

Caregivers and Digital Health:

A Survey of Trends and Attitudes of Massachusetts Family Caregivers

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Survey background

- Online survey of 700 non-professional caregivers in Massachusetts.
- Caregiver defined as “partly or fully responsible for the care or the coordination of the medical care of anyone who requires frequent care” who spent 2+ hours a week on care-related tasks.
- Questionnaire developed by MPG and MeHI.
- Field Dates: October 27 - November 7, 2016.

Key Findings

- Massachusetts caregivers are feeling overwhelmed, stressed, depressed, and isolated due by their responsibilities.
- The most common challenges for caregivers have nothing to do with the complexities of providing care.
- The biggest challenge is the time and energy caregivers need to balance caregiving with their personal lives and other daily tasks.

Key Findings

- The most appealing technologies are ones that:
 - Serve as a platform to facilitate peer-to-peer support;
 - Provide access to medical records and/or resources; or
 - Manage and/or consolidate tasks and time.
- Caregivers are either unaware of available options, or are aware of *too many* options and do not know how to choose between them.
- Caregivers are not afraid of technology

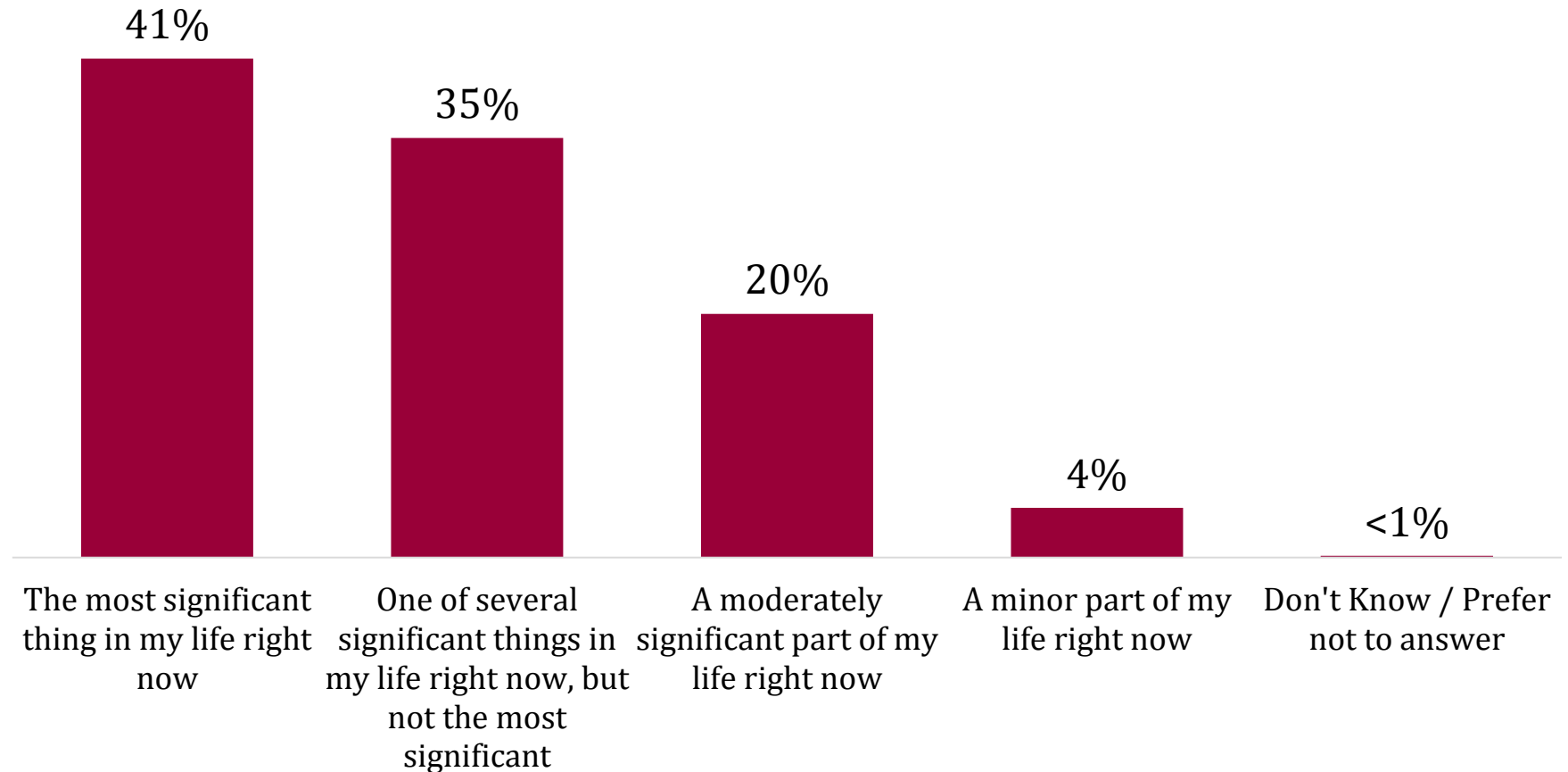
Who's caring for whom...the lifecycle

- About half (48%) are caring for a child, 64% for an adult.
- Overlap: 15% of adults caregiver also care for a child, and 22% of child caregivers also care for an adult.
- Demographics of adult and child caregivers are similar, except on age.
 - Younger caregivers more likely to be taking care of children.
 - Older caregivers more likely to be taking care of adults.

