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Preference-Based Assessments

What Constitutes Preferred Long-Term Care Provided in Residential Aged Care Facilities? An Empirical Comparison of the Preferences of the General Population, Residents, and Family Members



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ABSTRACT

Objectives: Relatively few studies to date have examined the preferences of members of the general population as potential future consumers of long-term aged care services. This study aimed to use discrete choice experiment methodology to compare the preferences of 3 groups: the general population, residents, and family members of people living in long-term aged care.

Methods: A total of 6 salient attributes describing the physical and psychosocial care in long-term residential aged care were drawn from qualitative research with people with a lived experience of aged care and were used to develop the discrete choice experiment questionnaire. The 6 attributes included: the level of time care staff spent with residents, homeliness of shared spaces, the homeliness of their own rooms, access to outside and gardens, frequency of meaningful activities, and flexibility with care routines. The questionnaire was administered to 1243 respondents including consumers (residents [n = 126], family member carers [n = 416]), and members of the general population (n = 701).

Results: For both the general population and resident samples, having their own room feeling “home-like” exhibited the largest impact upon overall preferences. For the family member sample, care staff being able to spend enough time exhibited the largest impact. Tests of poolability indicated that the resident and general population samples estimates could be pooled. The null hypothesis of equal parameters between the groups was rejected for the family members, indicating significant differences in preferences relative to the resident and the general population samples.

Conclusions: This study illustrates that preferences for residential aged care delivery may vary depending upon perspective and experience.

Keywords: family members, general population, long-term care, preferences, quality of care, residents.

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Introduction

Residential or institutional-based care forms an important part of the long-term care for older people in most high-income countries worldwide, and its use is becoming increasingly prevalent in low- and middle-income countries.^{1,2} Long-term care can be described as the environmental support and care activities undertaken to ensure people with loss of function and capacity are able to maintain their wellbeing. This includes care provided by paid professional carers and can be provided in settings including the person’s own home, community centers, assisted living facilities, and residential aged care facilities. The term “residential long-term care” refers to such care provided within institutions such as nursing homes or residential aged care facilities.³ It is well documented that the preferences of the vast majority of older adults are to remain living independently in their own homes for as long as possible.^{4–7} Nevertheless, within current systems, there

remains a need for residential care when the person’s physical functioning or cognitive capacity declines to a level where their care needs are greater than the amount of care able to sustainably be provided to them within their homes.³ Australia has a relatively high reliance on residential aged care as part of the long-term care system, with approximately 51 beds per 1000 population aged 65 years and older, above the Organisation for Economic Co-operation and Development (OECD) average of 42.8 beds per 1000 population.⁸ Although the use of home-based care is growing, public expenditure on residential aged care still accounts for a greater proportion of social services expenditures, with expenditure on residential care more than double that of home care services in most OECD countries.³

The World Health Organization describes the first key guiding principle of long-term care for older people experiencing a significant loss of functioning as “the freedom to realize their continuing aspirations to well-being, meaning, and respect”

(1, p126). Adherence to this principle broadens the scope of long-term care from the narrow focus of meeting basic needs for survival, to incorporate wider domains including the ability for older people to contribute to their community and society, build and maintain relationships, and continue to learn and exercise their right to choice. Nevertheless, the World Health Organization also acknowledges that the type of care provided currently is often at odds with this main objective of long-term care. A lack of integration of long-term care within the community and with the healthcare sector and low priority by governments given to providing the necessary funding, oversight of the system, and regulations to drive innovation in aged care hamper efforts to achieve high-quality care. Providing high-quality care has long been an aim of health and social care sectors, but despite its ubiquity it remains difficult to reach consensus upon a definition and its determinants.⁹ Consistently, quality of care is acknowledged as a multifactorial concept, incorporating not only the technical care provided (such as effective medical treatment, or providing care that is in line with what is considered “best practice” for a clinical condition or client) but also aspects of the interpersonal care provided (including how care and information is provided to the person by the clinician and how the person is involved with decision making to ensure care provided is appropriate for their needs).

Concurrently, the sustainability of the current systems for providing long-term care is being called into question, given the growing demand for services and burgeoning government expenditures.^{1,10} The proportion of the population aged 80 years or older in 2017 in OECD countries was 4.6% and is expected to rise markedly to 10.1% by 2050.¹¹ Spending for long-term care by government and compulsory insurance schemes accounted for 1.7% of gross domestic product across OECD countries in 2017, and projections indicate that this share will need to double by 2060 to accommodate the growing number of older people living longer with increasing frailty and health conditions requiring care and support.^{2,11} To maximize the benefits of long-term care for individuals and society, it is imperative that these services are designed to meet the needs of the population and ensure that the highest quality of care is provided.

There is currently a small and emerging literature regarding the preferences of aged care facility residents and family members for care provision.¹²⁻¹⁹ Adams et al¹³ investigated the expectations of 104 residents living in skilled nursing facilities for dining practices using a standardized survey. They identified the most important factors determining satisfaction with meals were temperature of food, taste, and the level of choice over the meal. Bangarter et al^{12,14} have used the standardized Preferences for Everyday Living Inventory to undertake structured interviews with residents about their perceived choice and satisfaction across domains of living in nursing homes, including interpersonal interactions, coping strategies, personal care, and healthcare. They identified a relationship between residents having a high level of personal choice over their care in a domain and a higher level of satisfaction in the care provided in that domain. Chau et al¹⁷ reviewed the preferences of 707 community-dwelling older people and their family caregivers about when they would consider moving into a residential aged care facility. A greater proportion of older people with cognitive impairment (37.4%) disagreed with their family caregivers about when they should move into residential aged care than those without cognitive impairment (20.5%), with family caregivers more likely to prefer the older person moving into a facility than the older person themselves. Relatively few studies examining consumer preferences for aged

care services have applied discrete choice experiment (DCE) methodology, a quantitative approach grounded in random utility theory. Chester et al¹⁶ examined the preferences for psychosocial home support in early-stage dementia in 44 people with dementia and 103 carers using a DCE approach. Strong preferences were identified among family carers for support with personal feelings and concerns provided by a trained counselor at home and information on coping with dementia provided by an experienced worker at home. For people with early-stage dementia, opportunities for social and recreational activities were considered as the most important characteristics for psychosocial home support. Milte et al¹⁸ has previously identified strong preferences for psychosocial aspects of care provided within residential aged care settings among residents including those with mild to moderate cognitive impairment.

