



# A Community Academic Partnership to Understand Needs and Improve Support for Rural Latino Family Caregivers



Kristen Overbaugh PhD, RN, ACNS-BC, CHPN, Gabriella Zaragoza MSN, RN, Carole White PhD, RN

With recognition of our community partners: Nancy Ortiz, Letty Hernandez, and Margie Villanueva

## Introduction

In the spring of 2016, nursing faculty from UT Health San Antonio were invited by the Frio County Translational Advisory Board to explore opportunities to partner with community members living in a rural region of South Texas, populated predominantly by Latino persons, to address concerns of family caregivers caring for relatives with Alzheimer's disease.

In response to this request, school of nursing faculty and students have been engaging with family caregivers and stakeholders to build capacity in this community to support family caregivers.

To inform the development of a program of support that is both meaningful to this community and sustainable, nursing faculty were interested in better understanding existing community assets, caregiver needs, service utilization, the nature of caregiving, and the impact of caregiving on the life and health of the caregiver.

## Methods

**This descriptive study, guided by principles of community based participatory research, utilized a mixed-methods approach.**

Purposeful sampling was used to engage participants in focus groups and to recruit participants (N=29) to complete a survey that assessed demographics, caregiver/recipient characteristics, service utilization and included the Caregiver Assistance Scale (CAS), Caregiver Reaction Assessment (CRA) and the Rand 36-item Health Survey1(SF-36).

An initial focus group (N=21) was held in the summer of 2016 and a follow-up focus group (N=7) was held in the summer of 2017. Focus groups were co-facilitated by a community member and a faculty member and audiotaped and transcribed verbatim. Content analysis was conducted by two members of the research team and findings were shared with community partners.

Survey data collection occurred between the spring of 2017 and 2018. Descriptive statistics were examined, as appropriate, using SPSS® (V 24).

## Quantitative Findings

Participants were predominantly white (79%), Latino (83%), female (79%), and identified English (86%) as their primary language, with a mean age of 57 (range 20 to 84) years. Caregivers consisted primarily of adult children (41%), with 48% of caregivers living with care recipients. Caregivers reported providing care for a mean of 7 (range 1-35) years. The mean average of hours spent providing care in a week was 44 hours.

Participants reported providing a **moderate amount of caregiver assistance with ADLs and IADLs (M = 48.72, SD = 20.97).**

Most of the caregivers (80%) reported having some degree of difficulty finding services to support them, with 41% indicating either very great or extreme difficulty in finding services. Less than 25% of caregivers were utilizing the range of services traditionally available for caregivers. However, 41% of caregivers reported using a homemaker to assist with chores and 31% reported using home nursing services.

| SF-36                       | Mean (SD)     | Cronbach's alpha |
|-----------------------------|---------------|------------------|
| General Health              | 66.30 (22.81) | .82              |
| Physical Functioning        | 83.27 (19.08) | .90              |
| Social Functioning          | 70.67 (30.61) | .85              |
| Emotional Well-Being        | 70.15 (25.23) | .85              |
| Pain                        | 71.11 (25.34) | .91              |
| Role Limitations: Physical  | 61.54 (47.03) | .96              |
| Role Limitations: Emotional | 65.43 (42.85) | .87              |
| Energy/Fatigue              | 58.85 (25.97) | .77              |

| CRA                    | Mean (SD)   | Cronbach's alpha |
|------------------------|-------------|------------------|
| Disrupted Schedule     | 2.61 (1.03) | .84              |
| Lack of Family Support | 3.22 (1.05) | .81              |
| Financial Problems     | 3.42 (0.87) | .63              |
| Health Problems        | 3.64 (0.76) | .48              |

## Conclusion and Implications

Although participants reported that their role as a caregiver had, in general, a moderately negative impact on family support, finances, and health, they perceived their general health, including physical and social functioning and emotional well-being as good, and also described the ability to find strength and resilience in this role.

Caregivers described needs largely related to education, resources, and support services, including emotional support throughout the stages of caregiving.

To date, findings have informed the development of caregiver support/education sessions, including a virtual dementia tour, and community outreach.

We acknowledge limitations related to the small sample size and low reliability of the CRA subscales, financial problems and health. However, we consider this study an important first step in better understanding the context and needs of caregivers living in this rural community.

## Background and Significance

There are over **16 million Americans** providing care to a relative or friend with Alzheimer's disease, an illness that currently impacts **5.5 million Americans**.

A substantial body of literature suggests that family caregivers experience significant adverse physical, psychosocial, and financial outcomes as a result of the caregiving role.

**Latinos are more likely to use unpaid, informal caregivers than non-Latino Whites and current projections estimate that the number of Latino's affected by AD will increase to 3.5 million by 2060.**

**In Texas, 25% of caregivers live in rural areas and Latinos comprise over 50% of the population in South Texas.**

Although evidence-based interventions have been shown to improve caregiver outcomes, their effectiveness in ethnically diverse populations, living in rural settings, has not been well established.

## Qualitative Findings

### Initial focus group results revealed:

***Interest in establishing a support group for all caregivers within the community regardless of care recipient diagnosis***

***Educational sessions on Alzheimer's disease, other chronic illnesses, resources, and services, including respite care***

### Themes from the follow-up focus group consisted of:

***Confusion and challenges surrounding access to services***

***Emotions surrounding accepting changes and assistance***

***Finding strength and resilience in the caregiving role***

## References

Adelmann, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA, 311(10)*, 1052-1060. doi: 10.1001/jama.2014.304

Alzheimer's Association. (2018). *2018 Alzheimer's disease facts and figures*. Retrieved from <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>

Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review, 62(3)*, 340-350. <http://dx.doi.org/10.1111/inr.12194>

Gitlin, L. N., Marx, K., Stanelly, I. H., & Hodgson, N. (2015). Translating evidence-based dementia caregiving interventions into practice: state-of-the-science and next steps. *Gerontologist, 55(2)*, 210-226. doi: 10.1093/geront/gnu123

USC Edward R. Roybal Institute on Aging and the Latinos Against Alzheimer's Network. (2016). *Latinos & Alzheimer's disease: New numbers behind the crisis*. Retrieved from [https://www.ucdmc.ucdavis.edu/latinoaging/news/latino\\_alzheimer\\_new\\_number.html](https://www.ucdmc.ucdavis.edu/latinoaging/news/latino_alzheimer_new_number.html)

Williams, F., Moghaddam, N., Ramsden, S., & De Boos, D. (2018). Interventions for reducing levels of burden amongst informal carers of persons with dementia in the community. A systematic review and meta-analysis of randomized controlled trials. *Aging Mental Health, 18*, 1-14. doi: 10.1080/13607863.2018.1515886