Family Caregivers' Perception and Experience with Medical and Community Services



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The research reported on this poster was supported by the Gary and Mary West Health Institute. The investigators retained full independence in the conduct of this research.

Introduction

There are roughly 43.5 million unpaid family caregivers in the US, and they provide much of the care for their charges ranging from activities of daily living to nursing tasks. Caregivers often turn to the health system for support when they are stressed or overwhelmed with caring for their loved one. Understanding caregivers' views and interactions with the healthcare system is a first step in identifying the gaps in support of family caregivers and their care recipient.

Methods

- Data were from a sample of US adults aged 30 to 89 years from the National Opinion Research Center AmeriSpeak® panel, which is a probability-based representative panel of civilian noninstitutionalized adults living in the US.
- Surveys were conducted Sept.-Oct. 2016 by phone and web platforms and took about 26 minutes to complete.
- Participants' views on aging, healthcare and community resource priorities, and views on how well healthcare and the community are meeting needs of seniors were analyzed.
- Participants were stratified by whether they are currently or have provided ongoing living assistance directly to an older family member or close friend (caregiver).
- Weighted logistic regression (or weighted linear regression) was used to assess differences between caregivers and noncaregivers controlling for age, gender, race/ethnicity, income, education, home ownership, and living area.

Demographic and Health Measures	Caregiver N = 1379	Non-Caregiver N = 1638	P-value
Age (mean and SD)	57 years (13.5)	50 years (14.3)	<0.0001
Gender: Female	59.5%	46.1%	<0.0001
Race/ethnicity			
Income (mean and SD)	\$58,601 (\$44,370)	\$65,632 (\$49,531)	<0.0001
Married or living with partner	57.3%	64.1%	0.001
 Education Less than Highschool High school diploma College diploma or higher 	49% 11.5% 39.5%	43.5% 10.3% 46.1%	0.011
Home ownership	73.5%	69.4%	0.034
Living in metropolitan area	85%	88.9%	0.009
Number of co-morbidities (mean and SD)	2 (1.7)	1.4 (1.54)	<0.0001
Reported health condition/ physical disabilities impact daily life/ limit activities	34.9%	24.5%	<0.0001

Views on Aging

- More caregivers (39%) felt aging for their generation will be worse than experience than the generation before them compared to non-caregivers (34.7%; OR = 1.43; p = 0.0002).
- Caregivers ($\mu = 3.1$; $\sigma = 1.0$) were more likely than noncaregivers ($\mu = 2.8$; $\sigma = 0.98$; $\beta = 0.3$; p < 0.0001) to respond they will require ongoing living assistance some day.
- Caregivers expressed more worry than non-caregivers (Figure 1)

