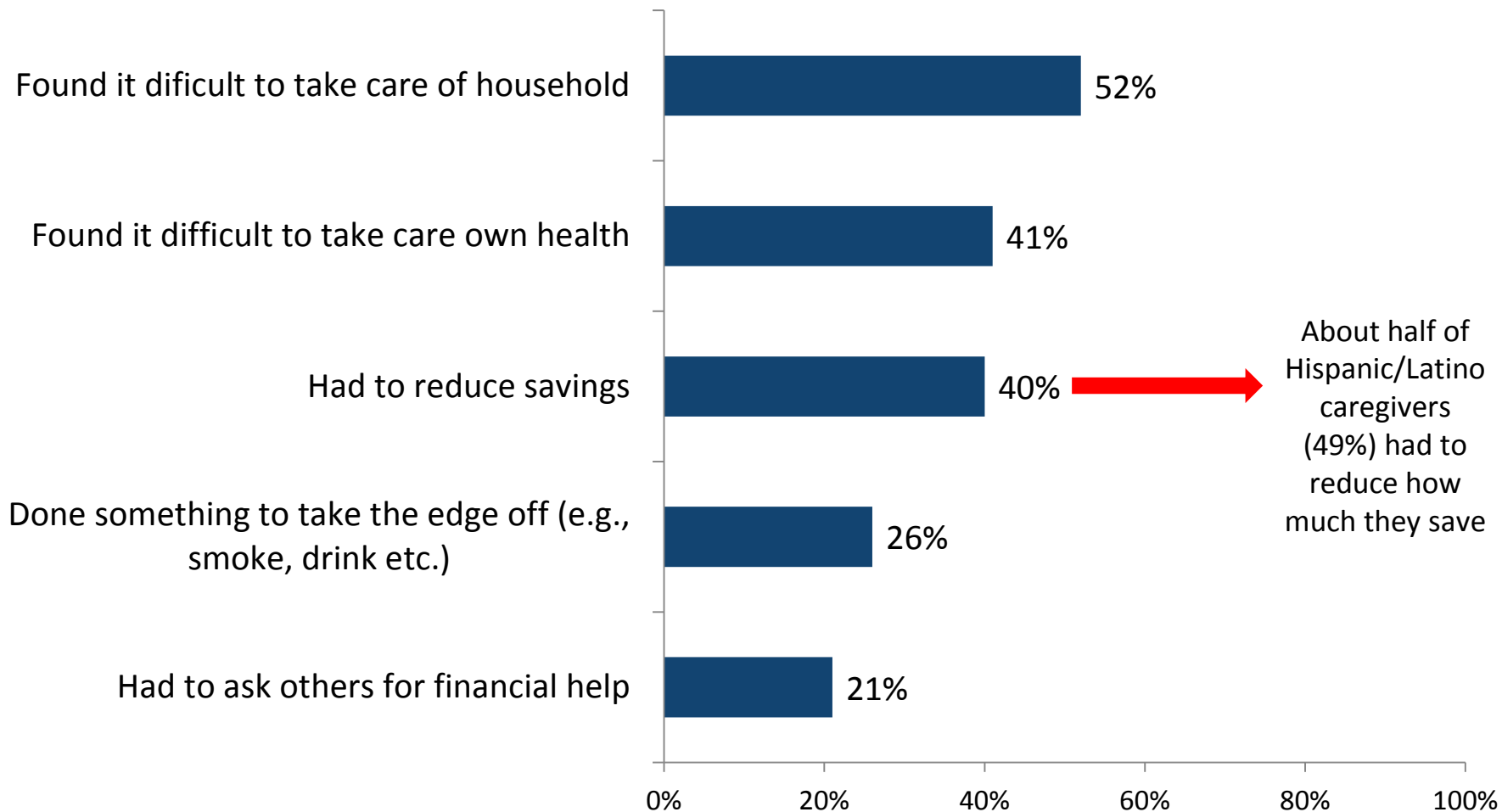
Q4. Thinking about your relationship with the person you provide care or assistance for, do you have any regrets or things you wish you had done differently?

More than half of caregivers are experiencing negative emotions such as feeling sorry for the person they care for, stress with work/life balance, and guilt for not doing more. Few are feeling angry or sorry for oneself.