Caregiving dominates caregivers lives

Most say caregiving is the / one of the most significant things in their lives.

Q: Which best describes your situation? Acting as a caregiver is...

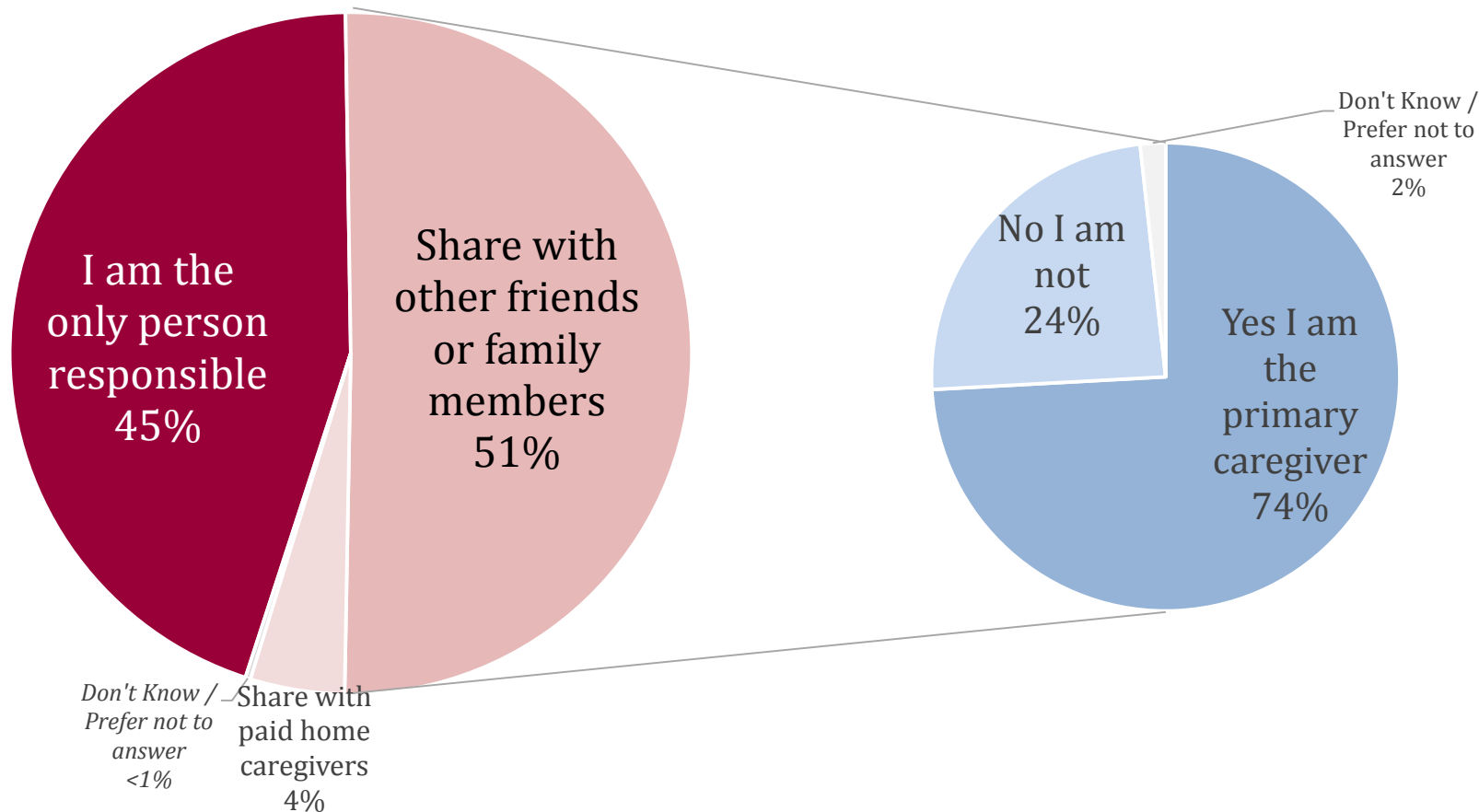


Most are solo or primary caregivers

Q: Are you the only person responsible for their care, or do you share the responsibility with others (not counting medical personnel)?

