RESEARCH IN THE RETIREMENT VILLAGE COMMUNITY – DOES THE RECRUITED SAMPLE REFLECT THE RESIDENT POPULATION?

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Abstract

Background Retirement Villages (RVs) for older people represent a burgeoning industry. However, we know little about residents' demographics and health/disability issues - information which could inform health planning, facilitate independence and reduce service demand. RVs are semi-closed communities: access for researchers is most conveniently gained via RV managers. We are studying RV residents in Auckland, New Zealand (NZ) to acquire demographic, health, disability and social data, with a randomized-controlled-trial of a multidisciplinary intervention aimed to reduce adverse outcomes. We here describe recruitment problems we encountered. Methods We planned to approach all RVs in Auckland/Waitemata Districts, with random sampling of residents in each village using unit/apartment lists as the sampling frame. Exclusions: Refusal of/inability to consent (complying with NZ legislation; ACER<65, or person clinicians felt lacked capacity). We planned access via RV managers and contact residents by 'letter-drop' then 'door-knocks'. In 'small' RVs (n<60 units), we planned to contact all residents, with random selection in 'larger' RVs. Results We approached managers of 53 of the 65 RVs. 38 initially replied positively, of which 34 permitted us to recruit residents, 6 did not reply. Another 9 declined our first approach, of which eight were 'small', seven independently-owned. Some managers prohibited 'letter-drops' or 'door-knocks' at all or without prior residents' meetings to assess acceptance of this methodology. Hence, we had to recruit volunteers (in 23 villages) via residents' meetings, posters/newsletters and word-of-mouth. We recruited 578 residents from 33 villages (one village had no volunteers) (median age=82yrs; 420 female; 217 sampled, 361 volunteers). Conclusions Due to organizational/managers' policy, and the fact that NZ legislation did not allow recruitment of residents without legal capacity to consent, our sample does not fully represent our RV population. Future RV research should consider alternative recruitment strategies e.g. random sampling from national census, electoral roll, or via residents' organizations.

Background

New Zealand (NZ) and international populations are ageing. From 1988 to 2008, the over-85 population of Auckland more than doubled,(1) an increase not mirrored by increases in long-term-care (LTC) 'beds', provision of which *decreased* from 95 to 67 per thousand over 20 years.(1) In part because of current focus on "ageing in place", (2, 3) people today are older and more physically dependent when entering LTC.(4, 5) During this period, the Retirement Village (RV) sector saw enormous growth:(6) resident numbers rose from almost none to 27,000 in 2010 in NZ,(7) of which 35% were in Auckland.(1) In 2017 12.6% of NZ's over-75s lived in RVs.(8) Estimates indicate that NZ has 382 registered RVs housing 39,000 people.(8) RV unit/apartment numbers increased from 10,000 (1998) to 17,250 (2010),(9) and to over 29,000 in 2017(8). Thirty-nine new RVs opened in NZ between 2012 and 2017 – an 11.4% growth rate over this time.

RVs fill a gap for those unable or not wishing to maintain their home but not needing 24-hour LTC. As RV purchase is resident-funded, RVs are available only to those with financial means. RV marketing focus is on quality-of-life and independence.(10, 11) RV support services vary markedly, from none, to alarms in

units/apartments and 24-hour staffing, to on-site medical clinics and nursing services, to home- and personal-care services. Co-location with LTC facilities is common with formal or informal arrangements to provide services facilitating independence. Many RVs provide a continuum of accommodation and care options: from independent units to serviced apartments (where increased support [household tasks and/or personal care] is available from the village at additional cost to the resident and/or provided through community services funded by local District Health Boards [DHBs]); and LTC. Overall, RVs provide privacy and security, usually with a “service-rich” environment designed to preserve independence.(12)

Bekhet found US RV residents were 65-95 (mean 82) years and 66% were female. Half were widowed.(13) A 2006 NZ Survey(14) revealed a similar resident profile: average age at entry was 78 years; 73% of residents were over 80 years-old;70% were women; 99% claimed European ethnicity. Most residents (61%) relied solely on NZ superannuation. Only 34% had no long-term disabilities; RVs have positive impacts on health/wellbeing.(10, 15, 16) RV residents report higher levels of general/mental health than community dwellers(17) and high quality-of-life.(18)