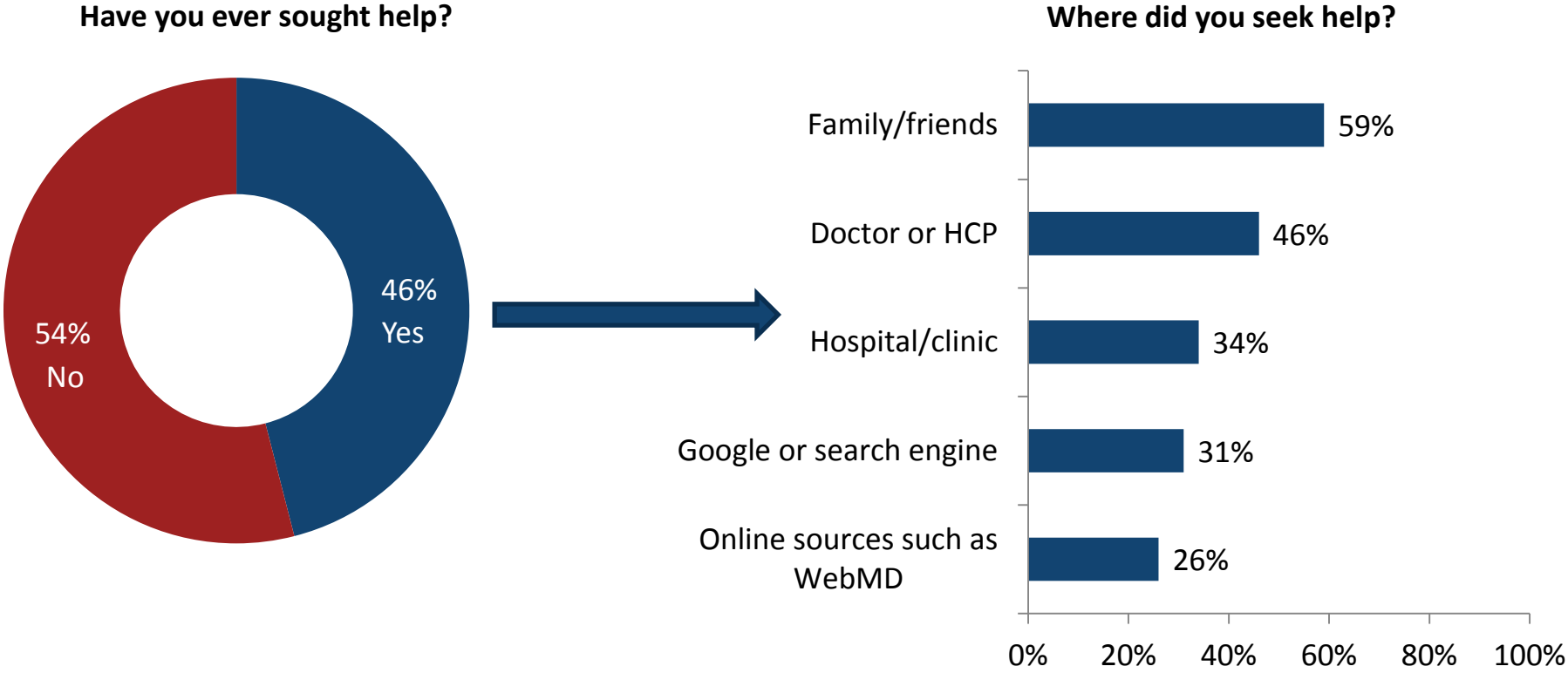
Q6. Thinking about your role as a family caregiver, have you ever...

Half of caregivers are having difficulty taking care of their own household and four in ten are having difficulty taking care of their own health. Many have reduced their savings suggesting there could be implications for caregivers' financial security.



Q6. Thinking about your role as a family caregiver, have you ever...

Less than half of caregivers have sought information or assistance in helping them take care of their loved one. Among those that sought help, the most common sources are family/friends, health care providers, or hospitals.