More evidence relating to the preferences of care recipients, their family member carers, and members of the general population for residential care service delivery is needed to ensure that these services are designed to best meet the needs of aging societies, now and into the future. The general population makes a substantial contribution to funding of aged care services in most countries worldwide, through government subsidies or contribution to long-term care insurance schemes, as well as forming the potential future users of the service, either for themselves or as an informal caregiver for a family member.³

The main aim of this study was to use a DCE methodology to determine the preferences of the general population and potential future consumers and the characteristics of institutional long-term care services and to compare these with the preferences of 2 groups of respondents: current residents of long-term care facilities and family member carers of current residents.

Methods

General Population Respondents

Members of the Australian general population were approached to participate in the study via an online panel company, PureProfile (www.pureprofile.com), an established organization providing online research services across several countries including Australia. PureProfile actively manages its own sample comprising 452 000 Australian panel members who are broadly representative of the Australian population in terms of age group, gender, and state of residence. The survey was offered to registered panel members aged older than 30 years. Quotas were applied to ensure the sample was representative of Australia's general population in terms of gender and state of residence.²⁰ Additionally, quotas were applied to ensure at least 300 respondents were aged older than 60 years and at least 300 were aged between 30 and 60 years. This target age range was considered most relevant by the research team because individuals in this age group were considered more likely to be beginning to engage with the sector on behalf of a spouse or an older parent or a family member requiring care or beginning to engage with the sector on their own behalf (for older respondents). The questionnaire was developed by the research team and then converted into an online survey format by PureProfile, which was reviewed and checked for completeness and readability before completion by the respondents. The questionnaire was administered to respondents in February 2015, after approval from the appropriate institutional Research Ethics Committee. The study was approved by the [Removed for Blind-] Research Ethics Committee (project number 6706).

Residents and Family Member Respondents

The general population sample was contrasted with a sample of participants recruited from 17 aged care facilities across Australia including both metropolitan and rurally located facilities.¹⁹ A total of 5 facilities were in New South Wales, 2 were in Queensland, 7 were in South Australia, and 3 were in Western Australia. A total of 13 facilities were in the major cities of Australia, whereas 4 were in inner or outer regional areas as classified according to the Australian Bureau of Statistics Australian Geography Standard Remoteness Structure.²¹ Recruitment occurred between January 2015 and February 2016. To be eligible for the study, residents needed to be a permanent resident of the facility, have been living there for at least 12 months, and have not currently receiving palliative care. Participants were approached by members of the research team to determine their eligibility to take part and undertake the process of gaining their informed consent to participate. Before recruitment, participants were screened for their cognitive function using the Psychogeriatric Assessment Scales-Cognitive Impairment Scale (PAS-CIS).²² The PAS-CIS is scored on a scale between 0 and 21, where higher scores indicate greater cognitive impairment. Residents with no or mild to moderate cognitive impairment (indicated by a PAS-CIS score of between 0 and 12) were eligible to complete the questionnaire themselves. For residents with greater cognitive impairment that precluded their completion of the questionnaire themselves, a proxy was recruited to complete the questionnaire on their behalf. A proxy was defined as a person who had a close relationship with the individual and who visited regularly and assisted with making decisions on their behalf. Usually, this person was a close family member (ie, spouse, sibling, or adult-aged child of the individual) and will be referred to as the family member sample from henceforth. Usually, participants with cognitive impairment have been explicitly (through exclusion criteria) or implicitly (through recruitment or data collection methods, eg, use of online surveys) excluded from participating in DCE studies. There have been only few studies undertaken that have explicitly included older people with cognitive impairment.¹⁸ Previous studies undertaken by us and others have identified that those with mild or moderate cognitive impairment can participate in a DCE with support provided for their participation.^{18,23} Therefore, we included those with mild and moderate cognitive impairment in our study for self-completion. Nevertheless, for those with more severe cognitive impairment who were unable to provide an informed consent and participate on their own behalf, a proxy was incorporated to provide a perspective on their behalf. People with severe cognitive impairment generally lose the ability to understand complex tasks and may lose the ability to respond directly to questions or to talk altogether.^{24,25} Therefore, it is common practice to incorporate a proxy perspective for studies involving questionnaires for participants with severe cognitive impairment. An informed consent was required before participation in the study.

Questionnaire Design

The DCE questionnaire was administered face to face via an interview with trained interviewers for residents and family members and via an online survey mode for members of the general population. For the interview, it was conducted at a time and location convenient to the participant and usually arranged in advance as an appointment. This was in a private space, away from distractions or other activities, for example, the resident's own room or a sitting room away from other people. Residents were able to have a support person with them during their participation if they chose (eg, a family member or friend). Nevertheless, that

person was advised at the outset that it was the resident's own answers to the questions that were important. The interviewers had a background in research and usually also a health discipline (eg, nursing, allied health, psychology) and were experienced in talking to people with cognitive impairment or health conditions that affected communication.

