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The Change in Nursing Home Residents' Preferences over Time

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Abstract

Objectives: Nursing home (NH) residents' preferences for everyday living are the foundation for delivering individualized person-centered care. Yet, work has not examined what the most and least important preferences of nursing home residents are and if those preferences change over time.

Design: This study examined the change in ($n=255$) nursing home residents' preferences for everyday living over a 3-month period. Participants were recruited from 28 NHs in the suburbs of a major metropolitan East Coast area of the United States.

Measures: Residents were interviewed face-to-face using the Preferences for Everyday Living Inventory-Nursing Home version at baseline (T1) and three-months later (T2). Change was analyzed in two ways: (1) percent exact agreement (e.g., respondent stated "very important" at both time points) and (2) percent of preferences that remained either important or not important between T1 and T2.

Results: Sixteen preferences were rated as very or somewhat important by 90% or more of NH residents. With regards to the stability of preference ratings, findings demonstrate an average exact agreement of 59%, and an average important versus not important agreement of 82%. In addition, 68 of the 72 preferences had 70% or higher stability over time. In other words, the preference either remained "important" or "not important" to the NH resident three months later. Preferences in the domain of enlisting others in care had the least amount of change.

Conclusion/Implications: This study highlights the most important everyday living preferences of NH residents' and provides assurance to care providers that the majority of preferences assessed via the PELI are both important to NH residents and stable over time.

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Preference-based care plans can be designed and utilized over a 3-month period with confidence by providers.

Keywords

person-centered care; everyday preferences; nursing home residents

Introduction

Person-centered care (PCC) is a concept that developed out of the nursing home culture change movement¹ and emphasizes the need to “elicit” an individuals’ preferences in order to “know the person” and provide tailored care to meet his or her holistic goals.² The Centers for Medicare and Medicaid Services (CMS) states in its Person and Family Engagement Strategy³ that consumers should share preferences with providers. One way of learning about a person is to have her rate her preferences for everyday living and provides the foundation for ongoing individualized care planning.

Evidence suggests that individualized care is an important element in quality of life models and results in enhanced physical and subjective well-being.^{4–7} Studies examining the integration of knowledge of individual psychosocial preferences (i.e., expression of how one would like his or her needs met) into care are related to improved decision making⁸, enhanced quality of care outcomes^{9–10}, increased satisfaction with care¹¹, and positive quality of life.^{12–15} However, provider communities often struggle to implement person centered care practices that consistently use individualized care plans based on resident preferences.¹⁶

One critical barrier to adopting and integrating preferences fully into care is a lack of understanding of how much fluctuation there is in an individual’s preference ratings over time. Practitioners, in particular, lack the knowledge of how frequently they need to assess preferences to maintain individualized care over time (i.e., at move in/admission, quarterly, annually). As a result, this study examines the change in nursing home residents’ importance ratings of everyday living preferences over time.

Conceptual Framework

At their core, preferences reflect how an individual would like his/her needs to be met. A need represents something without which an individual’s capacity for healthy functioning is diminished. Maslow famously proposed that humans have five hierarchical levels of need: physiological, safety, belongingness and love, esteem, and self-actualization needs.¹⁷ Focusing more narrowly on psychological needs, Deci and Ryan’s Self-Determination Theory specifies three innate needs for well-being: autonomy, competence, and relatedness.¹⁸ Conditions that support the fulfillment of these needs promote well-being, whereas conditions that thwart need fulfillment compromise well-being.^{18–19} We conceptualize preferences as one way nursing home residents can express self-determination. For example, understanding what a person wishes to eat or how they want to bathe is reflective of autonomy. Competence can be expressed through the modification of an activity so an individual with limitations can still engage in that preference. Finally, the preferences for

how and with whom someone wishes to spend their time contributes to relatedness. Honoring these preferences in care creates an environment within which a person's well-being can be maximized.