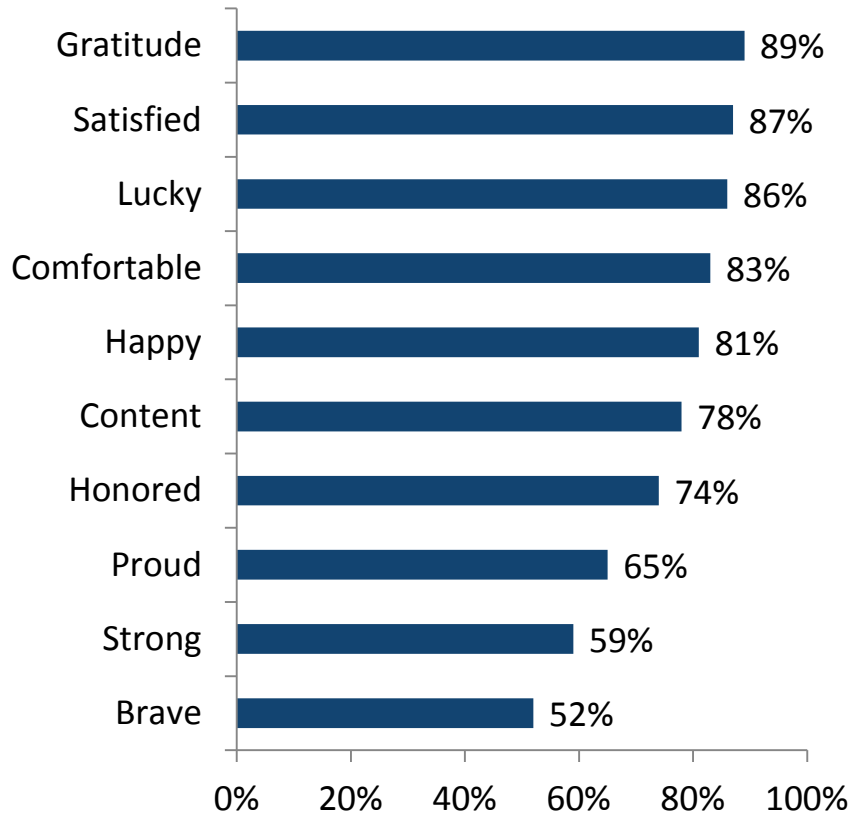


Q14. Have you ever sought help or information to help you in taking care of your loved one? This may be assistance for your loved one or help for yourself in your role as a family caregiver. If yes, where or with whom have you sought help?

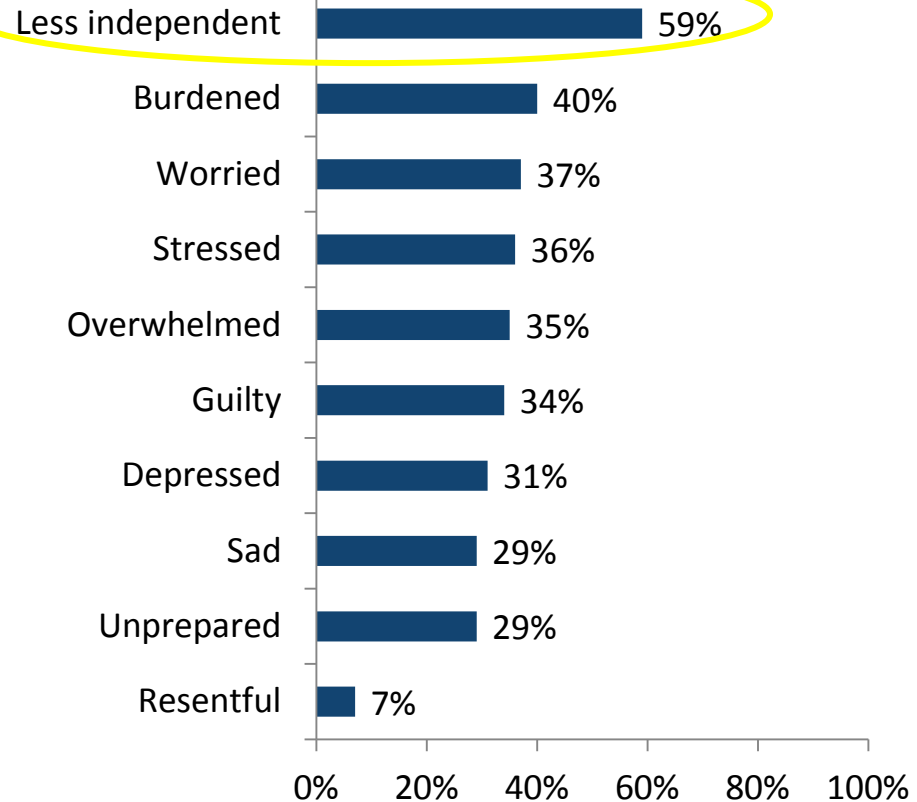
Care Recipients' Perspective

Like caregivers, care recipients also feel a variety of emotions with positive emotions far outweighing negative emotions such as a sense of gratitude (89%). However, almost six in ten (59%) say they feel less independent.