This questionnaire was completed as part of a larger-scale data collection that included collecting information on the characteristics of care they received at their facility, their health status and quality of life, and clinical and demographic characteristics. The questionnaire comprised 3 main sections. Section A comprised a series of attitudinal statements relating to service provision and characteristics of a nursing home. Respondents were asked to indicate how strongly they agreed or disagreed with each statement on a 5-point Likert scale ranging from strongly agree to strongly disagree. The attitudinal statements were drawn from previous qualitative work undertaken by the research team²⁶ and input from an expert panel of researchers and practitioners in aged care.

Section B of the questionnaire contained the DCE questions. The scenarios presented for consideration were based on 6 salient attributes identified through a previous qualitative study with people living with dementia and their family members to understand the key characteristics of a residential aged care facility that were important to them and that they felt identified a high-quality facility.²⁶ The use of qualitative research is increasingly being used to identify the most relevant attributes for inclusion in DCEs and has become the recommended best practice method for this purpose.²⁷ Additionally, the study advisory group supported the importance of using qualitative work in the design of the DCE, because they felt that this was important to promote the voice of people with a lived experience of dementia, who often are excluded from research and participation in the community more broadly. In Australia, more than 50% of aged care residents have a diagnosis of dementia. This is likely an underestimate because it is well known that diagnosis rates in older people are low.^{28,29} Only a relatively small number of people living in residential aged care (14.1%) had no or low care needs relating to cognition and behavior at aged care assessment, indicating a relatively large proportion of older residents have some symptoms of cognitive impairment.²⁸ Therefore, the study advisory group felt that the attributes identified as important to people living with dementia and their family members would be relevant to most people living in residential aged care. A systematic review of the determinants of high-quality residential aged care according to people living with dementia and their family members was also undertaken and considered by the study advisory group (unpublished).²⁷ The advisory group reviewed the qualitative study findings and found that these aligned with other frameworks for conceptualizing quality of care for older people more broadly in a variety of care settings,³⁰⁻³² including providing individualized and flexible care that treated the individual with dignity and respect and providing an environment that supported both physical and social well-being. The attributes included in the DCE were focused upon the level of time care staff spent with residents, homeliness of shared spaces, the homeliness of their own room, access to outside and gardens, frequency of meaningful activities, and flexibility with care routines (see [Appendix Table 1](#) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>). Trained interviewers explained the questionnaire and the procedure for the DCE questions to participants using standard prompts. The participants were then asked to complete a dominated choice task (where one option provided the assumed "worst" level for each attribute and one option provided the assumed "best" level of

each attribute, and thus logically participants are expected to choose the option with the presented “best” level of each attribute as a “warm-up” to the remaining DCE questions.

A total of 3 levels for each of the 6 attributes resulted in 729 possible scenarios ($= 3^6$) and a total of 265 356 possible pair wise choices ($[(729 \times 728)/2]$). Owing to the demands of the larger study, widespread piloting was not available to calculate priors for each of the subsamples, which therefore were not used to inform the design. Therefore, a D-efficient design with no previous parameter information for a main effects model with no interactions (D_2 -error, ie, zero priors assumed for all variables) was used to reduce the number of choice scenarios into a manageable number of 18 choice sets for presentation using the Ngene version 1.1.2 DCE design software package.³³ The resulting 18 scenarios were divided into 3 versions each with 6 binary choice sets presented in each version. For each choice set, respondents were asked to indicate their preferred choice between 2 hypothetical scenarios reflecting residential aged care they could receive at 2 different locations. Residential and general population respondents were asked to complete the tasks choosing the aged care facility they would prefer to live in themselves, whereas family members were asked to indicate the facility they would choose when making a decision for their family member in care. Given that the aim of the study was to determine preferred characteristics for residential care services, a “forced choice” experiment was considered appropriate and no opt-out option was provided. In Section C of the questionnaire, respondents were also requested to provide some basic demographic information about themselves including age, gender, education level, country of birth, whether they had any previous experience of or engagement with residential aged care, and the level of difficulty they had in answering the questionnaire.

Data Analysis

The data from the DCE were analyzed with a random utility theory framework. The term “Utility” in economics refers to the total satisfaction a person receives from the consumption of a good or service. The utility function can be specified as follows:

$$U_{ijt} = X'_{ijt}\beta_i + \varepsilon_{ijt},$$

where U_{ijt} is the utility individual i derived from choosing alternative j in choice scenario t , X is a vector of observed attributes (ie, the DCE attributes and corresponding levels), β is a vector of coefficients reflecting the desirability of the attributes and their levels (ie, the preferences of the individual for that attribute), and ε_{ijt} is a random error term. After estimation of the classical conditional logit model (which allows average preferences to be estimated only [ie, $\beta_i = \beta$]³⁴), the heteroscedastic conditional logit (HCL) model was applied that allowed for heterogeneity in scale function. Finally, a mixed logit model was estimated that allowed for heterogeneity in preferences by specifying β_i to follow a distribution of which the mean and SD can be estimated.³⁵ Akaike information criterion (AIC) and Bayesian information criterion (BIC) were calculated to indicate the preferred models (ie, the model with lower AIC or BIC would be preferable).

The abovementioned utility function was estimated for 3 subgroups of participants, allowing estimation of the preferences of the 3 subgroups for the attributes and their associated levels. Initially, the function was estimated for residents responding on their own behalf to the survey and for family member (proxy) respondents. The function was then estimated for the general population respondents. Effects coding was used for all attributes and levels. The mixed logit model was also estimated with the

inclusion of an alternative specific constant (ASC) (ie, a dummy variable indicating the alternative been presented on the left) to account for any effect of the presentation order of the alternatives for the participants.