If shared care:

Q: Are you the person most responsible for their care, or not?



Caregiving can be all-consuming

Caregivers describe extensive disruption in their lives

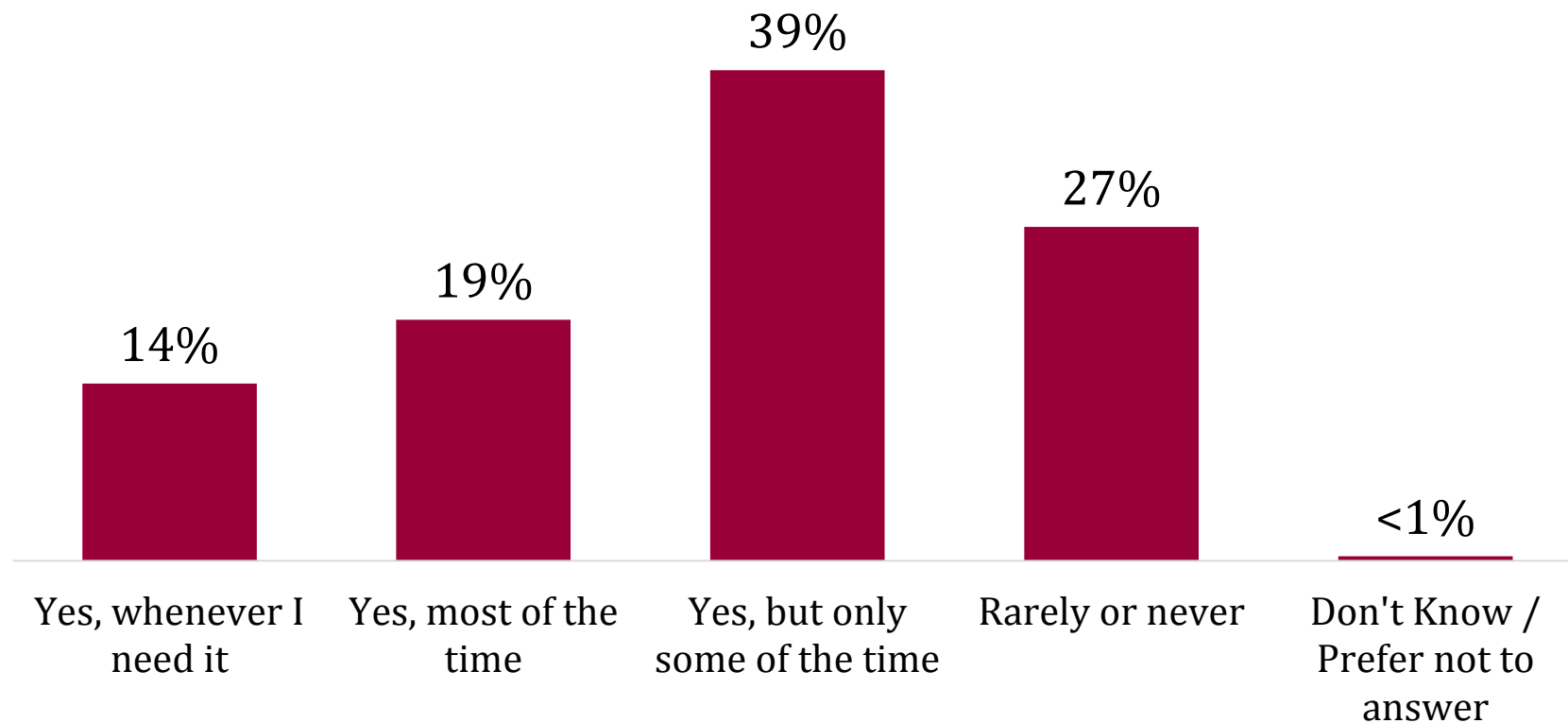
Q: To what extent does acting as a caregiver disrupt your life?

Response	%
A great deal	13%
A fair amount	47%
Not very much	27%
Not at all	13%
<i>Don't know / refused</i>	1%

Caregivers feel like they are “always on”