RV residents in NZ and elsewhere are older, more educated, have more financial resources but significantly greater dependency than those in private dwellings.(13, 17, 19) Much of the (limited) research in the sector comes from outside NZ and little is known about social, health or dependency characteristics and needs of NZ’s RV residents, despite, within the same or similar demographic, their greater dependency (vs. those in private dwellings) making them potentially more vulnerable to LTC entry, healthcare use, hospitalization and mortality.

Given the large and increasing numbers of older NZers living in RVs it is concerning that we know so little about their demographics, social engagement, and health and disability issues and trajectories over time. This information will inform health planning to improve quality-of-life, facilitate independence and reduce service demand.

In addition, our work in the LTC sector indicates that targeting of vulnerable, co-morbid older people and offering multi-disciplinary, gerontology nurse specialist (GNS)-led, complex intervention reduces unnecessary hospitalizations for many conditions by over 20% (vs. usual care).(20) (21, 22) It is feasible that similar interventions will benefit RV residents. RVs are not unique to NZ and our findings will inform planning and provision in NZ and internationally.

We are studying RV residents in Auckland NZ to acquire demographic, health, disability and social data, with a randomised controlled trial (RCT) of a gerontology nurse specialist (GNS)-led multidisciplinary intervention aimed to reduce adverse outcomes. We aim to (1) describe demographic, clinical and functional characteristics, healthcare use, and self-rated health of a cross-section of RV residents; (2) examine residents’ ‘cohort trajectory’ (2-3 years, [longer dependent on further funding]); (3) assess, by RCT the effect on trajectories of integrated care assessment and GNS-facilitated multidisciplinary team (MDT) meeting for ‘high risk’, multiply co-morbid residents over 2-3 years. Separate papers will describe the study’s findings regarding the above questions.

RVs are semi-closed communities: most RVs call for researchers to access residents through RV managers, potentially impacting residents' participation. The current paper describes recruitment problems engendered by this and other factors.

Methods

Methods are detailed elsewhere(23) but briefly comprised:

Phase1

RVs in Auckland/Waitemata DHBs (total population over 65yrs(24) approximately 152,000) were eligible to participate. We planned to survey all RVs in the study region (n=65) that provided housing predominantly for older/retired residents and included some shared or communal facilities. A village sampling frame was developed of all RVs within the two DHB regions, using a variety of sources (online and personal contacts). *Exclusions:* Refusal of/ inability to provide written, informed consent; (Addenbrookes Cognitive Examination Revised (ACE-R)(25) <65 or any person GNS/general practitioner [GP] feels lacks capacity) – this latter to comply with NZ legislation.

Recruitment was planned as a two-stage process: first to gain a list of village units/apartments from the village managers and then to contact residents by 'letter-drop' followed by 'door-knocks'. In smaller RVs (n≤60 units), we planned to contact all residents to assess eligibility. In larger RVs we planned to contact a random sample of units (about 30 residents per RV) with randomisation by computer-based random number allocation, carried out by a statistician blinded to the intervention. We received endorsement from the Retirement Villages Association of New Zealand (www.retirementvillages.org.nz), the industry body representing approximately 270 RVs nationwide (of 380+). Their feedback informed study design. We undertook pilot projects (including surveys of managers and residents)(19) to inform study design and develop a sampling frame of all villages. Managers were initially contacted by phone, followed by email introduction and information pack, and then hand-delivered information. When requested by managers, we contacted village operators to obtain endorsement.

GNSs facilitated the initial participant assessment, wherein residents' health and function were assessed with the interRAI Community Health Assessment (CHA),(21) and residents completed a survey questionnaire describing personal demographics, social engagement, decision-making paradigms (e.g. re. move to RV; any possible move from RV to LTC); views on the RV environment: health and functional items. The primary purpose was to describe residents' social, health and functional needs, including unmet needs. We also conducted a survey of each RV's characteristics, completed, following written informed consent, by village managers.