The Swait-Louviere test was applied based on the conditional logit model estimates to test whether the responses from residents and the general population or family members and the general population, in turn, could be pooled, as follows.³⁶ Separate conditional logit models for residents and general population subgroups were estimated. Data for each subgroup were then combined, and pooled conditional logit and pooled HCL models were estimated. In the pooled conditional logit model, the residents' scaling factors and preference parameters were assumed to be equal to those from the general populations. The pooled HCL model was less restrictive and assumed that only preference parameters were similar. A likelihood-ratio test was then conducted by comparing the pooled HCL model with separate residents and general population samples. A second likelihood-ratio test was undertaken for the pooled conditional logit and HCL specifications. If both tests were not rejected, then we would conclude that data from both samples are the same in terms of preference and scale, making it possible to pool both groups directly. This procedure was also conducted for the family and general population samples.

All econometric analyses were undertaken using Stata version 14 (StataCorp LLC, College Station, TX) using the `clogit`, `clogitthet`, and `mixlogit` commands.³⁷ Chi-square test or analysis of variance was undertaken to test for differences in demographics among the 3 groups. The marginal utility that was gained by an improvement in an attribute was calculated as the difference between the highest and lowest estimated coefficient and is presented in the Results section.

Results

Descriptive Statistics

The survey was distributed to members of the online survey panel aged older than 30 years ($N = 1724$). The survey remained open for approximately 1 week until a total of 701 online DCE questionnaires were completed. Of this, 335 were completed by people aged older than 60 years, and 366 by people aged between 30 and 60 years. In addition, a sample of 129 residents and 416 proxies were consented to complete the survey, and of this sample, 3 residents did not complete the DCE and were excluded from this study. This resulted in a sample of 126 residents and 416 proxies included in the analysis as the comparator. The socio-demographic characteristics of respondents from the general population and the resident and proxy samples are summarized in Appendix Table 2 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>. From the general population sample, most respondents (50.4%) had either a friend or a family member who had been admitted to residential aged care, whereas 42.2% indicated they had no previous experience with nursing homes. There were significant differences among the resident, family, and general population samples for age, gender, whether respondents were born in Australia, and the difficulty of survey. As expected, the resident sample was significantly older, with a mean (\pm SD) age of 84.6 ± 9.4 years in comparison with 62.8 ± 11.2 years and 56.2 ± 13.4 years for the family and general population samples, respectively. The resident (25%) and family samples (31%) had a lower proportion of males than the general population sample (47%). Most of the respondents in all 3 samples were born in Australia, with 75% of resident, 80% of family member, and 70% of the general population samples born in Australia. The general

population had a higher proportion of respondents who reported finding no difficulty in completing the survey (68%) than the resident (39%) and family member (34%) samples. A relatively small number of participants reported that they found the questionnaire very difficult, although this was more commonly reported among the resident participants (11%) than the family (6%) and general population (2%) participants. The general population sample was representative of the Australian population in 2015 for gender and proportion born in Australia.^{38,39} Our sample had slightly more participants who lived in Victoria (29% vs 25% in general population) and in South Australia (11% vs 7.1% in the general population) and slightly less living in Western Australia (7.4% vs 10.9% in general population) and the Northern Territory (0.4% vs 1% in the general population).

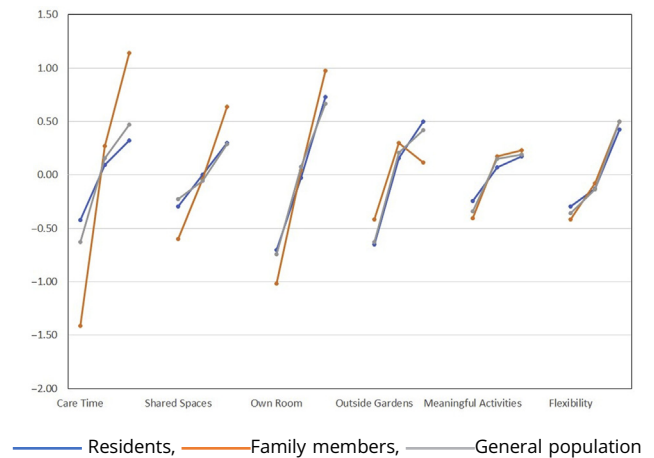
Attitudinal Questions

The vast majority of respondents (more than 80%) in all 3 samples agreed or strongly agreed with the following statements: “I would want to be able to make a room in an aged care home my own,” “It is important to me that I would be able to access therapists to provide physical exercise and keep me walking,” “It is important to me that I would have access to specialist services within the aged care home,” “Changes to my medication or healthcare should be explained to me,” and “It is important to me that I would be able to access morning or afternoon tea for myself and my family whenever I wanted.” Respondents were more divided in their responses to questions regarding whether it would be better if residential aged care homes provided care for people with dementia and without dementia separately and whether they would be willing to pay an additional \$100 000 bond upon entry to a residential care home as a consequence of a diagnosis of dementia to receive dementia specific care for a family member. Responses to the attitudinal questions can be found in [Appendix Table 3](https://doi.org/10.1016/j.jval.2021.09.001) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>.

