Excluding Non-English Speaking People from Health Research Including Falls Research for Community-Dwelling Older People

Karen Pedemont DOBA DipAppSc(Orth) MAppSc(Res)

Bankstown-Lidcombe Hospital, Bankstown, Australia

ABSTRACT

The exclusion of people with limited or no English language skill from health research occurs often, due to logistical and financial constraints. Exclusion limits the generalisation of study outcomes especially in culturally and linguistically diverse populations. This includes falls research for community-dwelling older people. Reduced vision has been reported in the literature to be a significant independent risk factor for falls in this population. Excluding non-English speaking people from health research also impacts on eye research. The aims of this review are to increase the awareness of the issues arising from the exclusion of non-English speaking older people from health research and to encourage researchers to include this vulnerable population in health research. English language skill is a valid indicator of health status and older people with limited English language skill have significantly poorer self-reported health status than those who speak English only. Despite this, guidelines governing inclusion of this population in health research are inconsistent. Resources and advocacy of inclusion will ensure ongoing equity of access to health care services for this population.

Keywords: non-English speaking, health research, falls, community-dwelling older people

INTRODUCTION

People with limited or no English language skill are often excluded from health research.[1-2] This includes research into falls for community-dwelling older people.[3-8] Falls are a major health concern and the main reason for trauma-related hospital admission in people aged 65 years and older.[9-10] Reduced vision has been reported in the literature to be a significant independent risk factor for falls in this population.[11] When this minority group are included in health research and falls research for example, but the research variable of English language skill is not reported,[12-17] their outcomes remain unknown. Excluding non-English speaking people from health research is an area of interest and clinical relevance as it also impacts on eye research. The exclusion of this population from health research limits the generalisation of study outcomes especially in culturally and linguistically diverse populations. The aims of this narrative review are firstly to increase the awareness of the issues arising from the exclusion of non-English speaking older people from health research, both qualitative and quantitative, including falls research in community-dwelling older people. Secondly, this review aims to target researchers and encourage inclusion of non-English speaking people in health research.

Corresponding author: **Karen Pedemont**
Bankstown-Lidcombe Hospital, Locked Bag 1600,
Bankstown, NSW 2200, Australia
Email: karen.pedemont@health.nsw.gov.au
Accepted for publication: 6th September 2018

DISCUSSION

The Australian guidelines by which human research is regulated, advocate equity of access and recognise the cultural diversity of Australia's population.[18] These guidelines include the values and principles of ethical conduct, and the ethical consideration of risk, benefit, consent, research methods, recruitment of participants and accountability.[18] The Department of Immigration and Border Protection[19] reported on this diversity, based on the statistics from the 2011 Australian Census. Twenty-seven percent of Australians aged 65 years and over, who spoke a language other than English, reported that they either did ot speak English well or did not speak English at all. This particular statistic was not included in the 2016 Australian census. In other countries like the United States for example, the United States National Institutes of Health (NIH)[20] also have guidelines in place to ensure that minority groups such as those with limited English proficiency are adequately

represented in clinical research. These guidelines suggest that minority groups must be included in all NIH-funded clinical research, unless inclusion is inappropriate due to the health of the participant or the purpose of the research.[20] Despite these guidelines, exclusion of people with limited or no English language skills has not declined, but in some cases has increased.[21]

Exclusion of non-English speaking people from health research

The reasons for exclusion of people with limited or no English language skill in health research include logistical and financial constraints.[1-2] Glickman et al[1] reported that clinical researchers are not always encouraged by their governing body to include people with limited English proficiency. The authors reported on the differences in American Institutional Review Board (IRB) policies, regarding the consent process of people with limited English proficiency in clinical research projects. The sample was limited to academic IRBs and restricted to policies posted on the Internet. The consent requirements for all clinical research of the IRB of 134 American academic health centres were reviewed and the authors found eight statements that could discourage investigators from including people with limited English proficiency. For example, one IRB cautioned the researchers to carefully consider the ethical and legal implications (obtaining informed consent) of recruiting subjects with limited English proficiency, whilst another IRB warned investigators to carefully consider whether, even with a trained interpreter, a legal informed consent can be obtained. Equally, there were eight statements that encouraged investigators to include people with limited English proficiency, for example, that care must be taken to not exclude non-English speakers and another statement reminded investigators that non-English speakers must not be excluded unless there is an ethical or scientific reason agreed on by the IRB. It is encouraging that inclusion is supported but there needs to be a consistency which is not always seen. A consistent approach will ensure equity of access to health research for this minority group.

