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Sociodemographic and socioeconomic characteristics of elder self-neglect in an US Chinese aging population

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ABSTRACT

This study aimed to examine the socio-demographic and socioeconomic characteristics associated with prevalence and severity of elder self-neglect in an U.S. Chinese older population. The PINE study is a population-based epidemiological study in the greater Chicago area. In total, 3159 Chinese older adults were interviewed from 2011 to 2013. Elder self-neglect was assessed with systematic observations of a participant's personal and home environment across five domains: hoarding, personal hygiene, house in need of repair, unsanitary conditions, and inadequate utility. Elder self-neglect was prevalent among older adults aged 80 years or over (mild self-neglect: 34.6% 95% CI 30.9–38.4; moderate/severe: 15.6% 95% CI 12.8–18.6), men (mild: 28.6% 95% CI 26.1–31.3; moderate/severe: 13.1% 95% CI 11.2–15.1), those with 0–6 years of education (mild: 32.2% 95% CI 29.7–34.9; moderate/severe: 12.6% 95% CI 10.8–14.5), and those with an annual personal income between $5000 and $10,000 (mild: 30.8% 95% CI 28.4–33.2; moderate/severe: 11.8% 95% CI 10.2–13.5). Older age (mild self-neglect: OR 1.02, 95% CI 1.01–1.03; moderate/severe self-neglect: OR 1.02, 95% CI 1.00–1.03) and lower education levels (mild self-neglect: OR 1.06, 95% CI 1.03–1.08; moderate/severe self-neglect: OR 1.07, 95% CI 1.04–1.09) were associated with significantly increased odds of elder self-neglect. Women (moderate/severe self-neglect: OR 0.73, 95% CI 0.58–0.93) had significantly decreased odds of moderate/severe elder self-neglect. No significant association was found between levels of income and overall elder-self-neglect of all severities. Future research is needed to examine risk/protective factors associated with elder self-neglect in U.S. Chinese older populations.

1. Introduction

The National Centers on Elder Abuse defines elder self-neglect as " . . . the behavior of an elderly person that threatens his/her own health and safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide himself/herself with adequate food, water, clothing, shelter, personal hygiene, medication (when indicated), and safety precautions" (National Center, 2016). In general, elder self-neglect encompasses five different phonotypes: hoarding, personal hygiene, house in need of repair, unsanitary conditions, and inadequate utility. Elder self-neglect is a significant public health issue and are the most frequently referred cases to Adult Protective Services (APS) (National Center on Elder Abuse, 2004). In addition, reports from the National Adult Protective Services Agency suggests that elder self-neglect is on the rise (National Center on Elder Abuse, 2004). Although such reports make an invaluable contribution to the field, they likely represent the "tip-of-the-iceberg." More comprehensive and systematic studies are needed to precisely define the issue, develop interventions, and establish appropriate policies.

Prior studies suggest that self-neglecting behaviors among older adults may be associated with increased likelihood of morbidity and premature mortality (Dong, Simon, Mendes de Leon, et al., 2009). Moreover, social services agency data suggests that minority older adults and those with lower socioeconomic status may be at higher risk for being reported to authorities for self-neglecting behaviors (Dong, Simon, Evans, 2010; National Center on Elder Abuse, 1998; Brien et al., 1999) Despite the extent of documented elder self-neglect, our existing knowledge relies heavily on case studies and case reports to social services agencies (O'Brien, Thibault, Turner, & Laird-Fick, 1999; Mosqueda and Dong, 2011).

To our knowledge, very few studies to date have examined the prevalence of elder self-neglect in a community dwelling population. In the Chicago Healthy Aging Project (CHAP), where 61.6% of the

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participants were African American, Dong, Simon (2011) found that the prevalence of self-neglect among African American populations was four times greater than among White populations. However, significant gaps remain in our current understanding of self-neglect among minority populations. Improved understanding of these issues is critical for informing research, education, practices and policies that provide targeted prevention, screening and interventions within specific cultural groups.

In addition, most prior studies are limited by an insufficient consideration of the different severities of self-neglect. The majority of previous studies have categorized self-neglect dichotomously – self-neglect versus no self-neglect – yet like many other geriatric syndromes, self-neglect behaviors occurs along a continuum that may develop and progress slowly over time (Dong and Gorbien, 2005). Evidence suggests is a gradient association between severity of self-neglect and lower physical and cognitive function (Dong, Wilson, 2010; Dong, Mendes de Leon, 2009), so more rigorous research may be needed on the full spectrum of self-neglect.