DCE Estimates

Empirical comparisons of the conditional logit and mixed logit model estimates indicated that the latter had better model fit (as indicated by AIC and BIC) and hence are presented as the preferred results reported in [Appendix Table 4](https://doi.org/10.1016/j.jval.2021.09.001) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>. The coefficients of the mixed logit model for the 3 subgroups of interest are presented graphically in [Figure 1](#). The sign of the coefficient indicates whether the inclusion of that component would lead to an increase (positive) or decrease (negative) in respondents’ utility; that is, a positive coefficient indicates the respondents preferred more for that component, whereas a negative coefficient indicates respondents preferred less for that component. The large SDs of some attribute levels also indicate the existence of preference heterogeneity among the sample, which the mixed logit model is best placed to estimate. We also estimated the mixed logit model including ASC for scenario A (presented on the left-hand side of the choice scenarios) as a dummy variable to investigate the effect of presentation order on preferences (presented in [Appendix Table 5](https://doi.org/10.1016/j.jval.2021.09.001) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>). The ASC for scenario A was not statistically significant for the resident or family member samples, but was statistically significant for the general population sample (0.195, $P = .002$), indicating that general population members were more likely to choose the alternative presented on the left-hand side. Nevertheless, the estimates for the attributes are broadly similar between the mixed logit models estimated with and without the ASC included, and therefore, the mixed logit

Figure 1. Comparison of the coefficients estimated from the mixed logit for the 6 attributes for the resident, family member, and general population samples.



results without the ASC included were chosen to be discussed in more detail below. Conditional logit model estimates are also included in [Appendix Table 6](https://doi.org/10.1016/j.jval.2021.09.001) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>.

General Population Sample

The estimates for the levels of the attributes generally followed a logical progression (ie, a negative coefficient for the level corresponding to the assumed poorest level of care for a given attribute, progressing to a positive coefficient for the level assumed to correspond to the best level of care) for the general population sample. For the mixed logit estimates (reported in [Appendix Table 4](https://doi.org/10.1016/j.jval.2021.09.001) in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2021.09.001>), the largest impact upon preferences (ie, the largest change in utility when moving from the lowest to the highest level of an attribute) was observed in the attributes “Is your room here set up to make you feel ‘at home?’” (utility range $1.404 = 0.664 - [-0.740]$) and “Care staff are able to spend enough time to my needs” (utility range 1.099), closely followed by “Access to outside and gardens” (utility range 1.048).

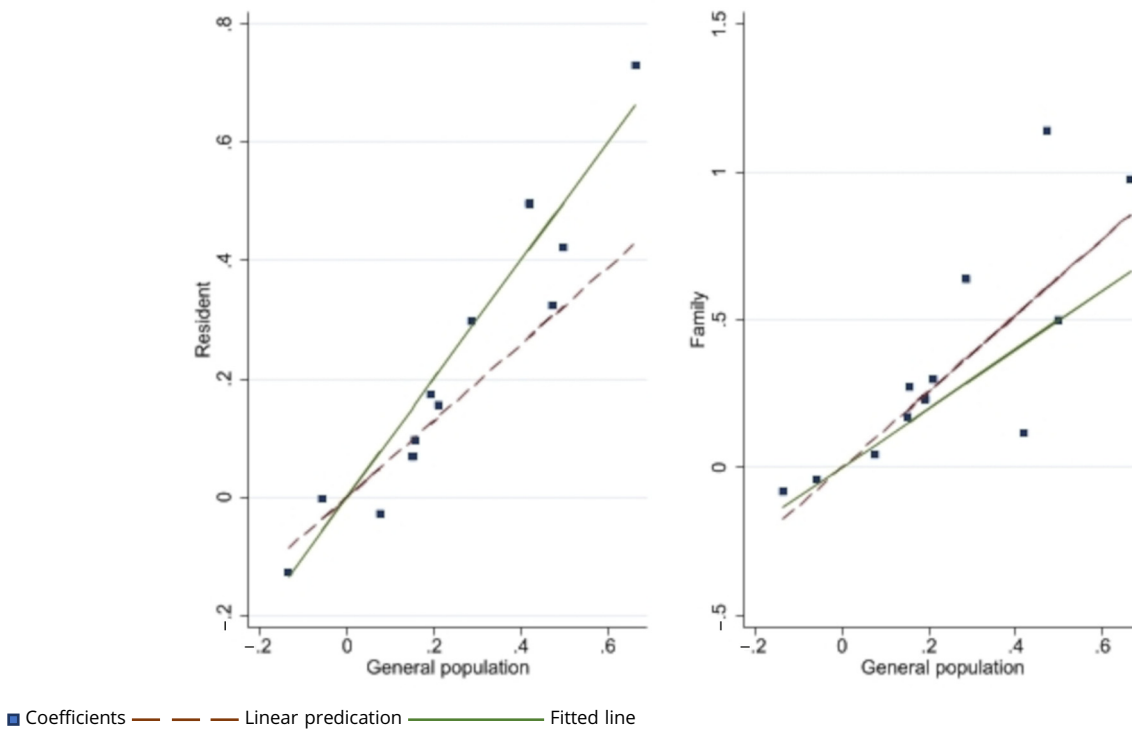
Resident Sample

Similarly, to the general population sample, the estimates for the levels of the attributes generally followed a logical progression from a negative coefficient for the assumed worst level for an attribute to a positive coefficient for the assumed best level of a given attribute. Signs (eg, positive or negative value) for the coefficients for the general population and resident samples were the same for all attribute levels excepting for the attribute “Is your own room set up to make you feel ‘at home?’”, in which the level “sometimes” was negative for the residents (-0.028) but positive for the general population sample (0.076). Similarly, the attributes with the largest impact on preferences for the resident sample were observed in the attributes “Is your own room here set up to make you feel ‘at home?’” (utility range 1.434) and “Access to outside and gardens” (utility range 1.150), followed by “Care staff are able to spend enough time to my needs” (utility range 0.744).

