

## Research Article

# “It Depends”: Reasons Why Nursing Home Residents Change Their Minds About Care Preferences

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## Abstract

**Purpose of the Study:** Understanding and honoring preferences are fundamental in the promotion of well-being for frail elders. This study aims to understand and describe nursing home residents' perspectives on why the importance of their preferences may change in daily care.

**Design and Methods:** Secondary data analyses of cognitive interviews with 39 cognitively capable nursing home residents regarding their importance of preferences for everyday living were completed. Interviews were coded by 5 team members for reasons why residents may change their minds about the importance of their preferences or why their preferences may be restricted; discrepancies were reconciled through consensus.

**Results:** Content analysis revealed 4 major domains: *within person* (e.g., functional ability, personal schedule), *facility environment* (e.g., facility schedule, facility policy), *social environment* (e.g., quality and type of interactions), and *global environment* (e.g., weather, current events, special occasions). Residents reflected that the importance of their preferences fluctuated “depending upon” the circumstances related to these factors or their ability to perform the preference (i.e., barriers they encountered). A total of 27 themes for dependencies and barriers were identified.

**Implications:** Findings indicate that nursing home residents' preferences may change in importance or fulfillment in relation to personal or environmental circumstances. In order to develop formal care that matches older adults' preferences, regular assessment of both elders' preferences and the contextual factors affecting preferences is needed. However, given the changing nature of preference importance, there is also a need to determine how to best balance older adults' changing preferences within care delivery environments.

**Key Words:** Person-centered care, Preferences, Nursing home residents, Consumer-directed care, Assessment

According to the Institute of Medicine, high-quality health care is “safe, timely, effective, efficient, equitable, and *patient-centered*” (as cited in Lavizzo-Mourey, 2010, p. 1208). Quality care goes beyond just meeting medical need; it responds to specific needs of the person being treated. Truly person-centered care puts the person and his or her values at the center and focus of care delivery (Edvardsson & Innes, 2010). It encourages choice, a

sense of purpose, and meaningfulness in life and is theorized to ultimately improve the quality of life and well-being of individuals receiving care (Koren, 2010).

One of the primary tenants of person-centered care is understanding an individual's values and preferences for daily care routines and activities. Knowing an individual's everyday preferences can inform care goals, care planning, and ultimately allow for a match, or congruence, between an

individual's wishes and care goals or outcomes (i.e., including an individual in a specific activity that she/he prefers; Cvengros, 2009; Jahng, Martin, Golin, & DiMatteo, 2005). This match can form the foundation of person-centered care practices, which are linked to positive care outcomes. The integration of knowledge about individuals' preferences into care is related to improved decision making about care services (Whitlatch, Judge, Zarit, & Femia, 2006) and enhanced quality of care outcomes such as food intake (Simmons & Schnelle, 2004), continence (Thompson & Smith, 1998), increased satisfaction with care (Applebaum, Straker, & Geron, 2000), and positive quality of life outcomes such as decreased agitation (Gerdner, 2000) and increased positive affect and well-being (Lawton et al., 1998).

In the field of gerontology, recent work documents the feasibility and benefits of asking older individuals about their preferences in care (Edvardsson & Innes, 2010; Van Haitsma et al., 2012). Older individuals, even those with mild-to-moderate dementia, are able to report on their own values and preferences in care and are relatively reliable over short test-retest periods of time (Carpenter, Kissel, & Lee, 2007; Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001; Karel, Moye, Bank, & Azar, 2007; Whitlatch, Feinberg, & Tucke, 2005a, 2005b; Whitlatch, Piiparinen, & Feinberg, 2009). However, work has yet to articulate whether elders' preferences stay the same over longer periods of time or more pointedly if there are circumstances or barriers that systematically affect the level of importance of elders' preferences at a given point in time.

Theoretical work discusses how individuals' preferences can shift as a person experiences greater health concerns and/or approaches death (Winter & Parker, 2007), while work around end-of-life preferences also links stability in preferences to gender, age, education, prior wishes, and the illness scenario the individual is facing (Ditto et al., 2003). It is likely that other contextual factors and life experiences may also alter elders' perceptions and importance of everyday preferences. Elders' abilities are changing as they age (Baltes, Freund, & Li, 2005), and they are at an increased risk for experiencing disability that results in a need for care and support (Banaszak-Holl et al., 2011; Verbrugge & Jette, 1994). Such changes are likely linked to barriers that affect the ability of these individuals to have important preferences met.

Older adults in nursing homes may experience additional factors that affect their preferences. In nursing homes, assessment of elders' everyday preferences can improve the understanding of individuals' wishes (Pietrukowicz & Johnson, 1991; Ruland, 1998; Van Haitsma et al., 2014). However, the preferences of older adults are often constrained within the workings of the institution (Ulsperger & Knottneurs, 2011). An individual's preferences are more likely to be met if they match the institutional routines (Harnett, 2010). This environmental resistance may result in resident perceived barriers to their preferences being met or a resultant change in preference importance given a lack of perceived ability to meet the preference.

As a result, there is a need to understand the contextual factors, both barriers and circumstantial characteristics, which may affect elder residents' preferences in daily care. Initial assessment of preferences, while an essential first step, can only be informed by the elder's current circumstances. It is vital to know what environmental, personal, or interpersonal (i.e., social support) factors may cause preferences to fluctuate from one time to the next. Such knowledge will inform the design of assessment, treatment, and education protocols that seek to match care with individual needs over time. It will additionally equip practitioners with knowledge around how to respond to elders' preferences accurately, and, ultimately, inform the process for providing person-centered care in nursing homes.