Few feel they can take breaks when they need them

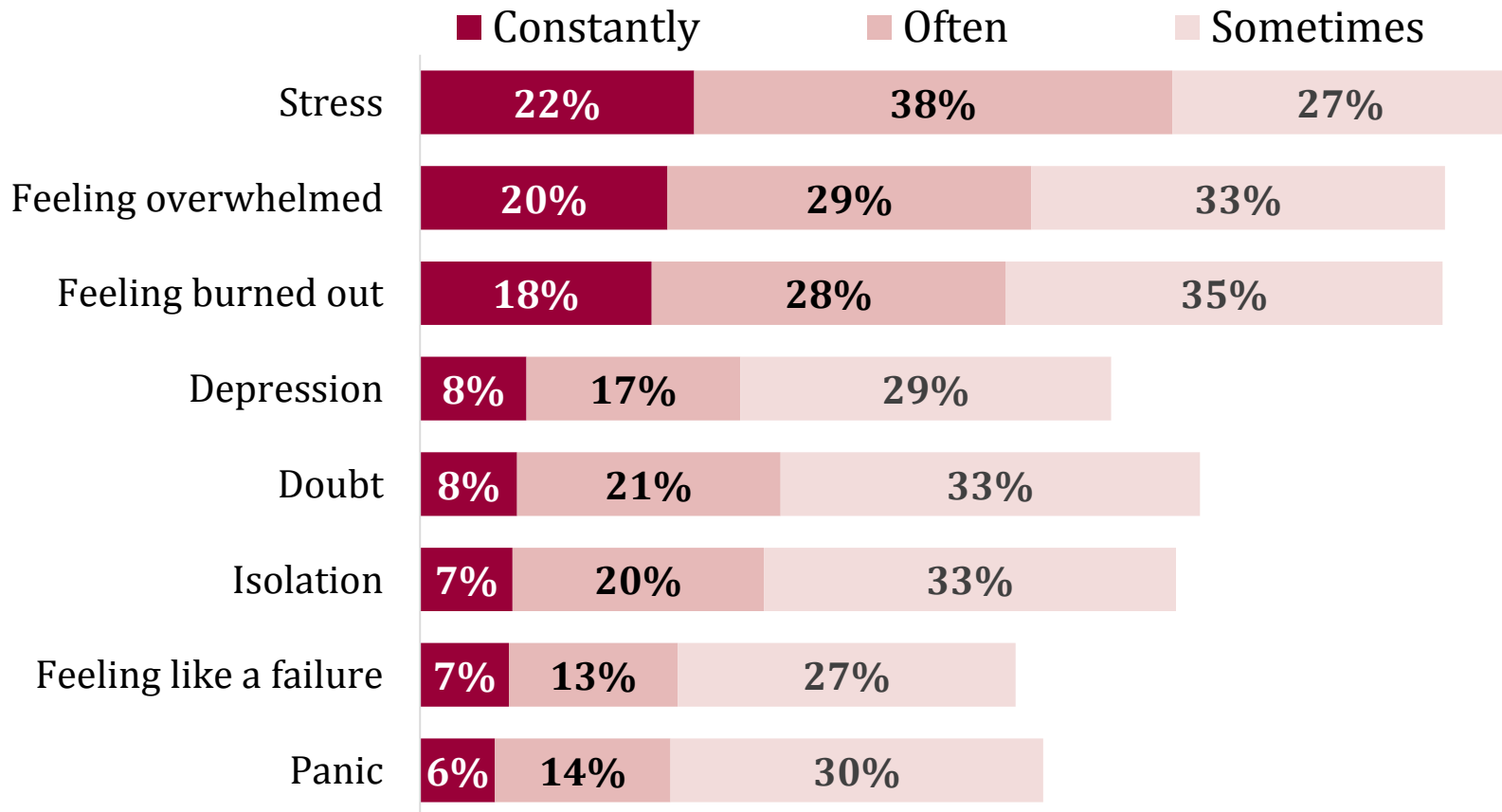
Would you say that you could take a break from providing or coordinating care if you needed one?



Caregiving takes an emotional toll

Caregivers report stress, feelings of being overwhelmed, burned out

Q: In your life as a caregiver, how often do you feel each of the following?



In their own words...

Respondents were asked: *In your experience, what is the hardest aspect of being a caregiver?*

- 28 percent cited time demands (constant availability, no breaks)
- 21 percent cited the emotional drain (sorrow, helplessness, isolation)
- 20 percent cited balancing their personal needs with their caregiving

A sample of responses:

- “The stress of remembering everything that needs to be done and feeling overwhelmed and alone.”
- “The stress and emotional drain it puts on you.”
- “The hardest aspect is watching my mother go downhill, knowing that she won’t be getting any better. It’s a feeling of helplessness.”
- “Watching someone you love deteriorate; having to readjust your relationship with the individual being cared for.”

