

DGIM Project Summary

Name of Project: Living Alone with Cognitive Impairment

Investigator(s): PI/primary contact: Elena Portacolone elena.portacolone@ucsf.edu

Research question(s): The main purpose of the study is to increase our awareness of the experience of living alone in older age with cognitive impairment so that tailored services and programs are created for this population. Research questions include: What is the lived experience of older adults living alone (OALA) with cognitive impairment such as Alzheimer's disease (AD) or mild cognitive impairment (MCI)? What kind of formal and informal support OALA with AD/MCI have/desire/miss? How do OALA with MCI/AD make decisions? How do the experience of OALA with MCI or AD differ from cognitively healthy OALA?

Brief Background/Significance: One out of four community-dwelling adults over 70 has cognitive impairment such as AD or MCI, usually a precursor of AD. A great concern is that many older adults with AD and MCI live alone. At least one in seven individuals with AD lives alone (800,000 Americans). Very little is known about the subjective lived experience of OALA with cognitive impairment.

Inclusion/exclusion criteria (list):

OALA with MCI/AD. Thirty OALA with a diagnosis of MCI and 30 OALA with a diagnosis of AD will be recruited. Participants will be age 65 and older, fluent in English, and living alone in any of the nine counties of the San Francisco (SF) Bay Area, an area with 7.2 million residents. Age, living situation and English language fluency will be assessed through self-report. Living alone is defined as living without a cohabitant in a non- institutional setting. Those living in an institution such as assisted living facilities will be excluded because residents of those facilities access services usually unavailable to non-institutionalized OALA. Their ability to provide consent will be assessed with a consent form for persons with cognitive impairment successfully used by other investigators at UCSF.

Cognitively healthy OALA. For comparison, 30 cognitively healthy OALA will be recruited and matched in age range and sex with OALA with MCI/AD. Participants will be ≥ 65 , fluent in English, and living alone in the SF Bay Area. We estimate 30 participants will provide ample data for comparison, since the size of this subsample is equal to that of the other sub-samples.^{159,160} To exclude controls with undiagnosed cognitive impairment, exclusion criteria include presence of: active neurologic or psychiatric disease; medication use in the type or amount that suggests neurologic or psychiatric disease; and cognitive complaints by the participant¹⁶¹ as assessed by a physician. In addition, we will exclude OALA who score < 26 ¹⁶²⁻¹⁶⁴ (or < 23 for OALA with < 5 years of education^{165,166}) in the Montreal Cognitive Assessment administered by the PI.

Method of contact/recruitment (be specific): OALA will be recruited over three years from different academic and community partners. I plan to recruit a maximum of 3 OALA per month. Please note that DGIM is one of these partners. It would be great if providers at DGIM support the PI with the recruitment of a portion of the sample. To recruit a portion of these participants, I would like to ask providers at DGIM to identify potential study participants among their patients, and inform them

about the study. If the patient is interested, the provider will ask the permission from the patient to provide their name and telephone number to me as the PI. Once I have this information, I will call them, answer any questions about the study, send a copy of the consent form, and meet them. I understand from Dr. Alka Kanaya that I will have to list the providers who will support with recruitment as co-investigators in my CHR application, which I will do once I have their names.

Benefits/burden for participants (clearly identify potential for harm): In terms of benefits, OALA will spend time with the PI five times over three months. It is likely that OALA will enjoy the interaction with the PI, an investigator well trained in creating rapport and trust. The 12 participants of the preliminary study enjoyed spending time with her. Past participants have used these sessions to voice thoughts and concerns to a person who does not judge them and simply is there to learn from them. In addition, the OALA will receive a \$30 gift card at the end of the first interview as a thank you. In terms of burden, talking about their situation may make OALA sad. Please note that the PI will ask several times to OALA if they are tired and will leave if they are tired to avoid burdening physically.

Any benefits or burden to DGIM practitioners? In terms of benefits, DGIM practitioners will increase their understanding of the overall experience of living alone in older age with MCI/AD since I plan to disseminate my publications to them. I am also available to give presentations to DGIM of course. In terms of burden, a small portion of their interaction with their patients during one visit may be dedicated to see whether their patient is interested in joining this research

Timeline for recruitment (projected start and stop dates): Recruitment will start January 1 2016 and end on December 31 2018. I plan to recruit 3 OALA per month.

Funding source: National Institute on Aging, K01 mechanism

Potential for DGIM collaborators? (We encourage DGIM resident and fellow involvement in particular) I welcome all sorts of collaborations. They may include: design and participation in related new investigations; co-authorship of publications; fellows may become research assistant and I could hire them and train them to interview healthy controls. I am open to all sorts of collaborations.

Do you agree to notify us when recruitment is completed? Sure.

Date form completed: October 14 2015