The purpose of this study is to identify and describe older adults' perspectives around why the importance of their preferences may change in daily care and what barriers may influence fulfillment of their preferences. This study takes a ground-up, exploratory approach to understand nursing home residents' reflections on the dependencies and barriers that can affect their reports of preferences. More specifically, the study addresses the following questions:

1. What preferences do residents indicate may change in importance from one time to another?
2. What personal, environmental, or social contextual factors are related to individuals changing the importance rating of their preferences over time?
3. What personal, environmental, or social contextual factors act as barriers to individuals' preferences being fulfilled?

We hypothesized that in reporting on the importance of everyday preferences nursing home residents would identify both person-level and environment-level characteristics that affect their preferences (importance rating and fulfillment).

## Methods

### Participants

A convenience sample of 39 older adults living in seven nursing homes in the greater Philadelphia region was interviewed (see Table 1 for participant characteristics and Table 2 for facility characteristics). Potential participants were identified through social workers at their respective nursing homes and screened for cognitive ability. Individuals were deemed cognitively capable of providing informed consent based on a score of 22 or greater on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The decision to use a cutoff of 22 on the MMSE was based on norms identified by Crum, Anthony, Bassett, and Folstein (1993). Someone with a 5<sup>th</sup>–8<sup>th</sup> grade education level or higher who is 65 years of age or older is considered cognitively intact (Crum et al., 1993). Eligible residents were also English speaking, had been at their facility for at least one week, were expected to remain at the facility for at least one more week, and were cleared by their physician for capacity to consent and medical stability.

## Measures

### Preference Interview

A version of the Preferences for Everyday Living Inventory (PELI; Van Haitsma et al., 2012) was used to ask participants about their preferences. Questions cover a variety of everyday topics from food and dining to personal care preferences that fall into five domains: social contact, growth activities, diversionary activities, self-dominion, and enlisting others in care. A total of 118 items were examined in this study to gather an in-depth understanding of how individuals interpreted and answered the items (see Table 3 for list of items; includes 55 original PELI items—Van Haitsma et al., 2012—and 63 additional items developed to use in a skilled nursing home—K. Curyto, K. Van Haitsma, & G. Towsley, personal

communication). The PELI asks respondents to rate these items on “How important is it to you to . . . [insert preference]” with a 4-point Likert scale from 1 (*very important*) to 4 (*not important at all*). If residents responded that an item was “*important but can’t do*,” they were asked to respond to the question “why do you feel you can’t do it?” Residents were then asked, “If you could do that preference, how important would it be to you?” Preference items were grouped intuitively by topic (see Table 3 for items and groupings).

### Interview Protocol

The interview was initially designed to assist with the refinement and wording of the PELI items (K. Curyto et al., personal communication). Thus, a cognitive interview protocol

**Table 1.** Sample Characteristics

| Variable                          | N  | M (SD)        | Percent (n) |
|-----------------------------------|----|---------------|-------------|
| Age (years)                       | 39 | 78.6 (10.4)   | —           |
| Gender (male)                     | 39 | —             | 25.6 (10)   |
| Education (completed high school) | 35 | —             | 85.7 (30)   |
| Ethnicity                         | 39 | —             | —           |
| Not Hispanic or Latino            |    |               | 100.0 (39)  |
| Hispanic or Latino                |    |               | 0.0 (0)     |
| Race                              | 39 | —             | —           |
| Caucasian                         |    |               | 76.9 (30)   |
| African American                  |    |               | 23.1 (9)    |
| Marital status                    | 36 | —             | —           |
| Married                           |    |               | 8.3 (3)     |
| Divorced/separated                |    |               | 5.6 (2)     |
| Widowed                           |    |               | 63.9 (23)   |
| Never married                     |    |               | 22.2 (8)    |
| Religion                          | 35 | —             | —           |
| Protestant                        |    |               | 17.1 (6)    |
| Catholic                          |    |               | 37.1 (13)   |
| Jewish                            |    |               | 40.0 (14)   |
| Eastern orthodox                  |    |               | 0.0 (0)     |
| Muslim                            |    |               | 0.0 (0)     |
| Other                             |    |               | 2.9 (1)     |
| None                              |    |               | 2.9 (1)     |
| MMSE total score (0–30)           | 39 | 26.4 (1.6)    | —           |
| Length of stay (days)             | 39 | 646.1 (598.0) | —           |

Note: N = 39. MMSE = Mini-Mental State Examination.

**Table 2.** Facility Characteristics

| Facility number | % of sample (n) | Number of beds | Star rating | Ownership              |
|-----------------|-----------------|----------------|-------------|------------------------|
| 1               | 33.3 (13)       | 324            | 5           | Nonprofit—Corporation  |
| 2               | 12.8 (5)        | 180            | 3           | For profit—Partnership |
| 3               | 12.8 (5)        | 180            | 3           | Nonprofit—Corporation  |
| 4               | 12.8 (5)        | 226            | 4           | Nonprofit—Other        |
| 5               | 10.3 (4)        | 296            | 5           | Nonprofit—Corporation  |
| 6               | 10.3 (4)        | 170            | 5           | Nonprofit—Corporation  |
| 7               | 7.7 (3)         | 120            | 3           | Nonprofit—Corporation  |

Note: N = 39 residents from seven facilities in the greater Philadelphia region. Data are pulled from [Data.Medicare.gov](http://Data.Medicare.gov)

was utilized to structure the sequence of questions. The cognitive interview questioning produced a rich data set revealing spontaneously offered commentary on the barriers to preference fulfillment and situational dependencies related to preferences. A secondary data analysis of these spontaneous comments is the focus of this paper.