The Chinese community is the largest and the fastest growing Asian American subgroup population in the U.S., numbering approximately 4 million (American Community Survey, 2011). The U.S. Chinese population aged 65 and over has increased by 55% in the past decade, far exceeding the population growth rate of 15% among U.S. older adults (U.S. Census Bureau, 2010). Compared with the general population, the Chinese population is older in average age and less acculturated in comparison with other U.S. immigrant groups (Shinagawa, 2008). A lack of language competency, coupled with cultural barriers and social isolation, may exacerbate frailty and dependency, and further predispose U.S. Chinese older adults to greater risk of elder self-neglect.

In this study, we aimed to examine: (1) the prevalence and severity of elder self-neglect and its phenotypes, including hoarding, hygiene, house in need of repair, unsanitary conditions, and inadequate utility, across age and gender in a community-dwelling older Chinese population; and (2) the prevalence and severity of elder self-neglect and its phenotypes across different socioeconomic characteristics.

2. Methods

2.1. Population and settings

The Population Study of Chinese Elderly in Chicago (PINE) is a community-engaged, population-based epidemiological study of U.S. Chinese older adults aged 60 and over conducted in the greater Chicago area. Briefly, the purpose of the PINE study is to collect community-level data of U.S. Chinese older adults to examine the key cultural determinants of health and well-being. The project was initiated by a synergistic community-academic collaboration among the Rush Institute for Healthy Aging, Northwestern University, and many community-based social services agencies and organizations throughout the greater Chicago area.

To ensure the study's relevance to the well-being of the Chinese community and increase community participation, the PINE study implemented extensive culturally and linguistically appropriate community recruitment strategies guided by a community-based participatory research (CBPR) approach (Dong, Chang, 2011). In particular, the community advisory board (CAB) played a pivotal role in providing insights and strategies for the research activities. Board members were community stakeholders and residents enlisted from over twenty civic, health, and social advocacy groups, community centers and clinics in the city and suburbs of Chicago. The board worked extensively with the investigative team and provided input on the design of the study instruments to ensure cultural sensitivity and appropriateness.

2.2. Study design and procedure

The research team implemented a targeted community-based recruitment strategy by first engaging community centers in the greater Chicago area. In total, twenty two social services agencies, community centers, health advocacy agencies, faith-based organizations, senior apartments and social clubs served as the basis of study recruitment sites. Eligibility criteria includes: (1) Community-dwelling older adults aged 60 years and over; (2) older adults who were self-identified as Chinese. Out of 3542 eligible older adults approached, 3159 agreed to participate in the study, yielding a response rate of 91.9%. Written informed consent was obtained from all of the participants who agreed to take part in the study. Details of the PINE study design have been published elsewhere (Dong, Wong, & Simon, 2014).

Research assistants were recruited through community partners and were equipped with multi-lingual abilities. Prior to field interviews, all hired interviewers attended an intensive training that covered from proper data collection techniques, survey questionnaire administration, to in-person communication skills, basic understanding of health sciences research and mock-interview role play. During the field data collection period, booster trainings combined with staff meetings were conducted once to two times a month to reinforce specific aspects of in-person training, and provide additional training on new issues emerged from the field work. Face-to-face home interviews were conducted by trained interviewers with participants in their preferred language (English or Chinese) and dialect (e.g., Cantonese, Taishanese, Mandarin, and Teochew). Data were collected using the state-of-science innovative web-based software which recorded English, Chinese traditional and simplified characters simultaneously. Based on the available data drawn from the U.S. Census 2010 and a random block census project conducted among the Chinese community in Chicago, the PINE study is representative of the Chinese aging population in the greater Chicago area with respect to key socio-demographic, socioeconomic and household characteristics (Simon, Chang, Rajan, Welch, & Dong, 2014). The study was approved by the Institutional Review Board of the Rush University Medical Center.

2.3. Measurements

2.3.1. Socio-demographics

Basic demographic information included age (in years), sex (female and male), education (years of education completed), annual personal income (0–$4,999 per year/$ 5000–$9999 per year/more than $10,000 per year).

2.4. Assessment of elder self-neglect

Elder self-neglect was measured using the Chicago Healthy and Aging Self-neglect instrument, which has been widely used and validated (Dong, Simon, Evans, 2009; Dong, Simon, Wilson, et al., 2010; Dong, Simon, Fulmer, 2010). All survey interviewers went through standardized training on these items with the investigative team. Additionally, the project coordinator accompanied each survey interviewers' first in-home interview. A 27-item assessment of elder self-neglect was conducted by trained interviewers making systematic personal and environmental observations across five domains: hoarding, poor basic personal hygiene, house in need of repair, unsanitary conditions and inadequate utilities.

Hoarding was assessed by the presence of accumulation of newspapers, magazines, boxes, bags, bottles, trash, and pets. *Poor basic personal hygiene* was assessed by presence of dirty nails, dirty or un-groomed hair, dirty skin, and presence of fecal or urine smells. *House in need of repair* included difficulty accessing the