Frayne et al[2] also reported on the exclusion of non-English speaking people from health research. Unlike in Glickman et al[1] the investigators in this review were not discouraged from including non-English speaking people. The main reason for exclusion was oversight. To determine how often non-English speaking people are excluded from medical research, Frayne et al[2] surveyed the authors of publications on provider-patient relations about their exclusion criteria. In this study, 'provider-patient relations' refers to activities such as patient education, health education, or patient satisfaction. Of the 172 authors surveyed, sixty-eight (40%) excluded non-English speaking people. The most common reason for exclusion was not having considered it (51%). The authors who did consider inclusion but decided to exclude non–English speaking people did so for a variety of reasons; 58% due to the absence of study instruments in languages other than English, 55% due to having to translate responses into English, 45% due to the expense of translating the study material and 45% due to problems recruiting bilingual staff. These percentages show that a large number of researchers understand the importance of including people who do not speak English. What is needed are resources targeted at these specific barriers to support researchers to include people who do not speak English.

Data quality concerns may also lead to the exclusion of non-English speaking people from health research. Ngo-Metzger et al[22] reported on data quality in health research by reviewing response rate and missing data. The authors compared response rates and missing data of telephone and mail surveys among Asian Americans with limited English proficiency. The authors concluded that their data quality was comparable to studies which had been conducted with English speaking subjects. This study is also an example of successfully including people who do not speak English in research using resources such as bilingual staff. In this particular study, 479 patients (mean age 44 years) were surveyed about quality of medical care. Eighty-three percent of the subjects did not speak English or did not speak English well. The survey contained 78 items and was delivered via two modes: a self-administered mail survey with telephone reminder and a telephone survey. Both survey modes were in the participant's native language, Cantonese, Mandarin or Vietnamese. An overall response rate of 67% (322 of 479) was achieved. There was a higher response rate to the telephone survey (75% of 240) compared with the mail survey (59% of 239) and the missing data was minimal with respondents completing over 90% of the survey questions. The conclusion made by Ngo-Metzger et al,[22] that their data quality is comparable with studies conducted with English speaking subjects is consistent with the findings of authors Sullivan et al[23] and Kerr et al,[24] who surveyed English speaking people about their health outcomes. Sullivan et al[23] surveyed 983 English speaking people with diabetes (mean age 60 years) on their health outcomes and reported an overall response rate of 70.9% (697 of 983) and a completion rate of over 84%. This particular survey was delivered via three modes; mail, handed out, and face to face interview. The overall response rates for Sullivan et al[23] and Ngo-Metzger et al[22] were similar as were the completion rates. More recently, Kerr et al[24] conducted a single mode, mail survey with 5,110 English speaking patients (mean age 72 years) on their satisfaction with hypotensive eye drops. The response rate was 50% (2,541 of 5,110) and the completion rate was over 99%. Once again, the completion rate reported by Ngo-Metzger et al[22] is similar to that achieved by Kerr et al,[24] and the response rate of 59% achieved by Ngo-Metzger et al[22] from the group

who received the survey via mail, compares with the response rate that Kerr et al[24] received for their survey which was also delivered via mail (50%). As response rates and missing data have been shown to be similar despite English language skill, the evidence does not support concerns about the data quality of subjects with limited English-language proficiency in health research.