Cognitive interview questions were modified from the semistructured interview protocols of Housen et al. (2008) and Beck et al. (2010) to develop a better understanding of the interpretation of the PELI questions by residents. Participants first rated a preference item as described previously; responses were followed by a series of questions:

1. What were your thoughts as you gave your answer? What came to mind as I asked you this question? What did you think about?
2. Can you give me an example of [insert preference item stem] when you gave your answer?
3. What does the phrase [insert preference item stem] mean to you?
4. Has this ever been more important to you?
5. How did you decide that [insert preference item stem] is [insert importance rating response]?
6. Tell me in your own words what this question is asking? Is there a different way we could ask this question? In a nutshell, what is this question asking?

Elders were further probed with questions about the amount of choice they felt they had in regard to fulfilling the particular preference on a 3-point scale from 1 (*free choice*) to 3 (*no choice*). Pending their response, individuals were asked why they felt they had free choice, some choice, or no choice. Residents were then asked to indicate how satisfied they were in regard to the fulfillment of their preference on a scale of 1 (*mostly or completely satisfied*) to 3 (*not satisfied at all*). Research assistants probed their responses with the following:

1. If mostly or completely satisfied, why are you satisfied with your preference being fulfilled?
2. If a little or somewhat satisfied, what would make you feel more satisfied with your preference being fulfilled?
3. If not satisfied at all, what are the reasons you have not been satisfied with your preference being fulfilled?

Last, residents were asked to reflect on why they thought an individual may change his/her mind about the importance of a preference from one week to the next, "In your opinion, what would make a person change their mind about how important [insert preference item stem] is to them?"

## Procedures

The secondary data were collected through the following techniques: participants were interviewed in their rooms or a place of their choosing. To minimize interview burden for any one participant, each individual was asked a small selection of PELI items that were followed by the cognitive

interview questions listed earlier. Questions were initially randomly selected for individual participants ( $n = 33$ ), with each question being asked to five participants. However, preliminary analyses revealed that some groups (i.e., males and those with more sensory impairment) changed their minds more frequently. The remaining individuals ( $n = 6$ ) were selected based upon their demographic characteristics (i.e., males) and/or sensory abilities (i.e., more impairment) to take a targeted approach to understanding why individuals would change their mind or what would make the questions more clear. Furthermore, items that appeared to be unclear and required revisions to wording ( $n = 30$  items) were asked more than five times to ensure that each revision of the question was adequately examined (i.e., to choose who is involved in discussions about your care; see Table 3 for listing of all items).

## Analyses

All open-ended comments provided by participants in the interviews were digitally recorded and transcribed verbatim. Initial review of transcripts revealed a common pattern of ideas around "it depends," whereby residents identified contextual factors related to why a preference was important or what would make it change in importance, and/or ideas about whether their preference could be fulfilled or if there were barriers in place. Informed by content analysis strategies of Graneheim and Lundman (2004), data were read for abstraction to identify common categories or domains that responses fell into. The goal of data analysis was to identify the explicit content (i.e., manifest content; Graneheim & Lundman, 2004) that referred to dependencies (i.e., comments reflecting situations that would change preference importance) and barriers (i.e., comments indicating something would prevent the preference from being met or fulfilled) expressed by residents in regard to their everyday preferences. A comment was coded as both a dependency and a barrier if it made reference to both a situation that would change the preference importance and a situation that would restrict preference fulfillment. A barrier code itself did not indicate that participants would change their mind in any way around the preference if the barrier was removed. Thematic codes classifying types of dependencies and barriers started broad (i.e., environmental, personal) and were subsequently refined as factors affecting preference importance (i.e., dependencies) or preference fulfillment (i.e., barriers) were identified. Five authors (A. Heid, K. Eshraghi, C. Duntzee, K. Abbott, and K. Curyto) met regularly to flesh out the coding scheme; discrepancies were resolved by consensus. Overall frequencies of citations of barriers and dependencies by identified code/theme were calculated.

In addition, frequencies of barriers and dependencies by PELI item were calculated to explore for which PELI items participants most frequently discussed barriers or dependencies. To account for the bias that a PELI item interviewed more times could present with more barriers/dependencies,

**Table 3.** Preferences for Everyday Living (PELI) Items by Content Area

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 PELI item stem (“How important is it to you to . . .”)
 