Family Member Sample

Contrastingly for proxy respondents in the family subgroup, the largest impact on preferences was observed in the attributes

Figure 2. Comparison of the mixed logit estimates for the resident, family and general population samples.



“Care staff are able to spend enough time to my family member’s needs” (utility range 2.555) and “Is their own room here set up to make your family member feel at home” (utility range 1.996). The family member estimates gave the only example of a logical inconsistency in the coefficients. For the family members, the coefficient for the level of “Is there access to outside and gardens in this aged care home?” for the level “always” was lower (0.116) than the value for the level of “sometimes” (0.298), although the value for “always” did not reach statistical significance. Estimates for the general population and resident samples did not display any logical inconsistencies.

Group Comparison

The results of the pooling tests for the general population compared with the residents and family members based on the mixed logit estimates are presented in Table 1. The findings of the Swait-Louviere test indicated that, for the general population and resident subgroups, the null hypothesis of equal preferences could not be rejected (chi-square 9.50; 11 df; $P = .576$). A scatter plot of the coefficients for the attributes for the residents and family members compared with those generated for the general population samples is presented in Figure 2. It can be seen that the coefficients cluster around the linear predication of equal coefficients between the 2 groups for the resident and general population samples, indicating similarity in preferences. By comparison, the coefficients for the family member and general population sample are not clustered around the linear prediction. This is supported by the findings of the Swait-Louviere test indicating that, for the family members compared with the general population, the null hypothesis of equal preferences was rejected (chi-squared 107.51; 11 df; $P \leq .001$), indicating significant differences in the preferences for these groups.

The results of the mixed logit estimates for the pooled sample of residents and the general population are presented in Table 2.

The largest impact on preferences was observed in the attributes “Is your room here set up to make you feel ‘at home?’” (utility range 1.402), “Access to outside and gardens” (utility range 1.056), and “Care staff are able to spend enough time attending to my needs” (utility range 1.034).

Discussion

There have been few studies published previously investigating preferences of the general population for how long-term care services are provided and none comparing these with the preferences of residents and their family member carers. A study of community-dwelling older people in Spain investigated individual’s preferences for aged care services in a variety of care settings.⁵ They found that most individuals preferred to receive care services in their own home if they remained predominantly healthy, whereas if they experienced a physical or cognitive limitation, most respondents preferred to receive care at a relative’s home. Nevertheless, for a significant proportion of older adults, remaining in their own home or living in a relative’s home can become unsustainable if the amount of care they require exceeds that which can practically be provided. A recent Japanese study has evaluated the preferences of members of the general population for characteristics of long-term care facilities for themselves when considering their future care needs as an 80-year-old person living with dementia.⁴⁰ They identified that respondents most highly valued scenarios where they did not have to relocate to another facility in the case their health deteriorated in the future. Respondents also valued facilities that were close to their current residence. Respondents who had a previous experience with family caregiving showed statistically significant preferences to avoid scenarios where they did not have access to individualized choice for care schedules and where they would be mostly alone

Table 1. Pooling test of resident, family, and general population based on the conditional logit estimates.

Test statistic	Residents vs general population	Family vs general population
LL (resident)	-393.768	-
LL (family)	-	-1266.676
LL (general population)	-2395.165	-2395.165
LL (pooled HCL)	-2793.68	-3715.59
df	11	11
LRT chi-square	9.50	107.51
P value	.5760	0
Number of observations	9850	13 330
Reject hypothesis of equal parameters (95% level)	Fail to reject	Yes

H1A indicates the hypothesis of Stage 1 of the Swait and Louviere test, namely the null hypothesis of equal preferences while allowing scale to vary; HCL, heteroskedastic conditional logit; LL, log-likelihood; LRT, log-likelihood-ratio test.

during the day, whereas this characteristic was not statistically significant for respondents without experience of family caregiving. In our study, care staff having enough time to spend with residents was valued by all respondents but was particularly valued by family member proxy respondents. It should be noted that members of the general population were not specifically asked to consider the care needs of a person living with dementia in our study. Nevertheless, family member proxies were asked to consider the care needs of their family member resident, who most often was living with moderate or severe dementia in the aged care facility.

Our study found significant differences between the preferences of family member carers of residents and members of the general population, despite 50% of our general population sample self-identifying as being a family member or friend of a person living in residential aged care. There are several potential reasons for this. One potential reason could be in the framing of the choice in the DCE tasks. In our study, participants from the general population and resident samples were asked to make choices considering themselves as the person needing residential aged care, whereas our family member proxy sample was asked to consider the choice on behalf of their family member in care. It may be that choosing on behalf of someone else initiates differences in cognitive processes that result in different preferences compared with choosing for yourself. Rabin⁴¹ highlighted the fallacy in the assumption of a coherent and stable concept of utility that is accessible to individuals when making decisions, and it is likely that the difficulties become even greater when making decisions on behalf of someone else. For example, a person may be less likely to accept risk or negative attributes on behalf of someone else, whereas when choosing for oneself a person may minimize the risk or accept a level of risk to achieve an outcome they desire.