Exclusion of non-English speaking older people from falls research

In Australian research studies concerning falls for community-dwelling older people, it is common for non-English speaking people to be excluded.[6-8] Falls are a major health issue for older people aged 65 years and over and are caused by the complex interaction between multiple risk factors.[25-26] Examples of such risk factors for falls include poor vision, impaired cognition, impaired balance, previous falls, the use of more than four medications and use of psychoactive medications, that is medications used for treating depression or anxiety.[26] A fall can be defined as 'an unexpected event in which the participant comes to rest on the ground, floor or lower level'.[12] Around 43% of older people living in the community (ie living at home or independently in a retirement village) have one or more falls each year (43.5%,[12] 43.6%,[27] 43.2%[6]), with the fall rate increasing with age,[1,17,28] along with the rate of fall-related injuries requiring emergency medical attention and hospital admission.[29-30]

The common barriers to inclusion of non-English speaking older people from falls research are once again operational and financial, for example, a lack of validated assessments available (neuropsychological, anxiety and depression) in languages other than English, questionnaires and falls calendars which are only available in English, physical assessments which require comprehension of oral instructions to ensure reliability and an absence of funding for language interpreters (A Tiedemann, February 8, 2012, personal communication; S Lord, February 9, 2012, personal communication). The barriers to inclusion of non-English speaking older people experienced by researchers over a decade ago[2] are the same today (A Tiedemann, February 8, 2012, personal communication; S Lord, February 9, 2012, personal communication). This is surprising considering the focus on positive health outcomes for our diverse community.[31-33]

English language skill, self-reported poor health and falls

English language skill is a useful variable for health research and a valid indicator of health status.[34-35] Older people with limited English language skill have significantly poorer self-reported health status than those who speak English only.[35-36] As self-reported poor health is a falls risk factor for community-dwelling older people,[37] then faller status for non-English speaking older people may differ from English speaking older people. As non-English speaking people are often excluded from falls research, then this association remains unclear.

In two large American studies on linguistic disparities in health access and health status in older people, data was analysed from the 2001[35] and the 2007[36] California Health Interview Survey. Both studies were conducted in similar languages including English, Spanish, Cantonese, Mandarin, Korean and Vietnamese. The study by Ponce et al[35] also included Khmer. The sample size in the study by of Ponce et al[35] was less than half that of Sentell and Braun[36] (n = 18,659 and n = 48,427, respectively) and also older (Ponce et al,[35] 53% aged 65 years and over; Sentell & Braun,[36] 11.8% aged 65 years and over). Despite this, each study had a similar percentage of respondents with limited English proficiency (Ponce et al,[35] 7%; Sentell and Braun,[36] 7.7%). Ponce et al[35] reported that the respondents with limited English language proficiency had 68% increased risk of poorer self-reported health (fair to poor health status) compared with the English only speakers (RR 1.68, 95% CI: 1.37 - 2.02, P<.001). Sentell and Braun[36] found that the adults with limited English proficiency were significantly more likely to self-report poor health status compared with those adults who were English proficient (42.9% versus 14.9%; OR 2.10, 95% CI: 1.7 - 2.58). These two large sample studies have highlighted the disparities in health status between older people with limited English language proficiency and older people who are English proficient. Both studies have shown that older people with limited English proficiency are more likely to self-report poor health than those who are proficient in English, even when questioned in their native language. Limited English proficiency is a major barrier to health care. The provision of health service interpreters is an example of how health care systems could reduce the linguistic barrier and improve access to health care, thus improving the health status of this vulnerable population.[35-36]

Gill et al[37] determined that self-reported poor health is a falls risk factor for community-dwelling older people. Their population-based survey, conducted in Australia, investigated a range of potential factors for falls defined in community dwelling older people. A definition of a fall was not included. Although language spoken at home was included as a demographic variable, English-language skill was not. One of the factors included in the survey was general health, self-reported as either poor, fair, good, very good or excellent. Two-thousand-six-hundred-and-nineteen older people responded to the survey (females n = 1,481) which was conducted via telephone. The respondents who self-reported poor or fair general health compared to good, very good or excellent general health were significantly more likely to have fallen in the previous 12 months (OR 1.34, 95% CI: 1.09-1.67, P< 0.001).[37]

The retrospective recall of falls data may have led to an under-reporting of falls, limiting the accuracy of the data analysis.