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## Active activities within facility

- Attend entertainment events
- Learn about topics that interest you
- Take care of plants
- Watch movies with other people
- Take care of the place that you live
- Do outdoor tasks
- Are sports to you
- To exercise
- Play games

## Environment/room

- Take care of your personal belongings or things
- Lock things to keep them safe
- Keep your room at a certain temperature
- Adjust the lighting in your room
- Set up your room the way you want
- Set up your bed for comfort
- To use tobacco products
- Be involved in choosing your room-mate

## Food and dining

- Have snacks available between meals
- Choose what to eat
- Choose when to eat
- Choose where to eat
- To drink alcohol on occasion
- Be involved in cooking
- Eat at restaurants
- Order take-out food
- Choose who to eat with

## Independent pursuit activities

- Have reading options for low vision available to you or have reading materials available to you
- Listen to music you like
- Keep up with the news
- Use the computer
- To watch or listen to TV
- Listen to the radio
- Do your favorite hobbies
- Try new things
- Do activities that challenge you
- Do your favorite activities

## Medical/care

- Choose your medical care professional
- Learn more about certain medical problems
- Use nontraditional health care treatments
- Take additional supplements to boost your health
- Use laxatives or suppositories
- To receive rehab
- To relieve your pain when you want
- Choose who is involved in discussions about your care

## Personal care

- Choose between a tub bath, shower, bed bath, or sponge bath
  - Choose how often to bathe
  - Choose what time of day to bathe
  - Choose what clothes to wear
  - Choose what time to get dressed
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**Table 3.** Continued

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 PELI item stem (“How important is it to you to . . .”)
 

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|  |
|--|
| To choose how to care for your hair                            |
| Choose how to care for your mouth                              |
| Choose how often to care for your nails                        |
| Privacy/respect/relationships with staff                       |
| Be able to use the phone in private                            |
| To have privacy  |
| Choose whether your daily caregiver is male or female          |
| Have staff show they care about you                            |
| Have staff show you respect                                    |
| Discuss personal things with staff you feel comfortable with   |
| Talk to a mental health professional if you are sad or worried |
| Which helps you feel better when you are upset                 |
| Choose what name to be called                                  |
| Reflection/traditions/helping others                           |
| Talk about spiritual matters                                   |
| Go outside to get fresh air when the weather is good           |
| Participate in religious services or practices                 |
| Volunteer your time  |
| Reminisce about the past                                       |
| Participate in your cultural traditions                        |
| Go shopping  |
| Do things away from here                                       |
| Be a member of a club  |
| Give gifts   |
| Routines   |
| Choose when to get up in the morning                           |
| Follow a routine when you wake up in the morning               |
| Take a nap when you wish                                       |
| Know your needs when going to the bathroom                     |
| Choose your own bedtime  |
| Follow a routine when you go to bed                            |
| Socializing with others  |
| Be around animals such as pets                                 |
| Do things with groups of people                                |
| Meet new people  |
| Spend time in your room  |
| Watch the activity around you                                  |
| Spend time one-on-one with someone                             |
| Spend time by yourself   |
| Be around children   |
| Regular contact with family                                    |
| Regular contact with friends                                   |

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*Note:* Respondents were cognitively interviewed on a total of 118 variations of PELI items, including those in the table ( $n = 88$ ) and an additional 30 iterative variations of the items.

all counts were averaged by the number of interviews completed for that PELI item. Frequencies for PELI items that reflected variations in wording of initial items ( $n = 30$  items) were also combined to reduce redundancy.

## Results

A total of 600 item-level cognitive interviews were completed. The overall number of PELI questions each person was asked

varied from 3 to 44 (mean = 15.41,  $SD = 12.34$ ). The average length of interview time per item was 6.6 min ( $SD = 13.35$ ; range: 2.9–15.0). Multiple sessions were used to complete the interviews, with the average number of interviews being 2.33 per resident ( $SD = 1.42$ ; range: 1–6 interviews).

Interviews demonstrated that individuals who live in nursing homes and report on their preferences in everyday living indicate that the importance of their preferences and fulfillment of their preferences can be affected by a variety



of factors. Results confirmed the hypothesis that both person-level and environment-level characteristics can affect preference fulfillment (i.e., act as barriers) or level of importance (i.e., act as dependencies) of preferences for nursing home residents. Table 4 provides the list of themes by major domain that were coded and are defined by examples in the data.

Four major domains were identified, including: (a) *within person* or personal characteristics (e.g., functional ability, personal schedule), and environmental contextual factors including (b) the *facility environment* (e.g., facility schedule, facility policy), (c) the *social environment* (e.g., quality and type of interactions), and (d) the *global environment* (e.g., weather, current events, and special occasions). Within the four major domains, 27 themes were coded. Each theme could affect resident preferences in two ways, it could act as (a) a situational dependency, whereby one's level of importance changed based on the situation and/or (b) a barrier, preventing fulfillment of the stated preference. In some cases, a comment reflected both a situational dependency and a barrier. For example, in reference to how important it is to choose what type of bath to take, Mr. Mack shared how functional ability restricts this choice (i.e., is a barrier): "At the present time I do not take a tub bath or shower bath because I cannot stand up. So my choices are really confined to what I can do at the present time." But he also shared that functional ability affected the level of importance of this preference (i.e., acted as a situational dependency): "I guess it was [more important] when I was at home and was able to take a shower every day. But since it's not possible, it's not as important right now." Table 5 provides a summary of total frequencies of barriers/dependencies identified by major domain and by theme.

### Within-Person Themes

Within-person factors, or personal characteristics, that affected individuals' preferences included factors of personal ability (functional, sensory, and cognitive), health, situational need, mood, level of interest, personal schedule, perceived level of choice or opportunity, personal resources, current life stage, competency, perceived social acceptability, new knowledge, and a general reference to changing one's mind. In considering the broad-level domains, preferences were cited to be affected by within-person characteristics most frequently ( $n = 283$  barriers and  $n = 454$  situational dependencies within 38 interviews). The most common *barrier* to preference fulfillment that was discussed in interviews was perceived level of choice or opportunity ( $n = 126$  citations;  $n = 30$  interviews). Residents reflected on the fact that they did not personally feel they had the choice or opportunity, but did not specify that this lack of choice was driven by any particular factor (i.e., facility policy, lack of resources).