Preference Importance and Preferences over time

Prior work has explored the overlap in important preferences among nursing home residents and home health clients.²⁰ Ten preferences were found to be shared by these two populations including items ranging from regular contact with family to listening to music. Recommendations for incorporating these ten preferences at the organizational level were provided. However, the authors were limited in their ability to examine a full range of preferences across settings as some of the questions were setting specific, such as keeping your room at a certain temperature (only asked in the NH context).²⁰ Understanding which preferences for everyday living are most important in the NH context can inform care delivery specific to this population.

In addition, preferences can fluctuate based upon one's environmental context and personal experiences. As circumstances shift, so too may one's needs and expression for how one would like to have his/her needs met.²¹ This potential change in preference expression may impact providers' ability to deliver preference-based person-centered care. Initial empirical work has sought to understand the consistency of individuals' preferences over short periods of time. Cognitively capable NH residents who were asked to rate their preferences via the *Preferences for Everyday Living Inventory* at baseline and one-week later demonstrated that preference ratings are relatively consistent and that consistency is related to the type of preference.²² For example, preferences related to personal care were more consistent over one-week than preferences related to leisure activities.²² Additional work looking at care values finds similar consistency in the short-term (1 week) for individuals with mild to moderate dementia.^{23–24}

However, limited work has explored if the most important preferences reported by NH residents change or remain stable over longer periods of time^{25–26}; there is only some evidence exploring the stability of end of life preferences for older adults.²⁷ Theory indicates that preferences may change as one's vulnerability or closeness to death approaches²⁸ and qualitative evidence indicates that residents may encounter a series of dependencies in care that influence their reported levels of importance at a given point in time.²¹ As a result, further exploration of this gap in understanding is needed.

Current Study

Given that in United States' NHs, preference assessment has been incorporated into the Minimum Data Set (MDS 3.0; Section F) upon admission and annually thereafter²⁹, it is crucial to understand which everyday preferences are the most important to NH residents and to determine if they change or remain stable over time. This knowledge will refine our understanding of how often preferences should be assessed and maximize positive outcomes associated with the delivery of preference-based care. The purpose of this study therefore was to present a ranking of important preferences and to examine the change in nursing home residents' reports of importance for 72 preferences for everyday living over a 3-month

period. Because prior work indicates consistency of important preference ratings over one-week²², we hypothesize that preference importance is likely to also remain stable over a three month time period, particularly for preferences rated as highly important for NH residents.

Methods

Participants and Procedures

Participants were recruited from 28 NHs in the suburbs of a major metropolitan East Coast area of the United States. Facility staff from each NH identified residents who would enjoy participating in an interview about their likes and dislikes, were English speaking, and had a length of stay of at least one week and an expected stay of at least 3 months. The attending physician or director of nursing at each facility verified that the residents were medically stable and had the cognitive capacity to consent for themselves or had a family member that could consent for them; 575 of the 581 residents identified by facility staff were deemed medically stable. Of the recruited participants 255 provided consent, passed a cognitive screen, and participated in two waves of data collection, at baseline (T1) and three-months later (T2).

Consent was obtained using simplified language and interactive questioning to ensure comprehension. Upon consent, a research assistant administered the Mini-Mental State Examination³⁰ to confirm that the resident had a minimal level of cognitive ability (MMSE score = 13). Participants completed the Preferences for Everyday Living Inventory-Nursing Home (PELI-NH) assessment.³¹ Three months later (T2), the process was repeated, re-confirming medical stability of residents, obtaining consent, and administering the interview. Comprehensive and quarterly Minimum Data Set (MDS) 3.0 data were collected for dates aligning with the T1 and T2 interviews for each resident. Our attrition rate from T1 to T2 was 25.4% which was due to death, transfer, change in cognitive ability, withdrawal, or change in medical stability over the 3 months. See Figure 1 for a flow diagram outlining these procedures.

IRB approval was provided by the Madlyn and Leonard Abramson Center for Jewish Life Institutional Review Board (*Assessing preferences for everyday living in the nursing home: Reliability and concordance issues*; IRB Protocol #: 120901). The authors report no conflicts of interest.

Measures

Demographics.