Caregivers busy with many tasks

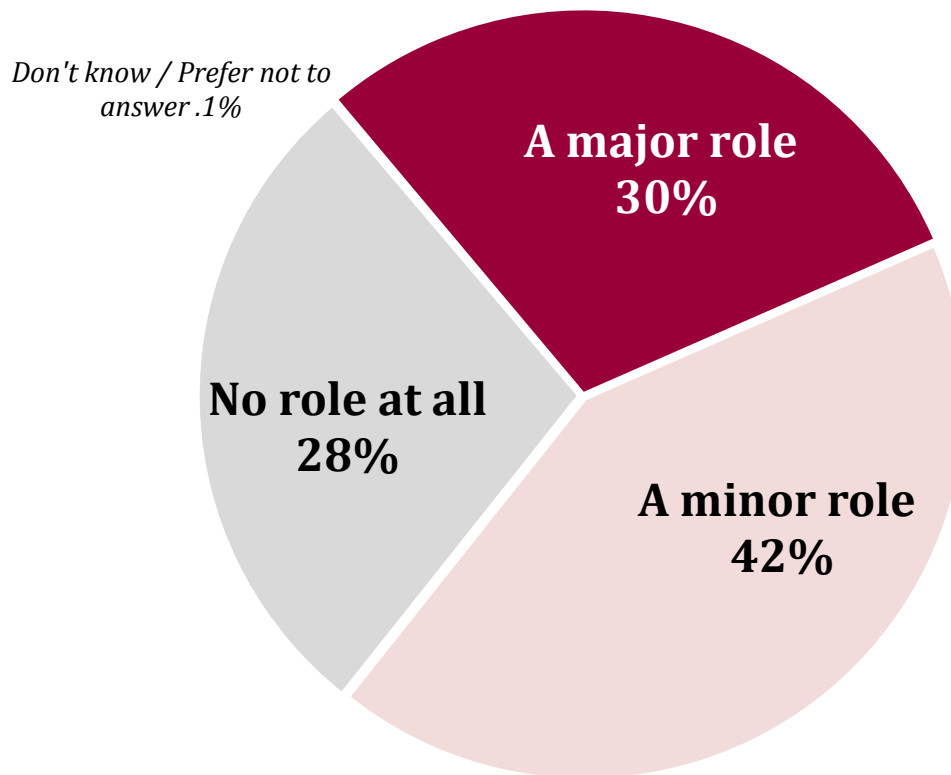
Daily, medical tasks combine to keep caregivers busy

% saying they performed each task in past 6 months	
Grocery shopping	90%
Transportation	88%
Giving Medicine	88%
Communicating with health care providers	87%
Housework	87%
Preparing meals	87%
Companionship in social activity	81%
Tracking daily activities	75%
Managing finances	71%
Working with insurance or Medicare	71%
Dressing and undressing	68%
Assisting with getting in and out of bed and chairs	66%
Feeding	64%
Arranging paid services	59%
Bathing	57%
Attending to wounds	56%
Toileting	47%
Dealing with incontinence or diapers	42%

Care is often not seen a tech problem

Few say tech plays a major role in providing care

Q: How much of a role, if any, does technology such as apps, devices like smartphones or tablets, or computer programs play for you in providing and coordinating care?



In their own words...

Respondents were asked: *What prevents you from making more use of technology in providing and coordinating care?*

- 24 percent said there was no need to do so
- 20 percent said they were already using technology
- 17 percent were unaware of useful tech / apps to use

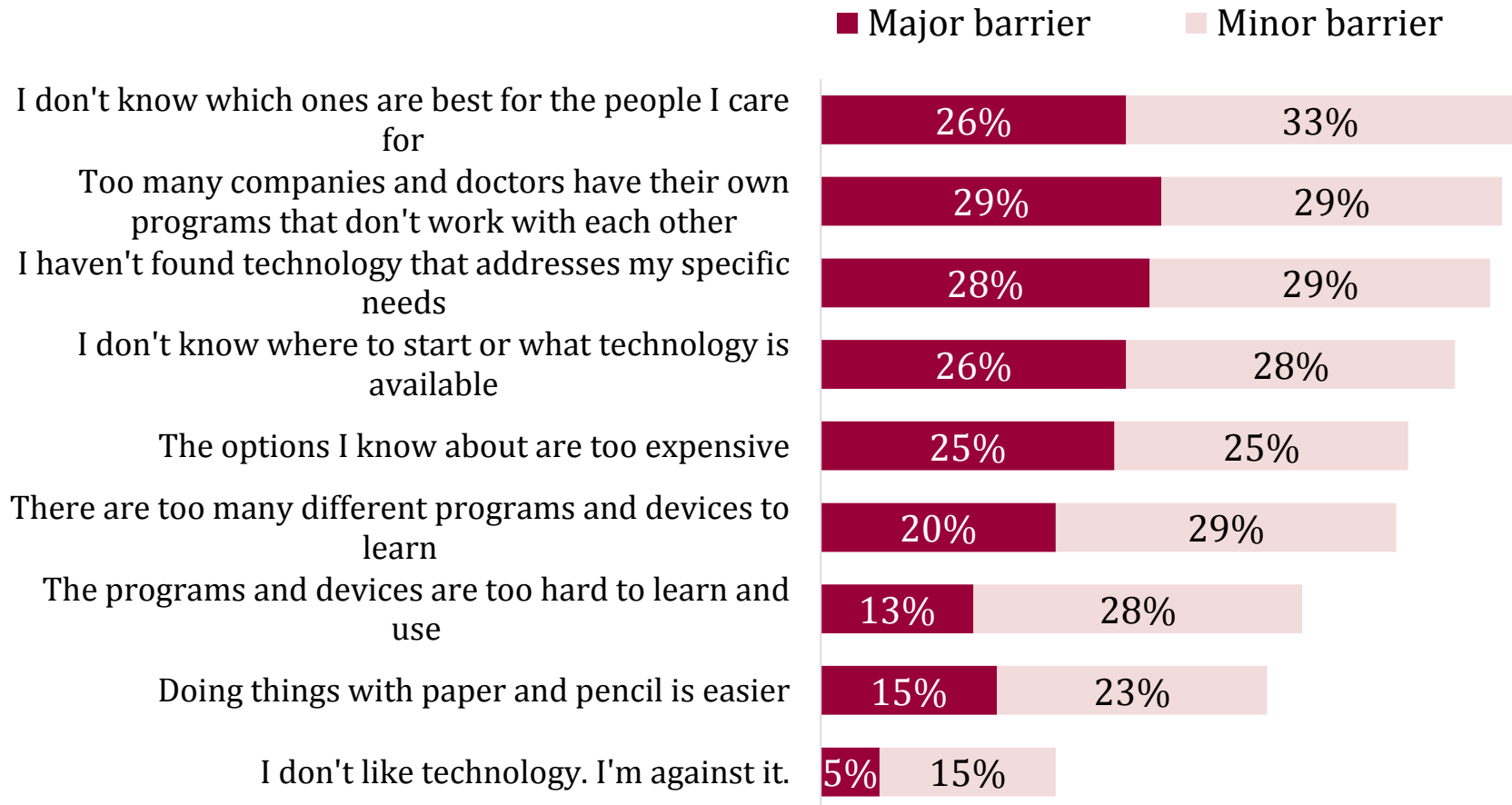
A sample of responses:

- “I need to be more hands-on in my care and [technology] takes too much time to work.”
- “I don't know of any technology that would help with the day to day needs I'm responsible for.”

Caregivers stymied by too many options

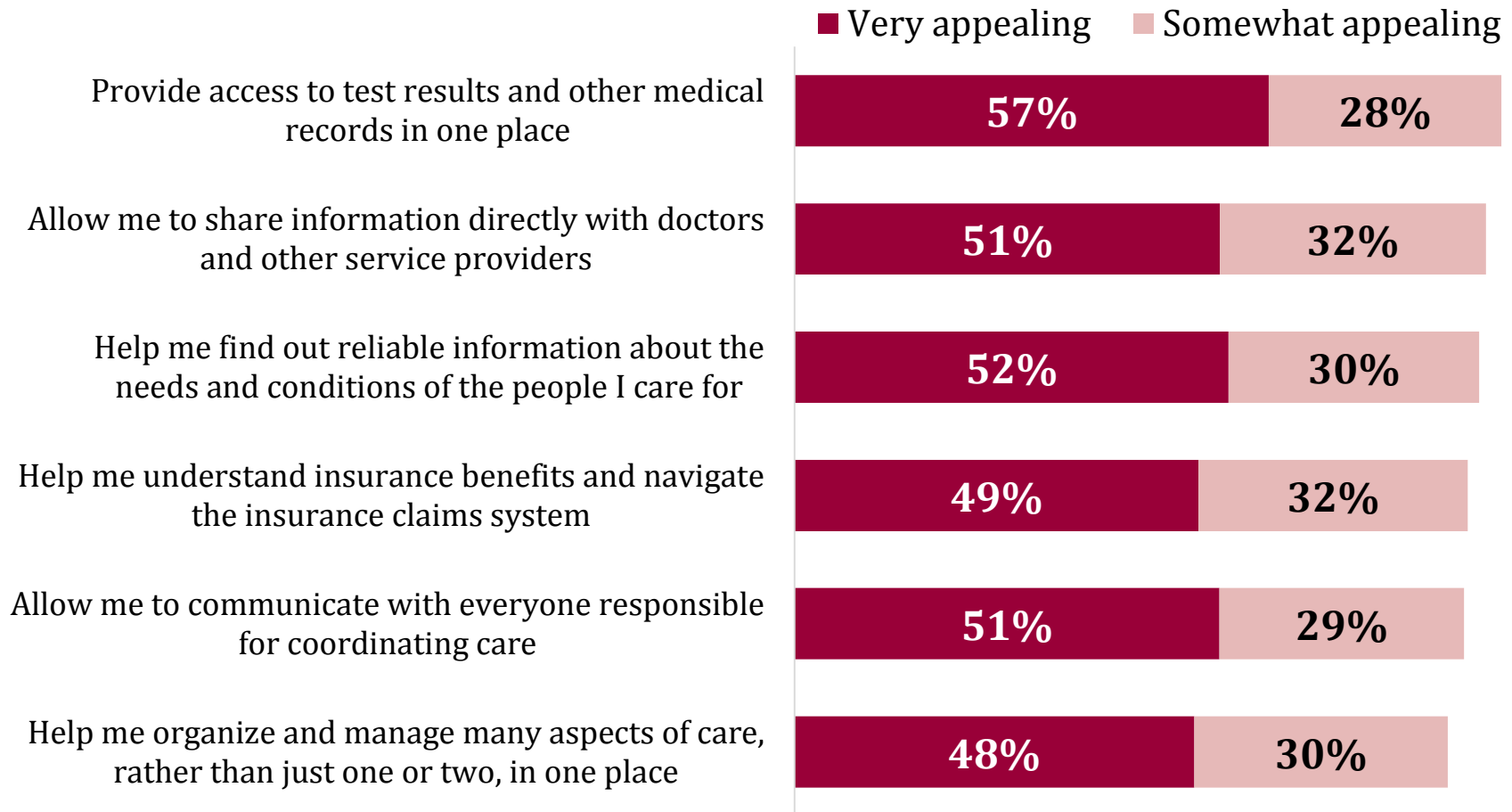
Biggest barriers are unfamiliarity and complexity of finding the right product