Positive emotions

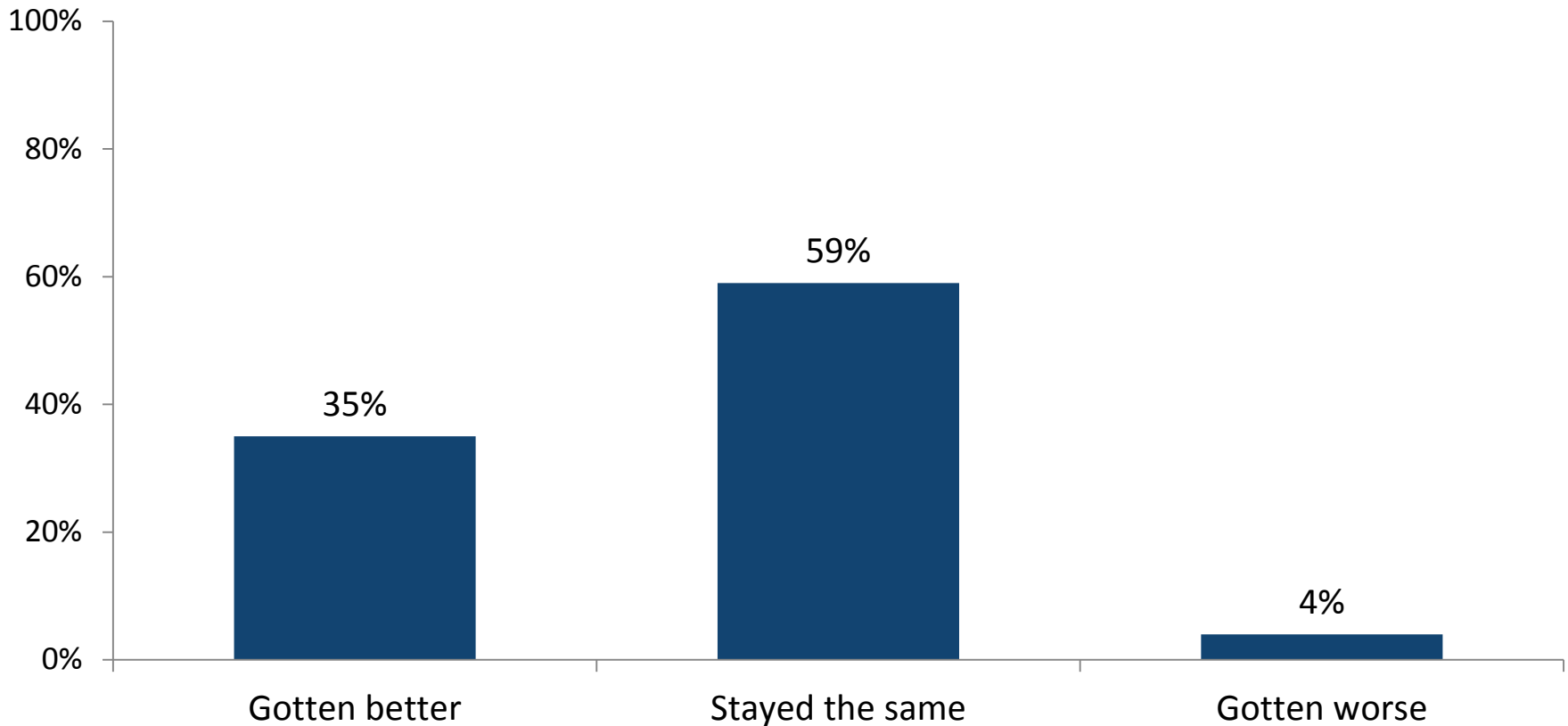


Negative emotions



Q10. Please indicate what words or phrases describe how you feel about receiving assistance from your family member or friend?

One in three recipients of care say their relationship with the person that helps them has gotten better since they began receiving care. Few said the relationship is getting worse.



Q11. Would you say your relationship with the person who provides care or assistance for you has gotten better, gotten worse, or stayed the same since you began helping them?

Half of care recipients say they experienced an unexpected joy or positive experience that they had not expected.

“We spend more time together. Because she does things for me I cook for her so we spend time together. She moved closer to me so she would be around.” (75-year old, female care recipient)

“I have more companionship and less time alone.” (64-year old, female care recipient)

51%

of care recipients say they experienced an unexpected joy

“All too often, my wife prepares special meals, runs errands I did not expect her to do, and generally cares for me in ways that I deem more than I can expect.” (79-year old, male care recipient)

“This person has really stepped up and offered to help after a recent back injury without being asked. I am touched by their concern for me.” (73-year old, female care recipient)

Q12. Thinking about your relationship with the person who provides care or assistance for you, have you experienced any unexpected joys or positive experiences you had not expected?

While half have experienced an unexpected joy, about one-quarter say they have regrets or things they wished they had done differently. Most regrets center around taking better care of oneself with the perception it would reduce the need for care.

