



IDENTIFYING RESEARCH CHALLENGES AND OPPORTUNITIES The Caregiver Perspective

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43.5
million
2015



53
million
2020

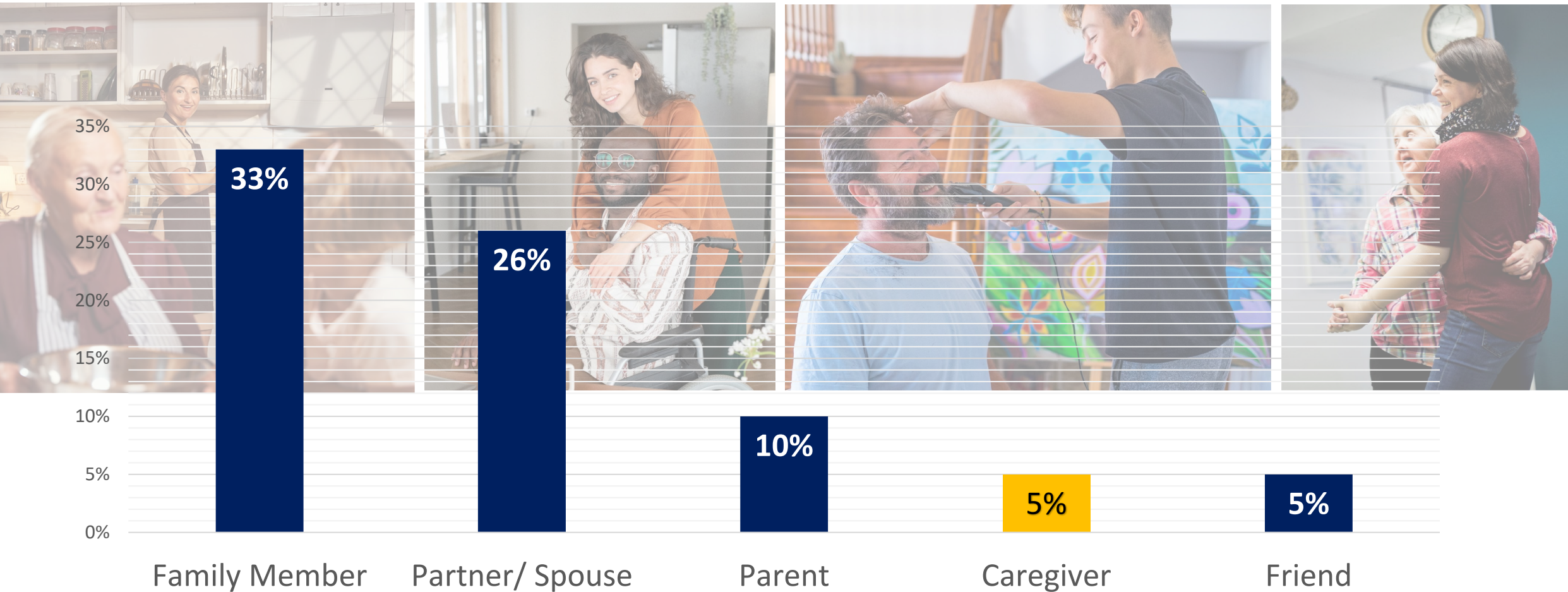


18%
2015



21%
2020

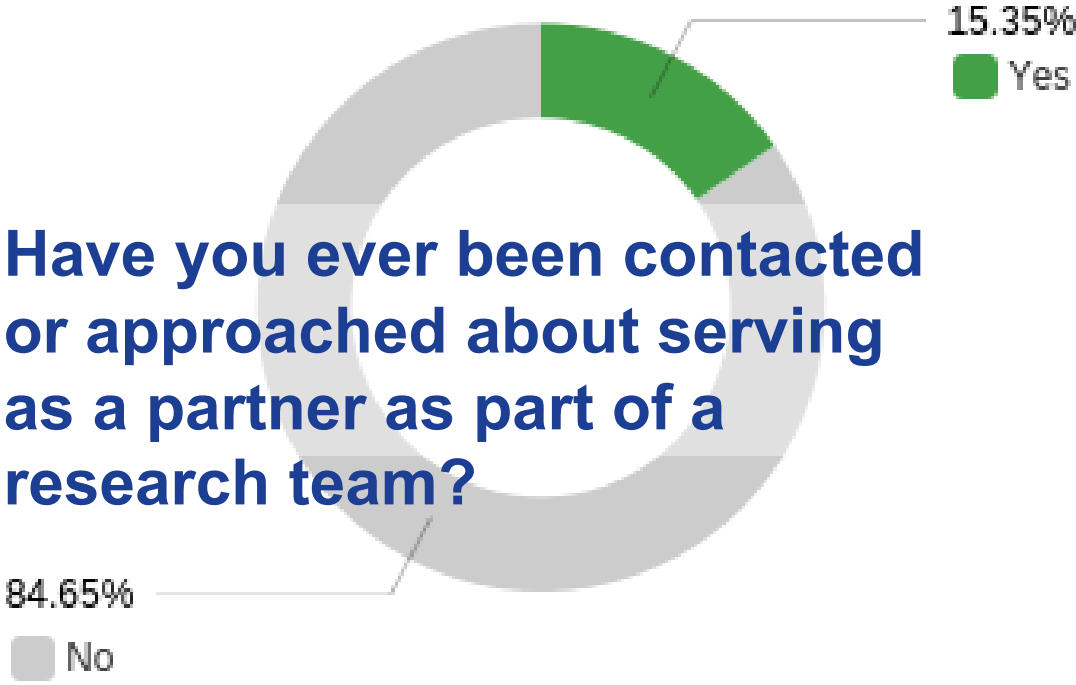
NEARLY ONE IN FIVE (19%) ARE PROVIDING
UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**



Unique Challenges

- Does not exist without a patient counterpart but has independent concerns and needs
- Identity and relationship(s) can be complex
 - Takes on caregiving role but does not identify as caregiver
 - Caregiver as gatekeeper to patient, but often it is the opposite
- Often under considerable time and resource burdens
 - Caregivers are trying to juggle their own needs as well as those of the loved ones they support

Have you ever been contacted or approached about serving as a partner as part of a research team?



To what extent do you feel you have valuable experience to share with health researchers?





- The total time necessary
- The time of day that I am required to participate
- Taking time off/away from work to participate
- Transportation
- Childcare
- Other caregiving responsibilities
- Lack of paid compensation
- I would not be listened to/ my experience would not be valued
- I would be intimidated by the role
- I cannot relate to Researchers or others on the team
- Health literacy barriers: I would not understand the content/conversation
- I have a disability or physical limitation that would make participation difficult

Unique Opportunities

- Expand Patient-Engaged initiatives to include caregivers
 - As part of the patient-caregiver dyad and
 - As stand-alone community
- Change outreach, recruitment, and communication tactics
 - Define caregiver in communications
 - Describe activities or details or role



Thank
you



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