Evidence evaluating the impact of status as a self or proxy decision maker on decisions has been mixed, particularly where decisions involve a potential risk. For example, some studies have shown that people are more willing to recommend risk taking behaviors to others (eg, in romantic relationships⁴²⁻⁴⁴) than to undertake them themselves. Others have identified few or no

differences in decision making regarding risk for others versus for individuals⁴⁴ or have found people to be more risk averse when making decisions for others (eg, for financial⁴⁵ or medical decisions⁴⁶). Several theories have been proposed as to why these differences occur, including the extent to which individuals consider all the relevant information when making a decision for themselves (and consider only partial information when deciding for others)⁴⁷ or the “risk as feelings hypothesis,” which proposed that people make risky decisions based on how much positive or negative emotion the risky option induces in them.⁴⁸

More recently, Stone and Allgaier⁴² have developed the concept of a Social Values Theory to explain these differences. They propose that when making a decision for another person, the decision maker does not rationally weigh all the pros and cons for a decision as we may expect them to, but rather makes a decision in line with their understanding (perhaps even subconsciously) of social norms around that decision. In further exploring this idea, Stone et al⁴⁹ compared the decision making of participants when asked to make a decision involving a physical health risk (where risk taking is generally disapproved of by society) and romantic risks (where taking of risks is generally promoted by society and a means to achieve your goal). For situations involving physical health risks, the participants were less willing to risk physical harm for others, but were more willing to accept a physical health risk to achieve an outcome they desired when making decisions for themselves. For romantic risks, the results reversed with participants more willing to recommend taking a risk to others than for themselves. Similarly, when evaluating decision making in doctors, Garcia-Retamero and Galesic⁵⁰ found that they were more likely to select a less risky medical treatment (where a chance of recovery was 100% after a period ranging from 1 to 7 weeks), even if they accurately predicted that a patient would opt for a riskier medical treatment (where they faced a 50% chance of immediate recovery and a 50% chance of severe disease for 7 months or even death). Stone and Allgaier⁴² suggest that this finding can be explained by Social Values Theory, given that societal expectations for doctors are that they minimize risk in their work.

Social Values Theory could also explain the findings in our study. Family members in our study were asked to answer on behalf of a person with dementia, and therefore, while acting in a caregiver role, they may give more weight to a societal expectation that they should protect the physical health of the individual than any knowledge about other goals and expectations of the person they care for (eg, their desire for freedom or autonomy). This may influence them to make a decision in line with reducing physical risks to the individual as the primary goal rather than weighing all of the potential pros and cons of the decision they are making in a broader sense.

Alternatively, in our study, family members were asked to respond on behalf of residents with more severe cognitive impairment, and therefore, the difference in preferences may reflect a difference in the type of care needed for this group. It may be that it is particularly difficult for members of the general population to consider the type of care that people with cognitive impairment would need, highlighting the importance of involving those with a lived experience of these conditions in planning and evaluating health and social care services. Previous studies have identified differences in preferences of older people or those with dementia and family members. Chau et al¹⁷ identified family carers were significantly more likely to show a preference for the use of residential aged care than older people and that this difference was more likely in older people with cognitive impairment (37.4% of dyads disagreed) than those without cognitive impairment (20.5% of dyads disagreed; $P < .001$). Chester et al¹⁶

Table 2. Results of the pooled mixed logit for residents and general population.

Variables	Coef.	SE	P > z	SD	SE
How much time are care staff able to spend with me?*					
Rarely	-0.588	(0.053)	.000	-	-
Sometimes	0.142	(0.036)	.000	0.237 [†]	(0.096)
Always	0.446	(0.048)	.000	0.554 [‡]	(0.070)
Do the shared spaces of the aged care home as a whole make you feel "at home?"*					
Rarely	-0.237	(0.042)	.000	-	-
Sometimes	-0.049	(0.036)	.184	0.239 [†]	(0.112)
Always	0.286	(0.033)	.000	-0.122	(0.170)
Is your own room here set up to make you feel "at home?"*					
Rarely	-0.730	(0.060)	.000	-	-
Sometimes	0.058	(0.033)	.083	0.060	(0.173)
Always	0.672	(0.056)	.000	0.432 [‡]	(0.073)
Is there access to outside and gardens in this aged care home?					
Rarely	-0.627	(0.052)	.000	-	-
Sometimes	0.198	(0.046)	.000	0.003	(0.130)
Always	0.429	(0.046)	.000	0.364 [‡]	(0.070)
How often does the aged care home offer me things to do that make me feel valued?*					
Rarely	-0.325	(0.041)	.000	-	-
Sometimes	0.137	(0.040)	.001	0.178	(0.128)
Always	0.188	(0.038)	.000	0.129	(0.152)
How flexible is the aged care home with the care routines?					
Not much	-0.345	(0.043)	.000	-	-
A little	-0.134	(0.036)	.000	0.278 [‡]	(0.090)
Very	0.479	(0.047)	.000	0.354 [‡]	(0.074)
Observations	9850				
Log-likelihood	-2763.054				
AIC	5574.109				
BIC	5746.794				

Note. Robust SEs in brackets.

AIC indicates Akaike information criterion; BIC, Bayesian information criterion; Coef., coefficient; SE, standard error.

*Wording for these attributes was slightly adjusted for the family member samples.

[†]P < .05.

[‡]P ≤ .01.

evaluated preferences for a home support package in early-stage dementia and identified that for people with dementia social and recreational activities were considered the most important support to provide whereas family member carers showed a greater preference for support with personal feelings and concerns and information on coping with dementia.

The findings of this study and previous work provide evidence that proxies may not provide the response that the individual would provide if asked themselves and that this difference may not occur at random but is caused by systematic differences in how an individual responds when asked to act as a proxy. It is important to consider this in survey research when asking proxies to participate on behalf of an individual. From the evidence currently available, it seems that different relationships with the individual the decision is being made on behalf of,⁵¹ professional backgrounds,⁴⁵ mood of the decision maker,⁵² level of contact with the individual, or characteristics of the individual themselves¹⁷ may influence the extent of agreement between the proxy

and the individual but this has not been extensively researched in the context of preferences for residential aged care.⁵¹ Further research is needed to investigate these concepts, given that the use of proxies to make decisions for older people with cognitive impairment not only occurs in research but also is common in society more generally. For example, where a person is permanently or temporarily incapacitated often another person (eg, a close family member or court appointed legal guardian or enduring power of attorney) will be called upon to make decisions for that individual on matters of health and social care received or management of finances. For the current research context, the use of proxies can be considered as an additional perspective but not a direct replacement for the response of the individual.