Phase 2. Participants' healthcare trajectories are being followed for at least two years from survey date using Ministry of Health (MOH) routinely collected data (LTC admission, emergency department [ED] attendance, hospitalization) and mortality, by means of their unique National Health Identifiers (NHIs).

The main objective is to describe trajectories of healthcare utilisation and identify resident clusters by baseline characteristics and trajectories.

Phase 3. Based on validated criteria(20, 21, 26) and on unmet needs or potential for improvement flagged by interRAI CHA triggering ≥ 3 'Clinical Assessment Protocols' (CAPs) designed to facilitate interpretation of information recorded, we selected from Phase 1's sample, a sub-sample of residents 'at high risk' of health and functional decline. An RCT then tested an intervention(20, 21, 26) with residents either continuing usual care or receiving a GNS-facilitated MDT to develop and implement an intervention plan in collaboration with the resident, their nominated support person(s), GP, geriatrician, and clinical pharmacist. Healthcare use (MoH databases) will be evaluated 1-year pre- and 1- and 2-years post-intervention (and 4-years with separate funding). *The primary outcome* will be acute hospitalizations at 1-year assessed by time-to-event analysis. Secondary outcomes will be ED presentations, LTC admission and death, assessed by time-to-event analysis.

The study was approved by the NZ Health and Disability Ethics Committee (Ref 16/CEN/34) and is registered with the Australia and New Zealand Clinical Trials Registry (ACTRN12616000685415). Its Universal Trials Number (UTN) is U1111-1173-6083. The study was funded by NZ's National Science Challenge - Ageing Well (Project F, UOOX1508, 12815/1, SUB1301), and by WDHB. It was approved by NZ's Health and Disability Ethics Committee (Ref 16/CEN/34).

Results

Due to time constraints we approached only 53 RV managers of the 65 RVs in ADHB/WDHB catchments from 2016 to 2018. Of these, 38 initially replied positively, of which four had not completed the village characteristics survey when the study ended and were therefore excluded. Six did not reply. Another nine declined our first approach, of which eight were 'small' (≤ 60 units) and seven were independently-owned. They did not give reasons for declining. This gave a potential sample of 34 villages (Table 1).

Our planned methodology proved problematic in that whilst most RV managers responded positively, many, laudably citing resident privacy, prohibited representative sampling methods (by letter-drop/ door-knocks in randomly-selected units) or permitted it only with approval from a residents' meeting to assess acceptance of this methodology. Access to residents was also hindered by intercoms and locked gates at RVs making physical access to residents' front doors impossible even when managers were assisting. Hence, in those RVs we had to recruit volunteers via residents' meetings, posters, newsletters and word-of-mouth, yielding a non-representative sample. Of the 34 consented villages, we obtained a random sample of residents in 11. In 23 we recruited only volunteers, of which one village had no volunteers.

We recruited 578 residents (median age=82yrs; 420 female). Of these, 217 residents (from 190 units) were recruited by representative sampling (from 539 randomized units, response rate was 35%), and 361 volunteers.

Given NZ legislative requirements to exclude residents who lacked (or potentially lacked) capacity to consent, even if they have a legally-appointed representative, 9 residents were thus excluded. However, it is likely that many such residents never approached us or were 'excluded' by RV managers.

Discussion

RV residents are a potentially vulnerable group about whom we currently have few data to guide service planning, including very limited understanding of access to and use of services by Māori and Pacific Peoples. This makes it even more important that data gathered on this group are representative, and in the absence of a complete survey of the whole RV population (impractical) the only way representativeness can be assumed is by recruitment of a random sample of villages, and within them, recruit a random sample of residents (or every person in a village). The first obstacle to our achieving this was the lack of a representative (or complete) sample of all RVs in Auckland/Waitemata DHBs. Much of the published research relating to RV residents, reports findings from a single RV or a very small number of RVs,(15-18) apparently without considering how participating villages might differ from non-participating villages. One NZ study, in 12 RVs, specifically mentioned agreement and involvement of RV managers in subject recruitment.(27) Other studies were able to randomly sample a large number of RV residents(16) , or to contact all RV residents in a specific geographical location(28) - though the full methodology employed in these studies is not detailed. One large Australian study mailed all members of the Retirement Village Residents Association of Victoria(29) though this does not guarantee representativeness.