Medicare and/or Medicaid certified NHs routinely provide comprehensive clinical assessments of residents' functional capabilities in the MDS 3.0.²⁹ Chart data from residents' most recent comprehensive and quarterly assessments were extracted from medical records based on the date of T1 interview completion. Data included age, gender, education (1 = *no schooling* to 8 = *graduate school*), length of stay in the nursing home (in days), marital status, race, and reports of activities of daily living as an indicator of functional ability.

Preference Importance Ratings.

Residents completed the Preferences for Everyday Living Inventory-Nursing Home version (PELI-NH) at T1 and T2.³¹⁻³² Questions covered everyday topics from leisure pursuits to personal care preferences that fell into five conceptual domains: self-dominion/autonomy in care (e.g., taking care of personal belongings), enlisting others in care (e.g., be involved in discussions about your care), leisure and diversionary activities (e.g., watching TV, doing outdoor tasks), social contact (e.g., having regular contact with friends), and growth activities (e.g., keeping up with the news).³³ Residents rated the importance of their preferences from 1 (*very important*) to 4 (*not important at all*).

Analyses

First we calculated the percentage of residents who endorsed each preference as very or somewhat important and ranked them in order from most to least important within the sample. Second, we sought to understand if nursing home resident ratings of preference importance for everyday living change over time. To address the second component of our research question we analyzed change in two ways. First, percent exact agreement and second, percent important versus not important. We calculated percent exact agreement between T1 and T2 for each PELI item. Exact agreement was defined as the resident reporting the exact same level of importance level to the preference question at T1 and T2. For example, a participant rated a preference as *very important* at T1 and also indicated that the preference was *very important* at T2.

Second, because the ultimate goal is to use the PELI to tailor care for frail older adults, in line with prior work, change was examined through a more clinical lens.²² Change was considered evident if a respondent reported a preference as either *very or somewhat important*, in contrast to reporting a preference as *not very or not at all important*. From a measurement perspective, those individuals who only changed one point over the 3 months—going from 1 (*very important*) to 2 (*somewhat important*) or vice versa (2 to 1) in rating preference importance—were not changing their importance rating. These individuals reported that a preference was *important*, but simply shifted slightly in level of that importance. The same was true regarding reports of *not very or not at all important*. These individuals were stable in reporting that a preference was *not important*, but simply shifted in degree of unimportance. However, if for example the response at T1 was *somewhat important* and the response at T2 was *not very important* this was considered a change because the response switched from the *important* side of the scale to the *not important* side of the scale.

Results

Participating residents were predominately widowed (44.3%) non-Hispanic Caucasian (76.9%) females (67.8%) with a high school education (48.2%) and a mean age of 81 years ($SD = 11.2$). Their mean MMSE score at T1 was 24.6 ($SD = 3.9$) and their average length of stay was 923.6 days ($SD = 900.9$). Participants scored an average of 21.91 ($SD = 8.25$) for ADL limitations, an expected level of impairment due to the clinical nature of the NH

sample. Participants completing both T1 and T2 were not significantly different than those that only completed T1 on age, race, education, or length of stay.

Sixteen preferences were endorsed by 90% or more of NH residents as very or somewhat important. These preferences fell into the domains of self-dominion ($n = 9$ preferences), enlisting others in care ($n = 4$ preferences), growth activities ($n = 2$ preferences), and social contact ($n = 1$ preference). Preferences included in the self-dominion domain relate to the resident's ability to express autonomy and include: taking care of personal belongings or things, doing what helps you feel better when upset, keeping your room at a certain temperature, choosing how to care for your mouth, choosing how often to bathe, taking care of the place you live, choosing how to care for your hair, choosing what to eat, and setting up your bed for comfort. Four of the preferences are a part of the enlisting others in care domain and include having staff show you respect, having staff show they care about you, choosing who you would like involved in discussions about your care, and choosing your own medical care professional. Growth activities of keeping up with the news and doing your favorite hobbies along with the social contact preference of having regular contact with family were included as preferences rated as important by 90% or more of NH residents. Table 1 presents findings of the percent of participants rating each preference as either very or somewhat important at T1.