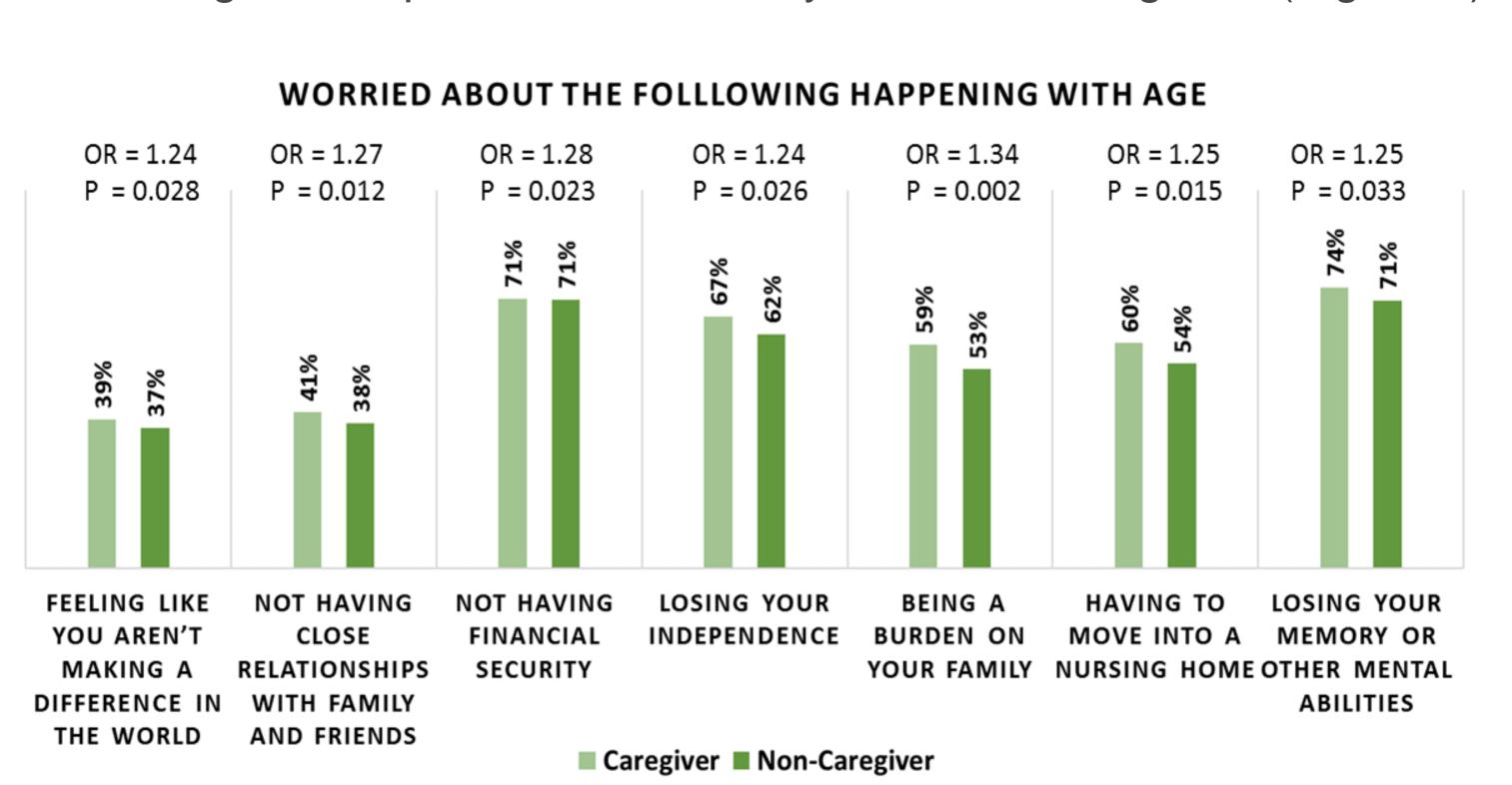


Figure 1: Response of caregiver and non-caregiver views on "How worried are you about each of the following happening to you personally as you age?"

More caregivers than non-caregivers responded they will need or currently need support and services as they age (Figure 2).