Our second obstacle to proceeding as planned was that many managers would not accept participation without first checking with the chain management (if the village was part of a chain), or with the governing body. Despite the endorsement of the Retirement Villages Association, a pilot study, and careful explanation of the need for this methodology to village managers, we achieved random selection of residents in only 11 of 34 of the participating RVs, and even here the resident response rate was only 35%. Equally if not more importantly, we were unable to recruit residents in some RVs at all. Whilst 'scientifically' unfortunate, this should perhaps have been expected. Whilst RV residents legally retain independence and autonomy, managers, in practice, act as gatekeepers, effectively turning RVs into semi-closed communities. Others have reported similar difficulty in engaging managers with research in RV residents: indeed, receiving cooperation from only 47% of managers (15% declined, 38% did not respond). (30) Managers, not unreasonably, see themselves as preserving residents' privacy. Whilst this may in part speak to the general ethos of RVs,(18) it is also likely that managers, who have established close relationships with residents,(31) have a genuine understanding that this is what many, though surely not all, their residents expect. This is to some extent supported by available research, in which RV residents cite privacy as a positive contributor to RV environments.(32) It is unclear whether residents perceive 'privacy' as extending to limitation of autonomy, which they also cite as important (8, 13, 17), including autonomy of decision-making, and if so to what extent they are prepared to sacrifice autonomy for privacy. The limited evidence available indicates that residents recognise the need for balance between these factors.(13) Residents certainly do not wish to sacrifice friendship and neighbourhood relationships

(concepts actively promoted by RVs) for the sake of privacy.(33, 34) It is, however, recognised that the service-rich environment may inadvertently discourage social participation in some residents, including(14, 28) interactions external to the RV. Within this, one might include participation in external research activities. Others have noted that the rules and social norms within RVs may restrict both autonomy *and* privacy of residents,(35, 36) and promote social isolation.(37, 38) This issue is a difficult one but the balance potentially may alter as society increasingly expects consumers to have their autonomy facilitated. It is thus likely to be, if it is not currently, an issue which RVs themselves will have to address. There is also increased public expectation that older people have access to research studies. In the UK, for example, the Care Quality Commission, the independent regulator of England's health and social services sectors, has an expectation that LTC facilities (not RVs) will participate in research(39), and the NHS National Institute for Health Research has established a "Research Ready Care Home Network" to further facilitate residents' participation.(40)

For researchers wishing to study this population, the issue is an immediate and important one, given its implications for planning, for service provision and for equity. The challenges in obtaining a representative sample of RV residents cannot be minimised and should be considered carefully in future study design. We did, post-hoc, consider study protocol changes. Indeed, we obtained post-hoc ethical permission to contact the Retirement Village *Residents* Association, which represents individual RV residents' groups, in order to try to obtain access to some of the villages where the manager had 'declined'. This might have widened participation but, as mentioned above, members of residents' associations are unlikely to be representative of the RV population. Another possibility would be direct access to resident data via the National Census or Electoral Registration, though this poses ethical and legal issues. Further, in NZ, RVs' addresses are not easy to distinguish from standard residential addresses (or from addresses of LTC facilities). Although many organisations argued to have RV specified as a type of residence in the 2018 National Census, it was not included. If it were in the future, a census would enable the sector size and demographic characteristics of residents to be described.