In addition, Table 1 presents the N and percentages of subjects having perfect and important versus not-important agreements between their T1 and T2 responses. Across the 72 PELI items the average score for exact agreement (e.g., responding *very important* at both time points) was 58.55% ($SD = 8.7$) with a range between 41% and 84% (see Table 1). The % *Agreement Important or Not Important* column in Table 1 provides a clinically meaningful picture of change. The average score for important versus not important agreement was 81.68% ($SD = 6.8$) with a range between 68% and 95% (see Table 1). In addition, we see 68 of the 72 preferences over three months with stable ratings of 70% or higher. The preference for having regular contact with family was the most stable while being a member of a club changed the most.

When we explore stability by level of importance within the sample and by PELI domain, we find additional insights. For the 16 preferences that are rated as most important within this NH sample, we see particularly high levels of stability on all these items, i.e., greater than 85% stability based on importance versus not importance ratings. In addition, by domain, enlisting others in care has the highest stability with an average of 62% exact agreement and 85% important/not important agreement (see items in Table 1 noted with EC). The items making up the domain of self-dominion had an average of 60% exact agreement and 83% important/not important agreement. Similarly, the domain of growth activities had an average of 59% exact agreement and 83% important/not important agreement. Items making up the social contact domain follows with an average of 57% exact agreement and 81% important/not important. Finally, the leisure and diversionary activities domain items averaged 55% exact agreement and 78% important/not important agreement.

Discussion

Efforts for assessing the delivery of person-centered, preference-based care are expanding. This has resulted in a need for building our understanding of important preferences and the stability or change in preference ratings over time to inform care planning practices in NHs. This study examined the importance and the change in nursing home resident ratings of 72 everyday preferences across three months. We found 16 preferences that were important to 90% or more of NH residents and 50 preferences endorsed as important to 70% or more residents. Only six preferences were endorsed as important to less than 50% of residents. In addition, we see very little change in importance ratings using an important vs. not important definition, particularly for preferences rated of high levels of importance by the sample. Results reveal that nursing home residents who report an important preference at baseline are considerably likely to report it as important three months later. This finding carries implications for research and practice.

One central finding is that the majority preferences in the PELI are endorsed as important to NH residents. We recommend that providers seeking ways to move towards preference based, person-centered care examine the range of PELI items and select a subset of items as a focus for clinical activities. Providers do not have to use all 72 items from the PELI as each item has been tested as a stand-alone item.³² From a quality improvement perspective, providers could start with a small set of items and add or replace items as they build capacity within their organizations. Selecting from the 16-items endorsed as important to 90% or more of NH residents found in this study would be an excellent starting point.

In addition, we found relatively low levels of change in importance ratings for preferences in care over a 3-month period for NH residents, particularly for those items that were endorsed as most important within the sample. This finding of overall stability of preference importance ratings is helpful for providers as care planning typically occurs every quarter (3 months) for the vast majority of residents. The lack of change in preference importance suggests that organizational efforts to invest staff time to assess resident preferences in care is meaningful, as important preferences are mostly stable over 3-months; reassessment would not necessarily need to occur each quarter. For the vast majority of preferences, care plans formed initially will remain reflective of authentic resident wishes for care between quarterly care planning sessions. These findings also parallel earlier work using a one-week test-retest period showing that the majority of preference importance ratings remain consistent.²² In addition, when viewing the PELI items grouped by domain, we find that enlisting others in care is the most stable domain. This is a positive finding because efforts to assess and integrate preferences for personal care upon moving into a community will help staff to 'get off on the right foot' with a resident by providing preferred care at the beginning of his/her stay.

In terms of measurement, our take home message is that the PELI is a reliable measure that can be used to capture a NH resident's important preferences and when someone changes his/her mind about a preference, this should not be equated to measurement error. The change in a reported preference from either important to not important or not important to important is an accurate reflection that the individual's authentic preference is changing.