I'm not satisfied because I do not have any choice. That's what I mean, if they ask you first, then we talk then I would be satisfied. Don't come and say, "This is what I am going to do." Of course I would say, "Why? Do we have any other options beside this?" [Preference to choose who provides medical care—Caucasian Male, Age 78]

I don't have very much choice. Because it's not available. [Preference to learn about certain medical problems—African American Male, Age 88].

The most common *situational dependencies* that were discussed in the interviews were also within-person characteristics: perceived personal health ( $n = 61$  citations;  $n = 22$  interviews) and level of interest in how the preference was fulfilled ( $n = 60$  citations;  $n = 21$  interviews). Residents reflected on the fact that the importance of their preferences depended upon their health state and/or interest in how the preference was fulfilled.

Well if I had a headache it's unimportant or if I had a cold it's unimportant. If I have a severe rash I can't control then that's important. It depends on the severity of the condition. [Preference to get medical check-ups when something is bothering you—Caucasian Female, Age 94]

When I was healthy I went. Now that I'm not healthy, I can't. I have to go with the flow so to speak. [Preference to go outside to get fresh air when the weather is good—Caucasian Male, Age 83]

It depends upon what we are talking about whether or not it is important to me or not. It depends upon the subject. [Preference to talk about spiritual matters—African American Female, Age 85]

### Facility Environment Themes

Factors related to the facility environment were also reported by participants to affect preferences. Facility-related factors included facility schedule, policy, physical environment, human resources, facility resources, and staff proficiency. Residents shared that these aspects of the facility environment affected the fulfillment and/or importance of everyday preferences. Facility-related factors additionally presented as *barriers* almost as frequently as within-person factors, but not as frequently for *situational dependencies*. The second most common barrier discussed overall was facility schedule; however, other facility-related factors were also shared:

Because I have no way of regulating the heat or the air conditioning. [Physical Environment barrier about preference to keep room at a certain temperature—Caucasian Female, Age 66]

Well you have things scheduled for you. Mostly your therapy. During that time you have to do the therapy.

**Table 4.** Dependency and Barrier Themes Within Domains

| Code                                     | Description and examples  |
|--|---|
| Within person                            |   |
| 01—Functional ability                    | Gross and fine motor deficits; paralysis, loss of function; e.g., “I can’t play cards because I can’t hold the cards in my hands,” “I can’t do that because I’m in a wheelchair”  |
| 02—Sensory ability                       | Deficits of the senses; sensory limitation, vision or hearing impairment; e.g., “I can’t see anymore, so reading is not important,” “I can’t hear, so listening to music isn’t important”   |
| 03—Perceived personal health             | Physical and mental health; experiencing pain, not feeling well, not sleeping well, sick; e.g., “If I’m not sick,” “If I’m not feeling well it’s not important”   |
| 04—Situational need                      | Situationally driven, adjustment issue; e.g., “If I had an accident,” “If I needed to talk to someone,” “If I had something stolen”   |
| 05—Mood                                  | Feeling words; e.g., “If I feel down in the dumps,” “I’m not in the mood”   |
| 06—Cognitive ability                     | Related to cognitive functioning; e.g., “If I have my mind,” “As long as I have my mentality,” “If I remember to go”  |
| 07—Level of interest                     | Cognitive words like interested; level of interest in how preference is met or what preference is; e.g., “If I like it is very important to me,” “I hate cats, but I love dogs,” “It depends on the band”   |
| 08—Personal schedule                     | Related to daily schedule; e.g., “Depends what is scheduled,” “If I’m late it’s more important,” “If I have to go to an appointment”  |
| 09—Perceived level of choice/opportunity | Feeling of lack of choice or opportunity (Only code if clear that it is not about the facility schedule/policy.); e.g., “I have no choice,” “They don’t have that here”   |
| 10—Level of personal resources           | Related to a person’s financial or other resources; e.g., “I have no money,” “I don’t have any valuables”   |
| 11—Life stage or history                 | Related to the stage of life or past history of person, NH vs. Home; e.g., “It was more important when I was younger,” “Important when I was married,” “It was more important when I lived at home”   |
| 12—Competency                            | Talent or achievement; e.g., “It’s not important because I’m not good at it”  |
| 13—Perceived social acceptability        | The perceived social acceptability of the preference; social conformity; gambling, drinking, sex, racial issues; e.g., “If I don’t say exercise is important they will think I’m lazy,” “They will think I’m an alcoholic if I say drinking is very important”  |
| 14—New knowledge                         | Gaining new knowledge leads to a change in preference fulfillment or preference importance  |
| 15—General changing one’s mind           | General talk about a change in perspective, not related to new information/experiences  |
| Facility environment                     |   |
| 16—Facility schedule                     | Related to timing and frequency of facility events; staff schedule; e.g., “We only can shower twice a week”; “I have to get up when they want me to,” “They tell us when to eat”  |
| 17—Facility policy                       | Based on rules/policies of the facility; e.g., “They assigned me my doctor and nurses,” “I can’t have a pet here”   |
| 18—Physical environment                  | Physical environment of the facility; transportation; includes auditory environment; e.g., “I can’t control the temperature, they do,” “I can’t move the furniture around in my room, it has to stay where it is,” “I need someone to take me outside”  |
| 19—Human resources                       | The people the facility has; related to staffing; no translator; e.g., “There are no men to bathe me,” “I have to wait to go to the bathroom because there is only one aide”  |
| 20—Facility resources                    | Related to the resources of the facility; not enough money to get transportation for a resident   |
| 21—Staff proficiency                     | Related to the abilities of the staff; overall comments of facility/staff performance included here too; e.g., “I can’t understand what they are saying because of their accent,” “Doesn’t matter as long as they know what they are doing,” “I don’t care as long as they are trained to do what they are supposed to” |