The third issue potentially affecting our sample's representativeness was that NZ legislation does not allow recruitment into *observational* research studies requiring participants' active involvement, subjects who are deemed not to have capacity to consent by reason of cognitive or other impairments. There is no provision within legislation for 'assent' by family, next-of-kin or those holding a legally activated power of attorney, or for participation by proxy. Given the prevalence of dementia in the age group represented in the RV population and given that some people with dementia may lack capacity, this is a very relevant issue, even more so because cognitive impairment is likely to increase vulnerability to the adverse outcomes the current study seeks to examine and intervene to prevent or ameliorate. NZ legislation does, under some circumstances, allow recruitment of those without legal capacity into *interventional* studies which may benefit the individuals recruited. Although this was arguably the case for Phase 3 of our study, an observational element (Phase 1) was necessary before we determined eligibility for the Phase 3 subgroup. Ethical review was thus compelled by current legislation to decline to allow recruitment into Phase 1 (and thus Phase 3) of subjects without capacity to consent, and we also chose to exclude also those in whom there was *any doubt* about capacity.

NZ's National Ethics Advisory Committee is currently reviewing the ethical guidelines for both observational and interventional research, and the 2018 draft of the newly proposed standards (41) states, in relation to those without the capacity to consent to research "Where the research imposes only minimal risk, the research should have the prospect of providing benefits to the participants *or to the group to which they belong*" (our italics). Though the draft standards "support" such an approach they stress that this is incompatible with current NZ law. There would need to be a change in the law before such an approach could be implemented, and in the current study, the representative nature of our sample in terms of those with cognitive impairment is therefore imperfect. We are unable to estimate with any accuracy the degree of underrepresentation of this sub-group because, although the numbers excluded by the investigating team on these grounds were small, we have no way of estimating, the numbers of cognitively impaired residents who did not approach us or who were 'excluded' by managers. Thus, despite anticipating being able to appropriately weight the sampled residents in order to achieve statistically valid population estimates, with confidence intervals, and to be able to test differences between sub-groups at baseline, the survey results will be reported for the residents surveyed only and will not be generalizable to the whole population of RV residents.

Conclusion

Due to organizational/ managers' policy in some RVs, and to the fact that NZ legislation did not allow recruitment of those without legal capacity to consent, our sample does not fully represent the RV population in Auckland/Waitemata DHBs. Whilst the latter restriction may not apply in all jurisdictions and is outside researchers' control, future RV research should consider alternative recruitment strategies e.g. random sampling from national census, electoral roll or via residents' organizations, in order to allow 'autonomous' RV residents the ability to choose or decline participation in research.

List Of Abbreviations

retirement villages (RVs)

New Zealand (NZ)

multidisciplinary team (MDT)

Gerontology Nurse Specialist (GNS)

randomised controlled trial (RCT)

long-term care (LTC)

emergency department (ED)

Addenbrookes Cognitive Examination Revised (ACE-R)

Community Health Assessment (CHA)

Clinical Assessment Protocols (CAPS)

Minimum Data Set (MDS)

Clinical Assessment Protocols (CAPs)

Ministry of Health (MOH)

National Health Identifier (NHI)

general practitioners (GPs)

Declarations

Ethics approval and consent to participate

This study was approved by the New Zealand Health and Disability Ethics Committee (Ref 16/CEN/34). All residents provided written informed consent.

Consent for Publication

Not applicable; Authors will be happy to sign a consent form upon request.

Availability of data and material

The data used during the analysis of this study is not publically available due to our IRB policy. Reasonable requests to the corresponding author will be considered.

Competing Interests

The authors declare that they have no conflicts of interest.

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Authors Contributions

MJC led design (along with MB, JB, KB, KP and DB). MJC also obtained funding for the study, and led manuscript writing. JB developed summary of planned and actual study design table. ZW and JB were responsible for statistical analysis. MJC, MB, KB, KP, AT, C, JH and A-MH contributed to the clinical aspects of the study and to subject recruitment. All authors contributed to reading, editing and approving the final manuscript.

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Table

Table 1 Recruiting process of the retirement villages

	No. of villages
All eligible retirement villages	65
Approached	53
Survey of RV characteristics completed	34
Permitted to have a representative sample	11
Permitted to have volunteers only*	23
Declined	9
Did not reply	6
Positive response, but ran out of time	4
Not approached	12

* one village had no volunteers.

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