The results of the mixed logit model estimated with the a ASC as a dummy variable also indicated that respondents in the general population sample were more likely to choose the alternative presented on the left-hand side of the choice set. This could indicate that members of the general population sample were not

engaged with the task and were taking “shortcuts” to complete the questionnaire or that they did not have a clear preference between the 2 alternatives presented. We did not find evidence of this effect in the family member and resident samples. This indicates that these samples were perhaps more engaged in the task, more likely to have clear preferences for provision of residential aged care, or more likely to weigh up both potential scenarios in their choices. Greater efforts should be made to directly seek the voice of the individuals most affected by a health or social care service in research rather than relying on proxy respondents.

This study found that the attributes presented (care staff spending adequate time, home-like nature of shared spaces, home-like nature of their own room, access to outside and garden spaces, access to meaningful activities, and flexibility in care routines) were all highly important determinants of preferences for aged care homes in the general population. These attributes provide potential target points for decision makers and the long-term care industry to focus on for improvement to meet consumer expectations. Nevertheless, making meaningful change to care systems to provide care that meets these preferences is not a straightforward proposition in a large and complex sector such as long-term care.⁵³ The extent to which residential aged care homes are currently providing care that meets the preferences set out in this study is not clear. To date, quality assessment processes for the sector have typically focused on the evaluation of the processes for continuous improvement at the facility or meeting standards for clinical care outcomes, such as incidence of medication errors or pressure ulcers.² Information from reports of residents and their family members in qualitative studies indicates a wide variation in practices of flexibility in care, adequacy of time staff spend with residents undertaking care activities, access to outside and gardens, and meaningful activities.^{30,54,55} What little information we have about facility performance on these aspects of care that are of critical importance to residents, family members, and members of the general population is concerning. In a 2018 study of residential aged care facilities in Australia, only 42% of residents in standard (large scale) models of residential aged care indicated they had a high level of access to outside and gardens.⁵⁶ In contrast, almost 78% of residents in a clustered (small scale) domestic model of residential aged care, which was specifically designed to support people living with dementia, had a high level of access to outside and gardens. Similarly, respondents felt the flexibility of the care routines was significantly better in the clustered domestic model (85% responding the care routines were very flexible) than the standard model of residential care (52% responding the care routines were flexible).

There is now significant evidence in the quantitative and qualitative literature around the aspects of residential aged care that need to be improved to meet the expectations of residents, their family members, and society in general.⁵⁷⁻⁵⁹ In addition, there is growing evidence that we can improve the care provided to residents by using targeted interventions and using innovative models of care that acknowledge the psychosocial and environmental aspects of care provided, in addition to the medical care and support for activities of daily living that are provided in long-term care facilities. It is critical that we act to improve the care provided for some of our most vulnerable citizens.

There are some limitations to the study design that should be considered. This was a study of the preferences for residential aged care at a single point in time; the extent to which these preferences may fluctuate over time or whether they reflect choices made in real-life situations (ie, revealed preferences) is currently unknown. Second, there are several other factors that may influence an individual to choose one care provider over

another that were not included in this study: for example, locality of the facility, cost, word of mouth, or presence of friends or other family members in a facility. In practice, often people are entering residential aged care at a time of crisis and waiting lists mean that people are often waiting for a place in aged care services for some time and there is pressure to take a place once it is available.⁶⁰ Future studies may identify other aspects of care that are important for consumers in the choice of a residential long-term care home. The general population survey was conducted online using a sample accessed from a commercial survey platform and therefore represents the views of those people most likely to be engaging with a survey platform (eg, they may be younger, more technologically literate, and in better physical health with less disability). Nevertheless, quotas were applied to ensure a significant proportion of older people were represented in our general population sample and the survey panel is large and broadly representative of the general population in terms of gender and whether participants were born in Australia. There were some small differences between the proportion of our sample living in a few states of Australia and the general population data available from the Australian Bureau of Statistics; nevertheless, we do not believe that these small differences would have a major impact of the findings. We also identified evidence of ordering effects in the presentation of the DCE scenarios for the general population sample, but not for the resident or family member samples. The method of administration (via an online survey) could have had an impact on this finding. Alternative methods of recruitment for the general population other than a self-selected participant (eg, using a probability-based sample to select participants from the general population) or changes in the administration (eg, randomizing the presentation order of the alternatives or considering face-to-face administration as appropriate) may help to reduce this effect. Given that this study was undertaken as part of a larger project, we were only able to include a limited number of attributes in our DCE that focused on physical and psychosocial aspects of care provided in a residential aged care facility. Whether these results would be replicated when considering other aspects of care provided in aged care is not known.

To promote greater measurement and reporting of improved care practices of value to consumers, an instrument has been developed to measure the extent to which residential aged care homes are delivering care in line with the preferences of residents and their family members, the Consumer Choice Index-Six Dimension.⁶¹ Evaluating the extent to which residential aged care homes are providing care that meets these expectations is an important first step to enable the development of targeted strategies to improve long-term care services in a way that makes a meaningful difference to people accessing these services now and into the future.

Supplemental Material

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.jval.2021.09.001>.

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