Table 4. Continued

| Code                             | Description and examples   |
|----------------------------------|--|
| Social environment               |  |
| 22—Quality of interaction        | Behavior of others; issues related to other's impairment; e.g., "Those people," "All depends on who they are, quiet, join me," "If they annoy me, distract me," "Depends how they act towards me"  |
| 23—Type of staff relationship    | Quality of relationship with staff; explicit about type of relationship to staff; floater vs. regular staff; e.g., "My psychologist, my doctor," "If I only had these two aides the rest of my life," "Some staff show they care others are indifferent" |
| 24—Type of nonstaff relationship | Quality of relationship with others besides staff; e.g., "I like spending time with my grandkids, but not other kids," "I like spending time with my family"   |
| Global environment               |  |
| 25—Weather/season                | Related to weather and season of the year; temperature, winter, weather forecast; e.g., "I have to look at the weather to see what I'm going to wear"  |
| 26—Current news events           | Current world, national, and local events in the news; e.g., "It depends what's going on in the world. World events. National. Like the November elections," "When you hear about something new happening, like a comet or a disaster"                   |
| 27—Special occasions             | Special events; holidays, birthdays, weddings; e.g., "It's more important at Christmas time," "It's important to look nice for a wedding"  |

[Facility Schedule barrier about preference to spend time by yourself—Caucasian Female, Age 69]

I don't get to choose. It's alright though. The rule is 2x a week. [RA: If you had a choice, how important would it be?] Oh it would be very important. Oh yes! [Facility schedule barrier and situational dependency about Preference choose how often to bathe—Caucasian Male, Age 74]

### Social Environment Themes

Social environment factors (i.e., quality of interaction, type of staff relationship, or type of nonstaff relationship) were also identified. Residents shared that the people or relations they had with others affected their preferences.

Because you have to have the aide help you and sometimes they aren't so helpful. [Quality of Interaction as a barrier about preference to set up your bed for comfort—Caucasian Female, Age 84]

Oh I can tell them anytime. I'm satisfied with being able to tell them, but that doesn't mean they are going to do it. Those are two different things. I tell them and hope for the best. It depends on which one I have. When my usual one is on vacation and a new one comes in here I've never seen before I have to start from scratch. So I don't even bother, I see them for just one day. [Type of Staff Relationships as a situational dependency about preference to follow a toileting routine—Caucasian Male, Age 83]

### Global Environment Themes

Lastly, global environment factors (i.e., weather/season, current news events, or special occasions) presented less frequently, but were reported as factors influencing preference fulfillment or importance as well.

You feel like you are in prison if you can't get out every once in a while. I haven't been out in a couple of months. The weather hasn't been good. [Weather/Season as a barrier about preference to go outside to get fresh air when the weather is good—Caucasian Male, Age 69]  
Well if it's a birthday depends on who, what store I have to go and what gift I have to get and how I have to get it wrapped. [Special Occasions as a situational dependency about preference to go shopping—Caucasian Female, Age 84]

### Themes by PELI Item

Further exploratory analyses examined the relationship among the identified themes and specific preference items from the PELI. Summary statistics revealed that all 118 preference items assessed may change in importance due to a situational dependency or be affected by a barrier. In particular, preferences of choosing where to eat, ordering take-out food, and choosing when to eat were most commonly linked to barriers. These preferences were most frequently talked about as being restricted by participants' perceived level of choice, facility schedule, level of personal resources, and level of interest in how the preference is fulfilled. For example, participants shared that their ability to order take-out food was limited by how much it cost (i.e., personal resources). Meanwhile, residents shared situational dependencies most frequently for the preferences of choosing what time to get dressed and ordering take-out food. Individuals talked about the importance of these preferences depending upon how much choice they felt they had, their personal schedules, and their facilities' schedules. Additionally, when we examine PELI items by preference subcategory (see Table 3 for subcategories), we see that participants talked about *barriers* most frequently