Q: When it comes to using technology to provide and coordinate care, how much of a barrier is each of the following to using technology more?



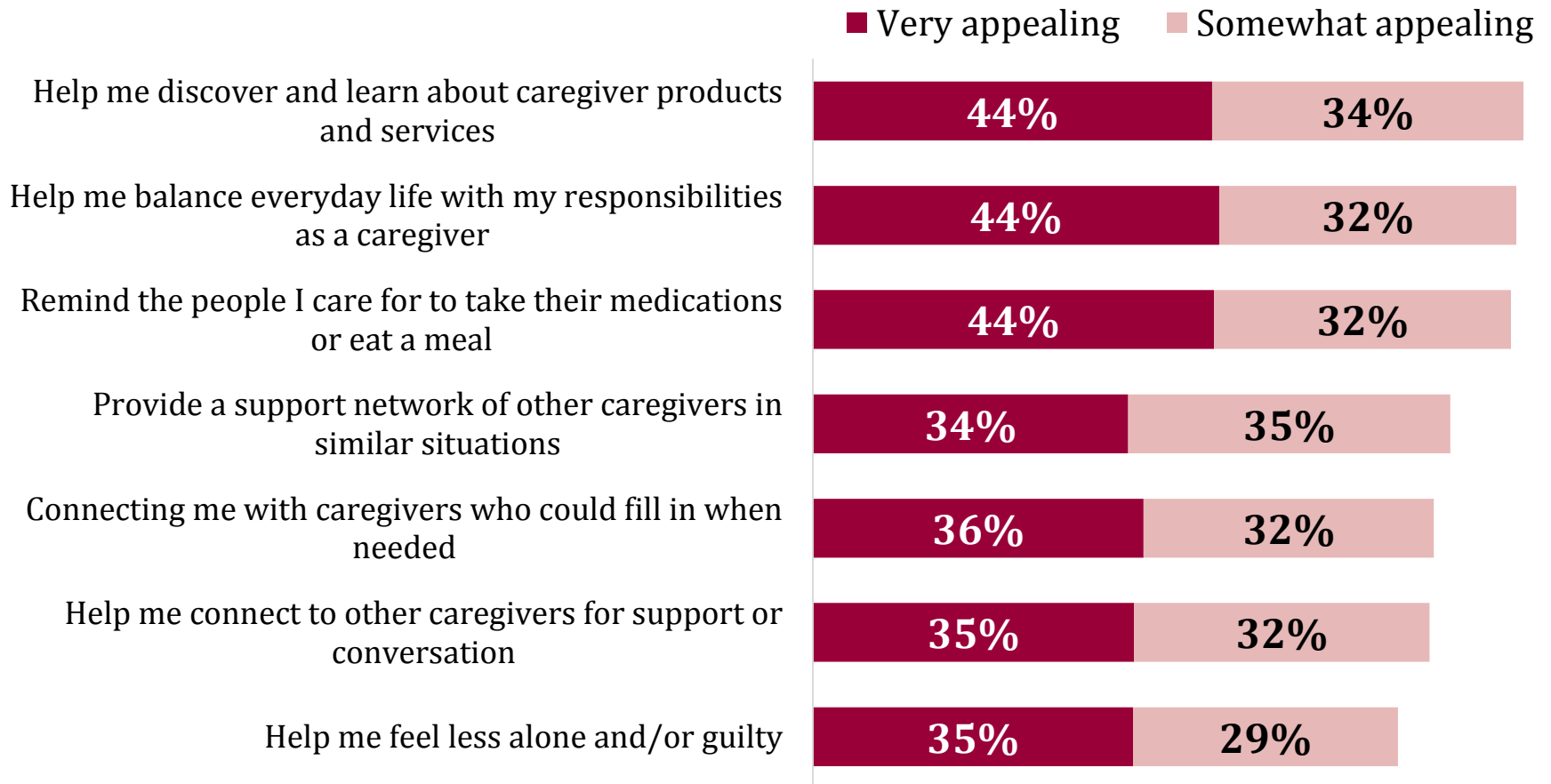
Caregivers want tech to help simplify

Q: Thinking about technology that could help in providing care, how appealing would technology be that could do each of the following?