Limitations and Next Steps

While this study is strengthened by its use of repeated measures analyses of a unique clinical population of individuals living in NHs, it is not without limitations. The sample of NH residents included Caucasian and African-American participants in the United States and was not representative of other racial or ethnic groups. Furthermore, these analyses only examine stability across 3-months, the vulnerability of a NH population makes longer-term follow-up on preferences ratings difficult. Next steps could involve preference assessments in assisted living or adult day settings, or other less intensive long-term care settings to see if similar patterns of findings exist over 3-months and over longer timeframes. In addition, this study did not explore how clinical attributes of residents may impact preference ratings over time. Work should consider the impact of environmental and other factors (i.e., clinical characteristics of the individual, complexity of the decision task, the equality of options, how a preference is elicited, or how options are presented) on individuals' stability of preference importance ratings over time.^{34–36}

Conclusion

Overall, this study expands our knowledge about the assessment of importance ratings of everyday preferences for nursing home residents. Providers can select from among the PELI items and be confident that they are measuring preferences important to NH residents. While we know preferences can and do change due to individuals' situational context²¹, we find overall everyday preferences to be stable across 3-months. These findings provide assurance to care providers that they can design preference-based care plans with confidence without having to frequently re-assess preference importance for most preferences. This work provides direction for future research and is critical in advancing our understanding of the assessment of preferences as a cornerstone to the delivery of person-centered care in nursing homes.

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Figure 1.
 Flow Diagram for Study Enrollment and Follow-up.

Table 1.

Agreement of preference responses over a 3-month period examined via exact agreement and sorted by percent agreement of important or not important (high to low).

Preference Domain	Preference	Total N	% Rating Very or Somewhat Important	% Exact Agreement		% Agreement of Important or Not Important	
				%	N	%	N
EC	Have staff show you respect	254	96.50	77.95	198	93.7	238
SD	Take care of your personal belongings or things	255	95.70	74.90	191	94.51	241
EC	Have staff show they care about you	250	95.20	68.80	172	92.0	230
SC	Have regular contact with family	252	93.30	84.00	210	94.8	237
SD	Do what helps you feel better when you are upset	245	93.20	68.98	169	89.39	219
EC	Choose who you would like involved in discussions about your care	254	92.90	66.93	170	89.37	227
SD	Keep your room at a certain temperature	254	92.90	62.60	159	88.98	226
EC	Choose your medical care professional	255	92.20	69.41	177	90.59	231
SD	Choose how to care for your mouth	253	92.10	73.91	187	91.3	231
SD	Choose how often to bathe	253	91.70	66.01	167	89.72	227
SD	Take care of the place you live	253	91.00	68.38	173	88.93	225
GA	Keep up with the news	253	91.00	69.57	176	88.93	225
SD	Choose how to care for your hair	253	90.60	65.22	165	87.75	222
SD	Choose what to eat	254	90.60	66.14	168	85.04	216
SD	Set up your bed for comfort	252	90.50	57.94	146	85.71	216
GA	Do your favorite hobbies	244	90.00	59.02	144	86.07	210
GA	Learn about topics that interest you	253	89.80	66.40	168	88.54	224

Preference Domain	Preference	Total N	% Rating Very or Somewhat Important	% Exact Agreement		% Agreement of Important or Not Important	
				%	N	%	N
LD	Do your favorite activities	248	89.20	62.50	155	86.29	214
SC	Have regular contact with friends	255	89.00	54.90	140	86.27	220
LD	Listen to music you like	253	89.00	68.77	174	86.17	218
SD	Choose between a tub bath, shower, bed bath, or sponge bath	254	88.60	61.81	157	83.83	213
EC	That your daily caregiver knows your needs when going to the bathroom	252	87.40	60.71	153	86.9	219
SD	Adjust the lighting in your room	255	86.70	50.20	128	79.61	203
LD	Watch or listen to TV	252	85.80	67.46	170	87.7	221
SD	Choose your own bedtime	255	85.50	60.78	155	83.14	212
SD	Have privacy	254	85.10	65.35	166	85.04	216
GA	Have reading materials available to you	210	83.50	61.43	129	87.14	183
SC	Spend time one-on-one with someone	255	83.50	49.02	125	77.65	198
SC	Go outside to get fresh air when the weather is good	253	82.40	66.40	168	86.96	220
SD	Follow a routine when you wake up in the morning	254	82.30	52.36	133	77.17	196
SD	Set up your room the way you want	255	82.00	61.18	99	80.78	206
SC	Spend time by yourself	255	82.00	60.00	153	77.25	197
SC	Reminisce about the past	254	80.70	53.15	135	82.28	209
SD	Choose what clothes to wear	255	80.40	60.00	153	83.14	212
SC	Give gifts	253	80.30	54.15	137	78.26	198
SD	Choose when to get up in the morning	254	79.90	51.97	132	80.71	205
GA	Exercise	253	79.60	56.52	143	84.98	215