**Table 5.** Frequency and Percentage of Sample Reporting Barriers and Dependencies by Theme

| Code                                     | Barrier    | Situational dependency | Total frequency of code |
|--|------------|------------------------|-------------------------|
| Within-person totals                     | 283 (87.2) | 454 (92.3)             | 737 (97.4)              |
| 01—Functional ability                    | 52 (48.7)  | 22 (25.6)              | 74 (48.7)               |
| 02—Sensory ability                       | 9 (15.4)   | 14 (23.1)              | 23 (23.1)               |
| 03—Perceived personal health             | 19 (28.2)  | 61 (56.4)              | 80 (60.0)               |
| 04—Situational need                      | 3 (7.7)    | 45 (51.3)              | 48 (53.8)               |
| 05—Mood                                  | 2 (5.1)    | 51 (48.6)              | 53 (46.2)               |
| 06—Cognitive ability                     | 5 (10.3)   | 29 (28.2)              | 34 (33.3)               |
| 07—Level of interest                     | 9 (20.5)   | 60 (53.8)              | 69 (61.5)               |
| 08—Personal schedule                     | 13 (25.6)  | 24 (28.2)              | 37 (38.5)               |
| 09—Perceived level of choice/opportunity | 126 (76.9) | 24 (30.8)              | 150 (79.5)              |
| 10—Level of personal resources           | 22 (33.3)  | 12 (20.5)              | 34 (48.6)               |
| 11—Life stage or history                 | 7 (12.8)   | 49 (53.8)              | 56 (56.4)               |
| 12—Competency                            | 7 (17.9)   | 10 (20.5)              | 17 (30.8)               |
| 13—Perceived social acceptability        | 6 (7.7)    | 3 (7.7)                | 9 (12.8)                |
| 14—New knowledge                         | 3 (7.7)    | 41 (35.9)              | 44 (38.5)               |
| 15—General changing one's mind           | 0          | 9 (12.8)               | 9 (12.8)                |
| Facility environment totals              | 188 (87.2) | 49 (53.8)              | 237 (87.2)              |
| 16—Facility schedule                     | 56 (71.8)  | 17 (25.6)              | 73 (71.8)               |
| 17—Facility policy                       | 42 (56.4)  | 6 (15.4)               | 48 (61.5)               |
| 18—Physical environment                  | 18 (28.2)  | 7 (17.9)               | 25 (35.9)               |
| 19—Human resources                       | 19 (35.9)  | 2 (5.1)                | 21 (35.9)               |
| 20—Facility resources                    | 21 (28.2)  | 4 (10.3)               | 25 (28.2)               |
| 21—Staff proficiency                     | 32 (38.5)  | 13 (30.8)              | 45 (51.3)               |
| Social environment totals                | 35 (61.5)  | 72 (71.8)              | 107 (84.6)              |
| 22—Quality of interaction                | 20 (38.5)  | 47 (51.3)              | 67 (64.1)               |
| 23—Type of staff relationship            | 8 (15.4)   | 10 (23.1)              | 18 (35.9)               |
| 24—Type of nonstaff relationship         | 7 (10.3)   | 15 (28.2)              | 22 (30.8)               |
| Global environment totals                | 3 (7.7)    | 20 (28.2)              | 23 (30.8)               |
| 25—Weather/season                        | 2 (5.1)    | 3 (7.7)                | 5 (12.8)                |
| 26—Current news events                   | 0          | 9 (15.4)               | 9 (15.4)                |
| 27—Special occasions                     | 1 (2.6)    | 8 (12.8)               | 9 (12.8)                |
| Sample totals                            | 509        | 595                    | 1104                    |

Note:  $N = 39$  interviews. Each cell contains the number of citations for each theme followed by the percent of participants that raised the dependency or barrier in parentheses.

for food and dining preferences. Participants shared “it depends” scenarios most frequently regarding active activities within the facility. These results indicate variance in the perception of barriers and situational dependencies by preference assessed.

## Discussion

Older adults living in nursing homes reported on the preferences that are important to them; however, in accordance with our hypothesis, results demonstrate that these preferences may change in importance as personal (i.e., *within person*) and environmental circumstances (i.e., *facility, social, or global environment*) also change. Furthermore, reports of preference fulfillment may be affected by personal and/or environmental barriers. All preferences individuals were interviewed about were linked to at least one instance of a barrier or situational characteristic affecting its fulfillment or importance. Experience of within-person

characteristics, in particular, including perceived opportunity, health concerns, or level of interest may result in change in ratings of importance over time. Furthermore, interview responses indicate preferences regarding dining or recreational activities may be linked most often with barriers or situational dependencies leading to change in importance or fulfillment of preferences.

Overall, the findings from this study carry several implications for research and practice. First, cognitively capable older adults in nursing homes can thoughtfully respond and articulate why their preferences are what they are, how they may change in importance, and how they may be restricted in daily care. Although this study is limited by its inclusion of only cognitively capable individuals, it demonstrates that the assessment of preferences is feasible within frail older adult populations. Prior work also demonstrates the capability of individuals with mild-to-moderate dementia in reporting everyday preferences (Whitlatch et al., 2005a, 2005b); further work can explore the use of a

preference battery, such as the PELI used in this study, with individuals who have mild-to-moderate dementia to determine how preference importance or fulfillment may change for this population as well.

Second, previous research findings indicate relative short-term reliability in preferences over time (i.e., Carpenter et al., 2007; Clark et al., 2008); however, results here demonstrate that everyday preferences can change in importance and in their ability to be fulfilled. More specifically, preferences can be affected by both barriers and/or situational dependencies. The fulfillment of preferences or the importance of preferences can be influenced by a host of internal and external factors. This study reveals four primary domains that influence stability in importance ratings and fulfillment: (a) *within person* or personal factors (e.g., sensory ability, level of interest in preference fulfillment), (b) *facility environment* factors (e.g., facility schedule, facility policy), (c) *social environment* factors (e.g., quality and type of interactions), and (d) *global environment* (e.g., weather) characteristics. *Barriers* present themselves as ways of inhibiting fulfillment of preferences. Such inhibition affects how or whether the individual even feels the preference can be met, and in some cases, the level of importance it is then given. Addressing such barriers, for example by providing greater flexibility around mealtimes to meet preferences for choosing what time of day to eat, may be a first step to achieving stability and congruence in care preferences. Additionally, *situational dependencies* present as factors that may alter the importance of an individual's preference. The changing contexts of the person and environment affect whether an individual rates a preference as very important or not. For example, a person may find doing activities with groups of people is very important only if it is a certain group of people or the activity itself is of interest (i.e., the importance "depends on" who is involved). In order to accurately assess preferences, these factors must be considered. Greater consideration of these dependencies will be necessary to match preferences with care consistently to yield the greatest return on well-being (Lawton et al., 1998). For example, similar to the need to maximize environmental fit of an individual's competence and context (Lawton & Nahemow, 1973), care matched to preferences may maximize well-being.