"I wish I burdened her less and learned how to do certain things myself so I wouldn't burden her." (68-year old, male care recipient)

"I wish I would have seen the doctor 30 years ago and fixed this problem back then, I would not have to rely on family for help." (83-year old, male care recipient)

26%

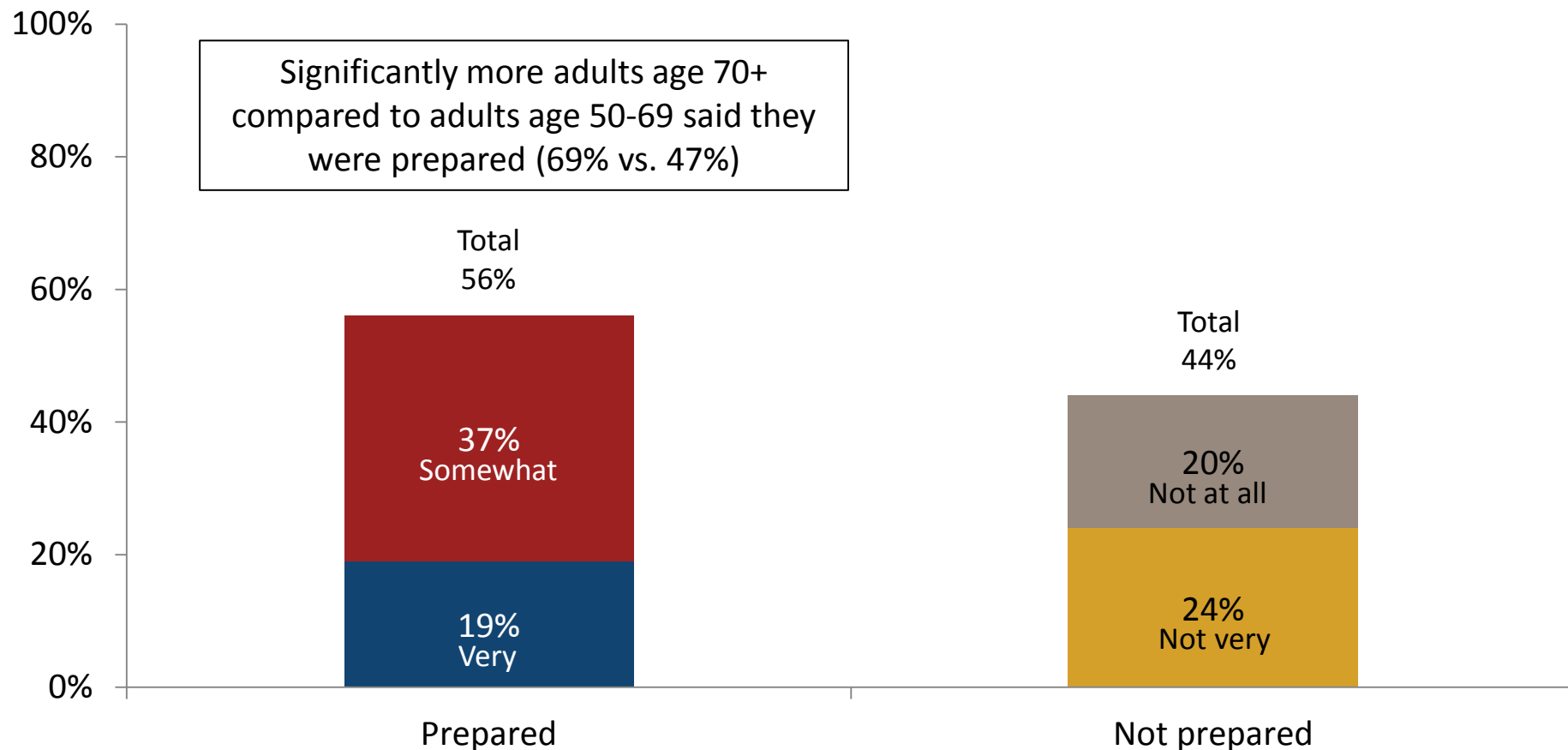
of care recipients say they have regrets

"Taken better care of self. To be more independent." (58-year old, female care recipient)

"I wish I would have taken better care of my health problems years ago so I won't have to ask someone to take time away from their life to help me." (72-year old, female care recipient)

Q13. Thinking about your relationship with the person who provides care or assistance for you, do you have any regrets or things you wish you had done differently?

While most care recipients say they were at least somewhat prepared to receive care or accept help, over four in ten (44%) say they were not prepared and one in five said they were not at all prepared.



Q14. Thinking back to when you first began receiving care or assistance, how prepared would you say you were to accept this help?