Also, it could not be established if the fall contributed to the self-reported poor health rating, that is whether it came before the poor health, or if self-reported poor health was a risk factor for the fall, or if both patterns occurred.

CONCLUSION

People with limited or no English language skill are often excluded from health research including falls research due to logistical and financial constraints. There are guidelines in place governing human research which generally support the inclusion of participants with limited or no English language skill and concerns such as limited data quality are not substantiated in the literature. Exclusion of this group from health research may have a negative impact on the general health outcomes of this culturally and linguistically diverse population as they are also more likely to self-report poor health compared to older people who are English proficient. This includes community-dwelling older people from this group who may not have access to evidence-based health care services including falls prevention. As poor vision is associated with an increased risk in falls for older-people then exclusion also limits the generalisation of important clinical findings especially in culturally and linguistically diverse populations. Awareness of the issues arising from the exclusion of non-English speaking older people from health research including eye research, need to be considered to ensure ongoing equity of access to health care services for this population.

REFERENCES

1. Glickman SW, Ndubuixu A, Weinfurt KP, et al. Perspective: the case for research justice: inclusion of patients with limited English proficiency in clinical research. Acad Med 2011;86(3):389-393.
2. Frayne SM, Burns RB, Hardt EJ, et al. The exclusion of non-English-speaking persons from research. J Gen Int Med 1996;11(1):39-43.
3. Boyd R, Stevens JA. Falls and fear of falling: burden, beliefs and behaviours. Age Ageing 2009;38(4):423-428.
4. O'Loughlin JL, Robitaile Y, Boivin J, Suissa S. Incidence of and the risk factors for falls and injurious falls among the community-dwelling elderly. Am J Epidemiol 1993;137:342-354.
5. Tinetti ME, Speechley M, Ginter SF. Risk factors for falls among elderly persons living in the community. New Engl J Med 1988;319(26):1701-1707.
6. Lord SR, Dayhew J. Visual risk factors for falls in older people. J Am Geriatr Soc 2001;49(5):508-515.
7. Morris M, Osborne D, Hill K, et al. Predisposing factors for occasional and multiple falls in older Australians who live at home. Aust J Physiother 2004;50(3):153-159.
8. Tiedemann A, Lord SR, Sherrington C. The development and validation of a brief performance-based fall risk assessment tool for use in primary care. J Gerontol A Biol Sci Med Sci 2010;65(8);896-903.
9. Lord SR, Sherrington C, Menz HB, Close JCT. Falls in Older People. 2nd Ed. New York: Cambridge University Press; 2007. p. 15.
10. Weir E, Culmer L. Fall Prevention in the elderly population. CMAJ 2004;171(7):724.
11. Lord SR. Visual risk factors for falls in older people. Age Ageing 2006;35-S2,ii42-ii45.
12. Callisaya ML, Blizzard L, Schmidt MD, et al. Gait, gait variability and the risk of multiple incident falls in older people: a population-based study. Age Ageing 2011;40(4):481-487.
13. Campbell AJ, Borrie MJ, Spears GF. Risk factors for falls in a community-based prospective study of people 70 years and older. J Gerontol 1989;44(4):M112-M117.
14. Cumming RG, Sherrington C, Lord SR, et al. Cluster randomised trial of a targeted multifactorial intervention to prevent falls among older people in hospital. BMJ 2008;336(7647):758-760.
15. Fletcher PC, Hirdes JP. Restriction of activity associated with fear of falling among community-based seniors using home care services. Age Ageing 2004;33(3):273-279.
16. Ivers RQ, Cumming RG, Mitchell P, Attebo K. Visual impairment and falls in older adults: the Blue Mountains Eye Study. J Am Geriatr Soc 1998;46(1):58-64.
17. Nevitt MM, Cummings SR, Kidd S, Black D. Risk factors for recurrent nonsyncopal falls. A prospective study. JAMA 1989;261(18):2663-2668.
18. National Health and Medical Research Council Australian Research Council and Australia's Vice-Chancellor's Committee. National statement on ethical conduct in human research; 2007 [Updated 2015, cited 2018 26th Apr] Available from https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72_national_statement_may_2015_150514_a.pdf.
19. Department of Immigration and Border Protection. The people of Australia: statistics from the 2011 census (pp. 41); 2014 [Cited 2017 19th Dec] Available from https://www.border.gov.au/ReportsandPublications/Documents/research/people-australia-2013-statistics.pdf.
20. National Institutes of Health. NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research; 2001 [Updated Nov 2017, cited 2017 19th Dec] Available from https://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm.
21. Brodeur M, Herrick J, Guardioloa J, Richman P. Exclusion of non-English speakers in published emergency medicine research - a comparison of 2004 and 2014. Acta Inform Med 2017;25(2):112-115.
22. Ngo-Metzger Q, Kaplan SH, Sorkin DH, et al. Surveying minorities with limited-English proficiency does data collection method affect data quality among Asian Americans? Med Care 2004;42(9):893-900.
23. Sullivan LM, Dukes KA, Harris L, et al. A comparison of various methods of collecting self-reported health outcomes data among low-income and minority patients. Med Care 1995;33(4 Suppl):AS183-AS194.
24. Kerr NM, Patel HY, Chew SS, et al. Patient satisfaction with topical ocular hypotensives. Clin Exp Ophthalmol 2013;41(1):27-25.
25. Kannus P, Sievänen H, Palvanen M, et al. Prevention of falls and consequent injuries in elderly people. Lancet 2005;366(9500):1885-1893.
26. Tinetti ME. Clinical practice. Preventing falls in elderly persons. New Engl J Med 2003;348(1):42-49.
27. Delbaere K, Close JC, Brodaty H, et al. Determinants of disparities between perceived and physiological risk of falling among elderly people: cohort study. BMJ 2010;341:c4165.
28. Tromp AM, Pluijm SM, Smit JH, et al. Fall-risk screening test: prospective study on predictors for falls in community-dwelling elderly. J Clin Epidemiol 2001;54(8):837-844.
29. Black A, Begg S. Rate and cost of hospital admissions due to fall-