Preference Domain	Preference	Total N	% Rating Very or Somewhat Important	% Exact Agreement		% Agreement of Important or Not Important	
				%	N	%	N
SD	Choose how often to care for your nails	255	79.20	50.59	129	82.35	210
SD	Lock things up to keep them safe	254	79.10	66.54	169	85.04	216
SD	Choose what time of day to bathe	254	79.10	55.91	142	79.13	201
SD	Follow a routine when you go to bed	255	78.80	56.47	144	80.78	206
LD	Attend entertainment events	253	78.80	50.99	129	78.66	199
SC	Be around children	255	78.40	60.39	154	81.18	207
SC	Participate in religious services or practices	253	77.60	64.03	162	81.82	207
SD	Be able to use the phone in private	253	76.50	57.71	146	79.05	200
LD	Do things away from here	254	76.50	48.03	122	76.38	194
SC	Be involved in choosing your roommate	174	75.70	54.60	95	81.61	142
SC	Volunteer your time	254	75.30	52.36	133	80.31	204
SC	Meet new people	255	71.40	53.73	137	80.39	205
SD	Choose where to eat	253	70.40	50.59	128	73.12	185
EC	Choose what name you would like me to use when I greet you	254	68.10	50.79	129	72.83	185
GA	Play games	253	67.50	49.01	124	77.08	195
SD	Choose when to eat	254	67.30	41.34	105	67.72	172
SC	Do things with groups of people	255	66.70	49.02	125	72.55	185
GA	Go shopping	254	66.30	52.76	134	75.59	192
GA	Participate in your cultural traditions	254	64.60	50.79	129	72.83	185
SD	Take a nap when you wish	254	63.00	48.03	122	71.65	182
LD	Have snacks available between meals	255	62.40	50.20	128	77.25	197

Preference Domain	Preference	Total N	% Rating Very or Somewhat Important	% Exact Agreement		% Agreement of Important or Not Important	
				%	N	%	N
GA	Be around animals such as pets	253	60.80	62.45	158	85.77	217
GA	Are sports to you	253	60.00	53.36	135	80.63	204
LD	Eat at restaurants	255	58.00	49.02	125	73.33	187
LD	Take care of plants	251	57.90	53.78	135	80.08	201
LD	Be involved in cooking	252	56.90	53.97	136	76.98	194
LD	Do outdoor tasks	251	56.50	47.41	119	69.72	175
LD	Watch movies with other people	252	54.90	47.22	119	67.86	171
EC	Choose whether your daily caregiver is male or female	253	53.70	47.83	121	74.7	189
EC	Talk to a mental health professional if you are sad or worried	254	46.70	51.97	132	75.59	192
LD	Order take-out food	253	45.90	52.96	134	78.66	199
SC	Be a member of a club	254	45.90	43.31	110	66.14	168
GA	Use the computer	249	32.70	68.67	171	84.34	210
LD	Drink alcohol on occasion	253	18.20	66.40	168	86.56	219
LD	Use tobacco products	12 *	83.00	58.33	7	66.67	8
Average (SD)			76.47 (9.6)	58.55 (8.7)		81.68 (6.8)	

Note. SD = Self Dominion, EC = Enlisting others in Care, LD =Leisure & Diversionary Activities, SC = Social Contact, GA = Growth Activities. ¹ MDS 3.0 Questions from Section F. Preferences for Customary Routine and Activities.

* Only 12 NH residents in this sample indicated that they use tobacco products, importance ratings and stability ratings reflect the views of these 12 residents.