The finding that within-person factors are most commonly linked to change in the importance of preferences is of interest. Consistent with the literature, as individuals experience increased disability (i.e., functional, sensory, health), they may also experience a change in their ability to respond in the same way to their environment (Baltes et al., 2005). Such a change may lead to conflict in their current or past personal goals and the adaptability of their environment to their changing needs. One may go through a period of readjustment of goals and preferences before settling on what is important (i.e., changing interests, life stage, perception of choice). It may be that we as a care community need to support individuals in this process of change by understanding

that the importance of preferences may shift as abilities, circumstances, and interests shift. From a different perspective, within-person factors such as perceived level of choice/opportunity or interest in how a preference is fulfilled could reflect a person's perception/interpretation or an actual environmental barrier or dependency that is not driven by the individual. For example, a perception of lack of choice may be reflective of a way of perceiving the situation or an actual lack of choice within a facility due to the barrier of limited facility resources or the facility's schedule. Additional interview work around the *causes* of the barrier/dependency of lack of perceived choice or opportunity would help to clarify this finding. Such work may demonstrate a greater occurrence of some of the other themes already identified in this study or highlight new barriers/dependencies to consider.

Third, results here also demonstrate that the importance of *any* preference in everyday living assessed can be affected by a barrier or situational context. In order to develop truly person-centered care that honors an individual's preferences in formal care settings, regular assessment of both elders' preferences and the contextual factors affecting preferences need to be completed. It may be beneficial to expand preference assessments with follow-up questions on "why" a preference is important or unimportant to the individual to drill down these factors (see PELI long-form; found at [www.polisherresearchinstitute.org](http://www.polisherresearchinstitute.org)). For example, a preference may not be reported as important due to a barrier in place, but if that barrier were identified and removed, the preference would regain importance and impact the well-being of that individual. Further, it may be that if care was adjusted to work around barriers and accommodate personal limitations that preferences may be less likely to change in importance. One could argue that importance in individual preferences change in small part because the care environment is also changing. This is exploratory work, but responses indicate that a number of barriers or situational dependencies were attributed to factors that are within the control of the care environment. Thus, assessment of these factors could mark the first step in understanding how to address preferences moving forward to make care more person centered. The only factors that were linked to change in preference importance or preference fulfillment out of the control of care were declining health, functional, sensory, or cognitive impairment. In these instances, in particular when an individual's status changes, repeated assessments of preferences appear necessary; it may also be that changing preferences provide cues into changing medical/personal needs. However, the exact frequency of assessment of preferences and/or contextual factors is not determined by this study. We can only conclude that as we work to align preferences with care goals and tasks, care may not remain "preference congruent" as preferences may dynamically change along with or be affected by individual and environmental factors. A flexible assessment process appears needed to both achieve and maintain congruence of care with preferences overtime.

Fourth, the findings here regarding barriers demonstrate that preference fulfillment must be considered within the context of the social community individuals live. Social contract theory and medical ethics (Hughes & Baldwin, 2006) challenge us to examine one individual's expression of autonomy and preferences in relation to the good of the whole community (i.e., social justice). All preferences of all individuals may not be able to be met at a given time. However, a start is to ask and understand a person's preferences. It may be that some barriers are immediately amendable to change and would not require extensive effort on behalf of staff or trade-offs with other residents' wishes to adhere to them. Yet, minor changes may result in direct increases to an individual's well-being. In other instances, more creative thinking may be needed to determine how to build a compromise between a resident's needs and wishes and those of others and the facility in which he/she resides.

This study is not without limitations. The findings are limited by the use of a small convenience sample, which precludes generalizations to all nursing home residents. Further exploration of these ideas within a larger more diverse sample may result in additional factors that affect preferences. Second, the questions in this study were not all purposely designed to capture why the individual would change his or her mind regarding the importance of preferences. Comments about dependencies and barriers were spontaneously shared. As a result many elders may not have shared all of their thoughts about what would change their minds about the importance of their preferences or what restricts their preference fulfillment. In fact, some residents reflected on the fact that their preferences and importance have conformed to align with the offerings of their facility (i.e., "I've conformed, what else? Is that good or bad, I don't know."). This adaptation or resolution of cognitive dissonance, whereby their preferences are matched to what can be offered, may act as a protective factor or coping mechanism in situations where control is relinquished to the facility or others (Festinger, 1962). Additional systematic work with more direct questions about changes in preferences is needed to tease out this process (i.e., What could make you change your mind and why?).

Overall, these findings are strengthened by the use of ground-up reports on the situational dependencies and barriers in place that may affect the importance or fulfillment of older individuals' preferences in daily care. Results here fill a gap in the literature on understanding elders' preferences and use data-driven approaches to delineate themes. The findings provide practitioners and researchers alike with information about the contexts that affect preferences in nursing homes. Such information is vital to the development of intervention-based work with elders and ultimately advances our understanding of the factors we must address to provide truly high-quality, person-centered care.

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