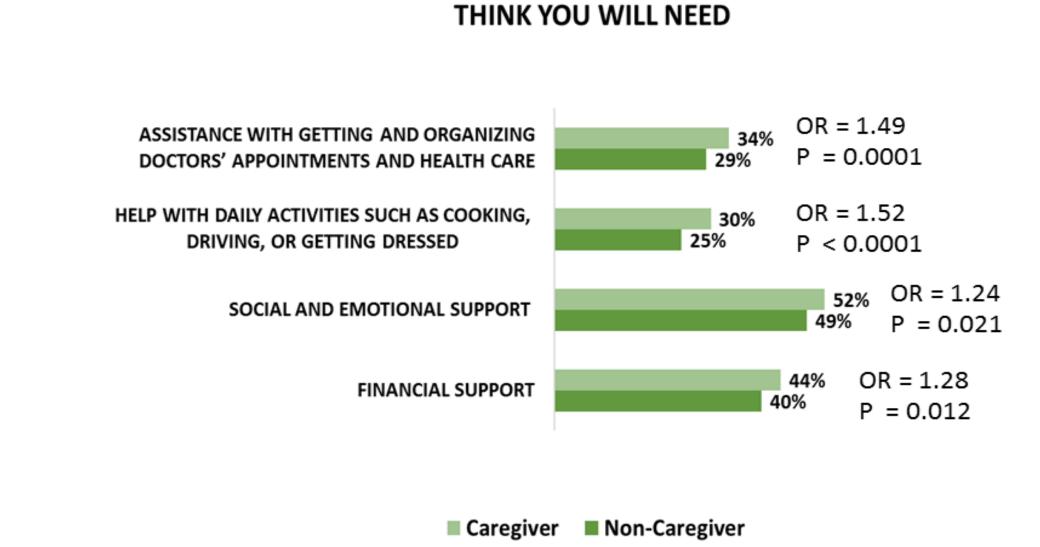


Figure 2: Response of caregiver and non-caregiver views on "Do you think you will need each of the following types of services as you age?"

Results

Healthcare And Community Resources Priorities

- More caregivers than non-caregivers responded it was important to their personal healthcare experience to have:
 - A professional who coordinates all aspect of care ($\beta = 0.15$;p = 0.006)
 - A way to receive healthcare services from our own home ($\beta = 0.19$; p = 0.0003)
 - A long term relationship with your primary care provider ($\beta = 0.16$; p = 0.0004)
- Caregivers felt it was more important for seniors to have community and medical resources and wanted more access to medical services in the home than non-caregivers (Figure 3)

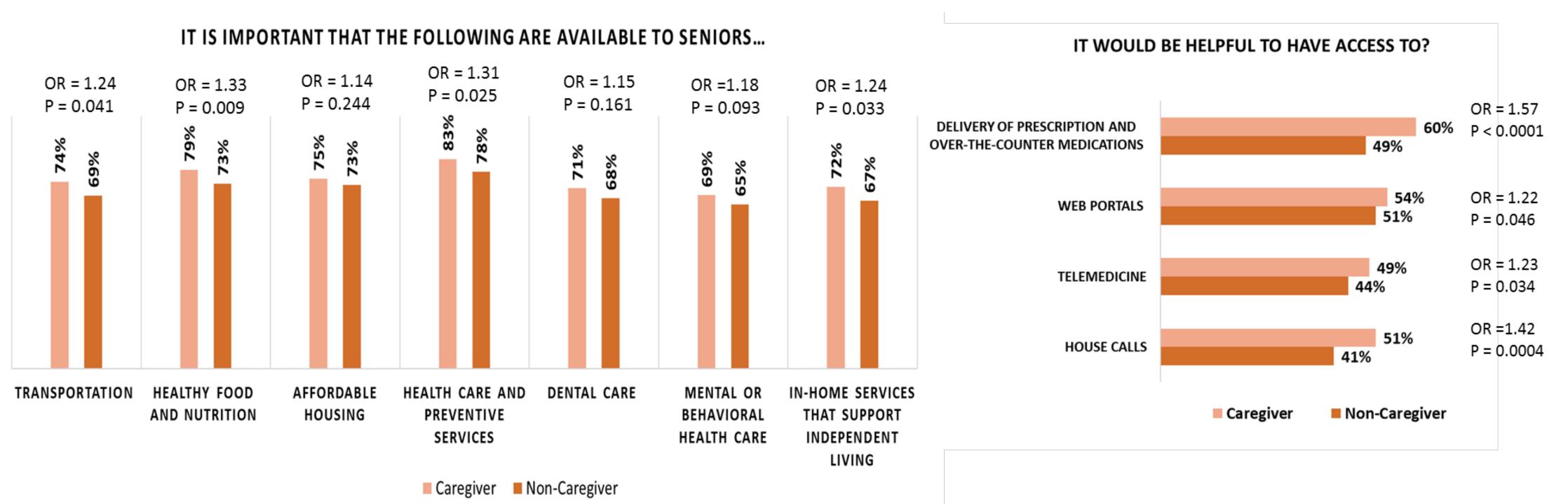


Figure 3: Response of caregiver and non-caregiver views on "How important is it that the following are available to seniors living in your area?" (Left) and "In addition to receiving healthcare at doctor's offices, clinics and hospitals, how helpful would having access to each of the following services be to you?" (Right)

