



RECRUITING HISPANICS FOR A RESEARCH STUDY ON FAMILY CAREGIVING

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ABSTRACT

More than 53 million persons in the U.S. are family caregivers, meaning they provide personal care support and/or medical care to a friend or family member in the home and in our communities. Respite is defined as a short period of relief from difficult tasks associated with family caregiving. It is the most sought out resource for caregivers. However, many caregivers are hesitant to use respite services. This is particularly true for Hispanic caregivers. Many Hispanics do not identify as a “caregiver” when they are caring for a family members. Some Hispanic caregivers do not realize the benefits associated with respite, while others do not realize that it is a resource they have access to. This is likely due to the fact that the advertisements for these resources do not resonate with many Hispanic caregivers.

During the summer of 2021, I worked with a multidisciplinary team on a research project funded by the NIA known as Time for Living and Caring (TLC). Team members of the TLC project have developed an intervention in the form of an online “app” that supports dementia caregivers who want to use respite services. The TLC research team is currently recruiting participants to evaluate the TLC intervention, but has not had much success in recruiting Hispanic caregivers to participate in the study.

Given that recruitment of Hispanic populations is particularly difficult, I worked on a special project to develop unique strategies to recruit, engage, and retain Hispanic populations in this study.

BACKGROUND

Most adults who suffer from dementia need extensive care and assistance when completing daily tasks. Around 6 million adults in the United States suffer from Alzheimer’s disease or a related dementia. Unfortunately, this number is expected to grow to about 14 million by the year 2050. The demand for caregivers is drastically higher than that of the actual number of caregivers available. Current caregivers are experiencing higher stress levels that may in turn be causing symptoms associated with anxiety and depression. The burden associated with caregiving has affected not only the mental well-being of caregivers, but has also deterred other potential individuals from becoming caregivers themselves. Often times, Hispanic caregivers are called upon to care for their family members with the expectation that they will deprioritize other commitments. Though many Hispanic caregivers do not believe that caring for a family member is associated with obligation, they still experience caregiver burnout for a variety of reasons. In order to prevent Hispanic caregivers from overlooking these beneficial resources, Yancey et al (2006) suggests that scientific studies must find a balance between initial selectivity and inclusivity. Inclusivity involves innovative thinking that takes into account the unique dialects present in one’s language, culturally competent advertisements, and an understanding of the important values apparent in the Hispanic community.

SUMMARY OF MY ACTIVITIES AS A MEMBER OF THE TLC RESEARCH TEAM

As a 2021 SPUR Scholar at the University of Utah, I participated in the following activities:

- Completed certifications and training for human subjects research and clinical trials: 1) Biomedical Research Investigators and Key Personnel certification (CITI) and 2) Good Clinical Practice certification required for all NIA funded clinical trials
- Participated in a 5-part webinar series presented by the Diverse Elders Coalition; formally presented information back to the TLC team and lead a discussion about the topics I learned
- Attended the 5-day International Short Break Association biannual research conference
- Observed and participated in weekly meetings with members of the TLC team
- Learned how to use REDCap to track participant recruitment, enrollment, and data collection
- Worked with a University of Utah librarian to conduct a literature search and write a literature review about the challenges of recruiting Hispanic persons to research studies
- Reviewed current recruitment practices and offered recommendations to TLC team

RECOMMENDATIONS



The flyer is a recruitment advertisement for the TLC (Time for Living & Caring) study. It features two photographs at the top: one of a man being embraced by a younger person, and another of two women smiling together. The text is organized into three main sections: a headline, a list of eligibility criteria, and contact information. The TLC logo and the University of Utah logo are also present.

We are looking for caregivers who need and want a break

This is a 20-week study—participants will be compensated up to \$250 in gift cards and/or a new Chromebook

Participation Eligibility

- + Are you currently caring for a person experiencing Alzheimer's disease-related dementia?
- + Are you the primary caregiver for this person?
- + Do you live with this person?
- + Are you able to read & follow instructions in English?
- + Are you 18 or older?
- + Do you have access to respite (a short period of rest or relief from caregiving) at least once per week?

Please contact us if you are interested in learning more or would like to participate.

Email:
tlc@utah.edu

Phone:
385-799-1515

TLC
TIME FOR LIVING & CARING

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Figure 1: TLC Recruitment Flyer

Recommendation	Examples
Linguistically and culturally competent resources	Replace the word “caregiver” with “family” or “the person you care for at home”
Personal engagement and approach	Develop personal relationships with each individual by engaging participants in shared decision making
Tactile documents	Physical documentation of research instructions and forms including informed consent form. The online and technology-delivered nature of the TLC project may make this challenging
Individualized instructions	Instructions that are tailored to the individual’s understanding. The self-administered delivery of the TLC app may make this challenging
Provide necessary self-care resources	Prepare resources that are applicable to the individual’s wants and needs

Figure 2: My recommendations to improve the success of Hispanic recruitment

CONCLUSION

In short, recruitment strategies should be targeted and tailored to the specific characteristics and cultural values of the population you would like to recruit, especially if they seek relief from the stressful tasks associated with caregiving.

REFERENCES

- Yancey, A. K., Ortega, A. N., & Kumanyika, S. K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*(1), 1–28.
<https://doi.org/10.1146/annurev.publhealth.27.021405.102113>