Emotional support a smaller market, still vital

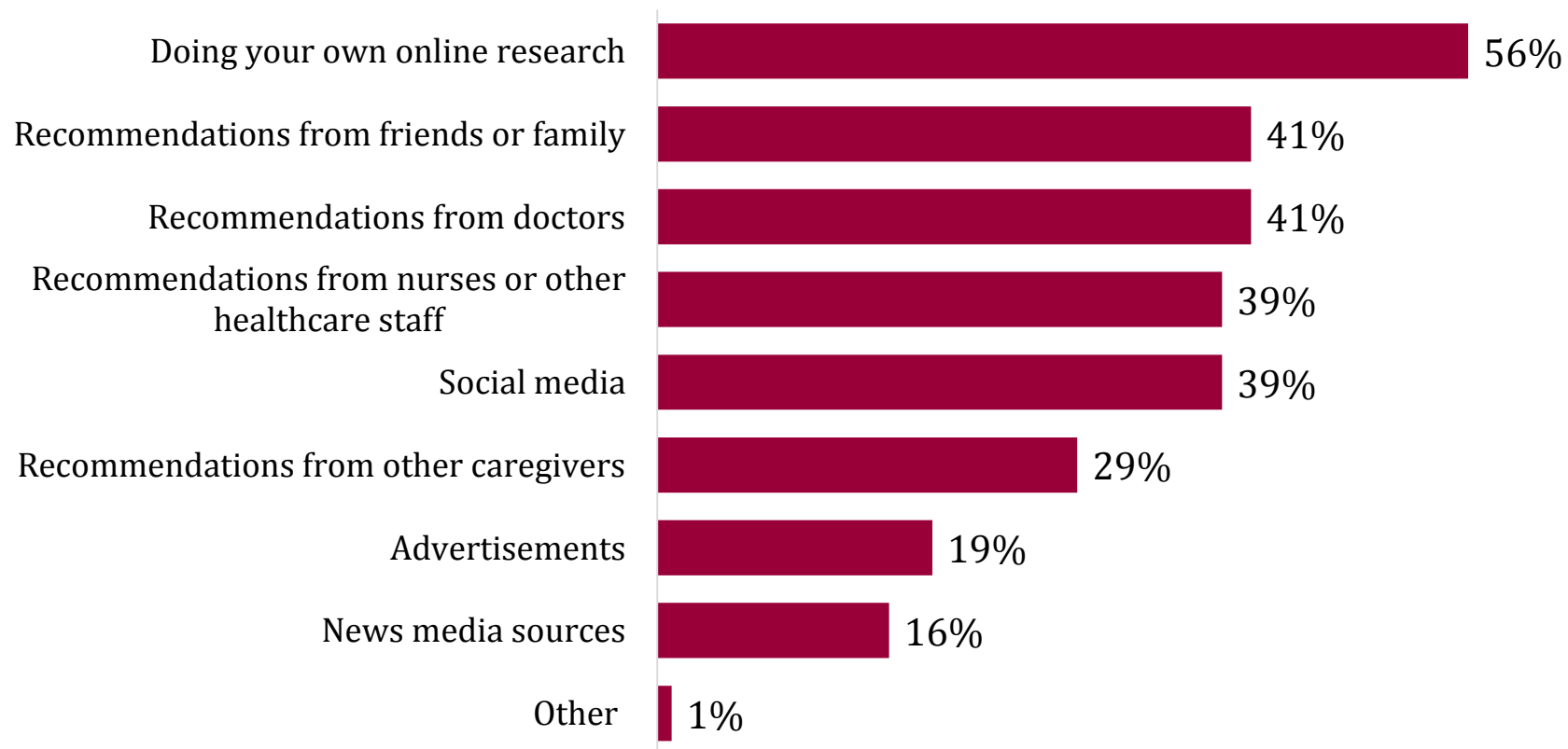
Q: Thinking about technology that could help in providing care, how appealing would technology be that could do each of the following?



Online research, word of mouth key

Caregivers rely on online research, recommendations when selecting technology.

Q: How have you mostly heard about the health devices or apps you decided to use in providing care?





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