Views on How Well Healthcare and Community Are Meeting Needs

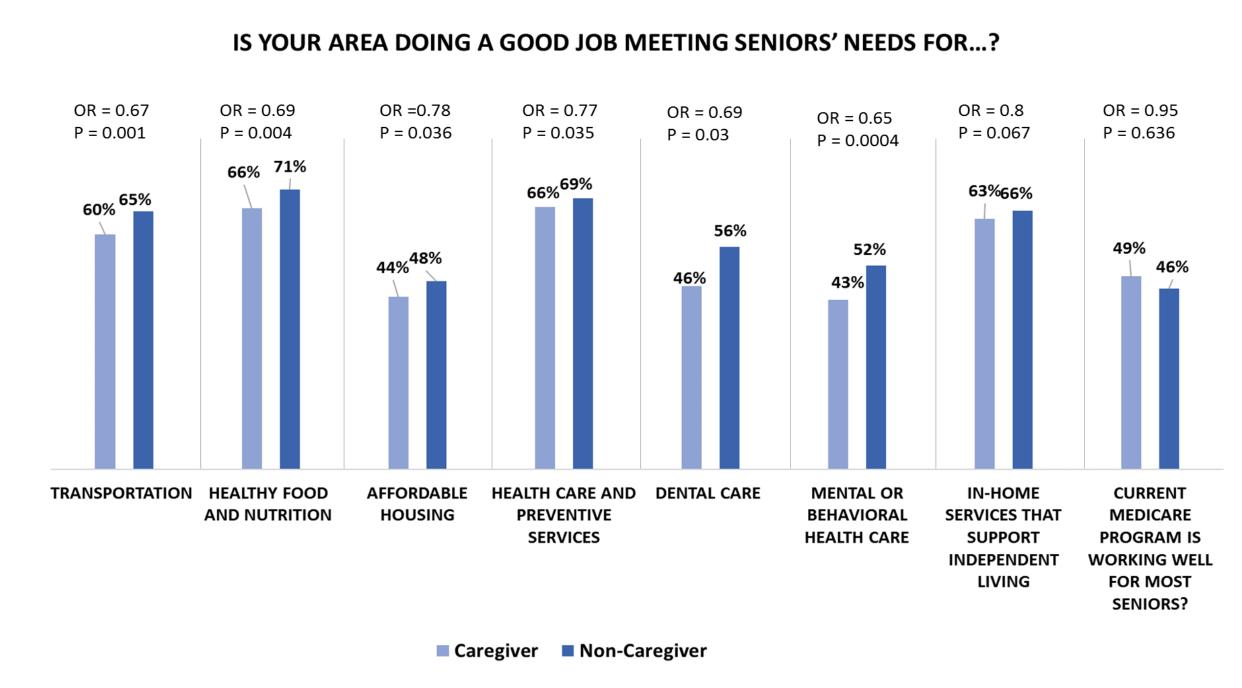


Figure 4: Response of caregiver and non-caregivers views on "Is your area doing a good job meeting the needs of seniors' for the following?"

- More non-caregivers than caregivers felt the healthcare system and community were doing a good job of meeting seniors' needs (Figure 4).
- In their own experience, fewer caregivers than non-caregivers felt it was easy to coordinate primary care, dental, behavioral health, obtain medications and get supportive services at home for themselves than caregivers (p < 0.0001).

Conclusions

Family caregivers are a vulnerable population relative to non-caregivers and are more pessimistic about the healthcare system in the US. They report more difficulties accessing care and believed innovative approaches such as in-home care and telemedicine would be helpful. Implementing these innovations could provided needed support to family caregivers.