related injuries among older Queenslanders, 2007-08; 2010. Queensland Health, Brisbane. Available from http://www.health.qld.gov.au/stayonyourfeet/documents/0708-hosp-admissions.pdf.

30. Sattin RW, Lambert Huber DA, DeVito CA, et al. The incidence of fall injury events among the elderly in a defined population. Am J Epidemiol 1990;131(6):1028-1037.
31. Ethnic Communities Council of Victoria. ECCV position paper on multiculturalism; 2011. Available from http://eccv.org.au/wp-content/uploads/2018/07/4-Final_Nov_2011_Multiculturalism_Position_Paper.pdf.
32. NSW Ministry of Health. Policy and implementation plan for healthy culturally diverse communities 2012-2016; 2012. Available from http://www.mhcs.health.nsw.gov.au/policiesandguidelines/pdf/policy-and-implementation-plan-for-healthyculturallydiverse2012-2016.pdf.
33. Orb, A. Health care needs of elderly migrants from culturally and linguistically diverse (CALD) backgrounds: a review of the literature. Curtin University of Technology, Centre for Research into Aged Care Services: Bentley, WA; 2002. Available from https://www.researchgate.net/publication/251676830_Health_care_needs_of_elderly_migrants_from_culturally_and_linguistically_diverse_CALD_backgrounds_A_review_of_the_literature.
34. Deyo RA, Diehl AK, Hazuda H, Stern MP. A simple language-based acculturation scale for Mexican Americans: validation and application to health care research. Am J Public Health 1985;75(1):51-55.
35. Ponce NA, Hays RD, Cunningham WE. Linguistic disparities in health care access and health status among older adults. J Gen Int Med 2006;21(7):786-791.
36. Sentell T, Braun KL. Low health literacy, limited English proficiency, and health status in Asians, Latinos, and other racial/ethnic groups in California. J Health Commun 2012;17(Suppl 3):82-99.
37. Gill T, Taylor AW, Pengelly A. A population-based survey of factors relating to the prevalence of falls in older people. Gerontology 2005;51(5):340-345.